Living with an ICD: Developing a brief psychological intervention for patients living with an implantable cardioverter defibrillator.

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Living with an ICD: Developing a Brief Psychological Intervention for Patients Living with an Implantable Cardioverter Defibrillator

Two Volumes

One of Two Volumes

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Abstract

The implantable cardioverter defibrillator (ICD) is a small medical device, implanted underneath the collarbone with wires leading from it to the heart. The device detects and terminates ventricular arrhythmias by delivering an electric shock, that otherwise would most likely lead to sudden cardiac arrest and sudden cardiac death. The ICD is perceived as the 'gold standard' treatment therapy for patients at risk of sudden cardiac death resulting from fast electrical rhythms (Bleasdale, Ruskin, O'Callaghan, 2005). However, ICD recipients have reported high levels of psychological distress such as anxiety and depression and a reduced quality of life (e.g. clinical review by Sears, Matchett & Conti, 2009). This thesis describes the development of a brief psychological intervention for patients living with an ICD based on the Medical Research Council's (2008) guidelines.

The first stage in the development of the intervention was a qualitative study. Thirty-six ICD participants (ICD patients and partner) were recruited in south Wales. Semi-structured interviews were conducted with each participant separately. Thirteen of the patients had not experienced an ICD shock. Transcripts were analysed by thematic analysis (Braun and Clarke, 2006) using a cognitive-emotional-coping framework. General findings revealed patients did not know how to regain normality after their ICD and highlighted common worries were identified. Accordingly, the intervention aimed to be a structured guide underpinned by cognitive behavioural theory. It aimed to address common worries and bridge the gap between hospital discharge and patient's 6-week follow up appointment.

The intervention was tested using a pilot randomised control trial. Ninety-nine participants were randomised to an intervention or control group. Differences between groups at baseline were adjusted by analysis of covariance (ANCOVA) to control for differences at 3- and 6-months. Results revealed the intervention group reported improved levels of depression, increased levels of mild exercise and increased patient acceptance to the ICD compared to the control group at 6-months. The simplicity and cost-effectiveness of this intervention suggests that not only is it theory and evidenced based, but should be sustainable long term. The next stage would be to carry out a fully powered randomised control trial.

CONTENTS

Part 1: Introduction to the Implantable Cardioverter Defibrillator

Section 1

Section 2

Section 3

Part 2: Qualitative Phase of the Study

Section 1

Section 2

Section 1

Section 2

Part 3: Intervention and Quantitative Phase of the Study

Section 2

Part 4: Final Summary

Dedication

In loving memory of my late husband and best friend Alan,
and my dear Dad 'KK'.

This thesis is dedicated to my sons, Jonathan and
David.

Acknowledgements

I would like to say a very big thank you to my supervisors: Professor Paul Bennett, Dr Rob Lowe and Dr Jaynie Rance. Their patience, guidance, editing, detailed feedback and support was excellent. I was blessed to have had such a caring and exceptional supervisory team led by Paul Bennett.

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Thanks as well to the Specialist Arrhythmia Nurses: Sisters Mandie Welch, Wendy Churchouse and Carolyn Shepherd. I am grateful for their time and help with this study. Also thanks to Dr Jenny Tagney for giving me access to some of her patients with an ICD.

Last but not least, thanks to all the patients I have been in contact with from 2010 to 2013. Their time, effort, and willingness to share their feelings and experiences with me were invaluable.

List of Photos

List of Figures

List of Tables

Abbreviations

AA	Arrhythmia Alliance
AACN	American Association of Critical-care Nurses
ARVC/ARVD	Arrhythmogenic Right Ventricular Cardiomyopathy/Disorder
AV node	Atrioventricular node
AVID	Antiarrhythmic Versus Implantable Defibrillators Trial
BHF	British Heart Foundation
BHI	Bristol Heart Institute
B-IPQ	Brief Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006)
CABG	Coronary Artery Bypass Graft-Patch
CASH	Cardiac Arrest Study Hamburg
CBT	Cognitive Behavioural Therapy
CIDS	Canadian Implantable Defibrillator Study
COMPANION	The Comparison of Medical Therapy, Pacing and Defibrillation in Heart Failure study
CM	Cardiomyopathy
CRT	Cardio resynchronisation therapy
CRT-D	Cardio resynchronisation therapy with a defibrillator
DASI	Duke Activity Status Index
DCM	Dilated Cardiomyopathy
DOI-P	Demands of Illness – Partner questionnaire
DVLA	Driver and Vehicle Licensing Agency
DS14	Type-D personality Scale
ECG	Electrocardiogram
EP	Electrophysiology
FPAS	Florida Patient Acceptance Survey (Burns, Serber, Keim, & Sears, 2004)
HADS	Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

HCM	Hypertrophic Cardiomyopathy
ICD	Implantable Cardioverter Defibrillator
IES	Impact of Events Scale (Horowitz, Wilner & Alverez, 1979)
JAMA	Journal of the American Association
LQT	Long QT syndrome
LVEF	Left Ventricle Ejection Fraction
MADIT	Multi-Centre Automatic Defibrillator Implantation Trial
MCMQ	Medical Coping Modes Questionnaire (Feifel, Strack & Nagy, 1987a)
MI	Myocardial Infarction
MRC	Medical Research Council
MUSTT	Multi-Centre Unstained Tachycardia Trial
NICE	National Institute for Health and Clinical Excellence
NSVT	Non-Sustained Ventricular Tachycardia
NYHA	New York Heart Association
PCI	Percutaneous Coronary Intervention ("stent")
POMS-SF	Profile of Moods-short form (Shacham, 1983)
QoL	Quality of Life
RCT	Randomised Control Trial
SCA	Sudden Cardiac Arrest
SCD	Sudden Cardiac Death
SCD-HeFT	The Sudden Cardiac Death in Heart Failure Trial
SF-12/SF- 36	Medical Outcomes Measure Short form 12 (36)
SQT	Short QT Syndrome
STAI	State-Trait Anxiety Inventory (Spielberger, 1983)
UHW	University Hospital of Wales
VT	Ventricular Tachycardia

Part 1

Chapter 1

INTRODUCTION TO THE IMPLANTABLE CARDIOVERTER DEFIBRILLATOR (ICD)

The implantable cardioverter defibrillator (ICD) is a medical device that is implanted in the body and its main function is to correct an abnormal dangerous heart rhythm caused by electrical instability. This chapter introduces the reader to the structure of the heart, its electrical system and the ICD.

***SECTION ONE**: A Brief Introduction to the Heart's Electrical System:*

- *The Abnormal Heart Rhythm: The Ventricular Arrhythmia*
- *Psychophysiology: the effects of Psychological Stress on the Heart*

***SECTION 2:** The Implantable Cardioverter Defibrillator includes:*

- *The ICD System, Past and Present: a brief overview of the ICD's history*
- *The Superiority of the ICD over Drug Therapies: Classic studies that show the ICDs efficacy as a treatment therapy*

SECTION ONE: A Brief Introduction to the Heart's Electrical System

The main function of the heart is to pump oxygenated blood around the body to all the vital organs e.g. the brain and the kidneys). See Figures 1.1 and 1.2.

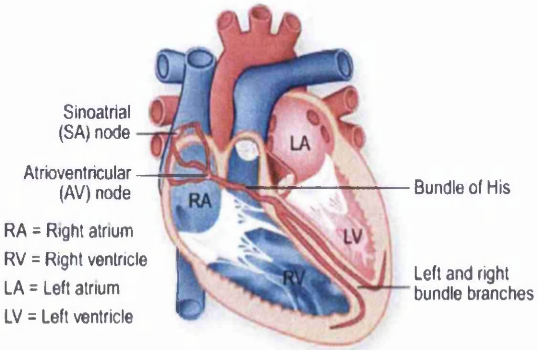

Figure 1.1: The Heart's four chambers and the SA node (heart's natural pacemaker). Image downloaded from http://www.ecgtest.org/

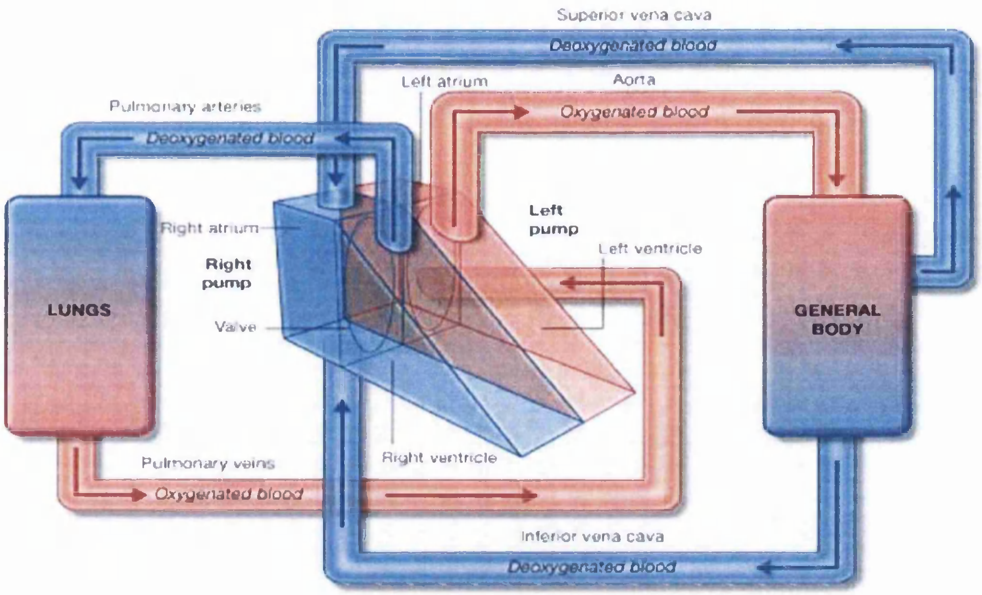

Figure 1.2: Blood flow through the heart. Illustration downloaded from Grey's Anatomy for Students 2012

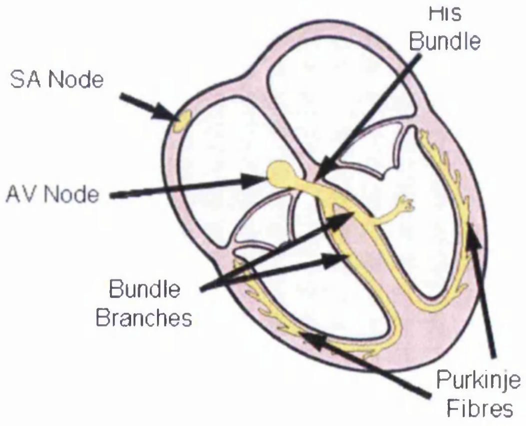

Figure 1.3: The travelling electrical impulse through the heart muscle. Illustration taken from Morrison and Bennett (2012). Permission granted.

The pumping action of the heart is controlled by the heart rhythm, which in turn is controlled by its own electrical system. An electrical impulse begins in the heart's sino-atrial node (SA node, see Figure 1), which lies at the top of the right atrium. This electrical impulse causes the muscle chambers of both atria to contract, which pumps the blood into the two ventricles (lower two chambers). The electrical impulse continues to travel to the atrio-ventricular (AV node), which acts as a 'junction box' and lies between the upper two atria and the lower two ventricles ("What is an implantable cardioverter defibrillator", 2011).

At the AV node, a further electrical discharge is fired, which travels along a system of nerves called the Bundle of His and Purkinje fibres. This electrical discharge stimulates the muscles of both ventricles to contract and pump, to complete a total cycle of the heart rhythm (see Figure 1.3.) The ventricles then relax and the heartbeat process starts again from the SA node.

An electrocardiogram (ECG) is used to measure the electrical impulse as it travels through the heart and can detect each of the nodes (SA and AV nodes) firing and recharging. The ECG records the strength and the timing of electrical signal as it travels through the heart. The ECG can be used to to detect an acute myocardial infarction (Daudelin, Sayah, Kwong, Restuccia, et al., 2010) or a conduct abnormality such as Long QT syndrome (Algra, Tijssen, Roelandt, Pool et al., 1991) (see Chapter 2: Familial Cardiac Conditions), which might indicate a need for an ICD.

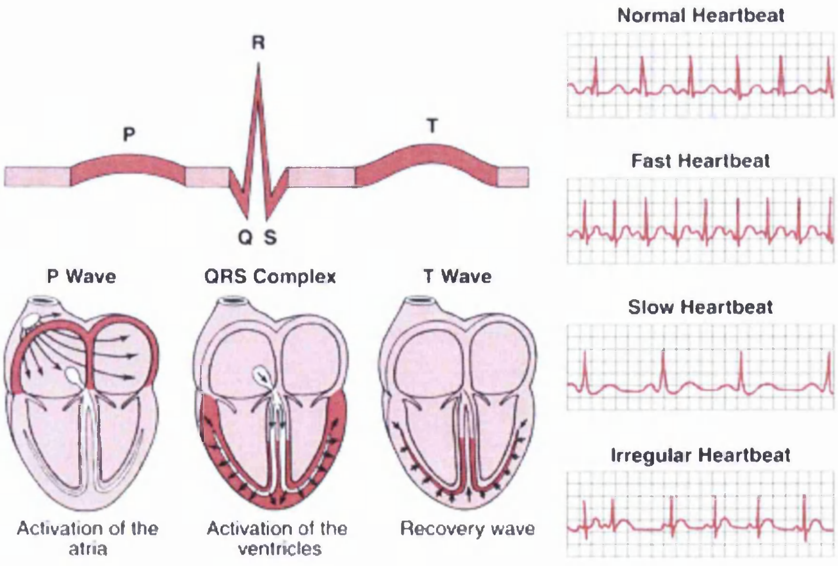

Figure 1.4: the electrocardiogram records the strength and timing of the electrical signal. Image downloaded from http://www.ecgtest.org/ (downloaded 8.8.2012)

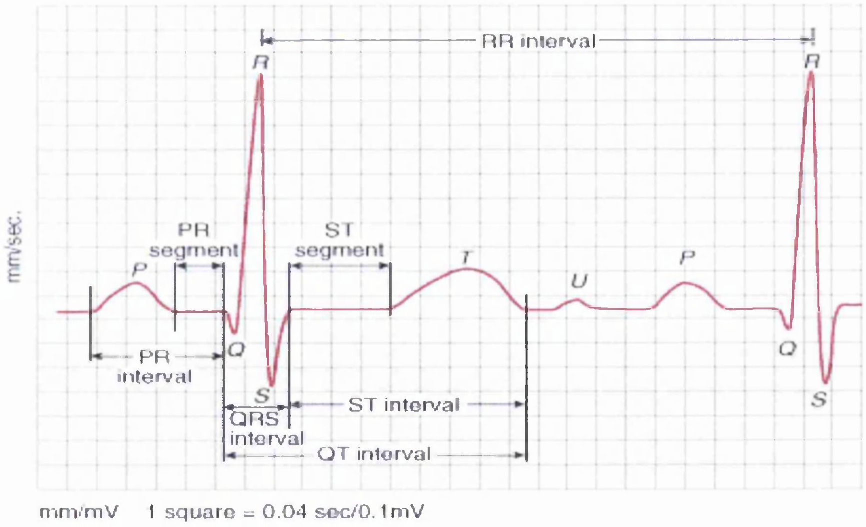

Figure 1.5. ECG data of normal heart output. Image downloaded from http://www.merckmanuals.com/professional/cardiovascular_disorders/cardiovascular_tests_and_procedures/electrocardiography_ecg.html (downloaded 8.8.2012)

The electrical impulse is traced by an ECG reading. The trace is divided into the P wave, PR interval, QRS complex, QT interval, ST segment, T wave, and U wave (see Figure 1.5).

- The P wave represents atrial depolarisation. This records the time needed for the electrical impulse from the SA node to spread throughout the atria causing them to contract.
- The PR interval is the time between onset of atrial depolarisation and onset of ventricular depolarisation.
- The QRS complex represents ventricular depolarisation (ventricles contracting).
- The QT interval is the time between onset on ventricular depolarisation and the end of ventricular repolarisation (the QT interval is corrected by the Electro-physiologist to take into account the individual's heart rate). The QT reading can diagnose Long and Short QT Syndrome (See Chapter 2: Familial Cardiac Conditions).
- The ST segment represents completed ventricular myocardial depolarisation.
- The T wave represents ventricular repolarisation.

- The U wave can appear in patients with ischemia (a reduced blood flow) although it is also often present in health individuals.

http://www.merckmanuals.com/professional/cardiovascular_disorders/cardiovascular_tests_and_procedures/electrocardiography_ecg.html (downloaded 8.8.2012)

The Abnormal Heart Rhythm: Ventricular Arrhythmias

Abnormal heart rhythms, (arrhythmias) are caused by an abnormality in the heart's electrical conduction system. Arrhythmias can be divided into two groups:

- Supraventricular arrhythmias, which develop in the atria and tend not to be dangerous
- Ventricular arrhythmias, which develop in the ventricles and can be dangerous

A healthy heart beats in a regular pattern (normal sinus rhythm) of 50-80 beats[1] a minute during rest. The heart beat increases to more than 100 beats a minute when under stress, such as during physical exertion or excitement, when the SA node is stimulated to release more electrical impulses. Ventricular arrhythmias are common and usually benign in those with a structurally normal heart (Drake et al., 2010). In patients with structural heart disease (usually coronary heart disease), ventricular arrhythmias can lead to sudden cardiac arrest and sudden cardiac death[2] (McComb, 2002). Ventricular arrhythmias range from asymptomatic non-sustained ventricular tachycardia (NSVT) to sustained ventricular tachycardia (Drake et al. 2010) (see Chapter 2 subsection: 'What is Sustained and Non-Sustained VT'). The heartbeat is defined as tachycardic when it beats more than 100 beats a minute. However, if the rate rises to 170-180 beats a minute, the heart rhythm becomes dangerous ("What is an implantable Cardioverter Defibrillator", 2011).

When the heart rate rises to more than 250 beats a minute, the rhythm is described as a 'ventricular flutter', whereby only a small amount of blood is being pumped into

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[1] One heartbeat = a complete cycle, for instance P wave to the next P wave

[2] Sudden Cardiac Death can be defined as the unexpected natural death to cardiac causes within a short period from the onset of symptoms, without any prior condition that would appear fatal (Thomas, Friedman, Kao, Inguito et al., 2006)

the body (Bleasedale, Ruskin & O'Callaghan, 2005). From a ventricular flutter the rhythm can rapidly develop into ventricular fibrillation (VF). During fibrillation, the heart beats at more than 300 beats a minute, not allowing any organised activity within the heart (Bleasedale et al., 2005). Rather than contracting and pumping blood, the heart's ventricles quiver, the person loses consciousness and goes into in cardiac arrest. Sudden cardiac death occurs within 10 minutes unless the heart is defibrillated to restore sinus rhythm (NICE, 2006; Thomas, Friedman, Kao, Inguito, et al., 2006; "What is an implantable ..." 2011).

Psychophysiology: the effects of Psychological Stress on the Heart

A number of physiological processes are involved in controlling blood pressure and many involve the autonomic nervous system. The brainstem receives continuous information from baroreceptors situated in the carotid arteries and aorta. This information is relayed to the centre in the brainstem to the hypothalamus. The autonomic division of the peripheral nervous system is directly responsible for regulating the heart rate, the force of each contraction and the cardiac output (Drake, Vogl & Mitchell, 2010). Reductions in blood pressure or physical demands (e.g. exercise) that require increased blood pressure causes an activation of the sympathetic nervous system. Sympathetic activation results in an increase in the strength and frequency of electrical heart contractions and contractions of the smooth muscle in the arteries (Morrison & Bennett, 2012). After a period of stress the parasympathetic nervous system is activated to reduce the blood pressure.

Hypertension

Psychological stress can cause or contribute to a number of cardiac conditions such as hypertension. Hypertension is a condition in which resting blood pressure is significantly above normal levels.

Table 1.1: Typical blood pressure readings in normal and hypertensive individuals (adapted from Morrison & Bennett, 2012)

	Diastolic (mmHg[3])	**Systolic (mmHg)**
Normal individual	≤90	≤140
Hypertensive individual	≥100	≥160

There are two types of hypertension: secondary hypertension, which is usually due to a disease involving the kidneys, adrenal glands or aorta and primary hypertension, which has no known disease (Morrison & Bennett, 2012). If psychological stress is sustained or frequent, the sympathetic nervous system begins to dominate and gradually pushes blood pressure up for longer periods until the individual develops chronically raised blood pressure. High blood pressure can increase the risk of a myocardial infarction, stroke, kidney failure, eye damage and heart failure and can contribute to the development of atheroma (Morrison & Bennett, 2012).

Coronary Heart Disease

The development of atheroma in the blood vessels is a long-term but silent element of coronary heart disease (CHD). Atherosclerosis is a disease in which atheroma builds up on the linings of the arteries. The main constitute of atheroma is cholesterol, which is a waxy substance present in blood plasma and all the body's cells. The distribution of atheroma within the circulatory system is not uniform throughout the body and the heart arteries are most likely to be affected. Atherosclerosis is the build-up of cholesterol, fatty and inflammatory deposits (called plaque) on the inner walls of the arteries that restrict blood flow to the heart. Without adequate blood flow, the heart becomes deprived of oxygen and the vital nutrients it needs to work properly. If a clot breaks off the artery wall, there is the

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[3] Blood pressure is measured in millimetres of mercury (mmHg)

risk blocking an artery to the heart resulting in a myocardial infarction, which can lead to death (Morrison & Bennett, 2012).

Psychological Distress and Arrhythmias

It has been documented that strong emotion can influence sympathetic arousal, which can trigger arrhythmias. For instance, a study by Lampert, Joska, Burg, Batsford et al. (2002) found anger could trigger an arrhythmia in patients with ICDs. Participants with an ICD were given diaries to record levels of defined mood states (e.g. anger, worry, happiness, challenge). A five-point intensity scale was used. Participants had to record their mood states for 2 periods that preceded an ICD shock (0 to 15-minutes and 15-minutes to 2-hours) and for a one week after the shock. The study found moderate levels of anger were more likely 15-minutes before a shock occurred to terminate a ventricular tachycardia or fibrillation than during a paired control period one-week later.

Burg, Lampert, Joska, Batsford et al. (2004) used the same sample of participants as above, and found that participants who reported moderate anger in the 0-15 minutes before ICD shock scored significantly higher on trait anxiety. This suggests that stable traits of anger might be a risk factor for a ventricular arrhythmia. The influence of stable traits was also seen with anxiety. Burg et al. (2004) compared participants who reported at least moderate anxiety in the 0 to15 range before ICD shock with those who did not report anxiety before their shock. They found that the subgroup who reported anxiety-triggered arrhythmia had significantly higher levels of trait anxiety.

Lampert et al. (2002) suggested that anger induced electrophysiological changes, which altered the repolarisation and conduction of the electrical heartbeat. These electrophysiological changes meant the heartbeat accelerated and the tachycardia was difficult to terminate. Studies by Lampert, Shusterman, Burg, Lee et al. (2004) monitored the ECG outputs of ICD patients during an anger-recall and mental arithmetic test and found changes in repolarisation indices in patients with heart disease and a history of ventricular arrhythmia. They concluded that psychological stress increased the T-wave alternans (a marker of cardiac electrical instability) by way of autonomic nervous system, which led to unstable repolarisation, which in turn led to an increased risk of a ventricular arrhythmia.

Another study by Kop, Krantz, Nearing, Gottdiener et al. (2004) found supporting evidence, that psychological stress induced cardiac electrical instability. Their study used a mental stress protocol (arithmetic test and a speech about an anger-provoking event), which was similar to that used by Lampert et al. (2004). They found that acute mental stress increased T-wave alternans, a marker of increased cardiac electrical instability in patients with coronary heart disease and vulnerable to ventricular arrhythmias. The vulnerability to increased T-wave alternans appears to be predictive of arrhythmias. Another study by Lampert, Shusterman, Burg, McPherson et al. (2009) found evidence higher magnitudes of anger-induced T-wave alternans was predictive of future ventricular tachycardias and fibrillation up to a year later.

Emotional states such as anxiety and arrhythmia can each occur unexpectedly and transiently, which can pose difficulties in assessing the relationship between the two as they are often recorded by questionnaires or interviews performed at one time point (Peacock & Whang, 2013). This means that reliability was not tested and the records of mood states were dependent on memory (Peacock & Whang, 2013). The causal direction is difficult to assess, as individuals who have frequent arrhythmias are potentially more likely to develop anxiety due to somatic symptoms associated with the arrhythmia and the possibility of an ICD shock (Peacock & Whang, 2013). However, evidence does suggest that stable psychological traits may increase sympathetic arousal with a similar transient emotional state. In addition, there is strong evidence that anger can lead to increased risk of ventricular arrhythmias by T-wave alternans being increased by sympathetic arousal.

SECTION 2: The Implantable Cardioverter Defibrillator

Approximately 30,000 people suffer an out-of-hospital cardiac arrest each year in the UK, who are treated by the emergency services (Resuscitation Guidelines, 2010). Survival rates for an out-of-hospital cardiac arrest are less than five per cent. Sudden cardiac death (SCD) occurs unless the arrhythmia is effectively treated with a defibrillator within 10-minutes of the onset of the cardiac arrest (NICE, 2006; Thomas, Friedman, Kao, Inguito et al., 2006). Due to the short time period in which to abort the arrhythmia, there are a high number of sudden cardiac deaths annually in the UK (NICE, 2006) (see below).

A sudden cardiac death can be defined as the unexpected natural death to cardiac causes, within a short period from the onset of symptoms in a person, without any prior condition that would appear fatal (Thomas et al., 2006). Sudden cardiac death occurs in approximately 50,000 to 70,000 people annually in the UK (NICE, 2006), of which about eighty per cent are due to ventricular tachyarrhythmia (see The Abnormal Heart Rhythm: Ventricular Arrhythmias above), the most common being sustained ventricular tachycardia (see Chapter 2: What is Sustained and Unsustained VT) (Thomas et al., 2006). The remaining twenty per cent consist of a number of conditions including cardiomyopathies (10-15 %) (See Chapter 2: Familial Cardiac Conditions), other structural heart defects (less than five per cent) and bradycardia (slow heartbeat) (NICE, 2006).

Many SCD events could have been prevented if access to effective treatment had been made instantly available (Thomas et al., 2006). For instance, approximately eight-five to ninety per cent of sudden cardiac deaths are due to a first arrhythmic event, which might have been avoided if a defibrillator had been available (Ezekowitz, Armstrong, McAlister, 2003). Nonetheless, despite the very high mortality rate, about ten to fifteen per cent of patients do survive. However these patients are often left with permanent brain damage and motor impairment caused by the delay in restoring sinus rhythm[4] (Di Marco, 2003; "A review of emerging technologies", 2011).

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[4] Therapeutic hypothermia has been shown to help reduce brain damage in patients who suffered a cardiac arrest; uptake of this therapy in routine clinical practice has been slow (DoH, 2011).

The implantable cardioverter defibrillator (ICD) is a medical device implanted in the body. The ICD circumvents the likely delay in receiving effective treatment by providing 24-hour definitive therapy to terminate any life-threatening ventricular tachyarrhythmia that might arise (Bleasdale, Ruskin, O'Callaghan, 2005). Patients who are successfully resuscitated, are at an approximate fifty per cent increased risk of a second SCD within five years even with pharmacologic therapy. However, this rate is reduced to approximately five per cent with an ICD (Thomas, Friedmann, & Kelley, 2001).

Consequently, the ICD is currently perceived to be the 'gold standard' treatment therapy for patients at risk of sudden cardiac death resulting from fast electrical rhythms (Bleasdale et al., 2005). The device's ability to apply treatment therapy within five to fifteen seconds of the onset of an arrhythmia allows for defibrillation success and the survival of almost hundred per cent of patients (Hussein, & Thomas, 2008). Rates of ICD implants are steadily rising in the UK with a ten-year average growth rate of approximately fifteen percent (Cardiac Rhythm Management, 2010). In Wales, the rate of new ICD implants was fifty-one per million in 2009 and this figure has since risen to seventy per million per annum, which currently matches the average English implant rate (Cardiac Rhythm Management, 2010). However, the national target remains at hundred new implants per million, and accordingly more people will be expected to be implanted with an ICD in the future, (Cardiac Rhythm Management, 2010).

The ICD System, Past and Present: A brief overview of the history of the ICD

Mirowski pioneered the ICD device in the late 1960s with the first prototype being tested on dogs (Matchett, Sears, Hazelton, Kirian et al., 2009). The first human implantation took place at the John Hopkins Hospital, Baltimore, Maryland, USA in February 1980. Accordingly, the ICD has only been in existence as a treatment therapy for about 30 years, although it has changed significantly since its inception in its size and its ability to detect a dangerous arrhythmia.

Despite changes to its size, the ICD system over the years has not changed in its basic composition of a pulse generator and leads (see Figure 5). About 30-years ago, the first generation devices were large and required a thoracotomy (surgical incision made in the chest wall) for insertion into the upper abdominal cavity, with a mesh-insulated epicardial patch sewn directly to the wall of the heart (Matchett, Sears, Hazelton, Kirian, Wilson & Nekkanti, 2009). Hence, this required an invasive insertion procedure. Moreover, early devices offered few options for patient-specific programming (heart rate thresholds), which meant that these ICDs were unable to discriminate rapid ventricular rhythms of supraventricular origin from ventricular-based rhythms. This led to their recipients experiencing a high incidence of inappropriate shocks in the range of twenty-five to forty per cent (Hussein, & Thomas, 2008).

Over the years, researchers have been developing smaller and smaller devices, and today's models are approximately the size of a small matchbox (or a third of the size of a mobile phone) and weighs about seventy-five grams (3 oz) (Implantable Cardioverter Defibrillators, 2010) (see photos 1.1 and 1.2). The ICD system's defibrillator leads transmit electrical signals from the heart to the pulse generator, which analyse whether the rhythm is malignant. The pulse generator houses analysis and data storage, as well as the circuitry that is used to deliver pacing, or a defibrillated shock. The battery is also housed in the pulse generator, which powers the device. If the pulse generator detects an abnormal ventricular rhythm, the leads carry and deliver pacing (low level energy shocks) and defibrillation to the myocardium (muscle tissue of the heart) to restore sinus rhythm.

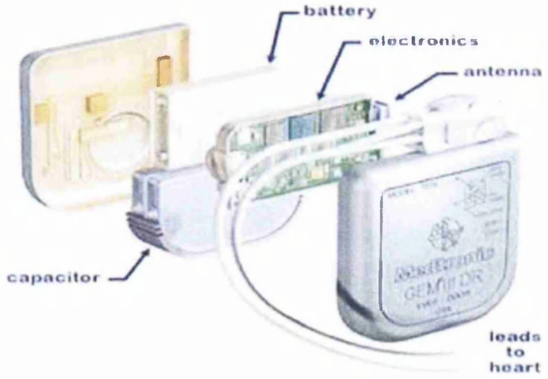

Figure 1.6: An exploded ICD, comprising of the battery, the connector holds the defibrillator leads and the computerised electronics monitors the electric signals and stores data. Image downloaded from Medtronic UK

Today's ICD can terminate a ventricular arrhythmia in three ways: (i) by antitachycardia (overdrive) pacing (ATP), (ii) by cardioversion (synchronised shock), or (iii) by defibrillation (non-synchronised shocks)(Glickson & Friedman, 2001). Ventricular tachycardias are often treated by sequences of overdrive pacing, or low energy cardioversion when overdrive pacing fails. Defibrillation is only delivered if the rhythm deteriorates or proves unmanageable to less aggressive measures (Glikson, & Friedman, 2001). In addition, to these pacing/shocking-type therapies, current models of ICDs also provide back-up bradycardia pacing. This is for when the heart rate becomes too slow and is needed by about twenty per cent of ICD recipients (Bleasdale, et al., 2005).

Photos 1.1 and 1.2: The Implantable Cardioverter Defibrillator in 2012. Photo 1 downloaded from http://www.enotes.com/topic/Implantable_cardioverter-defibrillator. Photo 2 permission by owner

Because of its smaller size, ICDs today are implanted pectorally into the subclavian area of the body without the need for a thoracotomy. The lead system is placed transvenously by way of the subclavian and cephalic veins (Hussein & Thomas, 2008). Having a non-thoracotomy procedure has led to the implant procedure becoming less invasive and therefore, less risk involved, (Hussein & Thomas, 2008) (see Figure 1.7).

Photo 1.3

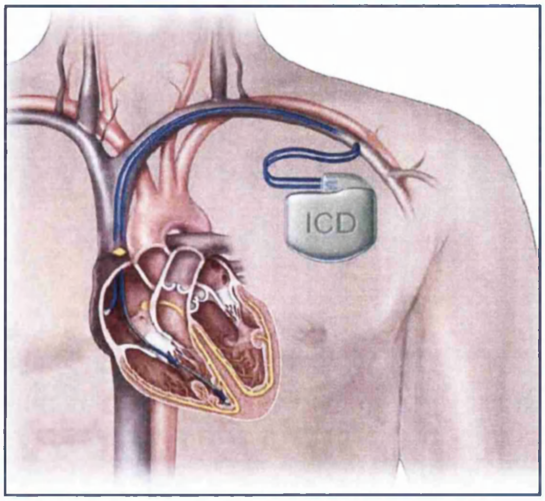

Figure 1.7

Photo 1.3: The non-invasive procedure placing the ICD under the left collarbone leaves a small scar and visible bulge. Photo downloaded from Elsevierimages.com OR unknown source

Figure 1.7: placement of the ICD under the collarbone. Picture taken from Snipes, Rosman, & Sears (2011: 1)

When the ICD is implanted, it is programmed to detect several specified tachycardia zones. This enables the less aggressive anti-tachycardia pacing (ATP) therapy to be delivered for slower, but haemodynamically stable ventricular tachycardia (Hussein & Thomas, 2008). Sophisticated rhythm-discrimination algorithms are able to distinguish between ventricular tachycardia from rapid supraventricular arrhythmia, which has resulted in a further decline in the delivery of inappropriate shocks (Hussein & Thomas, 2008). Therefore, the newer smaller ICDs are able to deliver lower-energy shocks with a higher specificity, and accordingly patients experience a reduced rate of inappropriate shocks. The most up-to-date devices allow clinicians to monitor an ICD patient's heart activity remotely using innovative remote surveillance technology (Implantable cardiac devices with remote monitoring facilities, 2009).

The Superiority of the ICD over Drug Therapies: Classic studies that show the ICD's efficacy

Several published randomised control trials have evaluated the implantable cardioverter defibrillator as a primary or a secondary preventative treatment therapy (see examples below). Primary prevention can be defined as a measure to prevent a life-threatening arrhythmic event occurring for the first time, whereas secondary prevention refers to the prevention of another SCA.

The outcomes of early secondary prevention trials suggested that the ICD was superior to drug-treatment therapy. For instance, the Antiarrhythmic Versus Implantable Defibrillators trial [AVID] (The Antiarrhythmic Investigators, 1997), and two smaller trials, the Canadian Implantable Defibrillator Study [CIDS] (Connolly, Gent, Roberts, Dorian, et al., 2000) and The Cardiac Arrest Study Hamburg [CASH] (Kuck, Cappato, Siebels, Ruppel, 1999) found patients with an ICD had a reduced level of mortality compared to those without an ICD. The AVID trial used patients who had been resuscitated after near-fatal ventricular fibrillation or those who had symptomatic, sustained ventricular tachycardia causing haemodynamic compromise (reduced blood flow into the body) and used all-cause mortality as a marker of death. Results from this study suggested the patients with an ICD had significantly increased survival rates compared with those who had only received antiarrhythmic drug therapy. Although results from the smaller CASH (1999) and CIDS (2000) studies did not reach significance levels, they nonetheless found a twenty to twenty-three per cent reduction in all cause mortality figures for patients who had received an ICD, thus lending further support that the device was a superior treatment therapy to drug treatment therapy.

As patients who have an out-of-hospital cardiac arrest have a very low probability of survival, ICDs were also tested on broader, lower-risk primary prevention populations (Tung, Zimetbaum & Josephson, 2008). Initial evidence that an ICD was superior to drug therapies for primary-type prevention was found in the Multi-centre Automatic Defibrillator Implantation Trial [MADIT] investigators, (Moss, Hall, Cannom, Daubert et al., 1996) and the Multicenter Unsustained Tachycardia Trial [MUSTT] (Buxton, Lee, Fisher, Josephson et al., 1999). Although a thoracotomy was needed at the beginning of the MADIT trial with all its inherent risks of surgery, the MADIT study (1996) found a significant reduction in overall mortality for high-risk patients[5] who were been implanted with an ICD. Although, physicians had prescribed antiarrhythmic-drugs to both study treatment groups, the

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[5] High risk patients are patients with coronary disease and left ventricular dysfunction, asymptomatic sustained left ventricular tachycardia and inducible sustained ventricular tachycardia

patients randomly assigned to receive an ICD had a significantly lower death rate caused by a primary arrhythmia than those assigned to a conventional therapy.

The MUSTT study (1999) tested the hypothesis that antiarrhythmic therapy guided by electro physiologic testing[6] would reduce the risk of sudden death and cardiac arrest amongst patients with coronary artery disease, left ventricular dysfunction, and spontaneous unsustained ventricular tachycardia. In this study, patients from one of the groups in this trial had been implanted with an ICD device. The trial concluded that the survival benefit associated with electro physiologic guided anti-arrhythmic testing was not due to the procedure per se, but due to the ICD device, which was associated with the reduction of a risk from an arrhythmia-related sudden death in high-risk patients with coronary heart disease. Support for the ICD's superior efficacy over electrophysiologic testing was also found in the Multicenter Automatic Defibrillator Implantation Trial II [MADIT II] (Moss, Zareba, Hall, Kelien et al., 2002). The MADIT II study found that the ICD reduced the rate of sudden death in those who had not undergone such invasive testing.

Congestive heart failure patients are another sub-group of patients at risk of sudden death due to an arrhythmia (Bardy, Lee, Mark, Poole, et al., 2005). The Sudden Cardiac Death in Heart Failure Trial [SCD-HeFT] (Bardy, et al., 2005) evaluated the efficacy of an ICD in patients with mild to moderate heart failure. The study found that patients with NYHA (see Chapter 2: New York Heart Association Classification System) classes II and III had a reduced rate of all cause mortality of 23% compared with those who were only prescribed amiodarone or a placebo. This suggested that an ICD for this population of patients might be an appropriate adjunctive therapy to beta-blockers.

Concurrent studies evaluated cardiac-resynchronisation therapy (CRT) in the form of biventricular stimulation. Bi-ventricular devices have a lead from the pulse generator that is placed in the right atrium, whilst two other leads (also from the pulse generator) are placed in the right and left ventricles. The extra leads make the two lower heart chambers pump in synchrony. Abraham, Fisher, Smith et al. (2002)

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[6] A therapy whereby an arrhythmia is induced and terminated by a programmed electrical stimulation in a controlled condition in a catheterisation laboratory. As a consequence, serial electrophysiologic testing was recommended to assess the efficacy of anti arrhythmic agents and to guide long-term treatment of patients (Steinbeck, Lüderitz, & Andresen, 1989)

found CRT therapy improved quality of life for patients with more advanced heart failure (NYHA III and IV). The Comparison of Medical Therapy, Pacing, and Defibrillation in Heart Failure [COMPANION] (Bristow, Saxon, Boehmer, Krueger, et al., 2004) trial found optimal drug therapy in adjunct with CRT reduced the risk of death (death or hospitalisation due to heart failure) in patients by 34 %. However, the risk of death was reduced further by 6 % when the CRT was combined with an ICD (known as a CRT-D device).

Although evidence from secondary prevention trials all suggested that the ICD could prolong survival, not all the trials for primary prevention were so convincing. However, this doubt over the ICDs efficacy in primary prevention trials might have been due to how death had been classified and whether death had been defined as all-cause mortality or arrhythmia related mortality. For instance, evidence from the Coronary Artery Bypass Graft-Patch [CABG Patch] trial (Bigger, 1997) found no improved survival rate for patients randomised to receive an ICD. However, Tung, et al. (2008) proposed that the incidence of death was significantly reduced (29 % control group versus 15 % ICD group) in favour of the ICD group. However, Tung et al suggested that this effect had been neutralised by the high incidence of death in the 30 days following the ICD implant from sterna and wound infections.

Nonetheless, despite the results from the CABG Patch trial (1997), the overall encouraging results from the other clinical studies (eg SCD-HeFT, 2005; MADIT 1996), has meant that ICD therapy has been transformed from being a restricted 'last resort' therapy to a broad-reaching prophylactic pre-emptive therapy for both primary and secondary prevention of SCD (Tung et al. 2008).

Next:

Chapter 2- Medical Conditions that Require an ICD

Part 1

Chapter 2

MEDICAL CONDITIONS THAT REQUIRE AN ICD

SECTION ONE: *Indications for an Implantable Cardioverter Defibrillator describes the NICE Guidelines [2006/2007] in line with ICDs:*

- *Secondary Prevention Therapy [NICE, 2006]*
- *Secondary/Primary Prevention Therapy [NICE, 2007]*
- *Primary Prevention ICD Therapy [NICE, 2006]*

Definitions of Cardiac Conditions in NICE (2006) Guidelines:

- *What is Sustained and Non-Sustained Ventricular Tachycardia?*
- *Bundle Branch Re-entry and Bundle Branch Block*
- *The New York Heart Association Classification System [NYHA]*

SECTION 2: *Familial Cardiac Conditions gives a brief explanation of the cardiac conditions that necessitate the ICD as appropriate therapy:*

- *Cardiomyopathies*
    - *Hypertrophic Cardiomyopathy*
    - *How is Hypertrophic Cardiomyopathy Inherited?*
    - *Dilated Cardiomyopathy*
    - *How is Dilated Cardiomyopathy Inherited?*
    - *Arrhythmogenic Right Ventricular Cardiomyopathy*
    - *How is Arrhythmogenic Right Ventricular Cardiomyopathy inherited?*

- *Channelopathies*
    - *Long and Short QT Syndromes*
    - *How is Long QT Diagnosed?*
    - *Brugada Syndrome*
    - *How is Brugada Syndrome Diagnosed?*

SECTION ONE: Indications for an Implantable Cardioverter Defibrillator

The National Institute for Health and Clinical Excellence [NICE] is an independent organisation responsible for providing national guidance on clinical practice in the

UK. This organisation provides guidance on which cardiac conditions should be treated with an ICD in the UK (Scott, Gorman, Andrews, Roberts, et al., 2008) and who should receive cardiac resynchronisation therapy (CRT-D) for the treatment of heart failure. NICE initially published guidance for the criteria for secondary and primary ICD implants in 2000, since which it has been reviewed and its criteria in some primary prevention areas were extended in 2006.

The criteria for secondary prevention in NICE (2006) remained the same as in NICE (2000) (NICE, 2006). Secondary prevention refers to the prevention of another life-threatening arrhythmic event in survivors of sudden cardiac death or in patients with recurrent unstable rhythms (Ezekowitz, Armstrong, McAlister, 2003).

Secondary Prevention Therapy [NICE, 2006]

NICE guidelines (2006) recommended Implantable Cardioverter Defibrillator treatment therapy for secondary prevention for patients who present, in the absence of a treatable cause, with one of the following:

- Having survived a cardiac arrest due to ventricular tachycardia (VT) or ventricular fibrillation (VF) (see Chapter 1: The Abnormal Heart Rhythm: Ventricular Arrhythmias)
- Spontaneous sustained VT causing syncope or significant haemodynamic compromise
- Sustained VT without syncope or cardiac arrest, and who have an associated reduction in ejection fraction (left ventricle ejection fraction [LVEF] that is less than 35 %)
- No worse than the New York Heart Association [NYHA] class III functional classification of heart failure

Secondary/Primary Prevention Therapy [NICE, 2007]

NICE (2007) guidelines recommend Cardiac resynchronisation therapy (and ICD) (CRT-D) for heart failure patients who fulfil all the following criteria:

- They are currently experiencing or have recently experienced NYHA class III-IV symptoms (see Table 2.1 for definition)
- They are in sinus rhythm:
    - **Either** with a QRS duration of 150 milliseconds or longer estimated by standard electrocardiogram (See Figure 1.5).
    - **Or** with a QRS duration of 120-149 milliseconds estimated by ECG and mechanical dyssynchrony that is confirmed by the echocardiography.
- They have a left ventricle ejection fraction [LVEF] of 35% or less
- They are receiving optimal pharmacological therapy
- And they separately fulfil the criteria for the use of an ICD

Primary Prevention ICD Therapy [NICE, 2006]

NICE guidelines (2006) recommend Implantable Cardioverter Defibrillator treatment therapy for primary prevention for patients who present with one of the following:

- A history of previous (more than 4 weeks) myocardial infarction (MI) and:
  Either

    - Left ventricular dysfunction with an LVEF of less than 35% and
    - Non-sustained VT on Holter (24-hour electrocardiogram [ECG]) monitoring **and**
      Inducible VT on electrophysiology (EP) testing

  Or

    - left ventricular dysfunction with an LVEF of less than 30% and
    - QRS duration of equal to or more than 120 milliseconds

- A familial cardiac condition with a high risk of sudden death, including long QT syndrome, hypertrophic cardiomyopathy, Brugada syndrome, Arrhythmogenic right ventricular dysplasia (ARVD) or have undergone surgical repair of congenital heart disease. (See below).

Definitions of Cardiac Conditions in NICE (2006) Guidelines: What is Sustained and Non-Sustained Ventricular Tachycardia (VT)?

Non-sustained ventricular tachycardia (NSVT) is defined as three or more consecutive beats arising from below the atrioventricular node with a rate of >120 beats a minute, that lasts less than 30 seconds and can be diagnosed using a Holter monitor[7] (Katritsis, & Camm, 2004). According to Katritsis and Camm, NSVT can be detected in patients with significant heart disease to asymptomatic, apparently healthy individuals. If there is an absence of heart disease, spontaneous NSVT does not carry any adverse prognostic significance, however if the NSVT has been induced through exercise, it may predict increased risk of sudden cardiac death (SCD) (Katritsis & Camm, 2004). In ischaemic (reduced blood supply to the heart) patients with a left ventricular ejection fraction of <40 %, NSVT has an adverse prognostic significance necessitating the need for an ICD (Katritsis, & Camm, 2004).

Sustained ventricular tachycardia[8] is defined as a ventricular rhythm that is >100 beats a minute that lasts longer than 30 seconds. Most patients with sustained tachycardia have coronary artery disease with previous myocardial infarction, and 20 % of these patients die within two-years (McComb, 2002). A minority of patients with sustained ventricular tachycardia and structural heart disease have underlying conditions other than ischaemic heart disease including dilated cardiomyopathy, hypertrophic cardiomyopathy and arrhythmogenic right ventricular dysplasia (McComb, 2002) (see Familial Cardiac Conditions below). However, sustained ventricular tachycardia can also occur in those patients who have structurally normal hearts including conditions such as bundle branch re-entry (see below), Brugada Syndrome and Long QT-syndrome (see Familial Cardiac Conditions below).

Bundle Branch Re-Entry and Bundle Branch Block

Bundle branch re-entrant tachycardia is an uncommon form of ventricular tachycardia incorporating both branches of the re-entry circuit (see Figure 1.3). Bundle branch block refers to one of the branches being blocked. Accordingly, when

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[7] A Holtor monitor is a valuable diagnostic tool in detecting patients with NSVT (Katritsis, & Camm, 2004)

[8] Sustained VT is diagnosed using a 12-lead ECG

the block is located in the right bundle branch it is right bundle branch block and a block in the left branch is referred to as left bundle branch block (Mazur, Kusniec & Strasberg, 2005). It is suggested that progressive heart failure is a common cause of death for patients with bundle branch re-entry and left bundle branch block and therefore they should fitted with an ICD, (Mazur et al., 2005; Chow, Lane & Cowie, 2003).

The New York Heart Association Classification System (NYHA)

The New York Heart Association (NYHA) is a classification system. Using this classification system, physicians clinically assess patients on the basis of the patient's limitations in physical activities caused by cardiac symptoms (Bennett, Riegel, Bittner, & Nichols, 2002) (see Table 2.1).

Table 2.1: 1994 NYHA Classification System from Bennett, Riegel, Bittner & Nichols (2002)

The 1994 New York Heart Association (HYHA) Classification System	
Class	Functional Capacity
Class I	Patients with cardiac disease but without resulting limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dsypneu (difficulty in breathing) or angina pain
Class II	Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Less than ordinary physical activity causes fatigue, palpitation, dyspnea or angina pain
Class III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary physical activity causes fatigue, palpitation, dyspnea, or angina pain
Class IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or the angina syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased

Functional capacity is a concept that represents the maximum physiologic function of which a person is capable (Bennett, et al., 2002). A related concept, functional performance, represents the amount of function that a person chooses to perform, i.e., a person may be capable of a high-level functional capacity but perform at a lower level) (Bennett, et al., 2002). According to Bennett et al. (2002), the concept measured by the NYHA classification system is not true functional capacity nor functional performance but rather measures what is defined as an individual's ability to do activities within his or her setting (which might be limited by personal, environmental and social factors as well as cardiac symptoms). Therefore the concept measured can vary due to physical disabilities caused by the cardiac disease and by individual perception of symptoms, barriers in the environment, the availability of social support and psychological factors such as depression (Bennett, et al,. 2002).

SECTION 2: Familial Cardiac Conditions

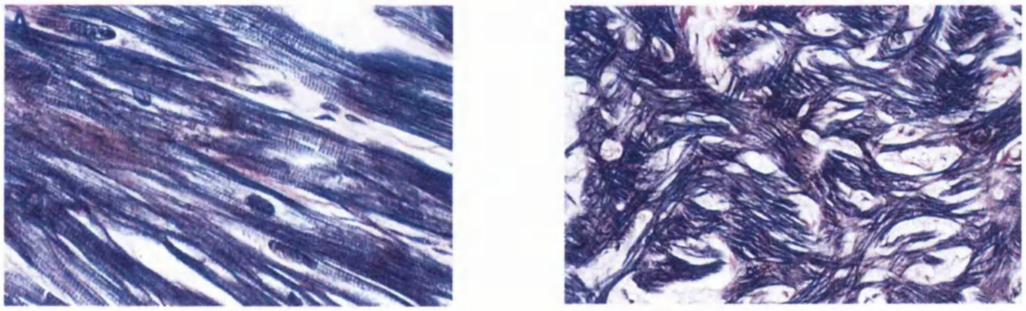
Cardiomyopathies

Cardiomyopathies are diseases of the heart muscle that make the heart muscle unable to pump enough blood around the body effectively (Ku, Feiger, Taylor, Mestroni, 2003). The changes to the heart are different for each type of cardiomyopathy and all affect the size and shape of the heart and can affect the conduction of the electrical pulse that produces the heartbeat (Ku et al., 2003). Hypertrophic cardiomyopathy (HCM or HOCM), Dilated cardiomyopathy (DCM) and Arrhythmogenic right ventricular cardiomyopathy (ARVC) are the three main types of inherited cardiomyopathies ("what is hypertrophic-cardiomyopathy?", "what is dilated cardiomyopathy?", "what is arrhythmogenic-right-ventricular-cardiomyopathy?" 2011).

Hypertrophic Cardiomyopathy

Familial Hypertrophic cardiomyopathy [HCM] affects about one in 500 of the UK population (Cirino & Ho, 2011). HCM is caused by a mutation in one of the 14 genes that encode a part of the myocardium (Cirino, & Ho, 2011). Hypertrophic cardiomyopathy is a common genetically transmitted disease defined clinically by the presence of thickening in the left ventricle, which can also sometimes occur in the right ventricle (McKenna & Elliott, 2011a; Elliott & McKenna, 2004).

Whereas in a normal heart, the cells of the heart muscle lie in smooth straight lines, with HCM, the cells lie in disorganised layers (myocardial disarray) (see Figure 5), and there is often scarring on the myocardium. The thickening and scarring of the myocardium make the muscle stiff and a higher blood pressure is needed to make the heart muscle contract and pump blood around the body. The abnormality of the heart muscle can sometimes interfere with the normal electrical activity of the heart. In the affected parts of the heart muscle, the electrical impulse may become disrupted as it crosses the areas of disarrayed cells and scarring, which can lead to an arrhythmia (McKenna & Elliott, 2011a).



Figures 2.1 A & 2.1 B: Hypertrophic cardiomyopathy. The two images show the myofibrillary structure with blue (PTAH stain) in the normal myocardium (A) where the muscle cells are arranged in parallel. (B) In HCM myocardium, the heart muscle cells are in disarray with increased fibrosis, which can lead to the electrical impulse travelling through the heart to become irregular resulting in an arrhythmia. Images downloaded August 2012 from Heart.BMJ.com Heart 2000; 83:469-474 doi:10.1136/heart.83.4.469

Approximately 10-20% of individuals with HCM have a lifetime-increased risk for sudden cardiac death [SCD], mostly resulting from ventricular tachycardia or ventricular fibrillation. Sudden death occurs with a frequency of about 1% or less per year in adults with HCM rising to 2-4% in children and adolescents (Elliott & McKenna, 2004).

How is Hypertrophic Cardiomyopathy inherited?

McKenna & Elliott (2011a) posited that the inheritance pattern for hypertrophic cardiomyopathy (HCM) is autosomal dominant[9]. The condition may be passed on from an affected male or female and does not skip a generation. They suggested that the majority of individuals with HCM have at least one other first-degree relative[10] with the same condition. They posited that children of affected parents should be screened using an ECG and an echocardiogram[11] every three years until puberty, and then every year until they reach the age of 20 years. However, if no evidence appears by early adulthood, it is unlikely that the person will develop HCM. Diagnosis can also be made through genetic testing; if a family member with HCM has been found to have a specific genetic mutation that caused the HCM, it is then possible to screen family members for the same genetic mutation.

Dilated Cardiomyopathy

It is estimated that one in 2500 people have dilated cardiomyopathy (DCM), although the disease is probably more common (Ku, Feiger, Taylor, Mestroni, 2003). In DCM the left ventricle becomes dilated (stretched) causing the myocardium to become weak, thin or floppy and unable to pump blood around the body efficiently (McKenna & Elliott, 2011b). As the heart enlarges, it becomes less effective in pumping blood, which then leads to symptoms of heart failure and arrhythmias (see Figure 2.2 B).

There are many possible causes of dilation and dysfunction of the heart, such as coronary artery disease, viral infections, auto-immune diseases, exposure to toxins, pregnancy, and excessive use of alcohol (Ku, et al., 2003; McKenna & Elliott, 2011b). However, it is unknown whether the people who go on to develop DCM is due to the one of the possible causes (just cited) or whether the individual already had a mutated gene (McKenna & Elliott, 2011b). In most cases, the DCM has an

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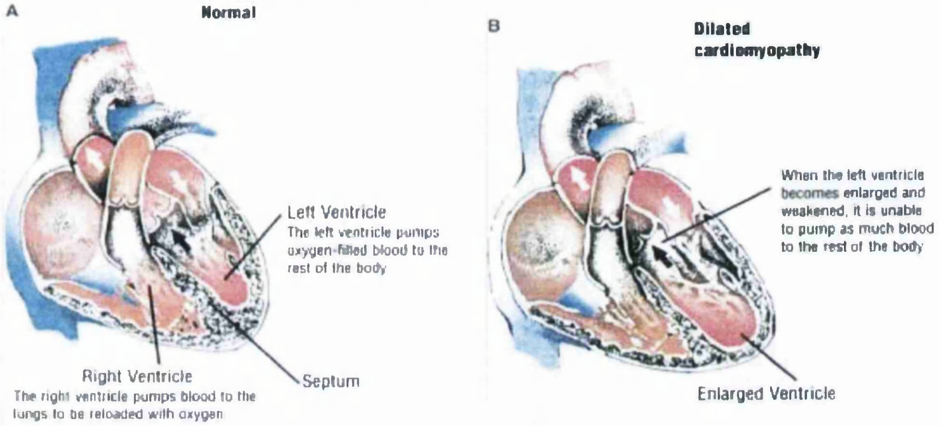
[9] Autosomal dominant means that each child of an individual has a 1 in 2 chance of inheriting the mutated gene (McKenna & Elliott, 2011a).

[10] First degree relative is a parent, brother, sister, or child

[11] Ultrasound waves assess the structure of the heart. This allows any abnormalities in the heart muscle to be identified and whether there is any leaking in the heart valves (McKenna & Elliott, 2011a)

unknown cause and therefore often called an idiopathic dilated cardiomyopathy [IDC] (Hershberger, Kushner, Parks, 2009).



Figures 2.2 A & 2.2 B. Normal (A) and DCM (B) hearts. DCM occurs as the result of an enlargement of the left ventricle. Inefficient pumping of the blood can cause heart failure, and DCM may be complicated by malignant arrhythmias leading to sudden death. Image copied from Ku, Feiger, Taylor, & Mestroni (2003)

When two or more close family members meet the diagnostic criteria for IDC, a diagnosis of familial dilated cardiomyopathy is made. Although arrhythmias and conduction system diseases commonly accompany advanced heart failure and advanced cardiomyopathy, they often precede heart failure in individuals with heritable cardiomyopathy. Individuals with DCM are treated for their arrhythmia and problems with the natural electrical signal with an implantable cardioverter defibrillator to stop any life threatening rhythm disturbances occurring which could lead to sudden death. When the heart failure becomes advanced, individuals may be implanted with a bi-ventricular pacemaker to help the ventricles work in synchrony.

How is Dilated Cardiomyopathy inherited?

The common inheritance pattern for dilated cardiomyopathy is autosomal dominant and the condition can be passed on from a male or female. McKenna and Elliott (2011b) suggested that the abnormal gene for dilated cardiomyopathy is transmitted on the one of the sex chromosomes (X chromosome). Men with this X-linked form of dilated cardiomyopathy will always pass the abnormal gene to their daughter but cannot pass it on to their sons who only inherit the Y-chromosome from their father. Women with X-linked dilated cardiomyopathy tend to be less severely affected but have a 1 in 2 chance of passing on the abnormal gene to sons and daughters. If someone has suspected dilated cardiomyopathy, diagnosis can be made using and ECG, a chest x-ray, and a echocardiogram. If a family member with dilated cardiomyopathy was found to have a specific genetic mutation that caused the condition, it would then be possible to screen family members for the same genetic mutation.

Arrhythmogenic Right Ventricular Cardiomyopathy

ARVC is an inherited heart muscle disease that can affect the left ventricle but predominantly affects the right ventricle (Corrado & Thiene, 2006). The estimated prevalence of Arrhythmogenic right ventricular cardiomyopathy [ARVC] is one in 2000 to one in 5000 and appears to affect more men than women with a ratio of 3:1 (Corrado & Thiene, 2006).

In a normal heart, proteins hold the cells of the muscle together and in individuals with ARVC these proteins have not developed properly due to gene mutation (McKenna & Elliott, 2009). As a result, when the heart is under stress (e.g. during physical exertion), the proteins cannot keep the cells together and they become detached and die. The damaged and dead heart muscle cells become fibrous and cause scarring and fatty deposits build up in an attempt to repair the damage. Because of these changes to the structure of the heart muscle, the walls of the ventricle become thin and stretched, which results in the heart being unable to pump blood around the body efficiently. In addition, the normal passage of electrical impulses through the heart is interrupted or altered causing life-threatening arrhythmias and in some cases sudden cardiac death (McKenna & Elliott, 2009).

ARVC progresses in four phases (McKenna & Elliott, 2009):

- Phase 1: The first phase is the concealed phase whereby there are some subtle structural changes in the right ventricle. Although there are generally no symptoms, the individual may be at risk of sudden cardiac death [SCD] particularly during physical exertion.
- Phase 2: The second phase is called the Overt phase in which there are noticeable structural changes to the heart. Palpitations, light-headedness and syncope are symptoms and there is the risk of SCD on exertion.
- Phase 3: The third phase is when the right ventricle becomes stretched and its pumping action becomes less efficient leading with the risk of ventricular arrhythmias and SCD.
- Phase 4: In the fourth and final phase, there are changes to the left ventricle and there is reduced pumping action in both ventricles leading to heart failure.

Not all people will develop all four phases and the overall risk of SCD in ARVC individuals is low, however there are certain times called 'hot phases' when the disease process becomes more active (e.g. unexplained dizzy spells, sustained palpitations), which increases the risk of SCD (McKenna & Elliott, 2009a). Those individuals who are at increased risk of SCD are implanted with an ICD.

How is Arrhythmogenic Right Ventricular Cardiomyopathy inherited?

McKenna and Elliott (2009) posited that the most common inheritance pattern for Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) is autosomal dominant. Although the genetic mutation may be passed down from an affected male or female, not everyone who inherits the abnormal gene mutation will develop the condition. A person who has the gene mutation but does not develop ARVC is known as an obligate carrier. However, the child of the obligate has a 1 in 2 chance of developing the condition. Accordingly, it might appear that ARVC has skipped a generation. McKenna and Elliott (2009) suggested that sometimes ARVC is inherited as an autosomal recessive, which means a person can only develop ARVC is both their parents are carriers and two copies of the genetic mutation are inherited.

ARVC is a progressive disease, and families of affected individuals usually screened regularly with an ECG and an echocardiogram (McKenna & Elliott, 2009). Diagnosis of whether someone is carrying the mutated gene can be carried out through genetic testing. If someone with ARVC has genetic testing which has found a specific gene mutation that has caused the ARVC then other family members can be tested to see if they carry the same mutated gene. However if results conclude the person is carrying the mutated gene, it is not possible to determine whether the person will develop the condition. They might be obligate carriers and need to continue to be regularly screened.

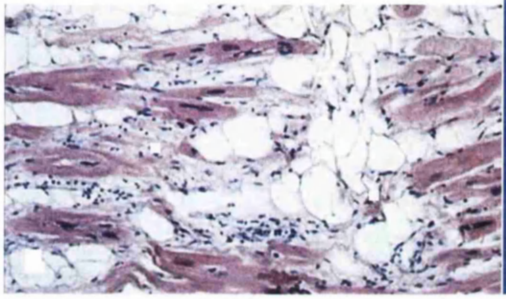


Figure 2.3

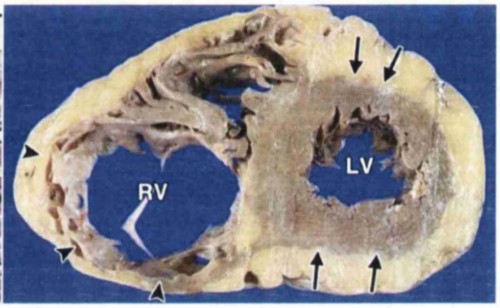


Figure2.4

Figure 2.3: The image above shows typical histological features of ARVC. Ongoing myocyte death (black spots) with early thickening and scarring, which can trigger an arrhythmia. The white areas are fatty cells that are replacing the pink heart muscle. Image downloaded August 2012 from http://www.bostonscientific.com/lifebeat-online/heart-smart/cardiomyopathy.html

Figure 2.4: Autopsy specimen of ARVC in a 67- year-old man who died of congestive heart failure (phase four of ARVC). Photograph of the cut surface of the heart shows marked thinning of the right ventricle free wall (arrowheads) with left ventricle involvement (arrows). The yellow part shows where the fat is replacing the heart muscle (brownish part). Image downloaded August 2012 from Radio Graphics October 2010 vol. 30 no. 6 1587-1602

Channelopathies

In about one in every 20 cases of sudden cardiac death [SCD], there is no structural cardiac abnormality found (Schimpf, Veltmann, Wolpert, & Borggrefe, 2009). If no definite cause of death can be found even after a post mortem, it is referred to as Sudden Arrhythmic Death Syndrome [SADS] (Behr, 2009b) of which about four in every 10 cases of SADS is due to a rare disease called an ion channelopathy (Behr, 2009b).

An ion channelopathy is an inherited heart rhythm disturbance whereby the electrical functioning of the heart is affected (Schimpf et al., 2009). An ion channelopathy is not common and caused by mutated genes and although they are usually inherited from parents, they can occur for the first time in a single-family member (Behr, 2009a). The heart is made up of millions of cells that form the myocardium. Each cell has pores in the cell membrane called ion channels. These allow the movement of chemicals such as sodium, potassium and calcium, into and out of the cells which provides an electrical signal that stimulates the heart to beat. In an ion channelopathy, the mutated genes affects the efficiency of the ion channels, resulting in the individual to be prone to arrhythmias, cardiac arrests and SCD (Behr, 2009b).

ICD implantation is cited to the primary therapy for high-risk groups of patients with a channelopathy (Kaufman, 2009; Veltmann, Schimpf, Borggrefe & Wolpert, 2009). The ICD is the only reliable therapy in patients with Brugada syndrome and SQT syndrome as no pharmacological interventions has been found to prevent sudden death in these disease types (Veltmann et al.,2009). Although LQT syndrome and CPVT patients are usually treated with beta-blockers, the ICD is indicated in high-risk[12] patients (Veltmann et al., 2009). Electrical cardiomyopathies include long QT syndrome (LQTS), short QT syndrome (SQT), and Brugada syndrome.

Long and Short QT Syndromes

Long QT Syndrome occurs in about one in 2000 people and in only about seven out of 10 LQTS occurrences have the gene mutations been identified (Behr, 2009b). In

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[12] Risk assessment is based on the ECG, this history of unexplained or disease-related syncope and sudden cardiac arrest. In LQT syndrome and CPVT, age, gender and genotype are also important risk stratification (Veltman, Schimpf, Borggrefe, & Wolpert, 2009)

most cases of LQTS, potassium channels that regulate the potassium ions from inside to outside the cells release the potassium out of the cell too slowly. Sometimes the sodium channels are affected and too much sodium is allowed into the cells. In both cases, this results in prolonged repolarisation, whereby the time-period for part of the heartbeat cycle is lengthened.

The three most common types of inherited Long QT Syndrome are called LQTS 1, 2 and LQTS 3. In Types 1 and 2 are caused by abnormal potassium channels and an arrhythmic episode can be triggered by emotional stress, exercise or a loud noise. In Type 3, the sodium channel is affected and during sleep or during rest when the heart rate is slow, SCD can occur (Behr, 2009a). Short QT syndrome (SQTS) has also been related to several mutations also affecting the ion channels resulting in a shortened repolarisation period. Unlike in LQTS, when potassium is released from the cell too slowly, SQTS causes too much potassium to flow out of the cell (Behr, 2009a).

The "QT" interval is found on an electrocardiogram (ECG) and represents the electrical activity of the heart (see Figure 1.5). It is measured from the initiation of the QRS complex to the end of the T-wave. The duration of the QT-interval in normal people at a heart rate of 60 beats per minute is between .35 and .44 seconds. In LQTS, the QT-interval is more than .44 seconds and in patients with SQTS the duration of the QT interval is been between .21 and .34 seconds. Abnormally long and short QT intervals (see Figure 2.5) have been shown to be associated with increased risk of life-threatening ventricular arrhythmias and sudden cardiac death (Goldenbert, Moss, Zareba, 2006), especially in the case of SQTS in which 34 % of SQ sufferers are diagnosed after a cardiac arrest (Moreno-Reviriego, & Merino, 2010) . Normal individuals have longer QT interval lengths when the heart rate is slow and shorter during fast heart rates. However, people with SQTS show constant QT values and a lack of adaptation to heart rate with failure to prolong adequately at slower heart rates and abnormal shortening during exercise (Moreno-Reviriego, & Merino, 2010).

Drug therapy appears to be the first line of treatment in LQTS, followed by an implantable cardioverter defibrillator as a secondary prevention if the drugs are unable to control arrhythmic events (Behr, 2009a; Veltmann, et al., 2009). However for SQTS, with its high risk of SCD, the ICD is the primary therapy. (Moreno-Reviriego, & Merino, 2010).

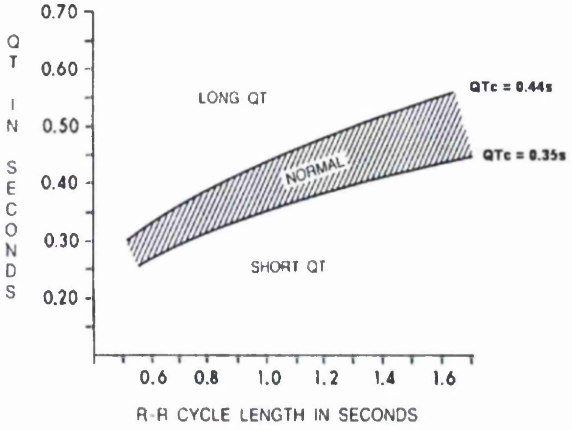

Figure 2.5: Image downloaded from Goldenberg, Moss & Zareba, (2006). Lower and upper limits of QT intervals for different RR cycle lengths based on QT-interval measurements in normal healthy sample

How is Long QT Diagnosed?

An ECG can determine diagnosis of long QT Syndrome (LQTS). However abnormalities of ECG rhythm may not show up for many people who might be carriers of the condition (McKenna & Elliott, 2009). Therefore, some people may need to undergo repeated ECGs, exercise tests and 24-48 ECG monitoring. However, even with these more comprehensive tests, there may be no abnormalities even when the condition exists (McKenna & Elliott, 2009). Genetic testing can sometimes identify carriers of LQTS, however this form of testing is of limited use as there are many unknown genetic mutations related to LQTS. Many families who do have mutations appear to have mutations that are unique to the family, which can make it difficult to determine whether a mutation is responsible for causing the condition (McKenna & Elliott, 2009).

Brugada Syndrome

Brugada syndrome is a hereditary disease associated with right ventricular conduction delay. The syndrome typically manifests itself during adulthood, with a mean age of sudden death 41 ± 15 years and is estimated to be responsible for at 4 % of sudden deaths and at least 20 % of sudden deaths in patients with structurally normal hearts (Antzelevitch, Brugada, Borggrefe, Brugada et al., 2005). Ventricular fibrillation and sudden death in Brugada usually occur in patients during rest periods and during the night and is more prevalent in males (Antzelevitch, et al. 2005; Kaufman, 2009). Risk factors for sudden death include, having a prolonged QRS (see Figure 2.5), and a family history of sudden death (Kaufman, 2009). To date there is no effective drug therapy for Brugada syndrome (Kaufman, 2009) and therefore the ICD device to date it is the only effective treatment for this disease.

How is Brugada Syndrome Diagnosed?

McKenna & Elliott (2009) posited that sometimes changes characteristic of Brugada can appear on ECGs. However, the ECG may not show any visible changes in which case a provocation test is carried out whereby the individual is injected with an anti-arrhythmic drug during an ECG reading. However, a negative ECG test from a provocation test does not necessarily mean the person has not inherited a mutated gene (McKenna & Elliott, 2009). Genetic testing for Brugada does not appear to be useful (McKenna & Elliott, 2009) as genetic mutations have only been found in a small proportion of people diagnosed as having the syndrome.

Next:

Chapter 3- Living with an ICD

Part 1

Chapter 3

LIVING WITH AN ICD

SECTION ONE: *Psychological Impact on the ICD Patient – Introduction and Qualitative Literature Review that explores the experience of patients and partners who live with an ICD. Also, a critical evaluation of the papers in the qualitative literature review*

SECTION 2: *Prevalence and Trajectories comprises:*

- *Prevalence of Anxiety and Depression in ICD patients*
- *Trajectory of Quality of Life in ICD patient*
- *Impact on the Partner: Prevalence and Trajectory of Anxiety, Depression and Quality of Life for Partners*
- *Risk Factors that Influence Psychological Distress in Partners*

SECTION 3: *Risk Factors that Influence Psychological Distress in ICD Patients:*

- *Age and Gender*
- *Type-D Personality Disposition*
- *Coping Styles and Behaviour*
- *Heart Failure Co-morbidity*
- *ICD-related Concerns*

SECTION ONE: Psychological Impact on the ICD Patient

Introduction

Evidence was suggested that an ICD is superior to anti-arrhythmic drug therapy in reducing mortality (see AVID, 1997; CASH, 1999; & CIDS, 2000 studies Chapter 1). However, ICD recipients have reported high levels of psychological distress such as anxiety and depression (e.g. clinical review by Sears, Matchett & Conti, 2009). The implications of high levels of psychological distress are two-fold; the first is that a high level of distress can in itself trigger a dangerous heart rhythm. For instance, findings from Kop, Krantz, Nearing, Gottdiener et al. (2004) suggested that mental stress induced cardiac electrical instability in patients vulnerable to arrhythmias. Psychological distress such as anger (Lampert, Joska, Burg, Batsford et al., 2002), having mild to moderate depression (Whang, Albert, Sears, Lampert et al., 2005; Suzuki, Shiga, Kuwahara, Kobayashi, 2010) or having a Type-D personality with anxieties (van den Broek, Nyklicek, van der Voort, Alings et al., 2009) have also been found to be associated with increased abnormal heart rhythms and mortality.

The second implication and more relevant to this research study, is the finding that ICD patients and their partners have not only reported high levels of anxiety and depression, but have also reported a reduced quality of life (Sears & Conti, 2002). Dunbar (2005) found depression and anger were commonly experienced by patients post-ICD implant. In Sears, Todaro, Lewis and Sotile's (1999) literature review, ICD-specific fears and symptoms of anxiety were reported to be the most common psychological symptoms experienced by ICD patients. In their review, Sears et al. (1999) found that the most common concerns for patients who were clinically anxious were trouble sleeping, memory problems, depression, overprotective family members, fear of shock, fear of device malfunction, fear of death, sense of loss of control and sexual difficulties. These anxieties resulted in patients using avoidant behaviours that consequently affected their quality of life (QoL). For instance, Bostwick and Sola (2007) suggested patients avoided activities, situations and objects if they were perceived to be associated with an ICD shock. Hussein and Thomas (2008) and Zayac, and Finch (2009) suggested avoiding activities led to a lower quality of life. They found sexual activity and mild forms of physical exercise were often avoided by patients after their implant, due to a fear of triggering a dangerous arrhythmia.

Qualitative research is a useful way to explore the psychological impact of the ICD on patient's lives. Serber and Rosen (2010) posited that ICD patients have a complex set of beliefs and reactions towards their cardiac disease and shock therapy, which can influence how they cope with their device. Whereas quantitative research forces participants to categorise answers (Serber & Rosen, 2010), qualitative research is able to explore and capture a patient's subjective experience of living with an ICD. For this reason, qualitative studies were examined to: (i) explore the complexity of beliefs held by ICD recipients and their partners and (ii) to explore coping behaviours used by patients and partners as they live with their ICD.

Qualitative literature review

An integrative approach that accommodated the inclusion of studies with different methodologies was chosen. An electronic search was carried out using a combination of the **databases** and "*search terms*" below:

- **BMJ Journals – Heart:** *"Implantable cardioverter defibrillator" (all words in text or abstract; years 2000-2010) AND "Psychosocial adaptation" (in text): "Implantable cardioverter defibrillator" (all words in text or abstract; years 2000-2010) AND "anxiety AND/OR exercise"*
- **CSA illumine:** "I*mplantable cardioverter defibrillator" (years 2000-2010):*
- **PsycARTICLES:** "*Implantable cardioverter defibrillator"*
- **PsycINFO (Ovid):** "*Implantable cardioverter defibrillator" (+2002 to current):*
- **PubMed:** *"Implantable Cardioverter Defibrillator AND adaptation" "Implantable Cardioverter Defibrillator AND anxiety" "Implantable Cardioverter Defibrillator AND Avoidance behaviour" "Implantable Cardioverter Defibrillator AND beliefs" "Implantable Cardioverter Defibrillator AND exercise"*
- **ScienceDirect:** *Basic Search: "Implantable cardioverter defibrillator AND avoidance behaviour" "Implantable cardioverter defibrillator AND avoidance behaviour AND anxiety"*
    - *Advanced Search: (All sciences, Journals: articles, 2000-2010)*
- **Web of Knowledge**: *"Implantable cardioverter defibrillator AND anxiety" (all years)*
- **Wiley Interscience:** *"Implantable cardioverter defibrillator AND anxiety" (in texts and abstracts; produce type: journal; years 2000-2010)*
- **EThOS:** *"Implantable Cardioverter defibrillator"*
- **Web of Science:** *"Implantable cardioverter defibrillator AND anxiety" (limited to "topic" +2000-2010)*

The criteria for inclusion into this systematic review were that the qualitative studies had to be recently published (e.g. After the year 2000) in a peer reviewed journal, and used adults participants (aged $\geq$ 18 years). The search identified 15 studies, however two articles (pre-year 2000) were later included from the reference lists of individual journal papers found.

Table 3.1: Studies included in the systematic review

Author (Year)	Number of Participants	Country of Origin	Name of Journal	Data Collection	Aim of Study
Albarran, Tagney, James (2004)	6 female partners/ 2 male partners	UK	European Journal of Cardiovascular Nursing	Interview: Number of months since ICD 3-20 months	To explore partner's experiences of living with an ICD
Bolse, Hamilton, Flanagan et al., (2005)	8 male patients/ 6 female patients	USA	Progress in Cardiovascular Nursing	Interviewed at approximately 2-years post-implant	To explore how patients perceived their life situation
Burke, (1996)	10 male patients/ 14 female patients	USA	Heart & Lung	Interviewed Patients at three time points: 1 day post-implant, 3-months and 6-months	To examine the process of adjusting to the ICD over the first 6-months
Dickerson (2002)	85 discourses from 62 ICD patients	USA	Qualitative Health Research	Data source 1[13]: individual & focus group interviews Data source 2[14]: Postings on an Electronic Bulletin Board for ICD patients Data source 3[15]: Written comments on a QoL survey	Secondary Analysis of three data sources
Eckert & Jones (2002)	3 male patients/ 3 Significant others	Australia	International Journal of Nursing Practice	Interview: Number of months since ICD: >5	To describe feelings and experiences of the patients and the impact on lifestyle for the families
Flemme, Hallberg, Johansson & Stromberg (2011)	9 male patients/ 7 female patients	Sweden	Heart & Lung	Interview at 6-24 months	To explore how the ICD impacts on daily life
Fridlund, Lindgren, Ivarsson, Jinhage, et al. (2000)	10 male patients/ 5 female patients	Sweden	Journal of Clinical Nursing	Post-implant ≤ 6-months (time unspecified)	To examine how patients conceived their life situation

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[13] Dickerson, Poslunszny, & Kennedy (2000)
[14] Dickerson, Flaig & Kennedy (2000)
[15] Dickerson, Wu, Kennedy, Nahigian et al., (2000)

Author (Year)	Number of Participants	Country of Origin	Name of Journal	Data Collection	Aim of Study
James, Albarran, Tagney (2001)	2 female patients/5 male patients 2 male partners/5 female partners	UK	Coronary Health Care	Interview: number of months since ICD ≤ 18	To examine the impact of the driving ban on patient's lives
James, Albarran, & Tagney (1999)	2 female patients	UK	Advanced Clinical Nursing	Interviews at Pre-implant, immediately post-implant, discharge home (time unspecified)	To examine the lived experience of two women around the implant and post implant period
Kamphuis, Verhoeven, Leeuw, Derksen, et al. (2004)	12 male patients 9 female patients	Netherlands	Journal of Clinical Nursing	Interviewed 1-, 6- and 12-months	To explore the experience of ICD patients during their first year
McDonough (2009)	8 male patients 12 female patients	USA	European Journal of Cardiovascular Nursing	Telephone and Internet interviews. Number of years since ICD (telephone): 1-6 Number of years (internet): 3 months-17 years	To explore the experience of young (18-40 years) participants living with an ICD
Mert, Argon, Aslan (2012)	15 male patients 4 female patients	Turkey	International Journal of Caring Sciences	Focus group interviews with 4-5 patients. Mean number of months since implant: 15	To describe the experience of living with an ICD
Morken, Severinsson & Karlsen (2009)	11 male patients 5 female patients	Norway	Journal of Clinical Nursing	Interview post implant. Number of years since ICD: 10 months-15 years	To explore patients' experiences over time
Palacios-Ceña, Losa, Fernandez-de-las-Penas, Salavdores-Fuentes (2011)	22 male patients	Spain	Journal of Clinical Nursing	Two phased study: Interviewed either once or twice at 3 months to 12-years. Data also included personal diaries and letters	To explore Spanish recipients' experiences of living with an ICD
Steinke, Gill-Hopple, Valdez, & Wooster (2005)	10 male patients/ 2 female patients	USA	Heart & Lung	One interview. Number of years since implant: 1-13. Mean number of years: 5.3	To explore the experiences of patients and partners return to sexual activity post-implant

Author (Year)	Number of Participants	Country of Origin	Name of Journal	Data Collection	Aim of Study
Tagney, James, & Albarran, (2003)	6 male patients/ 2 female patients	UK	European Journal of Cardiovascular Nursing	Interview: Number of months since ICD 3-20 months	To explore the experience of UK patients on returning home after their ICD implant
Williams, Young, Nikoletti, & McRae (2007)	8 male patients/3 female patients 8 female partners/3 male partners	Australia	International Journal of Nursing Practice	Number of years since ICD: <2 years to □3 years	Focus on the physical and psychological adjustment to the ICD

Seventeen qualitative studies were found (see Table 3.1). One paper was published in a qualitative research journal, and the remaining 16 papers were published in nursing journals. Five studies were from the USA, four were from the UK, three were from Scandinavia, two were from Australia and one was from the Netherlands. The two most recently published studies were from Spain and from Turkey. Studies varied in the number of participants interviewed which ranged from two to 24 and some included partners or family members as well as patients. The majority of studies focussed on experiences living with the ICD, although two (Steinke et al., 2005 and James et al., 2004) focussed on specific issues (sex and the driving ban) and how these issues affected ICD patients.

The method of data collection varied from study to study, with most using one one-to-one interview. Three studies however carried out one-to-one interviews using a longitudinal design over the first year post implant (Burke, 1996; James et al. 1999; Kamphuis et al. 2004). Three studies used methodologies that were not one-to-one; one study used a focus group interview (Mert et al., 2012). Another study used written evidence taken from personal diaries and letters (Dickerson, 2002) and one study used the mediums of the telephone and internet to collect data (McDonough, 2009). Although most studies used patients and/or partners who had been living with the ICD for approximately 1-2-years, four studies used patients who had lived with their ICD for longer (Morken, et al., 2009; Palacio-Ceña et al., 2011; McDonough 2009; and Steinke et al., 2005).

Despite the lack of homogeneity between the studies' methodologies, some inferences can be made from examining these studies' findings. One inference is that there appeared to be some commonality about how patients felt when they agreed to have the device fitted. Although patients had a choice whether to have an ICD, many patients felt this choice did not exist. Some patients believed that if they refused to have an ICD, they would be choosing to die (Burke, 1996; Dickerson, 2002). As such, Burke (1996) suggested the choice was a moral dilemma. This meant that patients had to choose to have an ICD or else they would die. Tagney et al. (2003) and Burke (1996) found this meant that the patient before their implant had not thought through other issues such as living with an ICD and coping with a shock, because the focus had been on the moral dilemma and these issues had not been anticipated.

The predominant themes found in the qualitative studies reviewed included living in fear, being fearful of the shock and the uncertainty and anxiety surrounding the ICD's ability to shock. Those who had not experienced a shock had fear of the 'unknown'. For example, Kamphuis et al. (2004) found patients were fearful of the 'unpredictable' nature of the shock, which created uncertainty as they wondered when and where the device would fire and how would it feel. James et al. (1999) found patients remembered that they had been advised that their chest would hurt after a shock, which contributed to feelings of apprehension.

Burke (1996) found patients believed that if they could experience a shock, it would help them accept their ICD and the shock would help them set aside any ambiguity about relying on technology to survive. Although patients appraised the ICD as 'life saving', their relationship towards their ICD could be described more as a 'love-hate' relationship (e.g. Dickerson, 2002; Palacios-Ceña et al., 2011), or alien (e.g. Fridlund et al., 2000). However, it was not clear from these studies whether these particular patients had experienced a shock from the ICD.

Patients who had an ICD shock continued to be fearful of the ICD shock. The shock experience for some patients had made them realise how quickly a shock could occur with little forewarning. This left them feeling uncertain and anxious. Patients were especially anxious when they were out in public, or in crowded areas (e.g. Eckert & Jones, 2002; McDonough, 2009), because they feared having a shock in a public place. Burke (1996) found that some patients feared it would not terminate the arrhythmia when it needed to. Therefore, some patients felt relieved after the shock occurred, as it meant that their device was functioning (e.g. Morken et al. 2009; Eckert & Jones, 2002). However, they also felt disappointed that their heart had needed the ICD and now had to accept that they were dependent on technology to survive (e.g. Tagney et al., 2003; Kamphuis et al., 2004; Dickerson, 2002).

Some of the studies, such as Dickerson (2002) and Morken et al. (2009) found patients described a shock as being a warning of imminent death. Other studies found patients reported being afraid of the shock because they believed it was tantamount to dying. For instance, Palacios-Ceña et al. (2011) reported that patients believed shocks were episodes of dying. The belief that a shock was an episode of death meant some patients had wondered if they were actually going to die whilst being shocked (Bolse et al., 2005; Mert et al., 2012). Although the shocks reminder of possible death clearly upset some recipients, the reminder did not have a negative influence on all patients. Some recipients found the realisation that they might be near death made them reassess their values, friendships, activities, and priorities and went on to have a deeper appreciation of life (e.g. Burke, 1996; Dickerson, 2002; Bolse et al., 2005; Flemme et al., 2011). For example, Fridlund et al. (2000) found that although patients perceived their careers had suffered due to the ICD, their careers were now perceived to be less important to them.

Not all patients appraised a shock as a meeting with death, but saw it merely as a setback and a knock to their confidence (e.g. Tagney et al., 2003). Interestingly, although Sears and Kirian (2010) suggested that often patients believed that a shock meant their heart condition was getting worse, only one of the qualitative studies mentioned that patients associated a shock with disease progression (see Williams et al., 2007). Dickerson (2002) suggested patients tended to treat death as a symptom, which could be treated by the ICD, and this might account for why patients did not focus on their heart condition getting worse. Generally, the qualitative studies in this review found patients did not perceive the shock to be a marker of disease progression but to be a close shave with death, which was both unpredictable and uncontrollable.

Despite patients' acknowledgement that shocks were unpredictable and uncontrollable, the studies found that patients tried to control this uncertainty by engaging in avoidant or restrictive behaviours. Tagney et al. (2003), Morken et al. (2009) and Fridlund et al. (2000) reported that patients were uncertain about how far they their heart rate could rise without it triggering a shock. Because of this uncertainty and a fear of being shocked, patients often avoided any activity that might make them out of breath. For instance, James et al. (1999) found that some patients in an attempt to prevent an arrhythmia avoided doing housework. Eckert and Jones (2002) found that some patients were fearful that they might act as a conductor for the shock, which meant some patients refused to hold grandchildren and reduced or avoided being intimate with their partner.

The qualitative findings found that the fear of shocks clearly encroached on the intimate sexual relationships of patients and partners. Steinke et al. (2005) and

Tagney et al. (2003) found that patients and their partners refrained from resuming sexual relations after the ICD or reduced its intensity and frequency. Although patients often wanted sex, they were so fearful that their increased heart rate might trigger a shock that they abstained. Whereas partners were frightened that the excitement of sex might trigger a shock, patients were often more worried that if they had a shock during sex, their partner might be harmed. One partner in Steinke et al.'s (2005) study described the experience of being shocked during sexual intercourse. He reported that the sheer force of the shock had physically thrown him off his wife, and described the shock as being like a bolt of lightning that had lit up the room. Steinke et al. (2005) found that once a shock was experienced during sex, couples tended to wait for a while for their confidence to be returned before resuming sex. Steinke et al. (2005) also found couples often tried to experiment using different positions to have sex to the one used when the shock was experienced.

For patients, the uncertainty surrounding shocks led some of them to become overly attentive to bodily cues, which in some instances resulted in patients having catastrophic beliefs. For instance, McDonough (2009) found some patients believed that shortness in breath or a rapid heart rate during exercise were indicative of a worsening heart, despite the fact that these symptoms are normal physiological reactions to physical activity. These catastrophic beliefs resulted in some patients refraining from doing any physically demanding activities.

Patients who had not experienced a shock were often apprehensive about how they would cope in the event of a shock. Consequently, this apprehension about a shock meant some patients avoided being alone for the first few months after their ICD implant. The fear of being left on their own resulted in some patients feeling dependent upon family members as they experienced a loss of autonomy (e.g. Williams et al., 2007; Kamphuis et al., 2004; Morken, et al., 2009; Tagney et al., 2003). Tagney et al. (2003), found a family's over protectiveness increased the patient's dependence upon the family, which led to increased feelings of loss and feelings of isolation already being experienced by the patient. Other studies found overprotection and hypervigilence by family members resulted in some patients feeling increasingly vulnerable (James et al., 2001), 'weighed down' (Palacios-Ceña, et al., 2011) and stifled (Kamphuis et al., 2004).

The Driver and Vehicle Licensing Agency (DVLA) prohibit ICD patients driving for 6-months post-implant. This driving ban can further intensify the losses of independence felt by patients as they can become resentful at being dependent on others for being taken to places. For instance, in a UK study, James et al. (2001) and Albarran et al. (2004) found patients became resentful to others because they were dependent on them for transport. However, after 6-months, and the patient was able to drive once more, some patients used avoidant and restrictive behaviours to prevent a shock being triggered, as they did not want to lose their driving licence for another 6-months.

The finding that partners and family members tended to be overprotective and often imposed sanctions on the patient, suggested that partners were very anxious about the ICD. Pedersen et al. (2009) posited that although partners of all cardiac patients were confronted with having to cope with a partner's potentially life-threatening disease, they suggested that the experience was worse for partners of ICD patients. They suggested that the ICD partners had an especially high level of anxiety, as they have to accept that their loved one was reliant on a medical device that could deliver aversive shocks in order to survive. A review that included qualitative studies by Van den Broek, Habibović and Pedersen (2010) concurred with this. Their review found that partner concerns were often related to caring for the ICD patient, feeling helpless, uncertain about shocks, role changes, sexual activities, and overprotectiveness, and driving. Albarran et al (2004) found some partners not only restricted the patient's physical activities but also sought support from friends and family to sanction these restrictions

Albarran et al. (2004) revealed how partners often felt unprepared for their role as sole carer, which included how to respond to a shock. Partners were often worried and felt unsure as to how they would cope if a shock occurred. Partners were concerned about what should they do if the patient loses consciousness. In an effort to reduce their anxiety, partners in Albarran et al'.s (2004) study found partners used unhelpful overprotective behaviours, such as being over vigilant and trying to 'safe-guard' the patient, in an effort to reduce their anxiety. Partners were often afraid to leave the patient on their own, especially during the early days after hospitalisation. Although they felt reassured by the ICD, they nonetheless felt anxious about the shock. These fears often resulted in partners monitoring patient's symptoms and becoming hyper vigilant.

The health of partners often suffered because of looking after the ICD patient. For instance, partners in Albarran et al.'s (2004) study tried their best to prevent the patient from feeling stressed. They often believed that by preventing the patient from stress, they could reduce the likelihood of the patient having a shock. Consequently, partners tended to avoid arguing with the patient and avoided confronting them with any adversity that might cause the patient to feel stressed. However, by doing this, partners found that they themselves felt annoyed, guilty and distressed, which negatively affected their own mental health and well-being.

McDonough's (2009) study focussed on 'young' participants (i.e. under the age of 40 years), and suggested that younger participants often had worries that were different to older recipients. McDonough (2009) found that younger patients with a genetic heart condition and with dependent children were often concerned that they had passed on their disease to their children. This concern should equally have affected older recipients as they often had children and grandchildren who might have inherited their genes, but older patients did not report this worry. McDonough (2009) found 'younger' patients often felt insecure and uncertain about their ability to continue to look after their children. McDonough cited a telling example of the vulnerability and fear felt by one mother who had taught her children to dial 911 (US emergency services) whenever their father was away, should they not be able to wake her in the morning.

McDonough (2009) also found that 'young' ICD patients reported being worried about having a shock in public. However, McDonough (2009) did not state the length of time patients had been living with their ICD, so this particular fear might not have been due to being younger but simply because they had not had their ICD for long. For instance, Burke (1996) had found a similar fear to that reported by McDonough (2009) whereby patients at 3-months post implant reported being worried that the public at large might witness them being shocked. Therefore, the fear of receiving a defibrillated shock in public might be a normal part of early adjustment especially as Burke (1996) reported that this fear dissipated at about 6-months.

ICD Patients used a variety of coping strategies in response to the anxieties they experienced. For instance, some patients reduced their caffeine intake (James et al., 1999), some wore a heart rate monitor whilst jogging (Fridlund et al, 2000) and others informed others when they were going out and how long they should be (Burke, 1996). A patient in Burke's (1996) study explained how she had given friends and family a list of telephone numbers to phone in an emergency as well as instructions on what to do. Another of Burke's participants described the fear paramedics that would not be able to reach her in an emergency at home was so great, that she redesigned her kitchen to make it easier for the emergency services to gain access.

Another coping strategy used by patients was avoiding activities and places. For example, participants in Flemme et al.'s (2001) study described how they avoided being in busy public areas, queues or crowds because of the fear that they might receive a shock. Participants in Mert et al.'s (2012) and Bolse et al.'s (2005) described how they avoided taking a shower or taking a shower without someone there 'on guard'. A patient in Mert's (2012) study explained that he had experienced a shock in the shower, which had made him feel like he was drowning. After this experience, he asked his mother to stand guard by the bathroom door whilst he showered. Tagney et al. (2003) found one patient who was too afraid to climb stairs after experiencing a shock. Accordingly, whenever the patient had a shock, he would remain downstairs even if it meant using a commode.

Some coping strategies used by patients were driven through a determination to enjoy the remainder of their life rather than the fear of being shocked. For example, patients in Kamphuis et al.'s (2004) study described how they had begun to live their lives with an emphasis on enjoying each day as it came rather than focusing on the future. Flemme et al. (2011) and Burke (1996) also found some participants re-evaluated their lives; they had re-assessed values, activities and even friendships to be more in accord with a new set of values.

In summary, the qualitative papers reviewed here demonstrated how patients, families and partners were all affected by the ICD. Participants in these studies demonstrated using a variety of coping strategies so they could accommodate the device so they could regain some normality. Many patients had a deep fear of shock because of its unpredictability, and connotation with death, and tried to regain control by avoidant and restrictive behaviours. Similarly, partners and family members tried to safeguard the patient, which often exacerbated patients' feelings of vulnerability and dependence. However, all the studies reviewed had weaknesses.

Qualitative Literature Review: Critical Evaluation of Studies

Some papers reviewed in this thesis might be termed 'key papers'. One reason they might be a key paper is that it came from a large parent study carried out in the UK study (i.e. Albarran et al., 2004; Tagney et al., 2003). Therefore, as they used a UK population, they are pertinent to the present research. Albarran et al. (2004) and Tagney et al. (2003) carried out qualitative interviews with eight ICD patients and their intimate partners. There are other papers from this parent study, which included one which only explored the experiences of two young women with ICDs (James, Albarran & Tagney 1999) and one which examined the effects of the driving ban on patients and partners (James, Albarran & Tagney, 2001). At the time, this parent study met a gap in the qualitative literature as it explored the experiences using a UK ICD population, which had not hitherto been done.

The two studies that are most pertinent to this research study, focussed on the experiences of patients and partners living with the ICD (Albarran et al., 2004; Tagney et al., 2003). However, there were some shortcomings. One shortcoming was with the study's methodology and the way in which participants were recruited. For instance, the patient's cardiologist invited them to join the study, which meant during the interview, participants might have been reluctant to criticise their care or reveal their real feelings especially as the study later uncovered a theme relating to concealment (albeit concealment of fears from their intimate partner).

Although 20 patients were invited to join the study, recruitment ceased after the first eight couples returned their completed consent forms. This might raise ethical concerns as participants might have joined the study, and interviewed for no purpose. However, the study did not mention what happened to the couples whose consent forms arrived after the first eight had been received. The authors suggested they limited the sample to eight couples because the interviews were generating many data and resources to analyse the data were limited. This meant therefore that the saturation of themes might not have been reached. In addition, only using the first eight patients to respond might have influenced findings. For instance, a patient who responded to a study more quickly than a patient, who took longer to respond, might be having a different experience living with their ICD. A 'quicker' patient might be having a 'good' experience living with the ICD and wanted to share their experience. On the contrary, the 'quicker' patient might simply have been more desperate to talk about what was a traumatic experience. This last suggestion is possibly more likely as one of the author's unique findings (to date) was that there were no opportunities for patients in the UK to discuss psychological concerns.

The study by Albarran et al. (2004), which focussed solely on the partner laid claim to the fact that partners moved through several stages when learning how to best support the patient. However, from the study design, which only interviewed the same participant once and the analysis, which was content analysis, this claim cannot really be substantiated (unlike that of Burke, 1996, see below, who used a grounded theory approach and interviewed participants more than once). The type of analysis chosen by the team of authors (Albarran, James and Tagney) might not have captured themes relevant to the experience of living with an ICD. For instance, the interview was semi-structured, which allowed the researcher to have some control over the discussion. As the qualitative analysis used was ethnographic content analysis, (in which significance of themes is derived through the repetition of coding, Altheide, 1987), their analysis might have been open to bias. However, their analysis was triangulated, which is considered to enhance inter-rater reliability and reducibility (McNiff, 2013).

The patients and their intimate partners in this study were interviewed separately. On the surface, this appeared an intelligent design as this meant the dyadic relationship could be explored and this might have allowed the theme of concealment to be discovered. However, the authors proceeded to write up the findings for patients and partners separately with no reference to each other, which meant that dyadic influences were not explored. Although half the sample had experienced a shock, the papers failed to discriminate between patients who had and who had not had a shock. Since, it has been well documented in the ICD literature that a shock is aversive (e.g. Dougherty, 1995; Schron, Exner, Yao, Jenkins et al., 2002), this was a major shortcoming. Accordingly, it cannot be determined if the feelings of relief and gratitude at being kept alive, (which had been reported by their patients), had been influenced by the experience of being shocked.

Another shortcoming with their studies was that although the studies aimed to explore the patient and partner's experience of the ICD around the time of the implant and after the patient returned home, the psychological sequelae reported was minimal. The small amount of psychological sequelae reported might have been because the studies were carried out from a nursing perspective rather than a psychological perspective (see below for a further comment on this issue). One of their findings was a theme relating to funding issues. However, again this might only have been a pertinent theme because nurses were carrying out the study and patients might have associated funding issues with nurses. Nonetheless, these studies were the first studies to document that patients concealed feelings from their partners, and partners concealed feelings from the patient, which has major implications for guiding how studies are carried out in the future with an ICD population.

Other papers were defined as key papers in this thesis because they were published in Heart and Lung, which is a very high quality journal (e.g. Burke, 1996; Steinke et al., 2005; Flemme, et al., 2011). These 'key' studies have several strong points and a few weaknesses.

Burke's (1996) study had strengths. Burke (1996) used a grounded theory approach, which was suited to understanding and explaining social processes. She interviewed each of her participants (ICD patient) on three separate occasions and was thus able to explore how patients adjusted over time. The design was well structured; male and female participants both took part (in an almost equal ratio), they represented a wide age range and the study included patients who did not have a long-term partner. Another good point about Burke's (1996) study was that she identified and approached patients directly and did not rely on nurses to find the sample. For instance, nurses might only identify patients whom they thought would be suitable for interview, which could lead to a biased sample. The design used by Burke (1996) provided insight into how patients initially wanted an ICD in order to stay alive, but afterwards they then had to try to accept the ICD, which they did by integrating technology into their lives and living their lives through technology.

To the researcher's knowledge, Burke's (1996) study appears to be the only qualitative study published that described the psychological changes that a patient goes through in order to live with their ICD. The study also documented common physical sensations from the first week to 6-months, which again to the researcher's knowledge had not been previously published. It is disappointing that the author did not carry out a similar study with partners of ICD patients in which she explored the processes they went through to adapt to living with an ICD. Unfortunately, since this study was carried out, the ICD device has become much smaller and less physically intrusive, so the changes in physical sensations over time documented by Burke (1996) might not be relevant to today's patient. Although Tagney et al. (2003) suggested that patients were so focussed on securing life with an ICD they had not thought about potential issues of living with the ICD, Burke (1996) first documented this. This finding has major implications for arrhythmia nurses who carry out the pre-ICD counselling.

Steinke et al.'s (2005) chosen method of a qualitative descriptive approach also appeared to be suited to the research question, which was to find out the sexual concerns and educational needs of patients/partners after an ICD. Similar to Burke (1996), Steinke et al. (2005) included patients who did not have a long-term partner and did not rely on a nurse to identify potential participants. Their participants came from two support groups that had previously taken part in an earlier parent study and who volunteered to be interviewed for this study. The aim of the study was to explore the experiences of patients and partners with regard to how they returned to sexual activity post-ICD implantation. This topic can be a delicate and private subject for some individuals. Therefore, the participants who volunteered to take part might have been individuals who were comfortable and confident talking about sex, and who therefore might not be typical of the majority of ICD patients, which was not acknowledged by the authors.

Another major criticism with this study was that couples in Steinke et al.'s (2005) study were asked if they wanted to be interviewed together or separately. Since Tagney et al. (2003) found that patients often concealed fears from their partners, and Albarran et al. (2004) found partners concealed concerns from the patient, it might have been best to have interviewed them separately. For instance, some patients or partners in Steinke et al.'s (2005) study might not have really wanted to be interviewed with their partner. However, because the couple were asked if they wanted to be interviewed together, (whilst they were together), they might have felt coerced into agreeing to be jointly interviewed. Therefore, there might be issues and concerns that were not raised because the couple were being interviewed together. However, by the time Tagney et al.'s paper was published it is likely that Steinke et al.'s (2005) study was already underway, and so they would not be aware of the issues surrounding concealment. Interestingly, Steinke et al. (2005) suggested that an implication from the findings advocated the need for educational strategies. However, from their findings it appears clear that psychological strategies would also be helpful for patients. This issue highlights how disciplines (e.g. nursing and psychology) do not always appear to be working together to benefit patients.

Flemme et al. (2011) used a grounded theory approach, which allowed them to explore how patients managed their main concern living with an ICD. Like Burke (1996) and Steinke et al. (2005), Flemme et al. (2011) included participants who did not have a long-term partner and therefore was representative of a typical ICD population. However, a weakness with Flemmeet al.'s (2011) study was the way in which participants were recruited and the way interviews were carried out. For instance, patients from the ICD outpatient clinic had been requested to take part by a nurse, and secondly a nurse conducted the interview. Therefore, patients might have felt obligated to take part in this study and as a nurse led the interview, they might not have been honest in the interview process.

From their analysis, Flemme et al. (2011) suggested that incorporating uncertainty into everyday life was the core category of their study. They addressed their findings by outlining ideas for health professionals who tend to part of the ICD team. However, similar to Steinke et al. (2005), although it was clear that psychological help would most likely benefit patients, they recommended that only very distressed patients were referred to a psychologist. Again, it appears that nurses and psychologists are not working together for the benefit of patients. If the nursing or ICD team were open to multidisciplinary working, the patient would likely benefit more than from just having the input from one discipline.

The key papers by Burke (1996), Steinke et al. (2005) and Flemme et al. (2011) have a weakness in common. None of the studies made a distinction between participants who had or who had not experienced a shock. Therefore, any difference in experiences due to receiving a shock was missing. Another weakness shared by Burke (1996) and Flemme et al. (2011) was that they only explored the experiences of patients. As previous research (e.g. Pycha, Calabrese, Gulledge, Maloney, 1986; Sneed & Finch, 1992) has suggested the partner can influence the recovery of the patient, the dyadic relationship (where appropriate) might have been insightful.

Of all the papers reviewed in this review, only Burke's (1996) study used a psychological approach. The remaining key papers cited (Tagney et al., 2003; Albarran et al., 2004; Steinke et al., 2005; Flemme et al., 2011) appeared to have been carried out from a nursing perspective rather than a psychological one. As such, these qualitative studies not only aimed to explore experiences of living with an ICD but also aimed to identify where nursing practice might be improved and appeared to have a more solution-focussed approach to issues, for example, Steinke et al.'s (2005) suggestion that ICD patients need more sex education. Although Burke (1996) used a psychological approach, the study is approaching twenty years old and some aspects might be dated, such as the physical sensations recorded. Accordingly, a more up-to-date qualitative research study is needed. This study should explore the experiences of living with an ICD from a psychological perspective. This would offer a greater understanding of the psychological processes involved in living with an ICD.

A further reason to carry out a qualitative research study using a UK ICD population is that it has been a while since a qualitative study has been carried out in the UK. The last qualitative study to use a UK population was carried out over a decade ago by Albarran and colleagues (e.g. Tagney et al., 2003; Albarran et al., 2004), since when ICDs have become smaller and less physically intrusive. Since that time, they have also become more sensitive to detecting an abnormal rhythm and therefore emit fewer inappropriate[16] shocks. Furthermore, to the researcher's knowledge, no qualitative study so far has used remotely monitored ICDs and explored the impact this might have on participants' psychological sequelae.

The proposed study also needs to ensure it addresses the shortcomings of the key papers cited above. For instance, the study should include the psychological sequelae

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[16] A shock is named 'inappropriate' when the heart rhythm is abnormal but not life-threatening.

of partners as partners have been found to influence patient recovery (e.g. Sneed & Finch, 1992). The partner and patient should also be interviewed separately in line with the finding from Tagney et al. (2003) who found they often concealed fears and emotions from each other. Lastly, the proposed study needs to ensure that the findings for beliefs, emotions and ways of coping that relate to the ICD are clearly distinguished from those that were influenced by a shock.

SECTION 2: Prevalence and Trajectories

Prevalence of Anxiety and Depression in ICD Patients

Rates of anxiety have often been documented in many studies to show that ICD patients commonly experience anxiety. Clinical rates of anxiety reported range from 13 to 38 % (e.g. Matchett, Sears, Hazleton, Kirian et al. 2009; Sears & Conti, 2002; Sears, Conti, Curtis, Saia, et al., 1999; Burke, Hallas, Clark-Carer, White et al., 2003). A systematic review by Magyar-Russell, Thombs, Cai, Baveja et al. (2011) found rates ranged between 11-26 %.

The systematic review by Magyar-Russell, Thombs, Cai, Baveja et al. (2011) that focussed on anxiety and depression in ICD patients found the prevalence of anxiety symptoms (based on a validated questionnaire) ranged from 27-63% in seven pre-implant studies. Prevalence rates for anxiety reported were 13-50 % in twelve studies at 0-6- months post implant. However, whereas the pre-implant measures were taken at approximately the same time, the mean times for the 0-6-month cohort varied widely. For instance, two studies (van den Broek, Nyklicek, van der Voort, et al., 2009; Dunbar, Langberg, Reilly, Viswanathan et al., 2009) measured scores at implant, whereas seven other studies took mean measures varying from 1- 6-months. Therefore, the patients in the studies were at very different stages of recovery.

Six studies in Magyar et al.'s systematic review reported prevalence rates of anxiety of 15-49 % at 6-12-months, which was similar to the rates at 0-6-months. However, Magyar-Russell et al. (2001) also found 8-59 % of patients in 30 studies had symptoms at 12 months or more post-implant, which demonstrated a wide discrepancy between scores. However, the highest prevalence rate of 59 % in one study (Bilge, Ozben, Demircan, Cinar et al., 2006), appears to be an anomaly as other studies suggested much lower scores. However, as the study was carried out in a Muslim country, unlike the twenty-nine other studies, there might have been cultural influences that influenced anxiety.

Magyar-Russell et al. (2011) found the prevalence of depressive symptoms (based on a validated questionnaire) ranged from 10-36 % in seven pre-implant studies. They found an 8-38 % prevalence rate at 0-5.9 months in ten studies and six studies showed 10-33 % at 6-11.9 months. At 12-months or more, the prevalence rate for symptoms of depression was 5-75 % in thirty studies, (see Table 3.2).

The prevalence rates of anxiety reported by studies found in Magyar-Russell et al.'s (2011) systematic review suggested that prevalence rates for anxiety appeared to be at its highest pre-implant (see Table 3.2). The rate appeared to remain stable for the first year after which the gap between patients with the highest and lowest rates widened. The pattern was similar for the prevalence of depressive symptoms with a wider discrepancy occurring after 12-months. However, the review did not consider if patients received treatment for their mental health. Nonetheless, the high prevalence rates after one-year might suggest that if anxiety and depression is left untreated, these disorders will worsen considerably after 12-months.

This would support the findings of qualitative studies in which the first year was perceived by patients to be a critical year in which to adjust to the ICD. Another reason for the high prevalence rate of anxiety and depression might be that after a year, the patient's underlying cardiac condition might have worsened. This might mean that there is a higher likelihood of shocks from the ICD, which has been suggested to be associated with anxiety (see Section 3: ICD-related Concerns, below). In addition, as heart failure has been found to be a risk factor for depression (see Section 3: Heart Failure Co-morbidity below), it might be that as the patient's heart condition worsens over the year, symptoms of depression increase.

The wide discrepancy between prevalent rates of symptoms of anxiety and depression reported by studies might have been because of the way in which clinical threshold criteria were interpreted varied across studies. For instance, Jacq, Foulldrin, Savoure, Anselme et al. (2009) used a threshold of ≥8 to assess clinical anxiety and depression using the Hospital Anxiety and Depression Scale [HADS] whereas Duru, Buchi, Klaghofer, Mattmann et al. (2001) used a HADS cut-off score of ≥11. Different measures were all used by studies and therefore it is difficult to quantify prevalence rates. For instance, self-report measures for anxiety included the Hospital Anxiety and Depression Scale [HADS], the Depression Anxiety Stress Scales [DASS], the State-Trait Anxiety Inventory [STAI], Beck Anxiety Inventory [BDI], and the Taylor Manifest Anxiety Scale [TMA]. In addition, due to cardiac and psychological symptom overlap, Magyar et al. (2011) suggested there might have been under or over-reporting of mental health symptoms, which might have influenced prevalence rates especially at 12-months or more post-implant. This might be because after a year patients have become used to their symptoms and have made attributions for them.

Table 3.2: the prevalence rates for anxiety and symptoms of depression over time from the studies in Magyar-Russell et al.'s (2011) systematic review

	Pre-implant %	0-6 Mths % (A) 0-5.9 Mths % (D)	6-12 Mths % (A) 6-11.9 Mths % (D)	12 + Months %
Prevalence Rates of Anxiety	27-63	13-50	15-49	8-59
Prevalence Rates of symptoms of Depression	10-36	8-38	10-33	5-75

Magyar-Russell et al.'s (2011) systematic review found three studies that assessed the prevalence rates of anxiety and depression using a diagnostic clinical interview (Crow, Collins, Justic, Goetz et al., 1998; Godemann, Butter, Lampe, Linden et al., 2004; Jacq, Foulldrin, Savouré, Anselme et al., 2009 – see Table 3.3). The prevalence rate of anxiety was 11 % (four of 35 patients) in Crow et al.'s (2004) study at the time of implant. This diagnosis was made using the Structure Clinical Interview for DSM-III-R [SCID] (Spitzer, Williams, Gibbon et al., 1988). The study found no new cases of anxiety at follow up (9-18 months post implant), which suggested that the ICD implant did not result in an increased prevalence rate of anxiety. However, an increased prevalence rate of 8.6 % to 14 % for a major depressive disorder (MDD) was found. They concluded that having a lifetime history of psychopathology at the time of the implant was a risk factor for a diagnosable psychiatric syndrome.

Unlike Crow et al. (1998), Godemannet al.'s (2004) study found evidence that suggested new cases of anxiety were diagnosed during the first year post ICD-implant. Using the Diagnostic Interview of Psychiatric Syndromes (DIPS)[17], they found 15 of 90 patients (16.7%) were diagnosed with an anxiety disorder (panic disorder and/or agoraphobia) which had developed during the first year post-ICD implant. The authors Godemann et al. (2004) concluded that patients with an ICD had an increased risk of developing a panic disorder and agoraphobia and suggested that the number of ICD discharges and catastrophic cognitions had contributed to the development of these disorders (see Section 3: Risk Factors that Influence Psychological Distress in ICD Patients below). However, in contrary to Crow et al. (1998), Godemann et al. (2004) did not find that having an ICD resulted in a higher prevalence rate of depression. They used the diagnostic interview DIPS and found that 12 out of 90 (13 %) patients had experienced a depressive disorder during the first year. Half of the 12 patients had developed the depressive disorder before the implant and so the depression did not appear to be a result of the ICD. However, as the DIPS generally focus on anxiety disorders it may not have been as sensitive to diagnosing depressive disorders.

Jacq et al.'s (2009) study used the Mini International Neuropsychiatric Interview [MINI][18] and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (see Chapter 9, for a comprehensive description of HADS) and found evidence to support Godemann et al.'s proposition that ICD discharges might have contributed to the development of a psychological disorder. Jacq et al. divided patients into shock and non-shock. They found a significantly higher prevalence of shock patients (37.5%) had a diagnosable anxiety disorder assessed by the MINI compared to 8 % of non-shock patients. They also found 32.5 % of shock patients had a diagnosable depressive disorder compared to 20 % of non-shock patients (although this prevalence did not reach significance). In most of the patients, the majority being shock patients (78%), these disorders had appeared after the ICD-implant. However, unlike the DIPS, the MINI did not allow the diagnosis of previous anxiety disorders,

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[17] The Diagnostic Interview of Psychiatric Syndromes [DIPS] (Margraf, 1994), which is also based on the DSM-III-R, is a semi-structured standardised interview that focusses on the diagnosis or anxiety disorders and registers both the presence of a mental disorder and the time at which it developed (i.e. before or after the ICD implant).

[18] The Mini International Neuropsychiatric Interview [MINI] (Lecrubier, Sheehan, Weiller, Amorim et al. 1997), is a short structured diagnostic interview based on the DSM-IV psychiatric disorders designed for multicentre clinical trials (Jacq et al., 2009).

which made the comparison of anxiety prevalence before and after the ICD implant difficult to determine.

Magyar-Russell et al. (2011) posited that the method used to diagnose rates of anxiety and depression and the size of the sample used would influence the prevalence rates of anxiety and depression. Magyar-Russell et al. (2011) posited studies found prevalence scores for anxiety and depression was higher when questionnaires rather than diagnostic interviews were used as the mode of assessment. Magyar-Russell et al. (2011) suggested that the prevalence rates also differed according to the sample sized used in studies with samples over two hundred showing a lower prevalence rate of anxiety and depression.

Johansen, Pedersen, Spindler, Andersen et al. (2008) who used 610 patients found a prevalence rate for depression of 12.6 % (n=77). However, the measures were taken over a 17-year period and accordingly some patients would have had their ICD for many years, which might have influenced these findings. Equally, prevalence rates might have been relatively low in Johansen et al.'s (2008) study due to the sample size's representativeness, such as the higher rate of response. This suggestion is supported by the findings of Kapa, Rotondi-Trevisan, Mariano, Aves et al. (2010) who also had a sample size of over 200. However, their patients who had their implant for less than 14-months at the 12-month follow up had a lower prevalence of anxiety and depression than Johansen et al. (2008). Kapa et al. (2010) found a prevalence of 15 % and 11 % respectively, which might have been due to their cohort's shorter follow up period. A shorter follow up period meant that there was less time for the heart to deteriorate. If the heart had deteriorated, this itself might have led to increased anxiety from shocks and increased depression from heart failure. (See table 3.3).

Magyar-Russell et al. (2011) proposed that the prevalence of anxiety and depression in ICD patients was similar to rates found in a systematic review that focussed on acute myocardial infarction [AMI] by Thombs, Bass, Ford, Stewart et al. (2005). Conversely, Dunbar, Dougherty, Sears, Carroll et al.'s (2012) scientific review, which is a review of scientific reviews, suggested the prevalence rates of anxiety and depression for ICD patients were estimated to be twice as high as the prevalence of 9.3 % of patients with general cardiac medical conditions. However, as the findings from Jacq et al. (2009), Johansen et al. (2008) and Kapa et al. (2010) are all different, it might be that the mode of assessment, the sample size and the length of time living with the ICD might have influenced these prevalence rates. However, Magyar-Russell et al.'s (2011) systematic review concluded that based on the three studies (Crow et al., 1998; Godemann et al., 2004; and Jacq et al., 2009) it was reasonable to estimate that approximately 20 % of ICD patients have clinically significant anxiety and 20 % clinically significant depression.

Table 3.3: Prevalence of anxiety and depression for patients assessed with a diagnostic clinical interview

Study Author & Year	Patients	Measure Used (Outcome)	Prevalence Baseline (pre-ICD to 2-mths post implant % (n)	Prevalence 6-mths % (n)	Prevalence ≥ 12-mths % (n)
Crow et al. (2004)	35	SCID (Anxiety) SCID (Depression)	11 (4) 8.6 (3)		11 (4) 14 (5)
Godemann et al. (2004)	90	DIPS (Anxiety) DIPS (Depression)	NS* 6.5 (6)		16.7 (15) 13 (12)
Johansen et al. (2008)	610	HADS (Anxiety) HADS (Depression)			18.9 (115) 12.6 (77)
Jacq et al. (2009)	40 (shock)	MINI (Anxiety) MINI (Depression)			37.5 (15) 32.5 (13)
	25 (non-shock)	MINI (Anxiety) MINI (Depression)			8 (2) 20 (5)
	Total (shock + non-shock)	MINI (Anxiety) MINI (Depression)			48.6 (17) 51.4 (18)
	Total (shock + non-shock)	HADS (Anxiety) HADS (Depression)			54.3 (19) 37. 1 (13)
Kapa et al. (2010)	223	HADS (Anxiety) HADS (Depression)	35 (78) 10 (23)	15 (34) 11 (24)	15 (34) 11 (25)

**NS=not specified*

The Trajectory of Quality of Life in ICD Patients

Health-related quality of life has been broadly defined as the impact of disease and medical treatment on patients overall functioning and well-being (Sears, Matchett, & Conti, 2009). The quality of life (QoL) however, is a multi-dimensional construct with core domains being disease and treatment-related symptoms, physical and psychosocial functioning (Sears et al., 2009). The trajectory of QoL in this essay encompasses both quality of life and health-related quality of life unless specified, as QoL was the term generally used by published studies.

Quality of life is an important issue. There are concerns have been raised about the effects that ICD shocks might have on QoL (Mark, Anstrom, Sun, Clapp-Channing et al., 2008). Mark et al. (2008) posed the question whether a quick painless (albeit premature) death might be favourable over a more unpleasant death from a progressive deterioration from a cardiac disease. Several randomised control trials have been carried out to assess the QoL of patients with an ICD compared to an alternative treatment therapy, such as amiodarone (e.g. Strickberger, Hummel, Bartlett, Frumin et al., 2003), or a device that only delivered anti-tachycardic pacing (e.g. Wathen et al., 2004).

May, Smith, Murdock, and Davies (1995) posited that ICD patients generally experienced a brief decline in QoL after their implant but which improved to pre-implant levels after one year. The evidence from some randomised control trials (RCT) studies offered partial support for Mayet al.'s (1995) claim that posited QoL does generally improve for patients after implant. Four of these RCTs used primary prevention[19]patients (Namerow, Firth, Heywood, Windle et al., 1999; Strickberger, Hummel, Bartlett, Frumin et al., 2003; Wathen, DeGroot, Sweeny, Stark et al., 2004; Mark, Anstrom, Sun, Clapp-Channing et al., 2008), and two of the RCTs used secondary prevention patients[20] (Schron, Exner, Yao, Jenkins, et al., 2002 [AVID trial]; Irvine, Dorian, Baker, O'Brian et al., 2002 [CIDS trial] – see also Chapter 1: Superiority of the ICD over Drug Therapies). (See Table 3.4).

The study by Namerow, Firth, Heywood, Windle et al. (1999) compared the QoL of patients at six-months after a coronary artery by-pass graft (CABG) in which a subgroup of patients were implanted with an ICD during surgery. The control group, (i.e. the subgroup of patients not implanted with an ICD) appeared to have better QoL scores compared to the ICD group. Using seven subscales of the Medical

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[19] Primary Prevention refers to the prevention of a first sudden cardiac arrest.
[20] Secondary prevention patients are those patients who have been resuscitated from a cardiac arrest.

Outcomes Short-Form 36-item questionnaire (SF-36)[21] (McHorney, Ware, Raczek, 1993), the control group had significantly better emotional role functioning. The control group also had significantly better psychological well-being, greater satisfaction with their appearance and reported to be less bothered by their scars from surgery.

The experience of a shock negatively influenced QoL for ICD patients in Namerow et al.'s (1999) study. ICD patients who received a shock reported reduced physical and emotional role functioning and had lower levels of psychological well-being compared to those patients who did not receive an ICD shock (see Table 3.4).

A smaller study by Strickberger, Hummel, Bartlett, Frumin et al. (2003) found no significant difference between the QoL reported by a group that received amiodarone compared with the ICD group. This study used the Quality of Well Being Schedule (Fazio, 1977) and found the scores between the two groups were not significantly different at one-year follow up. However, baseline scores for the ICD group were lower than the amiodarone group but had increased at one-year whereas the scores for the amiodarone group were largely unchanged. These findings suggested that the QoL of patients in the ICD group improved from baseline to one-year whereas QoL for the amiodarone group remained the same. Further, at one year, the Quality of Well Being Schedule was not significantly different at one-year between patients with an ICD who had a shock compared to those who did not have a shock. Accordingly, Strickbergeret al.'s (2003) study found evidence contrary to Namerow et al. (1999) and suggested that shocks from the ICD did not significantly influence QoL. (See also Section 3: Risk Factors that Influence Psychological Distress in ICD Patients: ICD-related concerns).

Whereas Strickberger et al. (2003) found no difference between patients treated with amiodarone or an ICD, Wathen, DeGroot, Sweeny, Stark et al.'s (2004) study found QoL scores improved for all the ICD patients who experienced ventricular fibrillation, and who had received ICD treatment. Wathen et al. (2004) randomised patients to receive fast antitachycardia pacing (ATP) when the patient was in fast ventricular tachycardia (FVT, 188 to 250 beats a minute,[bpm]) or to receive a 10-

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[21] The SF-36 health survey measures generic health status, comprising a physical component summary (PCS) score and a mental component summary (MCS), and each summary comprising sub-scale; a higher score represents a more favourable score.

joule shock (normal ICD treatment). The main benefit of ATP over a shock is the avoidance of pain (Wathen et al., 2004).

Wathen et al. (2004) did not publish a table of results and accordingly their scores cannot be cited, however they proposed that the ATP arm significantly improved QoL scores from baseline to 12-months. Using eight subscales of the SF-36 Health Survey (McHorney et al., 1993), Wathen et al. (2004) found that the ATP arm had improved significantly in five subscales (physical functioning, role physical, bodily pain, social functioning and role emotional and the mental and physical summaries). Both arms had improved QoL scores from baseline to one-year but more so in the ATP arm.

According to Wathen et al. (2004) both groups of patients experienced abnormal rhythms but those who received ATP as oppose to an ICD shock had better mental QoL summaries. This finding suggested that reduced mental QoL from an ICD shock might be due to the pain that it was associated with, rather than the knowledge that a shock had been needed to abort an abnormal heart rhythm.

Two RCTs that focussed on secondary prevention patients[22] (Schron, Exner, Yao, Jenkins, et al., 2002 [AVID trial]; Irvine, Dorian, Baker, O'Brian et al., 2002 [CIDS trial] – see also chapter 1: Superiority of the ICD over drug therapies) found that an ICD implant did not negatively affect QoL. Both studies randomised patients to receive an ICD or receive antiarrhythmic medication. The AVID trial defined QoL as a multidimensional construct that is individually perceived, dynamic, and quantifiable by self-report.

Schron et al. [AVID] (2002) compared QoL scores using the Medical Outcomes Short Form 36-item questionnaire (SF-36), a modified Patient Concerns Assessment (PCA[23]) and the cardiac version of the QL index (Ferrans & Powers, 1985, 1992). They found physical functioning (PCS) QoL scores significantly increased over 12-months from baseline in both groups. The summary mental well-being (MCS) score was lower at baseline in the ICD group. However, both groups improved over time but the changes were not significant. Similarly, there were no significant differences

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[22] Secondary prevention patients are those patients who have been resuscitated from a cardiac arrest.

[23] The PCA is the number of concerns that a patient identifies from a checklist and is intended for outpatients with ventricular arrhythmias (Brookes, Jenkins, Schron, Steinberg et al. 1998). The checklist evaluates disease-specific aspects of QoL. A higher score indicates increased concern and a poorer QoL.

between groups in patient concerns at baseline or at one-year. However, improvement was noted for concerns (PCA) and the QL Index. Schron et al. (2002) concluded that the poor QoL reported in their study was not due to the having an ICD. Rather poor QoL was due to having a deteriorating heart, such as heart failure.

The CIDS study (Irvine et al., 2002) used the Rand Corporation's 38-item Mental Health Inventory [MHI], which can be scored for total mental health, as well as two higher order factors representing psychological distress and psychological well-being. The Nottingham Health Profile [NHP] (Hunt, McEwen, McKenna, 1985) assessed health-related QoL, comprising seven sub-scales: physical mobility, emotional reactions, social isolation, energy level, pain, sleep disturbance, and lifestyle impairment. Irvine et al. (2002) found that all QoL variables apart from Social Isolation and Pain (see Table 3.4) had significantly improved in the ICD group from baseline to 12-months. Whereas they found QoL had significantly improved for NHI measures (energy levels, emotional reactions, sleep disturbance) from baseline to 6-months and 12-months, they found lifestyle had significantly improved from baseline to 12-months. All NHP measures indicated significantly improved QoL for the ICD group from baseline to 12-months. However, no QoL variables improved over time for the amiodarone group.

The total MHI mental health for the ICD arm and the amiodarone arm at baseline was 173[24] and 180 respectively in the CIDS study, which suggested that initially the amiodarone group had better mental health. However, by one-year, the ICD group's total mental score had increased to 184, whereas the amiodarone group remained stable at 178. Similarly, psychological distress remained stable for the amiodarone arm whereas it had improved for the ICD arm. However, QoL did not change over time for those in the ICD group who had five or more shocks. Irvine et al. (2002) concluded that QoL had improved more in the ICD group than the amiodarone group unless the ICD patient had received more than five shocks from their ICD.

A more recent RCT , the Sudden Cardiac Death in Heart Failure Trial, (Mark et al., 2008), which involved primary prevention patients also found psychological well-being in the ICD arm in the RCT was significantly improved compared to the medication arms at one-year. Mark et al.'s (2008) comprised three treatment arms:

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[24] A higher score on the MHI represents better functioning.

an ICD, an amiodarone and a placebo arm assess QoL. They used the Medical outcomes Study 36-item Short Form (SF-36) Mental Health Inventory 5 (MHI-5) to assess psychological well-being and the Duke Activity Status Index (DASI) to assess cardiac specific physical functioning[25]. Psychological wellbeing in the ICD arm was significantly improved at 3- and 12-months. However the DASI did not change over time and there was no difference between the groups; all had a median score of 24 at the 3-month, 12-month and 30-month follow up.

Dunbar et al. (2012) suggested that the results of all the above studies suggested it was likely that QoL in ICD patients is at least equal to or better than those taking antiarrhythmic medications. They concluded no difference in QoL was found between primary and secondary prevention patients as generally equivalent QoL scores were obtained for both primary and secondary prevention patients.

Table 3.4: Quality of life scores for patients

Study Author & Year	Patients % (n)	Measure Used (outcome)	Mean Baseline (±)	Mean 3/6-months (±)	Mean 12-months (±)
Namerow et al. (1999)	ICD: 53 (445) C: 47 (545)	Medical Outcomes SF-36* (Emotional Role)	NS	ICD: 55 (±43) C: 67 (±40)	
		(Mental Health)	NS	ICD: 72.5 (±18) C: 77 (±17)	
		(Satisfaction with Appearance)	NS	ICD:6.0 (±1.3) C: 6.3 (±1.1)	
		(Satisfaction with Scar)	NS	ICD:7.1 (±1.2) C: 7.2 (±1.1)	
		(Physical functioning)	NS	NS-ICD: 61.5 (±27.5) S-ICD: 53.2 (±27)	
		(Emotional Role)	NS	NS-ICD: 59.9 (±43.4) S-ICD: 49.1 (±42.8)	

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[25] A high score in the DASI indicates better function.

Study Author & Year	**Patients % (n)**	**Measure Used (outcome)**	**Mean Baseline (±)**	**Mean 3/6-months (±)**	**Mean 12-months (±)**
Strickberger et al. (2003)	ICD: 49.5 (51) C: 50.5 (52)	Quality of Well Being Schedule*	ICD: 67 (±15) C: 70 (±17)	ICD: 74 (±19) C: 70 (±22) NS-ICD: 67 (±15) S-ICD: 68 (±16)	
Wathen et al. (2004)	ICD shock: 50.6 (321) ICD ATP: 49.4 (313)	Medical Outcomes SF-36*	NS		NS
Schron et al. (2002)	ICD: 52 (416) C: 48 (384)	Medical Outcomes SF-36* (PCS and MCS) PCA** QL Index*	ICD: PCS: 37.4 ±10.9 ICD: MCS: 45.9±11.8 C: PCS: 36.5±11.2 C:MCS: 47.5±11.5 ICD: 15.9±8.6 C: 16.2±8.9 ICD: 22.1±4.9 C: 21.9±5		NS
Irvine et al. (2002)	ICD: 48.3 (86) C: 51.7 (92)	MHI: Total*	ICD: 173.2±25.5 C: 180.4±27.8	ICD: 183.1±30.2 C: 180.2±31.1	ICD: 184.3±27.9 C: 178.3±28.7
		MHI: Psychological** Distress	ICD: 51.3±14.1 C: 47.8±16.5	ICD: 45.1±17.6 C: 47.6±18.3	ICD: 43.4±15.9 C: 48.8±16.8
		MHI Psychological Well-being*	ICD:58.5±12.7 C: 62.2±12.3	ICD: 62.2 ±13.4 C: 61.8±14.1	ICD: 61.7±13.2 C: 61.1±13.3
		NHP Energy Level**	ICD:27.5±32.2 C: 24.4±32.4	ICD: 18.6±30.1 C: 27.8±32.1	ICD:17.7±26.1 C: 36.8±37.3
		NHP Physical Mobility**	ICD: 10.9±12 C: 13.2±20.5	ICD: 10.5±13.7 C: 15.1±19.2	ICD: 9.1±13.6 C: 17.7±19.2
		NHP Social Isolation**	ICD: 8.5±15.4 C: 9.9±17.7	ICD: 9.8±18.6 C: 12.2±22.4	ICD: 8.5±18.4 C: 11.1±22.6
		NHP Emotional Reactions**	ICD: 17.3±18.1 C: 14.3±20.1	ICD: 11.1±18.2 C: 15.3±22.4	ICD: 8.3±16.6 C: 14.5±19.6
		NHP Pain**	ICD: 4.4± 7.9 C: 7.5±15.1	ICD: 7.5±17.1 C: 6.3±13.6	ICD:4.5± 9.9 C: 8.2±15.4

Study Author & Year	**Patients % (n)**	**Measure Used (outcome)**	**Mean Baseline (±)**	**Mean 3/6-months (±)**	**Mean 12-months (±)**
		NHP Sleep Disturbance** NHP Lifestyle Impairment**	ICD: 31.4±27.4 C: 29.6±31.5 ICD: 2.0±1.9 C: 1.6±1.7	ICD:25±29.7 C: 30.8±31 ICD: 1.6±1.8 C: 1.9±1.9	ICD: 23.9±29.4 C: 30.2±32.4 ICD: 1.6±1.3 C: 1.8±1.9
Mark et al. (2008)	ICD: 32.9 (816) Amiodarone: 33.5 (830) Placebo: 33.6 (833	DSAI* Medical Outcomes SF-36 MHI-5*	ICD: 24.6±13.6 A: 25.3±14.1 P: 24.9±14.1 ICD:71.7±20.5 A: 72.1±20.1 P: 70.0±21.4	*ICD:26.9±141* *A: 26.2±14.7* *P: 26.2±14.3* *ICD: 74.4±19.3* *A: 72.9±20.6* *P: 71.3±21.5*	ICD: 26.8±144 A: 26.1±14.5 P: 26.6±14.8 ICD: 74.5±18.9 A: 72.9±20.5 P: 70.9±21.5

*ICD=ICD patients; C=control patients; NS-ICD= non-shock ICD patients, S-ICD= shock ICD patients, NS=Not specified. *a higher score indicates a more favourable score; **higher score represents poorer QoL or poorer functioning*

Impact on the Partner: Prevalence and Trajectory of Anxiety, Depression, and Quality of Life for Partners

The needs of the partner (or main care-giver) and family are important issues to consider after a cardiac illness, as patient's psychological adjustment has been linked to family function, and patients' adherence to modifying risk factors to prevent worsening cardiac health has been linked to partner anxiety and marital function (Dougherty & Thompson, 2009). Two studies focusing on partners reviewed by van den Broek, et al. (2010) (Dougherty & Thompson, 2009; Pedersen, van den Berg, Erdman, van Son et al. 2009) concurred that anxiety and depression tended to improve for partners over the first year post-ICD implant. However, another study reviewed (Jenkins, Powell, Schron, McBurnie et al., 2007) found QoL and the physical health of the partner tended to decline during the first year. Jenkins et al. (2007) assessed QoL for partners of the patients in the AVID trial (Schron et al. 2002) using the Short Form Health Survey SF-36 and the Quality of Life Index – Cardiac version. The study compared partners to patients who were randomised to receive an ICD or anti-arrhythmic drugs (ADD). The results from the SF-36 suggested that mental health for all partner's improved but physical health declined over the first year whereas the QoL Index- Cardiac remained stable, (see Table 3.6).

Jenkins et al. (2007) found that the partners of ICD patients appeared to fare better mentally and physically than their ADD counterparts although the ADD cohort initially began with better scores. Over the first year, ICD patients improved by a mental score of about 3.2 whereas ADD partners only improved by 0.9. Similarly, the physical health of the ADD partners appeared to decline at a greater rate than the ICD partners with reduction of 2.9 and 0.8 respectively. However, QoL scores for both cohorts remained stable.

Evidence from Dougherty & Thompson's (2009) study suggested that the most challenging time for partners was during or immediately after hospital discharge. This challenging time would remain high until three-month post ICD-implant, at which time the greatest improvement in partner outcomes had occurred. Anxiety and depression were assessed from baseline to 12-months post ICD-implant. The state items on the State-Trait Anxiety Inventory[26] (STAI; Speilberger, Gorsuch, & Lushene, 1970), the Centre for Epidemiological Studies Depression (CES-D) Scale[27] (Radloff, 1977) and the Short Form Health Survey (SF-12) (Ware, 1987; Ware, Kosinski & Keller, 1995) were used to measure the partner's psychological adjustment to the ICD.

They found that the level of anxiety at hospital discharge (baseline) for partners was almost at the 40 cut-off score on the STAI , which indicated that they had severe anxiety. However, by 3-months their anxiety had improved to a mean of 35.16, which remained stable at 6- and 12-months. The scores for depression at hospital discharge (baseline) were below the cut off score (□16, which indicated clinical depression) and were therefore unlike the scores for anxiety, which had bordered clinical levels. At hospital discharge, depression scores for partners had a mean of 14.45, which had reduced to 9.90 at 3-months and remained stable at 6-month and 12-month (see Table 3.6).

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[26] A high score in the STAI represents more anxiety with a cut-off score of ≥40 indicating severe anxiety.

[27] A high score on the CES-D represents more depressive symptoms, with a cut-off score of □16 to indicate clinical depression.

From these results, partner's anxiety and depression was at its highest at hospital discharge, after which it reduced over time. In line with scores for anxiety and depression, the SF-12 showed improved mental health over the year from a baseline mean score of 47.95, which improved to 51.32 at 3-months, after which it remained stable at 6- and 12-months (see Table 3.6).

Evidence suggests that partner's physical health declined over the first year post-ICD implant. Dougherty & Thompson's (2009) study found that partner's physical health significantly declined after the ICD implant as well as the number of physical symptoms reported by partners. Scores on the SF-12 that measured a summary for physical health (PCS)[28] found that partner's physical health significantly declined over the first 12-months post implant (see Table 3.6). These results supported those of Jenkins et al. (2007) who had also found physical health scores had declined in partners over the first year.

Although physical health appeared to decline in partners over the first year post ICD-implant, Dougherty and Thompson (2009) found the number of adverse physical symptoms reported by partners also reduced over time with hospitalisation being the time when partners reported the highest number of physical symptoms. Based on the Physical Symptom sub-scale from the Demands of Illness-Partner (DOI-P) scale[29] (Haberman, Woods & Packard, 1990; Woods, Haberman & Packard, 1993) baseline scores were 3.17, reducing to 2.56, 2.20 at 6-months and 12-months (see Table 3.6). The most common physical symptoms reported by partners at patient hospital discharge were feeling 'run down' and fatigue, which remained the most common symptoms at 12-months. The top five physical symptoms reported by partners included feeling run down (62%), headaches (36%), low back pain (33%), nausea and upset stomach (28%), and soreness of muscles (26%).

Dougherty and Thompson (2009) also assessed how the ICD had effected mutuality (the extent to which couples think similarly about the ICD), the dyadic adjustment between patient and partner and the caregiver burdens upon the partner. Partners reported increased sensitive communication between them and an increased understanding of what the cardiac arrest and ICD meant for them as a couple.

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[28] A higher score on the PCS-SF-12 indicates better health

[29] A higher score on the denotes more adverse physical symptoms

Dougherty & Thompson (2009) also found that care demands (e.g. preparing meals, thinking constantly about the patient, shopping and making appointments for the patient, checking on the patient in the night and managing family finances) reported by partners and its impact on the marital relationship also improved over the first year. They reasoned that as time passed, demands on the family were reduced as the patient recovered and resumed previous family roles and responsibilities.

Table 3.5: Prevalence for Anxiety, Depression, physical health and Quality of life for partners

Study Author & Year	Partners (Male/Female)	Measure Used (Outcome)	Prevalence Baseline %	Prevalence 6-months %
Pedersen et al. (2009)	196 total	HADS (Anxiety)	Female: 49.4 Male: 42.9	Female: 33.8 Male: 21.4
	Female: 21.4% Male: 80.1%	HADS (Depression)	Female: 25.3 Male: 26.2	Female: 19.5 Male: 11.9
	n= Female 42 n= Male: 157			

A more recent study included in van den Broek's (2010) systematic review, which was by Pedersen, van den Berg, Erdman, van Son et al. (2009) compared anxiety and depression between partners and patients. They found partners had elevated anxiety compared to patients but similar levels of depression at baseline to 6-months. Symptoms of anxiety and depression were measured with the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and used a cut-off score of ≥8 on both anxiety and depression to indicate probable clinical levels. Whereas at baseline, partners had a mean score of 8 for anxiety, patients had a mean of nearly 6 and in both cases anxiety significantly declined at 6-months to means scores of nearly 6 and 4 respectively. Pedersen et al. (2009) found no difference between scores for depression at baseline (mean score of five), which reduced for both to a mean score of 4 at 6-months (see Table 3.6).

Pedersen et al. (2009) also found the prevalence rate of anxiety was significantly higher in partners compared to patients. The prevalence rate for anxiety in partners was 92.36 % compared to 55 % of patients at baseline, which reduced significantly to 55.2 and 37.6 % respectively at 6-months and was irrespective of the partner's gender. Although depression rates were slightly higher for partners than patients, the difference was not significant at baseline or 6-months. There was a lower prevalence of partners to patients at baseline suffering with clinical depression with a prevalence rate of 51.5 compared with 64.6 % of patients and again at 6-months with 31.4 and 39.6 % respectively (see Table 3.5).

Table 3.6: Mean scores for Anxiety, Depression, physical health and Quality of life for partners

Study Author & Year	Partners	Measure Used (outcome)	Mean Baseline (s.d.)	Mean 3-mths (s.d.)	Mean 6-mths (s.d.)	Mean 12-mths (s.d.)
Jenkins et al. (2007)	124 AAD^(n=59) ICD (n=65)	Short Form Health Survey SF-36* (Mental Health)	51.1 ± 10.0^ 47.3 ± 11.4			52 (10.5)^ 50.2 (10.9)
		Short Form Health Survey SF-36* (Physical Health)	49.4 ± 10.0^ 44.3 ± 11.6			46.5 (6.1)^ 43.5 (11)
		Quality of Life Index – Cardiac* Version (QoL)	24.7 ± 3.2^ 23.6 ± 3.9			24.2 (3)^ 22.8 (3.4)
Dougherty & Thompson (2009)	127	STAI Inventory** (State anxiety)	39.91 (12.81)	35.16 (12.55)	34.62 (12.72)	35.65 (12.47)
		CES-D Scale** (Depression)	14.45 (10.52)	9.90 (9.60)	9.36 (9.45)	10.63 (10.01)
		Short Form Health Survey SF-12* (Mental health)	47.95 (11.02)	51.32 (9.53)	51.10 (10.43)	50.94 (10.25)
		Short Form Health Survey SF-12* (Physical health)	48.3 (10.44)	46.10 (10.75)	47.28 (10.55)	45.65 (10.58)
		DOI-P Scale	3.17 (2.96)	2.56 (3.44)	2.20 (2.94)	2.20 (3.07)
Pedersen et al. (2009)	196	HADS (Anxiety)***	8		6	
		HADS (Depression)***	5		4	

*^ AAD=Anti-arrhythmic medication. * A higher score indicates a more favourable score.*
*** A higher score indicates a less favourable score. *** Significant differences not reported.*

Risk Factors that Influence Psychological Distress in ICD Partners

There are mixed findings as to whether the experience of shocks, or being the partner of a primary or secondary prevention patient influenced anxiety, depression and QoL for partners of ICD patients. Van den Broek et al.'s (2010) systematic review reported three studies (Dougherty, 1995; Jenkins et al. 2007; Pedersen et al. 2009) that examined the influence of shocks on the partner's anxiety. Pedersen et al. (2009) reported no influence of shocks on partner anxiety, unless the patient had been implanted with the ICD after a cardiac arrest and consequently had been implanted for secondary prevention. Van den Broek et al. (2010) suggested partners of patients implanted for secondary prevention might have increased distress because they had witnessed the cardiac arrest, had called and waited for the ambulance, leading to distress when these events were relived.

Pedersen et al. (2009) found the highest anxiety scores using HADS-anxiety scale, were found in partners of secondary indication patients who had experienced shocks and in Type-D partners of secondary indication patients (mean scores of 12.17 and 14.25 respectively. From these findings, they suggested it was not the experience of a shock per se, that appeared to influence partner's anxiety, but it was whether or not the shock was experienced by a patient who had the ICD for secondary prevention or if the partner had a Type-D personality. Pedersen et al.'s (2009) findings supported Jenkins et al. (2007) who also found the experience of shock did not significantly influence partner's anxiety. Jenkins et al. (2007) also found partner QoL was unaffected by shocks.

Conversely, Dougherty (1995) found shocks did affect partner anxiety. Dougherty (1995) found the difference between anxiety at 12-months in non-shock and shock partners was statistically significant. However, their findings might be due to sample size, age of partner, and illness severity. For instance, whereas Pedersen et al.'s (2009) used a sample size of 196, Dougherty's study only comprised 15 partners (shock partners n=5) and Dougherty's study had a younger mean partner age by four years compared with Pedersen et al. (2009). Further, two patients died before the 6-months post-ICD follow-up, and the mean of the number of shocks in Dougherty's study was 26 with a range of 3-100, which is extremely high considering the sample consisted of 5 partners and suggests that the severity of the patient's cardiac illness was far greater in Dougherty's study.

The evidence for the influence of shocks on depression is similarly mixed. Pedersenet al.'s (2009) study showed no impact of shocks on levels of depression. Pedersen et al. (2009) found the only factors to increase the rate of depression in partners was if the patient was a secondary prevention coupled with the partner having a type-D personality but shocks had no effect on depression. However, Dougherty (1995) reported higher levels of depression in partners of patients who had received a shock. Dougherty found non-shock family members reported highest levels of depression at hospital discharge with a mean 8.6 on the Profile of Moods (POMS) Depression-Dejection subscale, which improved significantly with a mean of 1.4 at 12-months. Partners in the shock group reported their highest level of depression at 6-months (mean 15.4 POMS) meaning that their depression had increased after hospital discharge. The lowest level of depression reported by shock partner was at 12-months with a mean of 9.6 (POMS) which was higher than the highest reported level of depression by partners in the non-shock group.

Findings were also mixed about whether partners of primary prevention patients had increased anxiety and depression compared to those of secondary prevention patients. Pedersen et al. (2009) found that partners of patients, who had an ICD for secondary prevention had significantly higher anxiety compared to those partners of primary prevention patients (HADS anxiety mean score of 10.1 versus 5.4). However, the results reported in two studies, Jenkins et al. (2007), whose sample included partners of primary prevention patients and Dougherty & Thompson's (2009) study who only used partners of survivors of cardiac arrest (secondary prevention), suggested there was no difference if their QoL scores. Partners in both studies had similar levels of mental and physical health as measured by SF-36 and SF-12 at 12 months. The physical health scores of primary prevention partners at baseline were worse than the scores of secondary prevention partners. This suggests that over time, there was more improvement in the physical health of primary prevention patients.

SECTION 3: Risk Factors that Influence Psychological Distress in ICD Patients

Factors associated with psychological responses that have been examined and relevant to this research study include age and gender, personality disposition, co-morbidities, ICD shocks and ICD concerns, and coping behaviour.

Age and Gender

A patient's age and gender have been reported to be risk factors for being susceptible to psychological distress, with female ICD recipients and those under the age of 50 years found to be at risk of higher levels of distress (Bostwick & Sola, 2007; Dunbar, Jenkins, Hawthorne, & Porter, 1996). A young age (<50 years) is a commonly cited risk factor possibly because patients had an "age inappropriate illness" and possibly because the disease process is more intrusive at certain developmental points in the lifespan (Sears, Matchett & Conti, 2009), such as being the mother or father of young dependent children.

Findings concerning age however appear to be mixed. Vazquez, Kuhl, Bishop Shea, Kirkness et al. (2008) who only used females, found younger recipients ($\leq$ 50 years) were at greater risk of developing psychosocial distress, which was associated with shock anxiety, death anxiety and body image. However, a study by Hamilton and Carroll (2004) that used both sexes found older recipients ($\geq$ 67 years) were less satisfied with their physical functioning and had higher rates of anxiety than their slightly younger counterparts ($\leq$ 62 years). In contrast, Bilge, Ozben, Demircan, Cinar et al. (2006) used a sample with a mean age of 53 (± 14 years), age range between 18 and 86 years and found no significant relationship between age and anxiety and depression.

There also appears to be mixed evidence about whether female patients experienced higher rates of anxiety and depression and less satisfactory QoL than their male counterparts did. Palacios-Ceña, Losa-Inglesias, Álvarez-López, Cachón-Pérez et al.'s (2011) qualitative review found women were more likely to experience issues with body image after their implant, and were less likely to adjust to their familial roles caring for children. Bilge, Ozben, Demircan, Cinar et al. (2006) also found female patients had significantly higher anxiety and depression scores than males, and gender in this study was found to be a predictor for anxiety. However, Pedersen et al. (2009) and Habibović, van den Broek, Theuns, Jordaens et al. (2011) found no difference in mean scores of anxiety or QoL between male and female patients.

Brouwers, van den Broek, Denollet & Pedersen's (2011) systematic review examined the evidence for gender disparities in psychological distress and QoL, and concluded that gender was not a predictor for anxiety, depression or QoL. They concluded there was insufficient evidence to posit that gender per se was an autonomous predictor. Brouwers et al. (2011) suggested gender disparities that existed might be due to role expectations, socialisation, and a tendency for women to report symptoms. They further suggested that it was not gender per se that accounted for the disparities but the fact that female ICD recipients tended to be older and often had a worse clinical status than their male counterparts had.

Type-D Personality Disposition

The dispositional factor of the distressed (Type-D) personality feature has also been linked to poor psychological outcomes in ICD patients. The distressed (Type D) personality refers to the presence of two broad and normal personality traits, namely negative affectivity (NA) and social inhibition (SI) (Denollet, 2005). Negative affect refers to the tendency to experience negative emotions across time and situations. It has been conceptualised as neuroticism and with it shares 40-50 % common variance, which suggests that the two constructs are closely related but not identical (Denollet, 2000). Denollet (2005) posited that individuals with high NA experience more feelings of dysphoria, anxiety, and irritability. In addition, they tend to have a negative view of themselves and continually scan the environment for danger or threat.

Social inhibition refers to the tendency to inhibit the expression of emotions and behaviours in social interactions to avoid disapproval by others. Therefore, although high-SI individuals might appear quiet on the surface, they may be avoiding interpersonal conflict through excessive control over self-expression thus appearing reticent and withdrawn (Denollet, 2000). Therefore, high-SI individuals are more likely to feel tense and insecure when with others (Denollet, 2000). Denollet (2005) posited that individuals who are high in both NA and SI had a 'distressed personality' (Type-D) and were at increased risk of depression, anxiety, irritability and low levels of self-esteem, well-being and positive affect.

Pedersen, van Domburg, Theuns, Jordaens et al. (2004) found that ICD patients with a Type D personality were more likely to suffer from anxiety than their non-Type D counterparts. Similarly, Type D patients and partners were more likely to suffer from depressive symptoms than their non-Type D equivalents. A patient with a Type-D personality and has an ICD has been associated with a higher incidence of mortality (Pedersen, van den Broek, Erdman, Jordaens, et al., 2010). For instance, Pedersen et al. (2010) found that the rate of mortality was higher in Type-D patients with an ICD compared to their non-Type D counterparts. In addition, they found if a Type-D personality also had a high level of ICD concerns, they had an even poorer survival prognosis compared to patients with only one risk factor i.e. Type-D or high level of concerns. (See ICD-related Concerns at the end of this chapter).

The effect of a Type-D personality has a larger influence if both patient and partner have the same distressed personality (Van den Broek, Versteeg, Erdman, and Pedersen, 2011). Van den Broek et al. (2011) found that Type-D ICD patients reported more depressive symptoms if their partner also shared their personality characteristics. Van den Broek, et al. (2011) suggested this might be due to poorer communication between the couple and a lack of emotional support towards each other in their relationship. However, van den Broek et al. (2007) found that the risk of anxiety and depression was exacerbated in patients with a Type-D personality if the ICD patient had no partner. They found Type-D patients who did not have an intimate partner had the highest risk of anxiety and depressive symptoms compared to Type-D patients with a partner and non-Type-D patients without a partner.

A study by Pedersen, van Domburg, Theuns, Jordaens, et al. (2004) investigated whether Type-D was an independent predictor for symptoms of depression and anxiety in ICD patients and their intimate partners. They found that having a Type-D personality was independently related to anxiety and depressive symptoms in both patients and partners. They found that ICD patients and partners who had a Type-D personality reported more symptoms of depression and anxiety compared to their non-Type D counterparts. Notably, Type-D ICD patients had a seven-fold increased risk of anxiety. However, Pedersen et al. (2004) found that social support had a buffering effect on anxiety and depression for ICD patients and partners. They found that patients and partners who had a Type-D personality tended to perceive a poor level of social support, and therefore it might be this perception of poor support that led to high levels of psychological distress in Type-D personalities.

Pedersen et al. (2004) suggested that it was the negative affect aspect of their personality (suggested by them to be closely related to neuroticism) that accounted for most of their dissatisfaction with social support. This suggestion was supported by the findings from an earlier study by Pedersen, Middel and Larsen (2002). Pedersen et al. (2002) investigated the role of personality and social support and perceived health and distress (posttraumatic stress disorder, anxiety, depression, cognitive and somatic complaints) in post-MI patients. Findings showed that satisfaction with social support was an independent predictor for depression. However, they also found that neuroticism was an independent predictor for all outcome measures. From their findings, they suggested that neuroticism (closely related to Type-D's NA) influenced patients' perception of social support, which subsequently influenced distress and health complaints. This finding therefore suggested the way in which Type-D personalities *coped* with events increased their distress rather than it being because they were *distressed* people as was suggested by Denollet (2005).

Coping Styles and Behaviour

Overall, the findings suggested that a mixture of problem- and emotion-focussed coping strategies was the most effective approach to take in learning to cope with an ICD from both a physical and a psychological point of view. For instance, Kuiper and Nyamathi (1991) used a mixed qualitative/quantitative design to investigate how ICD patients adapted to their ICDs. They used the Lazarus stress and coping paradigm as the theoretical framework to understand their findings. Using the Jaloweic coping scale (JCS), Kuiper and Nyamathi (1991) found patients used more emotion-focussed coping styles (thinking positively, acceptance/defeatist, evasive, emotive, palliative, and self-reliance) than problem-focussed coping (taking action and seeking support) to cope with the psychologic and social adjustment to living with the ICD.

Kuiper and Nyamathi (1991) found being confrontive (taking action), was most used to cope with the physical adjustment to the ICD. However, in order to adjust to the physical, social and psychologic changes that the ICD implant had produced, the JCS revealed that patients used a mixture of both problem and emotion-focussed coping. Their qualitative findings supported their evidence from the JCS; patients used more problem-focussed coping strategies to deal with the physical adjustments to stress, and emotion-focussed strategies were used to deal with psychologic and social stress. Kuiper and Nyamathi (1991) further suggested that any one style of coping should not be preferred over another but did suggest that strategies to promote optimism should always be encouraged. This suggested that optimistic was not classified as trait optimism but as a distinct coping strategy. However, it is unclear whether Sears, Serber, Lewis, Walker et al. (2004) posited that optimism was a trait or was a coping strategy that could be learned; they also supported optimism to be an effective coping style, and suggested that optimism was a resilience factor against psychological stress.

Not all patients were able to use optimism as a resilience factor and patients often used the emotion-focussed coping strategy of denial to reduce psychological distress. Dougherty (1994) found survivors of sudden cardiac arrest (SCA) largely used denial in order to cope during the first year post- ICD implant. Dougherty's evidence suggested rates of denial were lowest at hospitalisation when anxiety and depression were at their highest and as anxiety and depression rates decreased, the use of denial increased. Although there was no data to support this claim, it could be posited that denial might have been adaptive during the first year post-implant by producing a distancing effect from the trauma of the SCA and ICD implant.

Whereas Kuiper and Nyamathi (1991) and Dougherty (1994) found emotion-focussed coping were effective in reducing psychological distress, Craney, Mandle, Munro, and Rankin (1997) suggested that this way of coping was a significant contributor to psychological distress in ICD patients at 2-years. Craney et al. (1997) found there was a significant negative correlation between physical functioning and emotion-focussed coping, which suggested that patients who were more physically active used less emotion-focussed coping. Which particular emotion-focussed strategies predicted the worse outcomes was not discussed but the authors suggested that denial, blame seeking and 'wishful thinking' should be targeted for change.

Dunbar, Jenkins, Hawthorne, Kimble et al. (1999) found similar findings to Craney et al. (1997) and suggested that emotion-focussed coping was a predictor of worse psychological outcomes. Dunbar et al. (1999) investigated how ICD patients coped up to 3-months post implant in terms of their appraisal-coping processes and emotional outcomes. They found higher levels of emotion-focussed coping was a significant predictor of total mood disturbance at baseline (before implant) and at 1- and 3-months post-implant. Dunbar et al. (1999) predicted that evasive coping should reduce a negative emotional response. However, their study found that evasive coping led to increased avoidance in the context of intense symptoms. The study also found that problem-focussed coping, such as support seeking and information seeking was a significant predictor of better functional status at 1-month post ICD-implant.

In summary, patients used a combination of emotion- and problem-focussed coping strategies as they have to cope with many different aspects of adjusting to living with an ICD, and some might be more beneficial than others depending on what the patient is trying to cope with. Adjusting to the ICD device encompasses adjusting to the physical aspects, such as its protrusion, scar and pain. They also have to adapt to its impact socially, such as possible limitations on exercise and activity, some that might be determined by their underlying cardiac disease rather than the device. Patients also have to adjust psychologically to their device, such as coping with the fear of a shock and worries about the future.

Heart Failure Co-morbidity

Heart failure affects three-quarters of a million people in the UK and the incidence is growing ("what is heart failure", 2012). Treatment with an ICD in combination with cardiac resynchronisation therapy (CRT-D) relieves chronic heart failure symptoms, and potentially promotes improved QoL for ICD patients (Johansen, Pedersen, Spindler, Andersen, et al., 2008).

The prevalence of depression in heart failure patients was estimated to be one in three and is associated with higher levels of morbidity and mortality with cardiovascular disease (Suzuki, Shiga, Kuwahara, & Kobayashi , 2010). Suzuki et al. (2010) found a higher rate of depression in patients hospitalised due to an upgrade from ICD to CRT-D. Johansen et al. (2008) found symptomatic heart failure was the most important correlate of impaired QoL, and the most important correlate of anxiety and depression. However, although symptomatic heart failure is an important correlate of depression, no causal relationship has been found. For instance, Pedersen, Hoogwegt, Jordaens, and Theuns (2011) found patients with persistent depression were more likely to have CRT-D device, have heart failure, be classified as New York Heart Association Class III and IV, as well as being older, a Type D personality and report a high level of ICD concerns.

ICD-related Concerns

ICD-related concerns, in particular fears about the ICD firing, have been identified as a major determinant of anxiety, depression and reduced QoL (e.g. Sears & Conti, 2002; Pedersen, van Domburg, Theuns, Jordaens, et al., 2005). Within the first year after implant, approximately 10-14 % of patients experience a shock from their ICD, although patients who have been implanted for secondary prevention generally experience a higher incidence (John & Stevenson, 2012). Approximately, 30 % of these shocks are inappropriate, i.e. the shock was due to the ICD's inability to differentiate between an atrial tachycardia that is not dangerous and a ventricular tachycardia, which can be life-threatening (John & Stevenson, 2012). However, both types of shock are painful and the incidence of shocks has been associated with a reduced QoL and higher levels of anxiety and depression in ICD patients (John & Stevenson, 2012; Pedersen, van den Broek, van den Berg, & Theuns, 2010). Whether it is the pain that is experienced or other factors concerning a shock that causes increased psychological distress and reduced QoL has been examined elsewhere in this thesis (for an in-depth discussion about the relationship between shocks , psychological distress and QoL, see the Qualitative Literature Review).

The relationship between shocks and increased psychological distress and reduced QoL is not straightforward and there is mixed evidence to support this relationship.

For instance, Dougherty (1995) compared two groups of ICD patients. One group had no shock firings during the first year and the other group had one or more shock firings. Dougherty (1995) found significant differences in anxiety between the two groups (although the sample size was very small). Whereas the non-shock group gradually improved over time, the shock group's level of anxiety remained unchanged at the higher baseline level. Schron, Exner, Yao, Jenkins et al. (2002), who used a much larger sample size to Dougherty (1995) concurred that the occurrence of ICD shocks during the first year post implant led to decreased QoL and increased psychological distress.

However, a meta-analysis by Burke, Hallas, Clark-Carter, White et al. (2003) found no significant reported difference between levels of anxiety or depression in patients who had experienced a shock compared to those patients with no shock experience. Similarly, a study by Pedersen, van Domburg, Theuns, Jordaens et al. (2005) did not find an association between anxiety and depression and experience of ICD shocks. However Pedersen et al. (2005) did find an association between shocks and ICD concerns and also found that patient concerns about the ICD were a determinant of anxiety and depressive symptoms independent of shocks. They measured concerns using the ICD-Concerns questionnaire (see Chapter 9), which included device-related concerns such as the ICD not working when it is needed, the battery running out, problems occurring with the leads connecting the ICD to the heart, becoming a burden on partners and families and worry about the future. (For a more in-depth discussion about ICD-related concerns, see the Qualitative Literature Review).

Evidence from Lemon, Edelman and Kirkness's (2004) study, suggested it was not necessarily the fear of the shock that led to reduced QoL but that QoL was affected by changes in behaviours used to avoid a shock. They found 55 % of ICD patients reported that they engaged in avoidance behaviour after their implant, in order to avoid receiving a shock. The highest frequency of avoidance was avoiding activities (39%), followed by objects (27%) and places (17%). There was no relationship between avoidant behaviour and shocks experienced although the greater the number of avoidances reported, the greater the tendency for the avoidance to increase with time. However, this pattern was not seen with patients who associated avoidance with shocks. This suggests that shocks per se are not the root cause of avoidance but rather it is the fear of having a shock.

The evidence whether shocks influence psychological responses remains mixed but three points can be highlighted. The first point is Pedersen et al. (2010) suggested that patients vary greatly in their response to a shock ranging from those who feel profound distress to those who feel negligible concern, so therefore the shock's influence is an individual, unique response. The second point is that patients can experience high levels of anxiety and depression whether or not they have experienced a shock and lastly, Pedersen et al. (2010) posited that patient anxiety was not related to the shock per se but was related to their fear of being shocked, which was supported by the findings of Lemon et al. (2004).

Key Issues

- After the ICD implant, it appears that the first year is a critical year in which to adjust to living with the device. Levels of anxiety appear to be highest pre-implant and remain stable for one year.
- After one year, prevalence rates of anxiety and depression appeared to either increase or decrease.
- ICD patients who had not had a shock often had a high level of anxiety due to the *fear* of being shocked (e.g. Lemon et al., 2004).
- Psychological distress (e.g. high levels of anxiety) can increase the risk of a ventricular arrhythmia due to sympathetic arousal (see Burg et al., 2004; Kop et al., 2004).
- Experiencing a shock during the first year increases psychological distress and reduced quality of life during that year (e.g. Dougherty, 1995; Schron et al., 2002).
- The anxiety scores of partners were highest during the patient's hospitalisation.
- The physical health of partners of ICD patients declined over the first year post implant (see Jenkins et al., 2007; Dougherty & Thompson, 2009).
- Partners of ICD patients who experienced a shock or who were secondary prevention patients (i.e. already had experienced a SCA) experienced higher levels of depression during the first year post implant compared to those partners of primary prevention and non-shock patients.

The psychological distress of patients appears to be cyclical in nature (i.e., worry about fear of shock leads to increased risk of shock, which in turn leads to more psychological distress). Therefore, in order to help reduce patient's distress, an initial step would be to examine their distress using qualitative interviews to explore their worries and fears (see Chapters 5-7). The decline in physical health of partners, which were reported as being run-down, having headaches and feeling fatigued might have been psychosomatic in nature. Accordingly, in order to help improve their physical symptoms, it is necessary to reduce their psychological distress. Therefore, it would be useful to explore the worries and concerns pertinent to partners.

Next:

Chapter 4 - Psychological Theory to Explain Psychological Distress in ICD Patients

Part 1

Chapter 4

PSYCHOLOGICAL THEORY TO EXPLAIN PSYCHOLOGICAL DISTRESS IN ICD PATIENTS

This chapter describes the prominent behavioural and cognitive theories that explain the psychological distress experienced by ICD patients. This chapter also explains how some of these theories were used in the Brief Psychological Intervention for ICD patients. Finally, the reasons why Lazarus' appraisal theory of emotion was used to explain the findings in the Qualitative Study described in Chapters 6 and 7 are outlined.

Behavioural Theories: Anxiety and Avoidant Behaviours

A behavioural approach suggests that anxiety, depression and avoidant behaviours are due to conditioning processes. Mowrer's (1947) two-process theory was a behavioural model that explained anxiety and avoidance behaviour by combining Pavlov's (1927) classical conditioning theory with Skinner's (1938) operant conditioning theory. Mower (1947) suggested that mechanisms in the two conditioning theories (classical conditioning and operant conditioning) were together involved in avoidant behaviour (Domjon, 2010). At first classical conditioning has to occur in order to create a conditioned response, which is followed by operant conditioning that maintains the avoidant behaviour created.

Mowrer's behavioural theory was able to explain why ICD patients were avoiding situations or objects that had previously been associated with a shock. For example, Mowrer's theory could explain the finding in Bolse, Hamilton, Flanagan, Caroll and Fridlund's (2005) study in which an ICD patient continued to avoid taking a shower. This avoidant behaviour of the patient in question had begun after an episode[30] was experienced from her ICD whilst showering; she consequently had begun to associate the shower with the fear of being shocked. Mowrer's theory suggested that

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[30] The term 'episode' appears to be a common word for any therapy from an ICD from pacing to shock therapy.

her avoidant behaviour (to avoid showering) was being maintained through the negative reinforcement she received when she avoided the shower.

Mowrer's (1947) two-process model fails however to explain other occurrences of avoidant behaviour that have been found in the literature, such as in circumstances in which no initial classical conditioning had taken place. A fundamental premise of Mowrer's model was initially a conditioned response had to be made, but not all patients who engaged in avoidant behaviour had experienced an adverse experience associated with the avoided behaviour. For example, Lemon, Edelman and Kirkness (2004) found 23 of 143 respondents reported that they avoided places, however of the 23 respondents, only eight of them had previously experienced a shock when visiting the place. Similarly, Schron, Exner, Yao, Jenkins et al. (2002) and Dougherty (1995) found patients who had reported avoidant behaviours despite never having received an ICD shock. Therefore, some avoidant behaviours were not created by learned behaviour and cannot be explained by Mowrer's (1947) two-process model.

Cognitive Theories: Anxiety and Avoidance

The cognitive approach to understanding anxiety and avoidant behaviours in ICD patients does not rely on prior learning having taken place. It can therefore explain avoidant behaviours in patients, who try to avoid a shock despite never having experienced an ICD shock. If anxiety, depression and avoidant behaviours existed in situations where there was no experience of shock, this implied that it was not the shock per se that caused the distress but that distress was due to the *expectation* of being shocked and therefore was cognitive in origin.

Beck (1997) suggested that it was cognitive responses to events, rather than the events themselves that determined individual's moods; feelings of distress and moods were proposed to be consequences of *faulty* or *irrational* thinking. Beck (1976) put forward the cognitive content-specificity hypothesis, in which disorders such as depression (see Cognitive Theories: Depression below) and anxiety were characterised by cognitive content that were specific to a disorder. Beck (1976) suggested that transient automatic thoughts (non-volitional, stream-of-consciousness cognitions), their interpretations and imagery expressed by anxious patients were characterised by the theme 'danger' (Beck, Brown, Steer, Eidelson et al., 1987). Accordingly, anxious patients tended to misread benign experiences to constitute a physical or a psychosocial threat (Beck et al., 1987). Beck suggested that anxious patients tended to believe that the probability and intensity of the perceived threat would also occur in future situations (Beck, et al., 1987).

The creation of the Cognition Checklist (CCL) scale (Beck, Brown, Steer, Eidelson et al. (1987) was able to support this hypothesis and in addition supported the existence of automatic thoughts that were characterised by the theme of danger. The CCL was developed using verbatim reports of automatic thoughts provided by patients undergoing cognitive therapy. Using the Daily Record of Dysfunctional Thoughts (Beck, Rush, Shaw & Emery, 1979), a 43-item scale was devised using cognitions judged to be most typical in anxious or depressed patients. Patients were asked to rate the frequency of these automatic thoughts, and to label the predominant affect whilst thinking about each thought contained in the CCL. The findings supported the content-specificity hypothesis; patients who had a higher mean score on the CCL for anxiety also had an anxiety disorder as diagnosed by the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; American Psychiatric Association, 1980). (Similar support was found for the content-specific automatic thoughts found in depressed individuals, see below for Cognitive Theories: Depression).

Although Beck (1976) did not offer an explanation as to which cognitive processes were responsible for misreading threat messages, he suggested that anxious individuals tended to be involuntarily preoccupied by danger with a heighted perception to 'danger signals'. By avoiding the behaviour/situation, the individual is protected from the threat of danger. Accordingly, faulty beliefs (e.g. "if I feel nervous, it will cause the ICD to shock"), are what drive avoidant behaviours. This faulty cognition will continue to exist until it is challenged either by using a Socratic method or by engaging in the avoided behaviour to realise that the behaviour poses no danger. Whatever is being avoided needs to be confronted cognitively or behaviourally, e.g. taking a shower, and then the faulty belief, which is driving the avoidant behaviour can be corrected. Therefore, the findings in Lemon et al. (2004), Schron, et al. (2002) and Dougherty (1995) can be explained by this cognitive theory which would suggest that it was the anxiety (intense emotional state) that was driving the avoidant behaviour rather than the negative experience of being shocked.

According to Beck (1976), anxious patients have a tendency to catastrophise. For example, an ICD patient might catastrophise a benign bodily symptom to be a warning that something is wrong with their heart. A characteristic of catastrophising is that the person equates the hypothesis with a fact, and subsequently any situation or symptom that might constitute an element of harm, is perceived to be a real threat and very dangerous or harmful (Beck, 1976).

The brief psychological intervention devised for ICD patients was partly based on Beck's (1997) cognitive theory. Beck's suggestion that it was cognitive response to an event that caused psychological distress rather than the event itself purported that if cognitions were altered, psychological distress would be reduced. A chapter to teach patients how to cope with worries, using a structured format encouraged patients to challenge their beliefs and automatic thoughts. (See Chapter 8 for a more details of the intervention: Coping with Worries).

Behavioural Theories: Depression

Seligman's learned helplessness paradigm (1975) was a behavioural model, which explained depression based on operant conditioning. The theory was initially based on findings from Overmier and Seligman (1967) who found that dogs exposed to inescapable and unavoidable electric shocks in one situation later failed to learn to escape when experiencing electric shocks in another situation. Maier and Seligman (1976) explained these results as being a consequence of the dogs learning that termination of the shocks was independent of their responses.

The learned helplessness model of depression that posited that learning outcomes were uncontrollable resulted in motivational, cognitive and emotional components of depression (Abramson, Seligman, & Teasdale, 1978). Motivational deficits included passivity, intellectual slowness and social impairment, and cognitive deficits consisted of difficulties in learning that behavioural responses could change outcomes. Lastly, the model suggested that the depressed affect (the emotional component) was a consequence of learning that outcomes were uncontrollable. Of note, the main tenet of Seligman's theory of depression was that depression occurred through learned behaviour, and was not dependent on cognitive mediation.

The findings from a study by Hiroto and Seligman (1975) supported Seligman's theory. Their study investigated the generality of helplessness produced by uncontrollable events across cognitive and motivational tasks. The study involved four experiments. Two of the four experiments involved a pre-treatment with a noise (escapable, inescapable or control) or a cognitive condition (soluble, insoluble or control cognitive discriminant task). The pre-treatment was followed by escaping from a shuttle-box task or solving an anagram task. The group pre-treated with an inescapable noise exhibited a significantly weaker noise-escape performance compared to the control group and the group pre-treated with a noise from which they could escape. This finding demonstrated a learned helplessness in humans that was directly parallel to the learned helplessness that had previously been found in dogs by Overmier and Seligman's (1967) study. The groups in which an inescapable or insoluble task followed by an instrumental activity demonstrated significant impairment compared to those groups pre-treated with an escapable instrumental or soluble cognitive discriminant task. However, this study found that although the group pre-treated with an insolvable cognitive discriminant task did worse than the other groups when followed by another cognitive task, their results did not reach significance. In addition, this study found evidence of cross-modality in that pre-treated inescapable noise + unsolvable anagrams and unsolvable anagrams + inescapable noise led to similar findings. Hiroto and Seligman (1975) posited that with the evidence of cross-modality suggested learned helplessness appeared to be generalised across unrelated tasks, and therefore learned helplessness was best viewed as a trait rather than as a transient state.

Hiroto and Seligman's suggestion that learned helplessness should be viewed as a trait was supported by the findings in Goodman and Hess (1999). Goodman and Hess (1999) tested Seligman's theory of learned helplessness with a small group of ICD patients. They hypothesised that in ICD patients with no prior history of psychological distress (depression and anxiety) before the ICD, the number of shock firings would be predictive of greater depression and anxiety. Conversely, they hypothesised that in ICD patients with a prior history of depression and anxiety, there would be no significant relationship between the number of shocks and psychological distress.

Goodman and Hess (1999) offered no explanation for their hypotheses, but as they were testing learned helplessness the following could be suggested: they believed patients with no history of depression and anxiety would as they faced an inescapable aversive stimulus, exhibit levels of psychological distress in relation to the stimulus. However, in patients with a prior history of depression and anxiety, no relationship would be found between shocks and psychological distress as these patients would already exhibit learned helplessness from when they were previously depressed, which would mean they would not try to avoid a shock. Their findings supported their hypotheses; the mean scores of depression and anxiety were found to be higher for patients with a prior history of psychological distress despite receiving a fewer mean number of shocks, which might suggest these patients exhibited an enduring 'trait-like' learned helplessness. Although Goodman and Hess (1999) found evidence that supported the model of learned helplessness, a meta-analysis by Burke et al. (2003) found no significant differences in depression between patients who had experienced shocks compared to those who had not (see Chapter 3: Section 3: ICD-related Concerns).

Abramson, Seligman and Teasdale (1978) criticised Seligman's learned helpless model of depression on four grounds.

(1) The model failed to account for instances where uncontrollability did not lead to depression (e.g. see Blaney, 1977). For instance, Abramson et al. (1978) described how an individual would not show dysphoria on receipt of a large amount of money each month from a trust fund despite having no control over its delivery. However, they also suggested that receiving positive outcomes (e.g. money) independent of any action could lead to an increased vulnerability to depression. For instance, if the individual has repeatedly learned that positive events arrive independent of any action, when a negative event occurs, the individual might be vulnerable to depression if their response-outcome expectation set is activated. Therefore, it was not uncontrollability per se that led to a depressed state but the desirability and attainability of the outcome.

(2) The model failed to explain the relationship between lowered self-esteem and depression (see Blatt, D'Afflitti, & Quinlan, 1976).

(3) The model did not explain why depressed individuals tended to make internal attributions, (e.g. Klein, Fencil-Morse, & Seligman, 1976; Rizley, 1978).

(4) The model failed to account for the variations in generality, chronicity and intensity of depression.

Cognitive Theories: Depression

Seligman's model of helplessness was reformulated by Abramson et al. (1978) who incorporated into the model, cognitive mediation based on attribution theory (Heider, 1958), and the attribution of control based on the theory of locus of control (Rotter, 1966). By adding these cognitive components, Abramson et al. (1978) reformulated Seligman's model of depression to become the human helplessness model of depression.

In line with Seligman's (1975) behavioural model of helplessness depression, Abramson et al. (1978) agreed that the notion of controllability contributed to the development of depression. However, they argued that unlike Seligman's (1975) model, the expectation of uncontrollability per se was not sufficient to induce depression but that other factors were needed. In particular, the desirability of the outcome was important; Abramson et al. (1978) posited that depression would only result when the probability of a desired outcome was low. For instance, an ICD patient might wish to avoid receiving a shock at the same time as believing that a shock was likely to occur. Similarly, they posited that depression would also occur if the probability of an undesired outcome happening was high, such as the patient holding the belief that there was a high probability of receiving a shock.

The revised model suggested attributions about a stimulus were made along three dimensions that were continuums. The dimension 'stable-unstable' was orthogonal to 'internal-external' (personal-universal). Stable factors were long lasting or recurrent, such as living with a chronic illness, whereas unstable factors were short-lived or intermittent, such as experiencing an acute illness. The third dimension named ‘global-specific’ was orthogonal to internal-external and stable-unstable. Global factors affected many outcomes and implied that helplessness would be generalised over all situations whereas specific factors, implied helplessness would occur only in a specific situation. An internal attribution referred to an individual attributing the outcome (e.g. cope with an ICD) to being a deficit in them, whereas an external attribution would be made if the outcome was blamed on external reasons (e.g. the limitations imposed by the ICD) (see Table 4.1).

Abramson et al. (1978) suggested that the attributions made (e.g. stable, internal, global) by the individual influenced whether they would experience depression. Their model posited that individual differences influenced these attributions made and a tendency to make negative inferential attributions could predispose an individual to hopelessness depression (Abela & Seligman, 2000). These tendencies included:

(1) The tendency to infer negative characteristics about the self when negative events occur. Therefore, when a negative event occurred the individual would be inclined to apportion blame internally rather than to external causes. For example, an ICD patient might blame their lack of fitness if feeling tired after their ICD rather than attribute their tiredness to their medication.
(2) The tendency for an individual to attribute negative events to global and stable causes rather than limit the event to a specific cause. For example, an ICD patient might attribute a difficulty to adapt to their ICD due to their poor inability to cope in general rather than a difficulty coping with a particular aspect of the ICD.
(3) The tendency for an individual to perceive negative events as having many negative consequences. For instance, an ICD patient might believe that the ICD device is going to lead to difficulties such as unwanted changes to their role at work and in the family.

Each of the inferential style factors was suggested by Abramson et al. (1978) to predispose individuals to hopelessness depression by making it more likely, that they will make depressogenic inferences following a negative event. Therefore, the revised model posited that depressed people had distorted cognitions, which accounted for depression found in Rizley’s (1978) study. Rizley (1978) found depressed students attributed failure to incompetence (internal, global and stable factors), whereas non-depressed students had attributed their failure to task difficulty (external, specific and stable factors). Conversely, depressed students attributed successful achievement to the ease of the task (external, specific and stable factors) whereas non-depressed students attributed success to ability (internal, global and stable factors).

Table 4.1: Abramson et al.'s (1978) model of human helplessness depression

	Internal		**External**	
Dimension	**Stable**	**Unstable**	**Stable**	**Unstable**
Global				
ICD Patient failing To cope with ICD	Lack of ability	Tired	Devices are hard to cope with	Today is Friday 13th
	(I can't cope With things)	*(I can't cope When I'm tired)*	*(most people find ICD s difficult to Cope with)*	*(tomorrow might be ok)*
Specific				
ICD Patient Failing to Cope with ICD	Lack of coping with ICD	Fed up with its limitations	ICD devices are particularly Difficult to	The ICD needs to be be adjusted
	(I can't cope with) My ICD)	*(I'm tired so feel its limitations)*	*(why do they make ICDs So hard to live with?)*	*(At my next follow-up, the ICD will be adjusted)*

Abramson et al.'s (1978) model of human helplessness depression was adapted for use in the brief psychological intervention to help patients cope with their ICD. Activities were suggested that would help challenge and correct distorted cognitions, formed by faulty attributions. The intervention also incorporated activities to increase patient's sense of mastery and control as the theory posited that depression was likely to occur if an unlikely outcome was desirable and an undesirable outcome was likely. (See Chapter 8 for more details on the specific activities: Keeping Active and Coping with Worries). A chapter was included about keeping active and gave participants a 'planning diary' to use. The chapter explained the importance of physical activity, which would help reduce depression by increasing patient's sense of control, achieving goals and challenging cognitions.

Beck (1976) posited that the cognitions specific to depression (content-specificity hypothesis) differed to those of anxiety in which patients were preoccupied by danger and had a heightened perception of danger. He suggested depression involved transient automatic thoughts, interpretations and imagery that were self-depreciative and negative attitudes towards past and present (Beck et al. 1987). Central to Beck's (1967, 1983) cognitive diathesis-stress theory of depression was the construct of depressogenic schemata that were activated in individuals who were vulnerable to depression (Abela & D'Alessandro, 2002). Beck (1976) defined schemata as being stored bodies of knowledge that affected the encoding, comprehension and retrieval of information. These schemata were said to be created though negative events in childhood such as experiencing the loss of a parent or chronic rejection by peers. These schemata subsequently become activated in people prone to depression when they were confronted with a significant event later in life that has some similarities to the childhood event, which results in a negative thinking.

Beck (1976) posited that the schemata in people vulnerable to depression influence automatic thoughts to become negative automatic thoughts (NATS). These errors in thinking result in the individual having negative distortions known as the negative cognitive triad, which was defined as a having negative view of the self, world and future (Beck, 1976). Together with negative thinking triggered by schemata, the negative cognitive triad serves to maintain an episode of depression, triggered by the diathesis that activated the schemata. The automatic thoughts systematically misinterpret events and influence errors in thinking so that the depression-prone individual makes overgeneralisations. For instance, if the individual feels miserable, they believe they would always feel miserable (generalisation). Other errors in thinking include selective abstraction, such as only selecting information that is congruent to negative beliefs e.g. "the doctor said I was lucky to be alive – I ought to be dead", and dichotomous thinking such as "the doctor ignored me in the corridor. He obviously doesn't like me" (see Figure 4.1).

For example, an ICD patient will experience transient automatic thoughts (surface cognitions) which are influenced by cognitive schemata (unconscious beliefs about the self and the world, known as the cognitive triad). If the ICD patient has a depressive cognitive schemata (negative cognitive triad), and it is activated by a negative mood, it can influence the automatic thoughts so they become negative.

- A negative view of the world – "Everyone else is coping with their ICD"
- A negative view about self – "I can't cope with my ICD"
- And negative views of the future – "I'll never get used to the ICD because I find coping difficult"

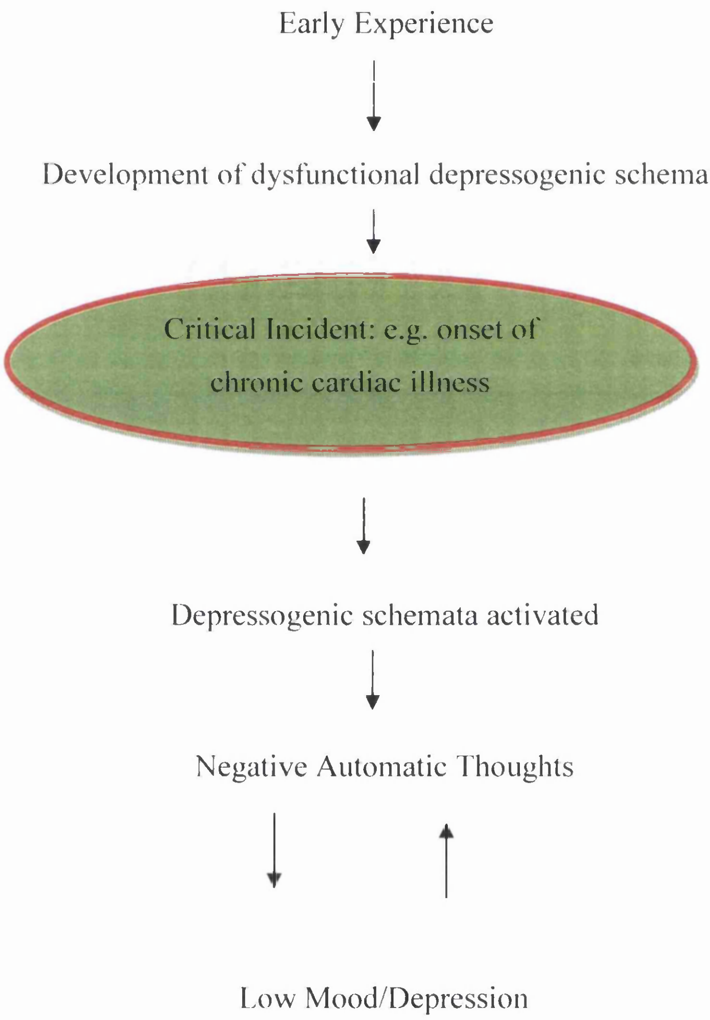

Figure 4.1: Beck's developmental model of cognitive and behavioural precursors to depression. Adapted from Bennett (2011)

A recent cross-cultural study by Beshi, Dobson, & Adel (2012) found evidence for Beck's (1979) cognitive triad. Using participants from Egypt and Canada, the study examined the relationship between current depressed mood and negative cognitions. They found that depressed participants in both countries reported significantly more negative thoughts about themselves, the world and their futures, which suggested evidence that the cognitive triad was a universal not cultural phenomenon.

Nevertheless, critics of the underlying schemata, questioned why dysfunctional thinking (including the cognitive triad) was only present in depressed individuals, and were not evident in depression-prone individuals who were currently asymptomatic (Miranda & Gross 1997). Myers (1995) found that a depressed mood induced a greater activation of underlying negative schemata that related to negative aspects of self-schema in those people vulnerable to depression. Using music to induce a negative mood, she found depression-prone participants reported a significantly increased number of negative words about the self, compared to non-depression prone participants. The depression-prone group also recalled a significantly greater number of negative words when in an induced depressed mood compared to the non-depressed group. This suggested that a depressed mood activated underlying self-schemata in the depression-prone group, which resulted in a greater negative attitude towards the self and an increased memory for negative descriptors.

Evidence from Hedlund and Rude (1995) also supported the existence of Beck's negative schemata. Participants who were either currently depressed (CD), had never been depressed (ND) or had formally been depressed (FD), underwent a self-focus attention task to prime self-schema. After the task, they then completed information-processing measures (Stroop test, scrambled sentence task and an incidental recall task). On the scrambled sentence task, they found the processing of FD participants was significantly more negative than the ND group. Similarly, on the recall/intrusion task, they found the FD group showed a negative bias relative to the ND group. The findings in this study supported Beck's claim for depressive schemata that influenced cognitions when activated.

Further evidence for the existence of negative or depressive schemata was found in Miranda, Gross, Persons and Hahn's (1998) study when they found it was activated at times of low mood. This study induced a negative mood in 100 women by showing a short film known to elicit high levels of sadness. Miranda et al. (1998) assessed dysfunctional attitudes before and after the negative mood induction. Participants were assessed for their vulnerability to depression, their mood state and their cognitive vulnerability to depression. Findings showed that the women, who had a prior history of depression, experienced increased negative mood after the film, leading to increased reports of dysfunctional attitudes, whereas in those with no prior history reported a similar negative mood to the depressed-prone but did not report increased dysfunctional attitudes. This study provided support that depressive schemata existed and was latent until it was activated.

The brief psychological intervention for ICD patients included activities based on Beck's theory of depression. Behavioural activities aimed to instil in patients a sense of mastery and control, by encouraging them to set and achieve attainable goals. The use of behavioural activities such as planning a daily walk was used to help prevent patients experiencing a low mood, which could trigger depressive schemata. (See Chapter 8 for full details about the intervention: Keeping Active).

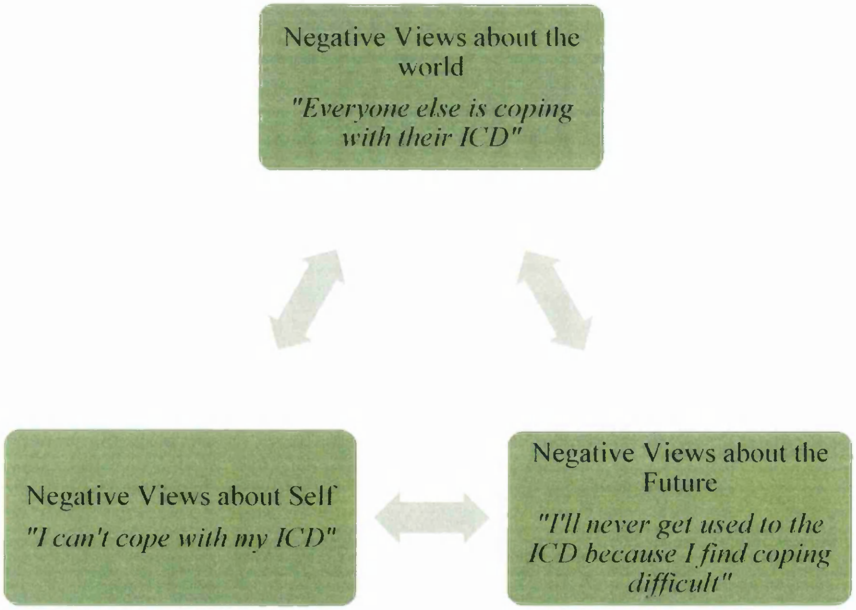

Figure 4.2: Example of Beck's Cognitive Triad

Social Cognition Models

Social cognition is concerned with how individuals respond to and make sense of socially derived situations (Albery & Munafò, 2008). The approach assumes that social behaviour is described best by people's perceptions of reality rather than some objective description of their social environment (Albery & Munafò, (2008). Therefore, social cognition models are those that emphasise the way in which cognitions, thoughts and emotions are affected by the immediate social context, and in turn how these affect social behaviour through learning processes (Albery & Munafò, 2008).

The Health Belief Model:

The health belief model (HBM), developed by Rosenstock (1974) and Becker, Drachman and Kirscht (1974) suggested a number of cognitively based factors were thought to be significant in understanding decision-making processes in health behaviours and sick role behaviours (Albery & Munafò, 2008) (see Figure 4.3), especially under conditions of uncertainty (Harrison, Mullen, & Green 1992).

The HBM focussed on two aspects of the individual's representations of health and health behaviour: threat perception and behavioural evaluation (Abraham & Sheeran, 2005). Threat perception was construed as two key beliefs, perceived susceptibility to illness or health problems and anticipated severity of the consequences of illnesses (Abraham & Sheeran, 2005). Behavioural evaluation also consisted of two distinct sets of beliefs and those concerning the benefits or efficacy of a recommended health behaviour and those concerning the costs or barriers to enacting the behaviour (Abraham & Sheeran, 2005). In addition, the model proposed that cues to action (e.g. a health promotion campaign), can activate health behaviour when appropriate beliefs are held (Abraham & Sheeren, 2005).

Abraham and Sheeran (2005) suggested although it was suggested that perceived benefits were 'weighted against' perceived barriers, no formula for creating an overall behavioural evaluation measure has been developed. Because of this, there is a lack of an overall behavioural evaluation of the model, the model has instead tended to operate as a series of up to six separate independent variables, which potentially account for variance in health behaviours (Abraham & Sheeran, 2005).

A review of 46 studies by Janz and Becker (1984) concluded that the HBM could significantly explain some health behaviours. The studies included in their review were heterogeneous in terms of designs, intervention techniques, target behaviours and populations. Findings revealed that 'perceived susceptibility' was a strong contributor to understanding preventive-health-behaviours, whilst 'perceived benefits' was a strong contributor for sick-role-behaviour.

The review by Janz and Becker (1984) was criticised by Harrison et al. (1992) because they had combined studies that were too diverse. Harrison et al. (1992) carried out a review on 16 studies to test the predictive validity of the HBM. They used more restrictive criteria than Janz and Becker and only included studies that had used valid and reliable measures. Their results indicated that less than 10% of the variance in health behaviour could be accounted for by any of the four dimensions (susceptibility, severity, benefits and barriers), which were analysed separately. They suggested that if they had put the four dimensions together, it was possible that their predictive ability might increase or decrease.

Abraham and Sheeran (2005) offered support for Harrisonet al.'s (1992) supposition. They suggested that in order to test the HBM, reviews that focussed on interventions to change particular behaviours would be the most informative. For instance, Yabroff and Mandelblatt (1999) who focussed on the efficacy of interventions targeted towards patients to increase mammography use found that cognitive interventions using generic education strategies had little impact on screening. However, those that were based on the health belief model increased screening rates by 23.6%.

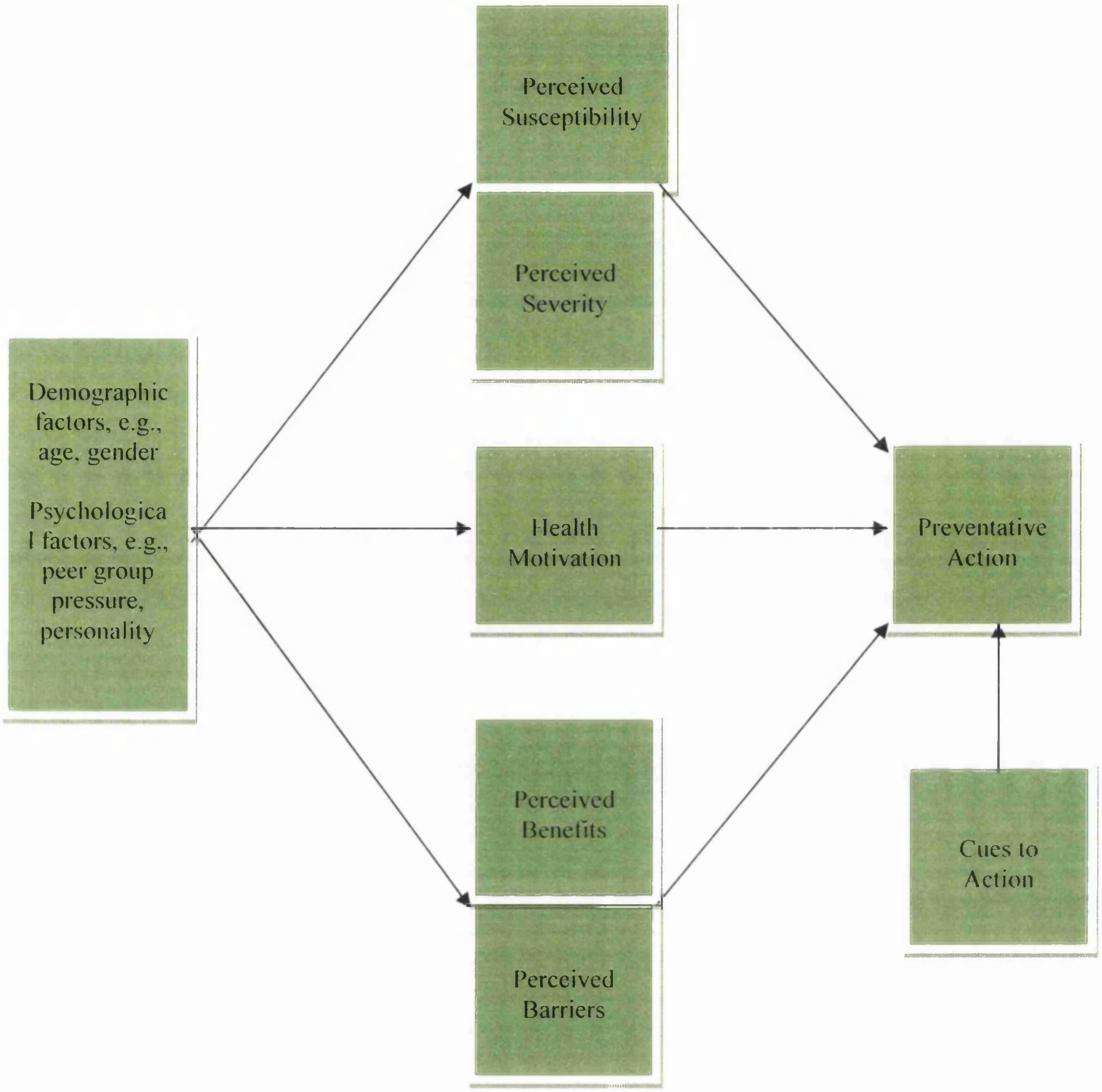

Figure 4.3: The Health Belief Model (Janz and Becker, 1984). Adapted from Albery & Munafò (2008).

The Theory of Planned Behaviour:

Ajzen's Theory of Planned Behaviour (TPB) focussed on the attitude-behavioural relationship and was an extension to the Theory of Reasoned Action (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980). Similar to the HBM, the TPB proposed that beliefs are structured to an expectancy-value framework. Accordingly, individuals hold expectancies about what outcomes they should get if they act in a particular way and its value. For instance, an individual might think taking exercise would reduce their likelihood of an arrhythmia (outcome expectancy) and that this would be good (value association).

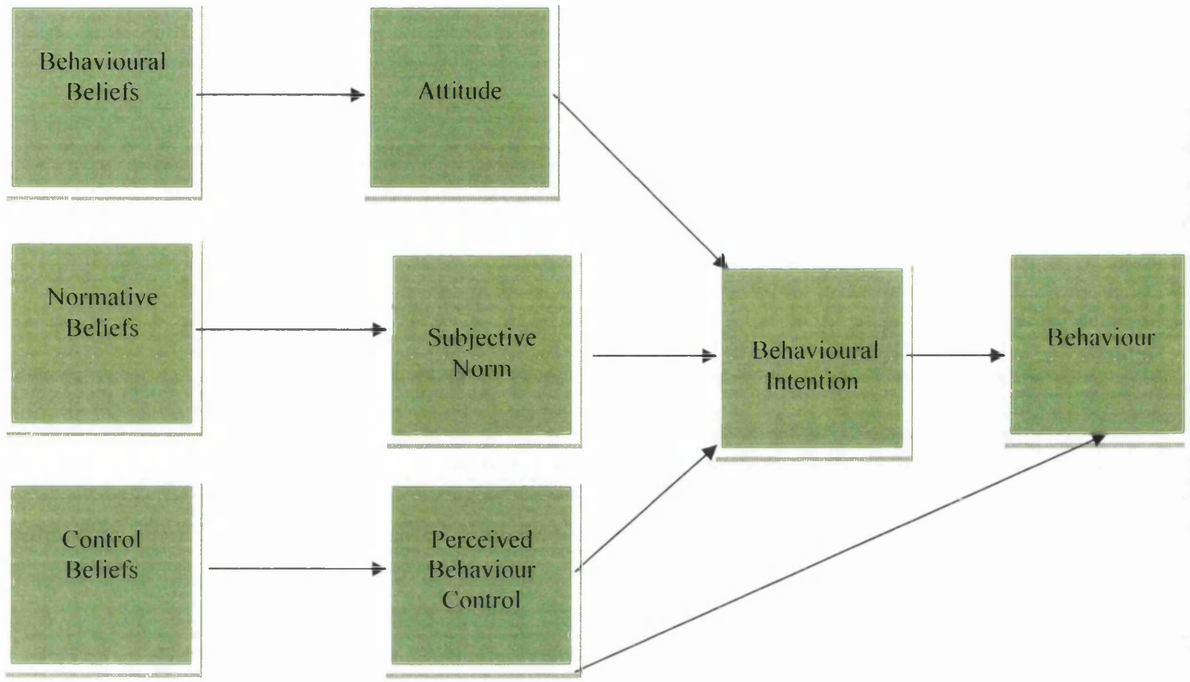

Figure 4.4: Theory of Planned Behaviour (Ajzen, 1991). Adapted from Armitage & Conner (2001).

The Theory of Reasoned Action and The Theory of Planned Behaviour differed in that the TPB included perceived behavioural control. One explanation for including perceived behaviour control was that it would allow prediction of behaviours, which were not under volitional control and its inclusion explains by intentions do not always predict behaviour (Armitage & Conner, 2001). The TPB proposed that the antecedent of behaviour was perceived behavioural control or was behavioural intention. Behavioural intention was in turn was predicted by three belief-based factors: attitude, subjective norm and perceived behavioural control.

- Attitude is made up of core beliefs about the outcomes of behaviour and the value of the outcomes. In general, the more favourable the attitude towards the behaviour, the stronger should be the individual's intention to perform it (Armitage & Conner, 2001).

- Subjective norm refers to the individual's perceptions of general social pressure to perform (or not perform) the behaviour
- Perceived behaviour control relates to how much control an individual believes they have to carry out a behaviour (e.g. take up exercise). In circumstances where intention is hampered by level of actual (volitional) control, perceived behavioural control should facilitate the implementation of behavioural intentions into actions and predict behaviour directly (Armitage & Conner (2001)

A meta-analysis by Armitage and Conner (2001) found evidence that supported the TPB for predicting intention and behaviour. The TPB accounted for 27% and 39% of the variance in behaviour and intention respectively. Although the prediction of self-reported behaviours was higher than observed behaviours, the TPB was suggested to be able to explain 20% of the variance in actual behaviour. Armitage and Conner (2001) also found that independently, perceived behavioural control could predict intentions and behaviour, which demonstrated the efficacy of the perceived behavioural control construct.

Another meta-analytic review, this time by Hagger, Chatzisarantis and Biddle (2002) found that key components of the TPB, namely attitudes, perceived behavioural control and self-efficacy were key influences in forming intentions to take part in physical exercise. The implications of this finding is that interventions to increase positive attitudes towards physical exercise might lead to associated increase in physical exercise behaviour.

Higgins and Conner (2003) used the theory of planned behaviour to understand adolescent smoking. Following an intervention, they found that the TPB was effective in predicting intentions and behaviour of smoking. As well as using the TPB, Higgins and Conner's (2003) study also incorporated implementation intentions. They found that the use of implementation intentions helped produce modest reductions in smoking and smoking initiation in the intervention group compared to the control group.

The process of implementation intentions provides a framework to conceptualise how a behavioural intention is translated into behaviour; although the TPB suggested that intentions would lead to behaviour, the model did not address how this would occur (Albery & Munafò, 2008). Implementation intentions are formed when an individual plans where, when and how to undertake a behaviour; for example, 'when it is 5 o'clock, I will switch off my phone and practice relaxation'. Forming an implementation intention creates a cognitive connection between a specific situation and a specific response in that situation (Gollwitzer & Branst□tter, 1997). It was suggested by Sheeren, Webb, and Gollwitzer (2005) that the cognitive connection behaves is such a way that behaviour is automatic; implicit cognitive representations are activated without the individual being aware that cognitions have been activated.

It is thought that implementation intentions are effective in translating a situation/stimulus to a behaviour because the individual becomes cognitively more 'committed' to a behaviour if the particular situation/stimulus occurs (Webb & Sheeren, 2004). Evidence that implementation intentions can be effective in increasing health-related behaviours has been well documented (e.g. Armitage, 2004; Milne, Orbell, & Sheeren, 2002; Higgins & Conner, 2003). For instance, Armitage's (2004) randomised controlled trial found that implementation intentions helped change dietary behaviour, regardless of a participant's level of motivation.

Metacognitive Theory and Cognitive-Attentional Theory

Wells (2000) posited that a limitation of cognitive-behavioural theories (or second-generation theories; e.g. Abramson, et al. 1978 and Beck, 1967, 1983) was that they were based on schema theory and only focussed on cognitions. According to Wells (2000), cognitive theory ignored the mechanisms of cognitive processing that gave dysfunctional thoughts their salience. For instance, whereas schema theory viewed beliefs as being specific propositions (e.g., the declarative belief "I am bad"), Wells and Matthews (1994, 1996) suggested that a process they named meta-cognition, controlled the creation of and the attention given to the dysfunctional thought.

According to Wells (2000), metacognition is a multifaceted concept and can be defined as any knowledge or cognitive process that is involved in the appraisal, monitoring or control of cognition. In short, metacognition is 'thinking about thinking' (Hjemdal, Hagen, Hordahl, & Wells, 2013). Wells (2000) suggested metacognition could be divided into metacognitive knowledge and metacognitive regulation (see Figure 4.5). Metacognitive knowledge refers to the beliefs and theories that individuals have about their own cognition (e.g., "if I think a bad thought, it will happen") and metacognitive regulation refers to a range of executive functions, such as allocation of attention, monitoring, checking, and planning. According to Hjemdal et al. (2013), in the metacognitive theory of psychological disorder (Wells and Matthews, 1994), metacognition is central in determining the maintenance and control of negative and biased thinking styles.

Cognitive processes that help metacognitive knowledge and metacognitive regulation communicate, operate on two levels called object level and meta-level. Information that flows from the object level to the meta-level is called 'monitoring', and informs the meta-level about the state of the object level. Information from the meta-level that flows back to the object level, is called 'control' and informs the object level what to do next (see Figure 4.5). According to Wells (2000), the flow of information between object and meta-level is important and which needs to be taken into account in order to understand how cognition might influence psychological distress.

Wells and Matthews' (1994, 1996) S-REF model was based on a multi-level cognitive architecture that consisted of three interacting levels: a level of automatic and reflexively driven processing units, a level of attentional demanding voluntary processing and a level of stored knowledge and self-beliefs (see Figure 4.6). This architecture was said to support the total number of emotion-related processing operations available to the individual. Different models or configurations of processing could be identified within this architecture, with the S-REF configuration being most relevant to emotional disorder (Wells & Matthews, 1996).

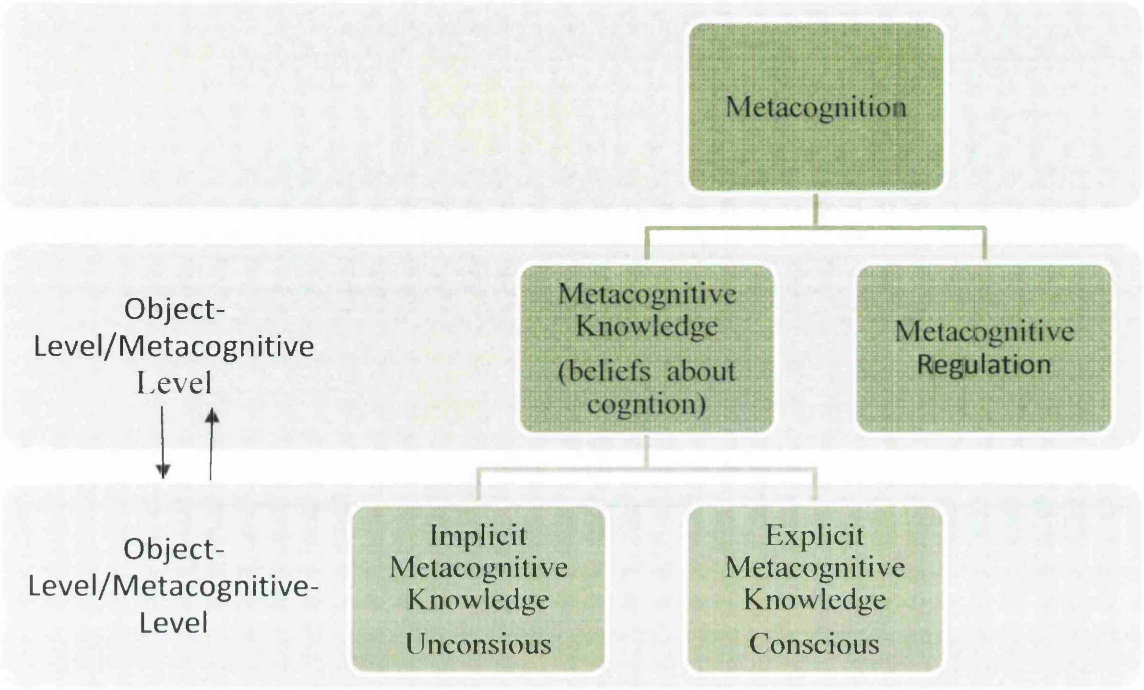

Figure 4.5: Wells and Matthews' (1994, 1996) Model of Metacognition. Metacognition is divided into metacognitive knowledge and metacognitive regulation. Metacognitive knowledge is further divided into implicit and explicit metacognitive knowledge. On-line processing enables communication between object and metacognitive levels of processing, which were implicated to influence psychological distress

Wells and Matthews' (1994, 1996) model of emotion disorder posited that the choice and implementation of coping strategy was the central determinant that maintained or ended psychological distress. They suggested that particular S-REF processing routines were capable of modifying the mode of operation of the processing system or maintaining dysfunctional processing configurations. For example, some coping strategies might lead to the assimilation of new information into existing knowledge structures, which might reduce distress. Alternatively, other coping strategies might maintain distress. For example, in health anxious patients the use of monitoring bodily sensations might lead to a heightened awareness to changes in the body, which might result in making the individual more anxious.

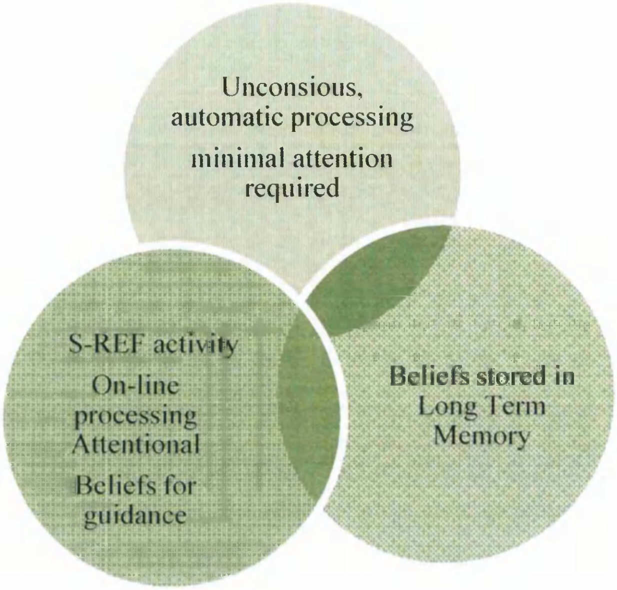

Figure 4.6: Multi-level cognitive architecture comprising automatic and reflexively driven processing, attentional demanding voluntary processing and stored knowledge and beliefs. Adapted by author.

Wells and Matthews' (1994, 1996) model also suggested that metacognitive beliefs might be responsible for the maintenance of maladaptive behaviours. For example, an ICD patient might have the metacognitive belief that if they monitored their body they would be forewarned of any impending shock. This individual would be compelled to monitor their body for symptoms until an internal state (equilibrium) was reached that signalled their vigilance could stop. However, if the patient had a metacognitive belief that by monitoring they were *preventing* a shock occurring then S-REF activity would be maintained. Borkovec, Hazlett-Stevens and Diaz (1999) found that many patients with generalised anxiety disorder (GAD) claimed that by worrying they were able to prevent something bad happening, even though they continued to suffer from the negative consequences associated with worry. Again, similarly to Beck's (1976) and behavioural theories such as Mowrer's (1947) two-process model, if the plan, which was constant monitoring in the above example, involves a behaviour, the patient would need to actively engage in the avoided behaviour in order to make the unwanted behaviour redundant. Mowrer (1947) proposed behaviour was being driven by negative reinforcement and Beck believed maladaptive behaviours persisted due to faulty beliefs but both failed to explain the cognitive processes that were responsible for converting the feeling or belief into a behaviour, which Wells and Matthews' model managed to achieve.

Wells (2000) posited that the S-REF configuration was activated when an individual was psychologically distressed (anxious or depressed). The aim of the activation was to eliminate the discrepancy between a current- and desired-self. According to this model, the type of psychological distress was determined by goal achievement. In general, anxiety was associated with an anticipated failure to achieve a goal, whilst depression was associated with failure to achieve the goal. In both cases, the emotions elicited contributed to the maintenance of S-REF activity by biasing the individual's retrieval of knowledge (Wells, 2000). This part of the model is similar to Beck's schema theory, in that they both suggested bias and misinterpreted information or knowledge maintained the distress. However, whereas schema theory suggested that an individual's beliefs and appraisals needed to be modified to reduce distress (Wells, 2000), the S-REF model explained that the distress could only be reduced if a different mode of thinking was achieved, i.e. a meta-cognitive mode

An example that shows how the S-REF configuration might operate in line with ICD patients might be when a patient becomes distressed because he wanted to drive his car during the week following his ICD implant procedure, but found that he was banned from driving for six-months due to DVLA restrictions. According to the S-REF model, the psychological distress in this scenario occurred because there was a discrepancy between the patient's current 'banned from driving' state and their desired 'being allowed to drive state'. The type of distress felt (i.e. anxiety or depression) would depend on whether the patient anticipated that they would fail to achieve the goal (driving) or was a failed attempt to achieve the goal.

However, in the above example, the patient's failure to achieve their goal to drive was not due to his own personal limitation but it was due to an external constraint (DVLA law). Therefore, the patient had the option to adapt his goal, for instance, he could have decided that he would aim to drive after 6-months and until then, he would use public transport. This modification to his goal would have lessened the S-REF activity. If the patient failed to modify his goal about driving, the model suggested that they would be stuck in an S-REF cycle of activity. This would result in the patient becoming increasingly drained (if using maladaptive coping strategies such as grumbling, ruminating), which would eventually lead him into a depression due to his failure to achieve his goal of being able to drive. Had the constraint been internal rather than external, i.e. the patient no longer had the capacity to drive, and the patient had been engaged in an object mode of thinking, the resulting distress would have been the same. This model suggested that in order for beliefs to be changed the patient would have to engage in metacognitive thinking, which would allow them to evaluate their options, rather than express a 'hot' emotional response such as anger. For instance, in the above example, metacognitive thinking would allow the patient to think through alternative driving arrangements rather than thinking in object mode, which limits the patient to dwelling on being banned from driving.

The evidence that reducing S-REF activity was able to reduce psychological distress was provided by three studies (see below) that focussed on a model for general anxiety disorder (GAD). Worry is the central defining characteristic of GAD (Wells, 2000). The GAD model (Wells, 1995, 1997) adapted for the specific disorder is a derivative of the S-REF Model and posited that metacognition, (beliefs, appraisals and control strategies) are central factors in the development and maintenance of GAD (Wells, 2000). During the development of GAD, sufferers not only have Type-1 worry (worry about external events and physical symptoms) but also have Type-2 worries (negative appraisal of worrying i.e., worrying about worrying) (Wells, 2006). According to Wells (2006), an implicit aspect of the GAD model is that its worry is not a symptomatic consequence of anxiety, but an active style of appraisal and coping with threat, driven by the individual's beliefs. Accordingly, metacognitive therapy focuses the specific mechanisms, which underlie difficult to control and excessive worry (Wells et al., 2010). Therefore, it focuses on changing negative appraisals and beliefs about worrying, and provides strategies for coping with stress and differs to traditional cognitive behavioural therapies that focus on challenging and restructuring Type-1 worries.

An important tenet that distinguishes metacognitive theory from cognitive behavioural theories is that the main cause of a psychological disorder is the response to dysfunctional thinking and not the dysfunctional belief itself. For instance, any inaccuracies or distortions in monitoring (object-level to meta-level) could contribute to psychological distress as the meta-level acts on the information from the object-level. Similarly, control processes (from meta-level) can change the object-level by for example, initiating a new activity/action. Therefore, if there are disturbances or biases in control, for example using a maladaptive coping strategy, this could contribute to psychological distress.

The S-REF model asserted that a universal feature of psychiatric disorders responsible for prolonging and intensifying distressing emotions was a specific thinking style called the cognitive attentional syndrome (CAS) (Hjemdal et al., 2013). The CAS is a thinking pattern of inflexible self-focussed attention (the focus is on self-observation and monitoring thought processes), perseverative thinking (worry and rumination), threat monitoring and coping behaviours that interfere with gaining adaptive knowledge (Wells, 2000; Hjemdal et al., 2013). Wells et al. (2012) posited that a problem with CAS is that it leads to extended negative thinking, reduced attentional flexibility which in turn can lead to a failure to control negative affection experiences. Accordingly, the CAS maintains threat-focussed processing and fails to provide information that could modify and individual's maladaptive appraisals and beliefs (Hjemdal et al., 2013). The metacognitive model proposed that positive and negative metacognitive beliefs are responsible in generating the CAS. Positive beliefs concern the usefulness of rumination, worry, threat monitoring and coping whereas negative beliefs consists of diminished meta-awareness of for example rumination, and having control over it (Wells et al., 2012).

However, Wells and Matthews (1996) proposed that rumination was particularly problematic for S-REF processing and played a key role in depression. They posited that rumination was driven by metacognition rather than mood or events and was a problem of 'over thinking' leading to harmful effects. Ruminating also used limited processing resources in the S-REF that were needed for carrying out plans in order to find evidence that could disconfirm dysfunctional beliefs. Wells et al., (2012) suggested rumination was part of the wider CAS involving worry, threat monitoring, and the depleted resources contributed to depression. In a similar way to Beck's negative schemata, rumination continuously primed dysfunctional self-beliefs. They suggested that rumination is a broad coping strategy used to find a cause to a negative mood. However, in doing so, rumination is often used to analyse past mistakes and failures.

Wells et al.'s (2012) study found evidence that CAS and metacognitive beliefs might be responsible for maintaining depression. In this study, patients who were relatively treatment-resistant to depression received metacognitive therapy, which focussed on attentional training, detached mindfulness, challenging positive metacognitions and reducing negative metacognitions. Results revealed significant improvements in depression symptoms, rumination and metacognition. These findings provided some support that the thinking pattern of CAS and metacognitive beliefs are responsible for the maintenance of depression.

Three studies (Wells, 2006; Wells, Welford, King, Papageorgiou et al., 2010; van der Heiden, Muris, van der Molen, 2012) all provided evidence that metacognitive therapy, can lead to a reduction in worrying for patients with GAD. The studies' findings suggested that the mechanisms of cognitive processing, as appose to changing cognitions or learning new ways of coping, was most likely to be the active ingredient that reduced distress. The findings from Wells' (2006) study suggested that focusing on these mechanisms was most likely the mediator that reduced anxiety. Wells (2006) treated 10 patients with GAD with metacognitive therapy and assessed different aspects/dimensions of worry (social worry, health worry, and meta-worry) pre- and post-treatment. The study found that the part of the therapy that was specifically directed to modify metacognitions lead to significantly decreased worry in *all* the other types of worries after the therapy. Therefore, the findings provided evidence to suggest that worry (for GAD sufferers), was being maintained by cognitive processes rather than the cognitive content.

Based on empirical evidence (e.g. Borkovec & Costello, 1993) that had demonstrated applied relaxation (AR[31]) and cognitive behavioural therapy (CBT) were equally effective for the treatment of GAD, Wells et al. (2010) randomised 20 GAD patients to an AR or metacognitive therapy (MCT) treatment condition. Their findings suggested that targeting metacognitions improved results over and above those of

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[31] Applied relaxation (Öst, 1987) was developed from progressive relaxation, is a coping technique found to be effective for panic disorder (Öst & Brietholtz, 2000).

using AR alone and provided evidence that mechanisms of cognitive processing were a key factor in maintaining anxiety in GAD.

A much larger study by van der Heiden et al. (2012) also provided evidence that a focus on metacognitions was effective in reducing anxiety in GAD patients. The study randomised 126 GAD patients to receive intolerance-of-uncertainty therapy[32] (IUT), MCT or to a delayed treatment condition. Results indicated that the MCT condition was more effective than IUT for reducing negative beliefs about uncertainty and its implications (which IUT focussed on), and in improving positive and negative metacognitions. These findings suggested that as well as improving metacognitions per se, the focus on underlying mechanisms might also have facilitated patient's improved negative beliefs about uncertainty and its implications. These findings therefore offer support that underlying mechanisms of cognitive processing might be responsible for maintaining anxiety in GAD.

The brief psychological intervention devised for patients to help them cope with their ICD and reduce any levels of psychological distress based some of its activities on the theory behind Wells and Matthews S-REF model. For instance, the S-REF model proposed that metacognitive regulation maintained depression and anxiety, which suggested that these mechanisms should be targeted in order to reduce S-REF activity, to reduce psychological distress and physiological arousal. The brief intervention taught patients how to relax, and how to distract themselves from worry. The aim of these activities were not to change faulty cognitions as was proposed in Beck's (1976) cognitive content-specificity hypothesis but to offer the patient techniques to use so they could have respite from their worries. The intervention also included the teaching of mindfulness skills, to cope with inflexible self-focussed attention, perseverative worries and threat monitoring. Skills in mindfulness would help patients from feeling overwhelmed with worry and would help increase their attentional flexibility. (See Chapter 8: Section 2 for a more details about the intervention and Getting to Sleep at Night and Learning to Relax and Coping with Worries).

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[32] Intolerance-of-uncertainty model of GAD suggests that intolerance of uncertainty is a dispositional characteristic that results from a set of negative beliefs about uncertainty and its implications (van Heiden et al., 2012).

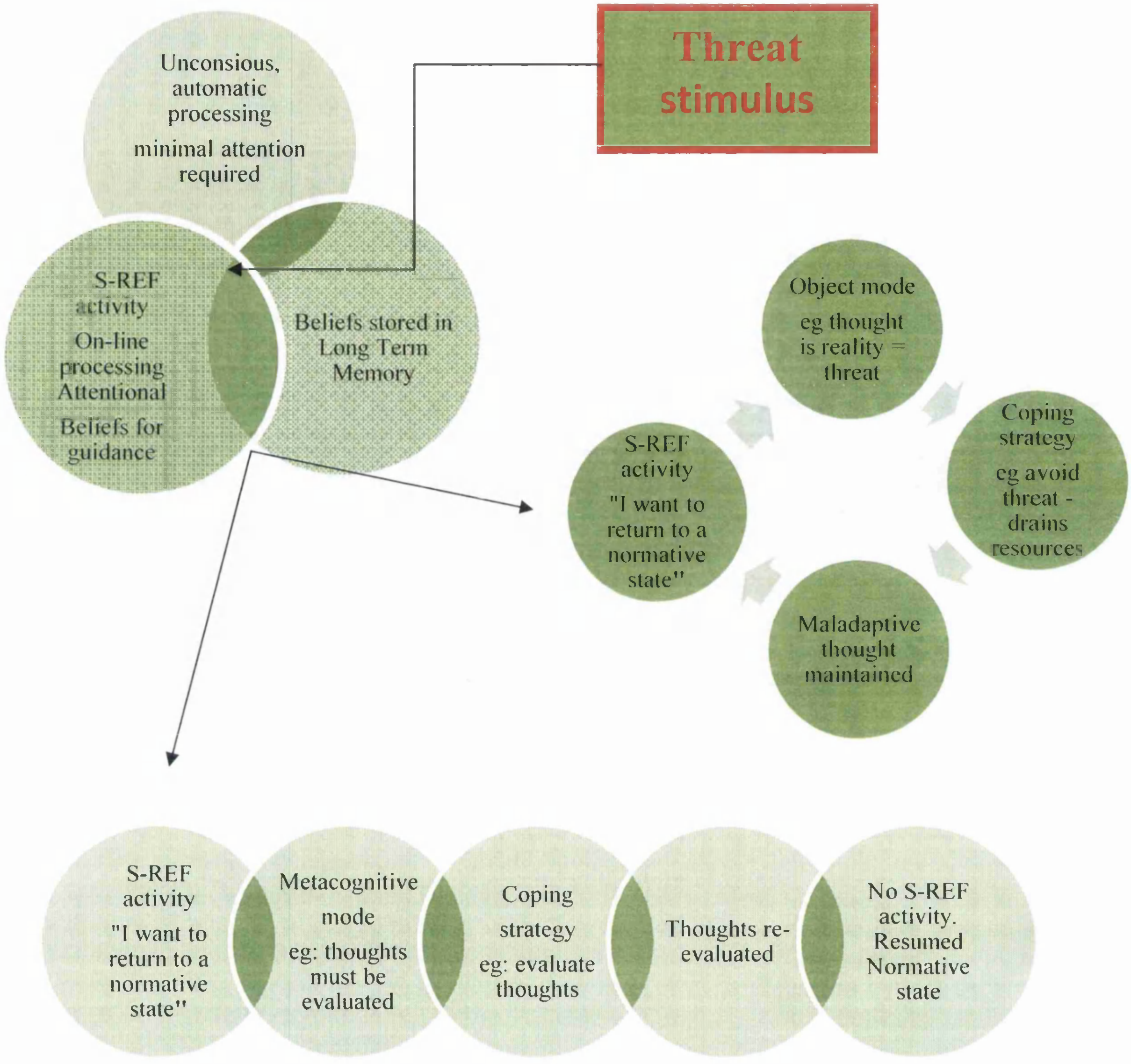

Figure 4.7: Model of S-REF adapted by author: S-REF processing is initiated by an external threat stimulus or internal cycles of processing that generate negative threat-related thoughts. Once activated the S-REF accesses the stores of beliefs in long-term memory in order to appraise the threat and select a coping strategy. On-line processing tailors the plans for appraisal and coping with the specific threat. On-line processing modifies or strengthens beliefs depending on metacognitive plan activated. If the plan specifies an object mode of processing whereby thoughts are taken as facts, (this is similar to Beck's [1975] idea who suggested that anxious individuals tended to catastrophise when interpreting symptoms as facts) then threatening thoughts are avoided, preventing exposure to information that might disconfirm fears (e.g. testing the avoided behaviour). The S-REF model posited that cognitive change was only possible when the plan specified a metacognitive mode of processing (Wells, 2002).

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984; Lazarus, 1999): Appraisal Theory of Emotion and Coping Theory

Another theory that has similarities with the S-REF model, as it also uses on-line processing to appraise and select a coping strategy, is Smith and Lazarus's appraisal theory of emotion (see Smith & Lazarus, 1990, 1993; Smith, 1990; Lazarus 1991, 1993). Smith and Lazarus (1990) suggested that whereas sensory-motor reflexes, physiological drives and emotions are adaptational resources for all animals, advanced species such as humans, have evolved to become more dependent on emotions (Lazarus, 1991). Human emotions are often based on complex social structures, and an interpretation between the subtle differences of what is harmful or beneficial and the consequences to well-being, and therefore appraisal is needed to determine the resulting emotion (Lazarus, 1991). This theory differs from cognitive behavioural theories that purported the importance of cognition, and the underpinning cognitive processes posited to be of key importance in the S-REF model. The cognitive-motivational-relational theory of emotion posited as its central tenet that the principle of appraisal was responsible for eliciting emotions.

Smith and Lazarus' appraisal theory of emotion is relational, motivational and cognitive. The relational element refers to the hypothesis that emotions are always about person-environment relationships (Lazarus, 1991). Accordingly, the environment per se or intra-psychic processes does not generate psychological stress and emotion. However, these are caused by changes in person-environment relationships that are altered over time and circumstance (Lazarus, 1991). For instance, 'being slighted or demeaned' would lead to anger, whereas 'fearing the worst but yearning for better' would lead to hope (Lazarus, 1991). According to this theory, the motivational element means that acute emotions and moods are reactions to encounters in relation to goals in life. Therefore the concept of motivation helps individuals understand what makes an encounter personally relevant, and whether it is harmful or beneficial (Lazarus, 1991). The cognitive element refers to knowledge (situational and generalised beliefs) and appraisal of what is happening. Appraisal consists of an evaluation of the personal significance of what is happening in an encounter with the environment (Lazarus, 1991).

Smith and Lazarus's theory suggested that an individual primarily appraises the stressor[33] to see its relevance to the individual's well-being. If an encounter with the environment is appraised as having no implication on the individual's well-being, it is deemed 'irrelevant' and there is no emotional consequence. However, if the stressor is appraised as relevant to the individual's well-being, the stressor is further appraised as to whether it is positive or negative. According to Lazarus and Folkman (1984), positive appraisals occur when the individual believes the outcome with the stressor is positive, i.e. it is expected to improve or enhance their well-being. Negative appraisals include harm, loss, threat and challenge and all differ slightly to each other. In a harm and loss appraisals, damage to the individual has already happened, whereas threat appraisals are harms or losses that have not yet happened but are anticipated to happen.

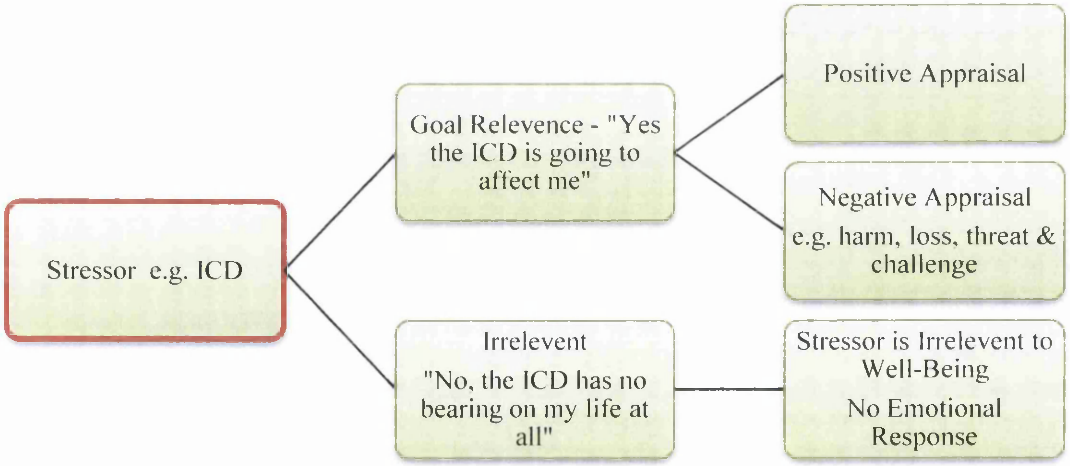

Figure 4.8: Model of Smith & Lazarus's (1974) Primary Appraisal Theory of Emotion. The stressor initiates an evaluation of whether the stressor is relevant or benign. If the threat or stressor is appraised as benign, there is no emotional consequence If the stressor is appraised as being relevant, i.e the individuals needs to heed this stressor, then a harm/loss or benefit appraisal takes place, with a harm/loss appraisal leading to negative emotions and a benefit appraisal leading to positive emotion

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[33] The term stressor will be used to refer to transaction, situation, environment, or object that is being appraised

According to Lazarus and Folkman (1974) and Lazarus (1991), secondary appraisal was a complex evaluative process that takes into account three main variables, (1) blame/credit, (2) coping potential and (3) future expectations. (1) Blame and credit referred to who should be made accountable for the harm, threat or challenge. For instance, if the individual blamed someone for an adverse outcome, then blame and anger would be evoked. Whether the outcome had been inevitable or could have been avoided and whether the outcome was unintentional or was malevolent would influence the strength and direction of the blame and credit. (2) Coping potential refers to the availability of coping strategies, the likelihood that a coping strategy would ameliorate or eliminate the harm, threat, challenge set before them, and that the individual had the capability of using the coping strategy effectively. The choice of a coping strategy and the primary appraisal of what is at stake interact with each other to generate the type and strength of the emotional response. (3) Future expectations referred to the belief that the troubled situation would change for the better or for the worse.

Lazarus (1999: 78) posited that primary appraisal and secondary appraisal happen concurrently – there is an active interplay between them both. Accordingly, one does not occur before the other but they differ distinctly due to their content and aim. Whereas primary appraisal focuses on whether the stressor is personally relevant, secondary appraisal identifies coping options and likely outcomes. According to this theory, the individual primary and secondary appraisal components can be combined into gestalts of relational meaning called 'core relational themes' (Smith & Lazarus, 1993). The core relational theme captures the central relational meaning derived from the configuration of answers to the individual appraisal questions, which produces different emotions but they do not describe the cognitive determinants of each emotion (Smith & Lazarus, 1993; Lazarus, 1991).

According to Lazarus (1991), each emotion, which has been defined by its core relational theme and pattern of appraisal, generates an innate action tendency (which is a biologically driven tendency that is rigid and automatic), which can be hidden or overridden by coping. For instance, in anger, the action tendency would be to attack, whereas in anxiety, the action tendency would be to avoid or to escape. Lazarus (1991) posited that the action tendency provokes a psycho physiological response pattern in preparation to deal with the person-environment relationship. Coping is the psychological equivalent of an action tendency. Coping is complex, deliberate, and often involves planning for action. For instance, whereas threat appraisals engender anticipatory coping – that is, being prepared for future difficulties, appraisals of challenge results in coping efforts being mobilised in the same way as threat, but is focussed on the potential for growth (see Figure 4.6).

A cardiac patient experienced the emotion "anxiety" when he was advised to have an ICD implanted because:

- ***Primary appraisal** of ICD = Congruent to self: Perceived to be a threat*
- ***Secondary appraisal** =*
    - *no blame or credit attributed*
    - *Having an ICD was appraised as unavoidable*
    - *Unsure whether he could cope with the device*
    - *Patient perceived his future situation would only get worse*
- ***Core relational theme** = facing uncertainty*

Whereas another patient in the same situation experienced the emotional response "relief" because:

- ***Primary appraisal** of ICD = Congruent to self: Perceived to be positive*
- ***Secondary appraisal** =*
    - *no blame or credit attributed*
    - *Having an ICD was appraised as unavoidable*
    - *Patient was confident he could cope with the ICD*
    - *Patient perceived that his future situation would become better*
- ***Core relational theme** = a goal-incongruent situation is going to be changed for the better*

Assessments of appraisals have been investigated in studies using vignettes (e.g. Roseman, 1991; Smith & Lazarus, 1993) and studies using previous real experiences (Smith, Haynes, Lazarus & Pope, 1993; Bennett, Lowe & Honey, 2003). Using vignettes Roseman (1991) combined different combinations of appraisals to determine which emotion would be experienced. Findings showed that each combination of appraisals (which included motivational state, situational state, probability, legitimacy, and causal agency) determined whether an individual in the given situation would experience joy, relief, hope, liking, pride, distress, sorrow, fear, frustration, dislike, anger, guilt or regret. The findings of this study supported the hypothesis that appraisal is of key importance in predicting emotion.

Smith and Lazarus' (1993) study used vignettes to test the predictions of four emotions - anger, guilt, fear/anxiety and sadness, which were commonly thought to be appraised responses to actual or potential harm (Smith & Lazarus, 1993). Relevant appraisals were manipulated twice using a two-stage guided imagery task of four hypothetical scenarios. In the first stage, participants imagined themselves to be in scenarios that evoked appraisals hypothesised to generate sadness (irrevocable loss and helplessness) or anger (other-blame). The first stage established the motivational relevance for the central character (undertaken by the participant), the motivational congruence and the components of a secondary appraisal. In Stage-2, the task was manipulated further to produce four appraisal conditions, (other-blame, self-blame, threat, and loss/helplessness. The findings found that various manipulations produced changes in appraisals and core relational themes, which were associated with predicted (as per Lazarus and Smith's model of appraisal) changes in anger, guilt and fear/anxiety. As predicted by the theory, core relational themes (which captured the essence of the emotion) were significantly strongly correlated to its theoretical emotion. There was a weaker association for sadness, which was suggested to have been caused by ineffective manipulation of the relevant appraisals. However, Lazarus (1991) had previously posited that sadness was a distinctive negative emotion that might be best viewed as a mood rather than an emotion. Lazarus (1991) suggested sadness involved an action tendency (see below), which would result in a withdrawal from everything in the world and this was coupled with the fact that sadness evolved slowly as an individual gradually accepted his or her loss.

A study by Smith, Haynes, Lazarus & Pope (1993) used previous experiences to test if appraisals could predict emotions better than attributions. Smith et al. (1993) posited that causal attributions (i.e. inferences concerning the perceived cause of an event) were strongly related to emotion. However, they suggested attributions were only relevant to emotion because they contributed to adaptational significance and therefore attributions on their own were not sufficient to produce emotion. In this study, participants reported retrospectively on their attributions, appraisals and emotions associated with previous experiences. Using prompts to elicit the type of incidents to be recalled, four were used to recall negative events, and four were used to recall positive events. The findings found that appraisals accounted for a significant 34 percent of the variance to explain emotions, whereas attributions only accounted for an additional 7-percent, which suggested that appraisals explained more variance than attributions. Further analyses in this study examined the exploratory power of appraisal components and core relational themes. Findings showed that by themselves, both the appraisal components and core relational themes accounted for significant amount of the variance in each emotion. These findings provided evidence that there is a difference between appraisals and attributions and those appraisals above attributions were more strongly related to emotions. These findings further suggested that both the individual appraisals components and core relational themes theoretically represented the relevant emotions, supporting the appraisal theory of emotion.

Bennett, Lowe and Honey (2003) also tested the appraisals and the core relational themes of four emotions, anger, guilt, anxiety and sadness. The study was similar to Smith and Lazarus (1993), as it tested the same emotional appraisals, however this study differed by prompting participants to use a real life previous experience of a stressful event. They found that appraisals and core relational theme as per Lazarus and Smith's model of appraisal provided a strong unique contribution to each of the four emotions. (The variance explained for each of the emotions was guilt, 18%, anxiety, 37%, anger 48%, and sadness 19%). An additional 3% of the variance in guilt and anger was explained by emotion-focussed coping potential, which had not been previously been found in Smith and Lazarus' (1993) study. Similarly, to Smith et al. (1993), Bennett et al. found that core relational themes significantly increased the variance in anxiety.

The studies outlined tended to test the emotions of anger, guilt, anxiety and sadness. The studies also either used vignettes (Roseman, 1991; Smith & Lazarus 1993) with made-up scenarios or asked participants to recall a stressful event that had happened during the previous week (Smith et al. 1993; Bennett et al. 2003). However, a recent study by Hulbert-Williams, Morrison, Wilkinson and Neal (2013) carried out a study that was more in line with ICD patients as they used patients who had experienced a major life event and were living with a chronic health condition. Unlike the other studies, this study found that their findings only found partial support for the cognition-emotion model that comprised part of the transactional model of stress and coping (Lazarus, 1999). Lazarus (1999) suggested that each emotion was made up of specific primary and secondary appraisals, which was not supported by this study. In addition, unique pairings between core-relational themes and emotion were also unsupported by their study's findings, with 13 of the emotions found to have multiple core-relational themes. For instance, they found five emotions included the core-relational theme 'threat'. However, overall they found emotions were best explained by a combination of both appraisals and core relational themes and each emotion had a unique combination of cognitive appraisals, which supported Lazarus' (1999) model. These findings suggested that perhaps Lazarus' (1999) model might have offered combinations of appraisals that were too specific in its hypothesis of cognition-emotion associations (Hulbert-Williams et al., 2013).

Lazarus (1991) posited that an action tendency was biologically driven, whereas coping was its psychological equal and was important to the theory of emotion. Coping was said to be important as changed or influenced emotions during the coping process. According to Folkman and Lazarus (1988), coping was a critical mediator[34] of the emotional response. The mediator or a coping process was said to arise during the person-environment encounter, and transforms the original appraisal and attendant emotion. They also suggested that the relationship between emotion and coping is bi-directional, with each affecting each other. Initially the person-environment encounter is appraised as harmful, beneficial or of no importance. If it is appraised as harmful or beneficial, it generates an emotion. The appraisal and present emotions influence coping processes, which in turn change the person-environment relationship. The altered person-environment relationship is re-appraised, and this reappraisal leads to a change in emotion quality and intensity (see Figure 4.9).

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[34] A mediating variable is generated during the person-environment encounter, and changes the relationship between the antecedent (e.g. appraisal) and outcome variable (e.g. emotion) (Folkman & Lazarus, 1988)

Table 4.2: Hypothesised Relationships between Transactional Model Components. Adapted from Smith, Haynes, Lazarus, & Pope, (1993) and Hulbert-Williams, Morrison, Wilkinson, and Neal (2013).

Emotion	Core Relational Theme	Important Appraisal Components
Anger	Other - Blame	Goal Relevant Goal Incongruent Other – Accountability
Guilt	Self - Blame	Goal Relevant Goal Incongruent Self-Accountability
Fear-Anxiety	Danger-Threat	Goal Relevant Goal Incongruent Low or Uncertain (emotion-focussed) Coping Potential
Sadness	Irrevocable Loss	Goal Relevant Goal Incongruent Low (problem-focussed) Coping Potential Negative Future Expectations
Hope/Challenge	Optimism	Goal Relevant Goal Incongruent Problem-focussed Coping Potential
Happiness	Success	Goal congruent
Incomplete models:		
Surprise	Unexpectedness	NS
Resignation	Loss/helplessness	NS
Tranquillity	Lack of concern	NS
Shame/humiliation	Self-consciousness	NS
Interest	Relevance	NS
Boredom	Irrelevance	NS
Relief	Threat removal	NS
Frustration	NS	NS
Self-directed Anger	NS	NS
Regret	NS	NS

NS=Not Specified. For some emotions, the core relational theme and/or the appraisal components have not been hypothesised (Hulbert-Williams et al. 2013).

According Folkman and Lazarus (1988), coping could be characterised in one of two ways: problem- and emotion-focussed coping. Problem-focussed coping often involved planning to change the person-environment relationship by directly acting on the environment or the self. For example, in line with ICD patients, a patient might feel discomfort lying on their 'normal' side of the bed because of the position of their ICD. In this scenario, a problem-focussed plan might be to change sides of the bed on which they slept. (Incidentally, this was a common problem-focussed coping strategies reported by many patients during the interviews for the qualitative study – see Chapters 6 and 7). Emotion-focussed coping alters what is in the mind by using attentional strategies (e.g. avoidance) or by changing the meaning of the relationship, e.g. denial or distancing to lessen the threat of the stressor (person-environment relationship) (Lazarus, 1991). In line with ICD patients, an emotion-focussed coping strategy might be to perceive the ICD to be a 24-h paramedic, with an ability to save their life, (which was also found in the qualitative study – see Chapters 6 and 7). Folkman and Lazarus (1985) posited that the multifaceted nature of a person-environment and the complexity of the coping process meant that individuals might have seemingly contradictory emotions, such as feeling threatened as well as feeling challenged when faced with a situation. As such, a combination of problem- and emotion-focussed coping would be used interchangeably as the person-environment, appraisal and emotions change.

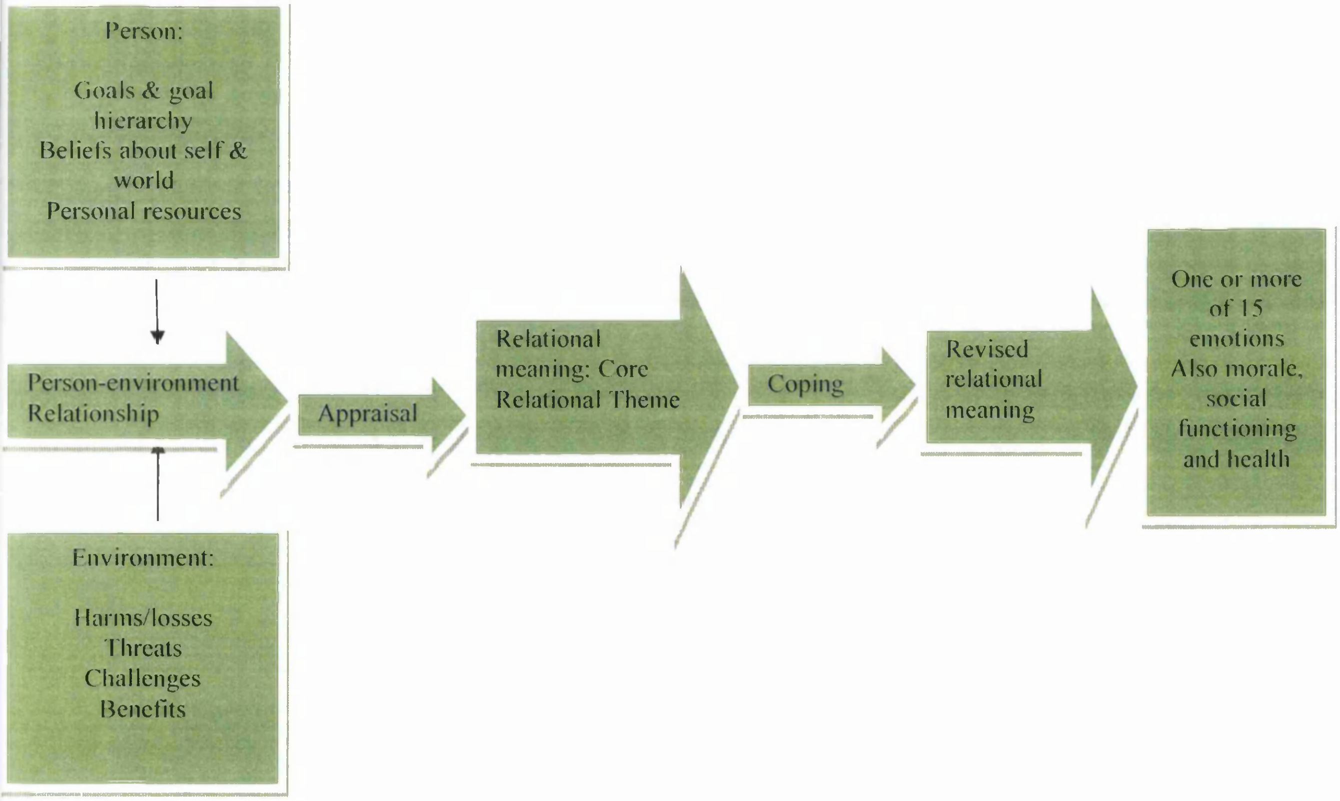

Figure 4.9: Revised model of Stress and Coping (Lazarus, 1999). Adapted from Lazarus (1999:198)

A study by Folkman and Lazarus (1985) examined how appraisals and coping influenced emotions. The study used students who were going to sit an exam. Students' emotions, coping and the use of social support were measured before the exam (Time 1), before their grades received (Time 2) and five days after receiving their grades. The findings from this study can be used as evidence to support the transactional model of stress and coping, which incorporates the theories of appraisal and emotion. At Time 1, the students in the study experienced contradictory cognitive appraisals and emotions such as feeling threatened and challenged at the same time. The complexity of emotions and their cognitive appraisals reflected ambiguity, which would be expected before a forthcoming exam. The study also found that students' coping changed as the exam period (Times 1-3) passed. They found significant changes in emotions as the exam period passed, which their appraisals and their coping influenced. For instance, the study found that before the exam, a large variance (48%) of the emotions threat and challenge could be explained by appraisals and coping, which highlighted the key influences that appraisal and coping had upon the emotional outcomes.

Findings from Lowe, Norman and Bennett (2000) also provided evidence that coping influenced emotions. Results concerning the relationship between coping and emotional outcomes in post-MI patients revealed concurrent emotional states (e.g. increased anxiety) was associated with a particular type of coping (emotion-focussed coping). However, the direction of the causality was not known; it was not known if increased anxiety led to or was due to emotion-focussed coping. Nonetheless, this study also found evidence that suggested that sometimes concurrent emotions e.g. happiness, and problem-focussed coping e.g. changing the side of the bed on which they slept, were often not associated at the time, but that this type of coping was predictive of later emotional outcomes. This particular finding suggests that in this instance, the benefit of problem-focussed coping for post-MI patients was not immediate and maybe a cognitive process was involved (i.e. re-appraisal), which slowly altered emotions.

Lowe, Vedhara, Bennett, Brookes et al. (2003) found further evidence for appraisal theory of emotion and coping theory. The study examined the emotions and the coping in female patients with suspected breast disease. They explored the distressing aspect of the diagnosis in patients who had a GP referral but had not yet attended the breast clinic. Unlike Smith and Lazarus (1993) and Smith et al. (1993), this study explored all three variables: appraisals, emotions and coping. They found appraisal components were associated with emotion and coping. Whereas depression accounted for 45 percent of the variance of anxiety, appraisals accounted for an additional eight percent. However, appraisals did not explain a significant proportion of depression, which again was consistent with Smith and Lazarus' (1993). According to Smith and Lazarus sadness was closely related to depression, and had not been well supported by the model of emotion. Lowe et al. (2003) found that secondary appraisals predicted coping and that the different emotions (i.e. depression and anxiety) were associated with different ways of coping. For instance, they found having a pessimistic coping potential (secondary appraisal) was a significant predictor of anxiety, which in turn was significantly positively related to using three coping styles (avoidance, confrontation and acceptance/resignation). However, depression, which was significantly related to self-accountability and marginally related to pessimistic problem-focussed coping potential, was found to be negatively related to confrontation. These findings again support the link between the appraisals, emotion and coping and the importance of appraisal in emotion and coping.

Lazarus' theory proposed that appraisals based on cognitions was fundamental in producing emotion and influenced coping. The importance of appraisals in emotion and coping was taken into account in the brief psychological intervention firstly by influencing the way in which the intervention was written. The intervention was written to present the ICD in a positive way, and to encourage patients to focus on the positive and what they could do, rather than the negative and what they could no longer do.

The individual appraisal components of fear and anxiety were targeted in the intervention. Patients were given emotion-focussed coping skills such as distraction or mindful tasks to increase their emotion-focussed coping potential. In addition, the appraisal components of sadness were targeted by suggesting attainable behavioural goals and changes patients could make to help them adapt to their ICD and to increase positive future expectations and increase problem-focussed coping potential. For example, from changing the side of the bed they slept on to ease the pressure of the ICD at night, to setting small incremental goals to increase patient stamina and physical fitness. In a further attempt to increase patient's sense of emotion- and problem-focussed coping potential, patients were given advice to make plans in the event of a shock. (See Chapter 8 for a more details on the intervention and Coping with Worries, Keeping Active and Planning a Shock Strategy).

Lazarus' appraisal theory of emotion was also used to explain the findings in the qualitative study in chapters 5-7. The aim of the qualitative study described and analysed in the following chapters (Chapters 5-7), was to gain a detailed understanding of issues that influenced anxiety and coping behaviours following an ICD implant for patients and their intimate partner. Although the theories reviewed in this chapter had some validity, only one theory, Smith and Lazarus (1993) appraisal theory of emotion and coping theory was deemed appropriate to explain the findings in the qualitative study.

The behavioural theory by Mowrer (1947) was limited to explaining avoidant behaviours but did not describe the antecedents of all types of avoidance. For instance, Mowrer's theory could not explain occurrences of avoidant behaviour in ICD patients who had not experienced a shock, which had been a finding in the qualitative literature review (see Chapter 3). Although the behavioural theories of Seligman (1975) and Abramson (1978), the cognitive theories of Beck (1976) and meta-cognitive theory of Wells (2000), offered theories to explain anxiety and depression, they failed to explain how other emotions, such as anger, relief or joy occurred. They also did not offer an explanation as to the relationship between emotions and coping. The Type-D personality theory by Denollet (2000) was also unsuitable as it is specific to Type-D personalities. As the qualitative study did not use psychometric testing to assess participants' personalities, this theory was also deemed unsuitable to explain our findings.

Models from the social cognition approach such as the theory of planned behaviour did not appear to be appropriate for this study. The social cognitive models discussed in this chapter (i.e. the health belief model and the theory of planned behaviour) explored trying to understand health related behaviours. However, these models do not consider the emotional response to events (such as an ICD or an illness). From the qualitative literature review and the quantitative literature review, patients experienced emotional responses when living with an ICD, which influenced behaviours (such as avoiding exercise to prevent a shock). Accordingly, the stress-coping framework appeared a better fit in understanding the emotional and behavioural responses to an ICD.

For the purposes of the qualitative study, the Smith and Lazarus (1993) appraisal theory of emotion and coping theory was deemed to be the most appropriate one to use in trying to make sense of the psychological sequelae experienced by ICD patients and their partners. Firstly, Smith and Lazarus' appraisal theory of emotion and coping theory was able to predict emotional responses other than anxiety and depression such as anger, sadness, guilt, and gratitude to name a few. The qualitative study (see chapters 5, 6, & 7) had found participants had experienced a myriad of emotions other than depression and anxiety, which this theory would best be able to explain.

Secondly, an added benefit of using Smith and Lazarus' theory was that they suggested that appraisals influenced emotions, and these appraisals could be explored from the participants' narratives. Thirdly, the theory suggested emotion had a direct influence on how individuals coped. As the qualitative study would explore how patients and partners were coping with the ICD, this theory was believed to be the most suited to the aim of the study. For these reasons, Smith and Lazarus's theory of emotion and coping was deemed the most appropriate to use in order to understand the ICD patient's adaptation to the ICD.

Next:

Chapter 5- Qualitative Study: Living with an ICD - Aim and Method

Part 2

Chapter 5

QUALITATIVE STUDY: LIVING WITH AN ICD – AIM AND METHOD

This chapter describes the aim and method of the qualitative study carried out to examine patients and partners experiences of living with an ICD in order to help inform a coping intervention for patients

AIM

Aim of Qualitative Study

This study used a qualitative research design to gain a detailed understanding of issues that influenced anxiety and adaptive and maladaptive coping behaviours following an ICD implant for both patients and their partners. It was important to recruit patients and partners. Patients' emotional and behavioural responses to the event will influence those of their partner, so too will the partners' responses influence those of the patient: increased vigilance and over protectiveness, for example, leading to patients feeling a loss of autonomy.

Issues explored included (I) patients and partners' initial appraisal of the cardiac illness and/or cardiac event, and how they felt being offered the ICD as a treatment option; (ii) how the patient and partner appraise the ICD; (iii) how these appraisals influence their emotions and (iv) how patients and partners cope with the ICD and their role in helping their spouse to cope with the ICD.

The aim of this study was to form the first stage in the developmental process of the Medical Research Council's 'Developing and Evaluating a Complex Intervention' guidelines (MRC) (2008). The data found in this study will be used to inform stage-two of the MRC's (2008) guidelines.

METHOD

Participants

Participants were recruited from three regional ICD implant centres in the UK. Two of these centres were hospitals in south Wales and one was a hospital in the south west of England. Participants comprised patients who had received their ICD for a period of three-months to one-year, and their long-term partner. The time limit of one-year for having the implant based upon research from previous studies that described a typical adjustment period of one year after implantation, during which ICD patients became less anxious and more secure (Burke, 1996, Kamphuis et al., 2004; Flemme et al., 2005; Morken et al., 2009). Participants were aged between 18 and 70[35] years.

The participants were allocated to one of four groups: Group (1a) comprised ICD recipients who had not experienced a defibrillated shock (Patient ICD-Non-shock group); Group (1b) comprised partners of these ICD recipients who had not experienced a defibrillated shock (Partner ICD-Non-shock group). Group (2a) comprised ICD recipients who had experienced a shock (Patient ICD-shock group) and Group (2b) comprised partners of ICD recipients who had not experienced a shock (Partner ICD-shock group). Recruitment ceased after data saturation was reached[36].

Participants with a serious co-existing morbidity such as cancer, or who were waiting for another heart procedure to be carried out after the ICD implant were excluded from this study. Participants were also excluded if they needed an interpreter in order to participate in the interview, as there was a risk that the meaning of language could be lost in translation. The Cardiff & NHS Welsh Trust referred to the Cardiff and Vale NHS Trust Welsh Language Scheme Guidelines as to whether the study had to be carried out bilingually (English and Welsh) (personal correspondence with Lewis, Cardiff & Vale University Local Health Board 5/5/2010). Lewis (2010) confirmed that the guidelines state that the Welsh Language Act (1993) recognised that people best express their needs and views in their preferred language, and as the

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[35] A substantial amendment was submitted to change the upper age range from 70 to 75 years; however, this only applied to the shock category (Groups 2a and 2b – see above).

[36] It was estimated that about six-eight couples would be needed as James, Albarran & Tagney (2001) found saturation occurred by their sixth participant.

researcher was not a Welsh speaker, the study did not have to be carried out in both languages.

Materials

Contents of Envelope sent to Participants (see Appendices)

Envelopes were given in advance to the Specialist Arrhythmia Nurse at each main hospital. Inside each envelope were an introductory letter, a Participant Information Sheet, and a stamped addressed envelope. Note: the Specialist Arrhythmia Nurse sent letters to potential participants.

Appendix 1 and 1a	Introductory Letter
Appendix II	Participant Information Sheet
Appendix III	Participant Consent form
Appendix IV	Confirmatory letter re: interview

Recruitment

Non-shock groups (Patient ICD Non-shock group and Partner ICD-non shock group) were recruited as follows:

1. The Arrhythmia Specialist Nurse sent a letter to known ICD non-shock recipients and their partners who met the study's criteria, to ask if they would like to take part in a study (see Appendix I). At the bottom of the letter was a tear-off slip that was to be completed and returned directly to the researcher in the envelope provided. The letter stated that the study wanted to recruit both the ICD recipient and partner, as one of the study's aim was to understand the anxieties of both parties.

2. For reasons of confidentiality, the documents (letter, participant information sheet, stamped addressed envelope) for each participant were put into blank stamped envelopes and given to the Arrhythmia Nurse Specialist by the researcher in advance. The Arrhythmia Nurse Specialist needed to take out the letter, sign, date and write in the name of the participant in the salutation.

The envelope containing the documents also had to be addressed by the Nurse to the individual participant.

3. When a tear-off slip was received, the researcher contacted the potential participant. The researcher answered any questions that they may have had about the study and ascertained whether they were willing to participate, a mutually convenient date and time for an interview was arranged. All participants were interviewed in their home as some patients may not have transport. In addition the home was viewed the most appropriate venue to offer a familiar setting, privacy, quietude and free from interruptions as deemed essential qualities for a qualitative venue (Smith, Flowers & Larkin, 2009).

4. The details of date, time and venue of interview were confirmed in writing and sent out promptly to the participant (see Appendix IV).

5. The day prior to the arranged interview, the researcher contacted the Arrhythmia Nurse Specialist to check that the ICD-recipient had not died since the interview had been made. This communication with the Arrhythmia Nurse Specialist was carried out regardless of whether the interview was with the ICD recipient or the partner.

6. On the day of the interview, the interviewer telephoned the participant in the morning to confirm the interview time to ensure that the interview could still go ahead as scheduled.

7. At the participant's home, and before the interview began, the researcher went through the ethical rights to ensure that the participant fully understood their rights as research participants.

    a. *The participant was informed that any personal or identifiable details in the transcript would be anonymised and that their names would be pseudonymised. Only the researchers and the researcher's supervisor would know the identity of the participant from the pseudonym.*

b. *The participants were told that the data from the interview might be used to write articles for a journal but assured that they would not be able to be traced by the details disclosed as all data will either by anonymised or given pseudonyms (examples will be given so that participants know fully what these terms mean. They were informed that the interview would be recorded with a digital recorder, and the recordings deleted after they have been transcribed, and after which all of their personal details would be deleted. Transcripts would be kept in a locked drawer, which could only be accessed by the researcher and the Chief Investigator (researcher's supervisor).*

c. *The participants were advised that they may stop the interview at any time or ask to reconvene another time. They were assured they could stop the interview without offering an explanation. The participant was assured of their right to withdraw from the interview or the study at any time; before the interview, during the interview or after the interview up until the data has been analysed. They were assured that they did not have to give any reason for their withdrawal and that their NHS care would not be affected.*

d. *The ICD participant and partner were informed that if driving during the ICD recipient's six-month medical suspension was disclosed, the researcher would be obliged to inform their Arrhythmia Specialist Nurse.*

e. *The participants were advised to contact their Arrhythmia Specialist Nurse if they had any concerns raised by the interview. Participants were also assured that if they needed medical help during the interview, the researcher would stay with them until appropriate help arrived.*

f. *Participants were advised their written consent must be given before the interview could begin and that they must be able to confirm that their partner had given consent that they might take part.*

8. If the participant was willing to proceed with the interview and consent had been sought from their partner, final consent forms were signed as evidence

that the participant was aware of their ethical rights and was happy to proceed with the interview (see Appendices VIII and IX).

Shock groups of participants (Patient ICD-Shock Group and Partner ICD-Shock Group) were recruited in the following way:

1. When an ICD-recipient contacted the ICD clinic or Arrhythmia Nurse Specialist to report a shock, the Arrhythmia Nurse Specialist sent a letter to the patient and their partner informing them of the study (if they met the study criteria). Each participant received a personalised letter (see Appendix Ia). The letter stated that the study wanted to recruit both ICD recipients with their partners, as one aim of the study was to understand both their experiences and fears. Included with the letter was a Participant Information Sheet either for patients or partners (see Appendix II), which outlined the study in more detail. At the bottom of the letter, there was a tear-off slip, which was to be completed and returned directly to the researcher if the participant was interested in taking part in the study. A stamped envelope printed with the researcher's address was also included.

2. For reasons of confidentiality, the documents (letter, participant information sheet, stamped addressed envelope) for each participant were put into blank stamped envelopes and given to the Arrhythmia Nurse Specialist by the researcher in advance. The Arrhythmia Nurse Specialist needed to take out the letter, sign, date and write in the name of the participant in the salutation. The envelope containing the documents also had to be addressed by the Nurse to the individual participant.

3. When a tear-off slip was received, the researcher contacted the potential participant. The researcher answered any questions that they may have had about the study and ascertained whether they were willing to participate, a mutually convenient date and time for an interview was arranged. All participants were interviewed in their home as some patients may not have transport. In addition the home was viewed the most appropriate venue to

offer a familiar setting, privacy, quietude and free from interruptions as deemed essential qualities for a qualitative venue (Smith, Flowers & Larkin, 2009).

4. The details of date, time and venue of interview were confirmed in writing and sent out promptly to the participant. (See Appendix IV)

5. The day prior to the arranged interview, the researcher contacted the Arrhythmia Nurse Specialist to check that the ICD-recipient had not died since the interview had been made. This communication with the Arrhythmia Nurse Specialist was carried out regardless of whether the interview was with the ICD recipient or the partner.

6. On the day of the interview, the interviewer telephoned the participant in the morning to confirm the interview time to ensure that the interview could still go ahead as scheduled.

7. At the participant's home, and before the interview began, the researcher went through the ethical rights to ensure that the participant fully understood their rights as research participants.

    a. *The participant was informed that any personal or identifiable details in the transcript would be anonymised and that their names would be pseudonymised. Only the researchers and the researcher's supervisor would know the identity of the participant from the pseudonym.*
    b. *The participants were told that the data from the interview might be used to write articles for a journal but assured that they would not be able to be traced by the details disclosed as all data will either by anonymised or given pseudonyms (examples will be given so that participants know fully what these terms mean. They were informed that the interview would be recorded with a digital recorder, and the recordings deleted after they have been transcribed, and after which all of their personal details would be deleted. Transcripts would be*

kept in a locked drawer, which could only be accessed by the researcher and the Chief Investigator (researcher's supervisor).

c. *The participants were advised that they may stop the interview at any time or ask to reconvene another time. They were assured they could stop the interview without offering an explanation. The participant was assured of their right to withdraw from the interview or the study at any time; before the interview, during the interview or after the interview up until the data has been analysed. They were assured that they did not have to give any reason for their withdrawal and that their NHS care would not be affected.*

d. *The ICD participant and partner were informed that if driving during the ICD recipient's six-month medical suspension was disclosed, the researcher would be obliged to inform their Arrhythmia Specialist Nurse.*

e. *The participants were advised to contact their Arrhythmia Specialist Nurse if they had any concerns raised by the interview. Participants were also assured that if they needed medical help during the interview, the researcher would stay with them until appropriate help arrived.*

f. *Participants were advised their written consent must be given before the interview could begin and that they must be able to confirm that their partner had given consent that they might take part.*

8. If the participant was willing to proceed with the interview and consent had been sought from their partner, final consent forms were signed as evidence that the participant was aware of their ethical rights and was happy to proceed with the interview (see Appendix III).

Interview schedule

Before the interview began, there was an attempt to establish rapport with the participant and put the participant at ease. The ordering of the questions was not important leaving the researcher to probe interesting areas that arose.

No set questions were used but the following issues were discussed:

- The cardiac event:
    - Participants were asked to describe their experience of the cardiac event that had led to the ICD being offered as an appropriate treatment therapy
- Feelings about the ICD – benefits and disadvantages
    - Participants were asked how they felt about the ICD
    - Participants were asked to consider if there were any benefits of the ICD and if so, what they were.
    - Participants were asked to consider if there were any disadvantages having an ICD
- Coping with the ICD
    - Participants were asked how they coped with their/their partner's ICD on a daily basis and what were their concerns (if any)
    - The ICD recipient was asked how the role of their partner affected their adaptation to the ICD
    - Participants were asked what information or support given so far by health professionals had been especially useful and what other information or support they would have liked to have received

The patient and the partner discussed the same issues; however, questions were adapted to be pertinent to their role as the ICD recipient or the partner. Each individual interview lasted approximately one hour.

Main Ethical Issues

Patient and Partner Well-being

Before contacting the participant the day before to confirm the interview time, the researcher contacted the Arrhythmia Specialist Nurse to check that the participant had not been admitted into hospital or had died to prevent further distress to the family of the patient.

If the participant appeared to get stressed or upset during the interview, the interview was paused and the participant asked if they wish to stop and withdraw from the interview. If the participant became unwell during the interview and wanted immediate medical attention, the researcher would have stayed with the participant until appropriate medical help arrived. At the end of the interview, the participants were advised to contact their Arrhythmia Specialist Nurse if there were concerns raised by this interview.

Confidentiality and Rigour of Study

All data was anonymised. All digital recordings were deleted following transcription. Any names or identifying information was changed to maintain anonymity and confidentiality. Permission for the study was granted from the South West Wales Ethics Committee, and Research and Development from the two research sites. Permission was also sought from the Consultant Electro physiologists whose patients the study was using. The Supervisor and the Chief Investigator ensured that the investigation conformed to the principles outlined in the declaration of Helsinki.

Analysis

The interviews were recorded using an Olympus DS4000 digital recorder. The interviews were transcribed verbatim by the researcher on the day of the interview. Each transcript had large margins either side for making notes. Only the researcher listened to the interviews and the recordings were deleted after they were transcribed.

Each transcript was sent electronically to two experts in qualitative research (Professor Paul D. Bennett and Dr Rob Lowe.) The data set was divided into two groups; one group belonged to the ICD patient and the other to the partners. The researcher carried out separate analyses on each group of patient and partner transcripts.

The transcripts were analysed manually using a thematic analysis approach based on the guidelines by Braun and Clarke (2006). The first transcript from each group (patient or partner) was read a number of times in order to become familiar with its account, as each new reading can reveal new insight.

Initial codes were produced for the first transcript. Codes identify features in the data that were interesting and refer to the raw data (Braun & Clarke, 2006). For example, sentences were paraphrased rather than using interpretation at stage. The process of coding helps to organise the data into meaningful groups (Braun & Clarke, 2006).

The entire data set was systematically coded giving equal attention to each data item. Each data item was coded by using highlighter pens and writing notes in the margins. Codes with the data extracts were typed up. Data extracts from each data item were then collated together within each code by cutting and pasting.

At this point, the process of coding was helped using a framework approach (see Gale, Heath, Cameron, Rashid et al., 2013). As this study was interested in patients' experiences, their beliefs and ways of coping, the coded extracts were organised around a theoretical cognitive-emotional-coping framework. In addition, any particularly interesting feature was also coded, and if there appeared to be a pattern emerging, these coded data were kept. If not, they were discarded.

The coded data extracts were named First Order Themes. These First Order Themes were examined to see if any could be grouped together into broader themes. Using the cut and paste facility on Word, First Order Themes that formed broader themes were named Second Order Themes (e.g. 'Anger and Frustration' 'Problem-focussed coping').

The Second Order Themes were examined to see how they could be combined into much broader themes to also reflect the cognitive-emotional-coping framework (e.g.

‘Emotional Responses’ ‘Coping with the ICD’). These much broader themes were called General Dimensions. The researcher and the two experts met regularly to discuss the themes. When a consensus of first and second order themes, and a general dimensions for all the transcripts had been agreed, these meetings ceased. Detailed tables were created for each cohort (Patients and Partners) of participants (see Appendices VI and VII). A brief concept map, which includes a raw data quote, first and second order themes and general dimensions was devised, see Tables 6.2 and 6.4). For individual transcripts of the patients and partners with and without an ICD shock experience, see Appendix V (Patients) and Appendix Vi (Partners).

Accordingly, the analyses were in line with the guidance given by Braun and Clarke (2006) but were also influenced by the framework method, which is useful when having to organise a large data set (Gale et al., 2013). One reason that a full Framework Method analysis was not used was that this study was interested in understanding the participant’s experience from a psychological approach. This study was not a multi-disciplinary project and did not want to explore the views of several different stakeholders. Srivastava and Thomson (2009) suggested that Framework Analysis was a useful tool when trying to assess policies and procedures from the people they affect. However, the aim of this study was not to find evidence to change policy or nursing procedures but to explore experiences of ICD patients and partners in order to inform a coping intervention.

Thematic analysis was chosen as it is an interpretative process in which data are systematically searched for patterns to provide a rich insight into complex phenomena. As well as this factor, thematic analysis was used because it is a suitable method to use when expanding or testing theory (Smith & Firth, 2011). (See Limitations of Qualitative Study, Chapter 7).

Next:

Chapter 6- Qualitative Study: Findings and Discussion for ICD Patients and Partners

Part 2

Chapter 6

QUALITATIVE STUDY: FINDINGS AND DISCUSSION FOR ICD PATIENTS AND PARTNERS

***SECTION ONE**: Qualitative Findings and Discussion for Patients*

***SECTION 2:** Qualitative Findings and Discussion for Partners*

SECTION ONE: Qualitative Findings for Patients

In total, 18 patients were identified as suitable participants. Recruitment ceased after 13 for non-shock as large amounts of rich data had been generated by the interviews with saturation of themes occurring. Five patients were recruited who had experienced a shock. Recruitment had to cease after these five due to time constraints and a general paucity of shock patients.

Participants included in this study comprised 11 males and seven females and ranged in age from 28 to 68 years (mean age 55.7 years, standard deviation 11.75) (see Table 6.1). The participants recruited came from a wide variety of educational and occupational backgrounds. Participants represented middle and working class occupations, such as Managing Director, Property Developer, Electrician, Head Teacher/Vicar, Homemaker, Technician, Carpenter, Builder, Nurse, Administrator, Accountant, Teacher, College Lecturer, a semi-retired clergyman, as well as one unemployed participant. All but one couple had children. Children ranged in age and included a 1-year-old, a 3-year old, and a 13 year old, mid to late teenagers as well as older married offspring who had children of their own.

Table 6.1: Characteristics of Patients

Code	Gender	Age	Cardiac condition	Time with ICD
S01	Male	66	Sustained Ventricular Tachycardia - Undiagnosed Cardiomyopathy (P)	≤ 1 year
N03	Male	47	Sustained Ventricular Tachycardia - Arrhythmogenic right ventricular Dysplasia (P)	≤ 1 year
N04	Male	68	Heart Failure (P)	≤ 1 year
S05	Male	50	Idiopathic Dilated Cardiomyopathy (S)	
N06	Male	56	Out of Hospital Cardiac arrest myocardial Infarction (S)	≤ 1 year
N07	Female	60	Sustained Ventricular Tachycardia Undiagnosed cardiomyopathy (P)	≤ 1 year
N08	Female	65	Out of hospital Cardiac arrest Undiagnosed cause (S)	≤ 1 year
N10	Male	49	Hypertrophic Cardiomyopathy (P)	≤ 1 year
N11	Male	67	Sustained Ventricular Tachycardia Enlarged heart (P)	≤ 1 year
N12	Male	67	Out of hospital cardiac arrest Myocardial Infarction (S)	≤ 1 year
S13	Male	68	Sustained Ventricular Tachycardia - Undiagnosed Cardiomyopathy (P)	≤ 1 year
N14	Male	56	Brugada Syndrome (P)	≤ 1 year
S15	Male	64	Heart Failure (S)	≤ 1 year
N16	Female	48	Multiple Cardiac Arrests during Routine operation (S)	≤ 1 year
N17	Female	58	Bundle Branch Block Syndrome (P)	≤ 1 year
N18	Female	30	Post Partum Cardiomyopathy (P)	≤ 1 year
N19	Female	28	Long QT Syndrome (S)	≤1 year
S23	Female	55	Long QT Syndrome (P)	≤ 2 years

N= ICD non-shock patient; S=ICD shock patient

Table 6.2: Hierarchical Development of the Raw Data, First Order, and Second Order Themes and General Dimensions (See Appendix VI for the complete table of themes for patients)

Raw Data: Key Exemplar Quotes	1st Order Themes	2nd Order Themes	General Dimension
"... but this thing [ICD], every time I turn over in the night it's there like ... Sticking out of my shoulder .... I'm conscious of it" (50-59)[N10]	Physical Sensations		
" Although I'm not a doctor, I know in my mind there was a very thin line between me being here now and not being here" (398-400)[N14]	Feeling Traumatised		Emotional Consequences
"The first time we went away for a night was in December .... and my first thought when I went in the door was 'there's no phone' ... 'I wonder where the nearest ambulance is ' ... and we went down the Gower, and my first thought was 'they'd never have got to me in time ... so I suppose you do sort of ... 'where's the nearest hospital? ... 'is it accessible for somebody to get to you?' (117-132)[N08]	Vulnerability & Uncertainty		
" ... [husband] he says '... you can't do this, you can't ...' And I think I'm not an invalid, I'm not a cripple, I might have had a heart operation but I'm still me. But I'm not ... I don't feel the same person I was a year ago" (114-117) [N18]	Loss of Identity	Feelings of Loss	
"I was always going to use that HGV license as a backup ...so my whole life had to alter ... I got to re-evaluate everything ... suddenly it's like somebody pulling the carpet from under your feet" (216-242) [N10]	Loss of Goals /Dreams /Future Self		
"I can't go anywhere on my own. 'You can't go, you can't go on your own'. ..... So you've lost your independence as well" (261-266) [S23]	Loss of Independence /Autonomy		
"My confidence suddenly went down ... it was the fact that my heart had gone into this rhythm and I hadn't been doing anything out of the ordinary .... certainly to me there was no outward sign as to why this should happen and that's the thing that unnerved me a lot" (213-226)[S15]	Loss of Confidence		
" ... most of the time-when I'm occupied I forget it. But when I sit down quietly thoughts go round my head-it's always at the back of my mind ... that I don't know what's going to happen, how it will affect me, will it hurt, will there be more than one ..." (363-371)[N11]	Anxiety and Fear of Shock		
"I don't want to sound like a Jonah ... what do you do? Got this [ICD], out of work [cries] .... maybe I should have gone to ... it was in the booklet, you can go to a sort of club where other people have had it. I don't know ... like Alcoholics Anonymous, Defibrillators Anonymous" (443-495)[N14]	Pessimism		

Raw Data: Key Exemplar Quotes	1st Order Themes	2nd Order Themes	General Dimension
"From a comfort point of view [I would have it taken out]. It's an uncomfortable-ness, an awkwardness. I'd said I'd have it out, but I'd have to talk to my wife. ... But I think this should have been done at the beginning lie, like I said, if I'd been given the choice at the beginning I'd have chosen no" (429-434)[N10]	Doubt and Regret having the ICD		
"I find it frustrating cos there I was in April playing rugby, full 40 minute each way, full contact, running about and then bang, in June this happened and ever since, I struggle to run. I can run but now very far and not very fast, whereas before I used to enjoy running, I used to enjoy extending myself. I find it frustrating now. I can't experience that cos it's a struggle to run, so for whatever reason, I can't do it" (117-123)[S05]	Frustration at Situation, Others and Self		
"I think a lot about dying, which I've never thought about before. I'm not scared to die ... this [ICD] is just there as a standby, it's like a marker to say 'right you're nearing the end of your time" (271-280)[S23]	Feeling Mortal		
"... when I'm doing something strenuous, I keep telling myself 'you must pace yourself'. Cos if it starts ... going too quickly, there could be a problem, so you must pace yourself... If I feel a drag on my arm, my heart going a bit faster, then I think about it. If I walk too fast, which I tend to do, I have to tell myself to slow down. It's a conscious effort to do it" (407-473)[N17]	Limiting Activity	Problem-Focussed Coping	Coping with ICD
"... I do all the things that I used to do, hang out washing, sweep ... go up ladders ... just be more careful.... If I work, I make sure somebody's around, you know especially if it's manual sort of stuff, it it's only light stuff I'm alright" (102-111)[N12]	Protective Behaviours		
"We've swapped roles. I always did everything, you know he didn't even know how to switch on the washing machine... I do what I can but I can't mop the floor ... so he does a lot of the cleaning and he learned to cook more. So, it's sort of-we've split the role, if I can't do it, he'll do it... So the dynamics of the family have changed-he's looking after me more whereas I'd always looked after him... he's very good, 'you've always looked after me, it's my turn to look after you' " (683-694)[S23]	Re-assessing Role Identities		
"I'm afraid I'm going to set myself off... I'm afraid I could have an attack or have a shock, it will get too much for me that way... I'm too afraid to go that extra mile, to stand my ground like I used to" (100-103)[N18]	Avoidant /Restrictive Behaviour	Emotion-Focussed Coping	
"My wife being a nosy blighter, she reads them [doctor's notes], and I'd rather not know... just get on with it, as long as it works ok, fine. If it don't work, I don't know what to expect...If something is beneficial, that's fine. If it doesn't work, I didn't about it anyway, so I'm not missing it, you know what I mean?" (239-249)[S13]	Cognitive Avoidance		

Raw Data: Key Exemplar Quotes	1st Order Themes	2nd Order Themes	General Dimension
"Initially the only way I could cope was thinking 'he got it wrong, it couldn't be that, I'd better have this [ICD] just in case.. but it was disbelief really. And that's how I coped... It were a shock but that was the only way I could deal with it" (77-87)[S23]	Denial, Distraction and Cognitive Disengagement		
"My faith makes a big, big difference of course ... I don't care what they put in... whether it's a machine or whatever it is, I'm going to go as long as the Lord kind of wants me to go and that's the end of it, and I'm content with that" (316-3360)[N04]	Religious Coping		
"I still get my moments when I think I can't cope with this anymore; I just want everything back to normal. You know 'there's nothing wrong, I don't need this ICD'" (698-700)[N16]	Blaming and Venting		
"I thought maybe one of blood vessels here had blocked up... they did all these tests, they said my arteries are pristine, which 'what a waste' I thought (small laugh)" (365-368) [N11]	Maintaining Self-Esteem		
"... [I tell myself]... Well, I could be dead, but I'm alive... luck to be here is the end result... I could be in Afghanistan, a child bombed for no reason... like that poor girl getting shot in London at her age and I'm 56 and I've lasted this long... It puts things into perspective" (568-571)[N14]	Social Comparison		
"... As for the ICD, well I suppose it's the essential friend, that's the way I look at it... not sure if it's a welcome friend but it's an essential one" (409-410)[N11]	Acceptance		
"... When I went back for my follow up... my daughter came with me because she was going to be tested and my husband was there. And they said 'are you alright about it? [ICD] .But you don't actually want to say how you really feel, cos they [family] are worried enough as it is... You know, they've got their own worries, so you got to feel 'Oh don't worry, everything's going to be ok'. I didn't want my daughter-my daughter has got it [LQT], so I didn't want her worrying about it. So, it was 'oh look at me, I'd doing fine, it hasn't affected me really if it [ICD] comes to you, you'll be the same" (128-145)[S23]	Concealment		

First Order Theme: Physical Sensations of an ICD

Most patients[37] were physically aware of the ICD device inside their bodies, and some patients described the physical encumbrance in detail. Most patients had been shown a device before their implant, and most had had the opportunity to hold and feel it, yet the majority commented on its 'incredulous' size once implanted. The finding that patients were surprised by the size of the ICD has not been reported in previous studies, although Dickerson (2002) cited that participants found 'bulkiness an issue'. One explanation for the present study's finding might simply be that recent technological advances have reduced the size and bulk of most precision instruments and therefore patients might have perceived the ICD to be a much smaller device. Nonetheless, as most patients had held an ICD device before their implant, this does not explain their reaction to its size.

The adaptation to the size of the device might have been hindered by descriptors of the ICD found in routine medical literature (e.g. British Heart Foundation Booklet, 2010 page 14), suggesting the device is the size of a small matchbox. This descriptor was evidently fixed in the minds of patients, for example one male non-shock patient reported: *"I was a bit alarmed at first really [thought of having ICD]... don't like the idea of having anything stuck in my body ... it was an unpleasant idea and when I saw how big it was .. at first he said a matchbox, but there are matchboxes and matchboxes ... it was quite a big matchbox, more like a Swan-even bigger than a Swan Vesta box .. And also they said you wouldn't be able to see it. You can see how big it is, quite prominent really. I wasn't hugely affected by that but it does remind you that it's there all the time" (108-120) [N11].*

Adjustment difficulties to the physical problems associated with the ICD have been well documented in previous studies. For example, Williams, Young, Nikoletti, and McRae (2007) reported patients post implant, attributed problems such as feelings of weakness, difficulties in sleeping, and reduced energy to the ICD. However, most of their participants claimed them as 'normal symptoms' during the settling of the ICD. Tagney, James and Albarran, (2003) found patients often complained of pains in their arms, although they reported that these pains had abated over time.

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[37] To avoid confusion, participants who were patients (recipients of the ICD) will be referred to as 'Patient' and their partner will be referred to as 'Partner'

Nonetheless, the reporting of physical symptoms during settlement of the ICD highlights a possible clinical issue. For instance, male non-shock patient [N06] was so convinced his arm pain was due to the ICD, he contemplated having it removed: *"... I have got to be truthful, I have thought of asking the doctor about removing it, because of what's happening to my arm" (348-350)[N06].*

This patient's (N06) arm pain might have been exacerbated by his ambivalent attitude towards the ICD or it might have been a warning that something was seriously wrong. This example highlights the difficulty patients have in assessing whether their pain is 'normal' and should abate with time, or is more serious and needs urgent medical attention. This raises another clinical issue caused by reduced face-to-face contact with medical staff due to remote monitoring. Male non-shock patient (N06) wanted reassurance that the pain was 'normal' but because he had a remote monitoring box, it meant any visit to the hospital to discuss his pain, was not imminent. He claimed: *"but I need to go and see someone to reassure myself. Because at the moment I can't talk to the box" (287-289)[N06].*

However, the experience of adverse bodily sensations post-ICD implant was not a consistent finding across all patients. All patients had been interviewed at approximately one-year after their implant so it would be logical to assume that patients would have reported similar physical sensations. However, it was apparent, that those who complained of adverse physical sensations tended to be those who were finding it difficult to adjust to the ICD. This might be explained using Lazarus's model of appraisal and how it influenced the patient's ability to cope; some patients appraised the ICD not only as having caused considerable harm but also as continuing to be a threat. This negative appraisal was often compounded by negative beliefs attached to the ICD, such as male non-shock patient's (N14) belief that the ICD made him unemployable (see later second order theme: Feelings of Loss). Male non-shock patients (N14 and N10) were finding it very difficult to accept the ICD and deliberated on its uncomfortable sensations, and provided detailed descriptions such as: *"... it feels like a stone in jelly. ...And it moves in bed as well"* (294) [N14] and *"I feel it's there ... Very, very heavy at first it was, don't seem so heavy now"* (332-333)[N10].

It was not surprising therefore when the patients who adapted well to their ICD did not reporting adverse physical sensations from the ICD or if they did, were quick to dismiss them as unimportant. As male non-shock patient reported *"In the beginning it was very awkward. ... They said it would be below the collarbone, you know I expected it to be ... between the shoulder and the neck ... but it's literally over – by my arm. .. So as soon as I start to move my arm, you start hitting it straight away, which I used to find very awkward ... but now, it doesn't bother me at all ... I think it's found its own pocket" (314-324)[N03].*

Patients, who voiced anxiety about their ICD or who appeared to be having difficulty adapting to it, were constantly reminded of its presence. Male non-shock patient N10, who had been clearly struggling with his ICD from the initial diagnosis of cardiomyopathy who reported that in hindsight he wished he had not been given the device. He perceived its physical presence to be a constant source of aggravation, both to him and his wife: *"... but this thing (ICD), every time I turn over in the night it's there like, you know what I mean? Sticking out of my shoulder, it's tough like ... my missus, my wife puts her head on my shoulder ... she's conscious of it, I'm conscious of it ... "* (50-59)[N10]. It was not surprising to find out that this patient later experienced emotional turmoil because of the implications the ICD was having on his lifestyle, and his negative appraisal of the ICD was being driven by beliefs that it had been an unnecessary procedure (see second order theme: 'Feelings of Loss').

Interestingly, patients did not complain about the bruising and soreness around the ICD site wound unlike the patients in Tagney et al.'s (2003) study. However, Kamphuis et al (2004) found that pain around the location of the device implant was reported to be much less painful after 6-months. Therefore, non-reporting of wound pain might have been due to the fact their wounds had healed by the time of the interview and were either forgotten or were not perceived to be important.

Patients who were finding it hard to adapt to the ICD protested that the device appeared to be moving around, and this finding has been found in other studies (e.g. Dickerson, 2002; Williams, Young, Nikoletti & McRae, 2007). However, the movement of the ICD appeared to be more annoying than worrisome, especially as patients were particularly conscious of movement whilst trying to sleep at night. The majority of patients found getting into a comfortable sleeping position at night difficult and therefore the device's constant movement did not help. Male non-shock patient reported *"it's annoying as much as anything else ... when I lie in bed and it twists itself and sometimes it's here and it's on one edge"* (335-342) [N12.] Although, patients had been told the ICD takes about a year to settle into the body, evidence from this present study suggested that many patients had not processed this information.

Many patients had been surprised at where the ICD had been implanted. Most patients had assumed the implant would be nearer to the heart, protected by muscle and tissue rather than be inserted just below the collar bone. In addition, most patients reported the shape of the device as being clearly visible under the skin and nearer their neck than anticipated. The implant site might have contributed to patient's complaints of arm pain and mobility issues as the arm in question was always adjacent to the ICD: *"it hurts .. it wakes me up in the night if I'm sleeping .. If I turn over on that side (points to left side), I can't, it does wake me up and as I say movement in my arm in certain directions, it is really painful on the muscle. They give no warning of this whatsoever" (210-218)[N06][Male non-shock patient].*

Burke (1996) suggested that coping with the ICD could be conceptualised as three stages, and offered an explanation as to why some patients might have had trouble in adapting to the actual physical aspects of the device. The three stages suggested by Burke (1996) were choosing life with technology, integrating technology into life and living life through technology. Burke suggested patients had two motives for choosing to accept technology; the primary motive was to secure life, with a secondary motive to ensure, maintain or improve quality of life. Accordingly, some patients might have found it difficult to adapt to the physicality of the ICD once implanted because they had been so focussed on its life-saving ability that any physical constraints of the ICD had been hitherto ignored. However, once the daily hassle of living with the ICD is realised, the device was thereafter perceived negatively.

The extent to which the physical presence of the ICD is felt might be a marker of adaptation achieved by the patient. The patient's positive or negative appraisal of the device could be an indicator of acceptance. It was clear from the present study that the size and positioning of the ICD was one cause of physical and mental discomfort to many patients albeit in varying degrees. However, it was notable that those patients who reported difficulties in adjusting in general to the ICD often reported experiencing much physical discomfort from the ICD. On the other hand, patients who appeared to be adapting well to the ICD, reported fewer physical symptoms or if reported, patients were quick to dismiss the discomfort as minimal and transitory.

Similar to the non-shock patients, shock patients[38] were also conscious of the physical encumbrance of the ICD. Similar as well, was the finding that those patients who appeared to be struggling with their ICD reported more discomfort from both its physical presence, as well as its mental presence. For instance, although female shock patient S23 reported not being constantly conscious of the ICD, she was nevertheless very aware of its constant movement. She also suggested that when her heart began to beat fast, the presence of the ICD was a constant reminder that she had an arrhythmia: *"I don't walk around conscious of it ... it's just when I feel my heart starting to beat faster, cos I got this arrhythmia thing .. it's a constant reminder then but apart from that I just get on with [it], forget it's there, cos you can't feel it in there .... "I've learned to sleep on my back, cos I can't sleep on my side ... it feels as it if it moves and if I sleep there I can feel it poking me and if I turn on that side, I can feel it moving out like that, if you see what I mean.... Some days it's under my arm and then other days, I can feel it up here. Like today, it's tucked in under my arm and then other days, I can feel it there [points to chest]. So, it moves around"* (335-349)[S23].

Similarly, another patient who appeared to be struggling with both his diagnosis of heart failure and the ICD, also commented on how the ICD for him was a constant reminder of his illness: *"You see, when the ICD is put in, you notice it all the time. You've got a constant reminder cos you can feel it all the time and sometimes it gets a bit itchy and rubbing it, so you're aware of it all the time. So that's a physical thing that's a constant reminder ... a constant reminder of the fact I've got one there, which then reminds you of why you got one .. But the very fact it is there is constant reminder" (410-422)[S15][Male shock patient].*

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[38] Shock patients referred to patients who had experienced a shock from their ICD

Interestingly, whereas S23 and S15, had both keenly felt that the ICD was a reminder of their mortality (see first order theme: Feeling Mortal), and reported physical and mental discomfort from the ICD, male shock patient S01 viewed the cardiac event as a 'wake-up call'. This wake-up call had made him determined to make the most of the following ten years of his life. His positive attitude might have been responsible for him finding that although he was consciously aware of the device, he reported its awareness with no mention of discomfort to his physical or mental self: *"It's not uncomfortable. I can feel it, I'm conscious of it ... It's just when you do that [you can feel it] [crosses one arm in front of the other. It's quite easy to move about [wiggles ICD box through his shirt]* (25-32)[S01].

Notably, male shock patients S05 and S13 did not report having a conscious awareness of the ICD, although S05 did comment feeling self-conscious at first when he was in a swimming costume: *"I know we went on holiday not long afterwards to Spain... I can remember walking alongside the swimming pool and being very conscious of this ... it seemed to be much bigger ... I mean I'm over that now. It's there, it's there, that's it. But it is prominent. The boys think I got my wallet in their so I can't buy them a drink anymore!"* (142-147)[S05]. However, he was quick to explain that his awareness was probably because the ICD had not long been implanted and he joked about its prominence, thus minimised its intrusion. McDonough (2009) also reported this feeling of self-consciousness about the protruding ICD when swimming in public.

Male patient S13 did not report on feeling consciously aware of the ICD, however for S13 and S05, both were waiting for another procedure to be carried out, which they hoped would put an end to their arrhythmias. Their focus on future procedures and their hope in them, might have accounted for why they had not been currently consciously aware of the device. Therefore, similarly to the non-shock patients, those patients for whom the ICD and diagnosis had been appraised negatively reported physical and mental discomfort. Also, similar was the patient who reported awareness but no discomfort who was intending to turn the cardiac event so that it had a positive outcome.

Therefore, the findings for shock and non-shock patients in relation to conscious awareness of the ICD were similar; shock patients who were struggling with their illness and device reported physical and mental discomfort. Further, having hope in an additional medical procedure to alleviate their cardiac illness or a having a positive attitude to the cardiac event resulted in minimal or no reporting of conscious awareness of the ICD.

GENERAL DIMENSION: EMOTIONAL CONSEQUENCES

First Order Theme: Feeling Traumatised

The theme of trauma was only pertinent to those patients who had experienced a cardiac arrest. Female non-shock patient had been left traumatised with the realisation that she was lucky to alive after surviving a cardiac arrest. However, comments from other people about her survival appeared to have compounded her trauma: *"And they had to shock me and ... but everybody tells me I shouldn't be here (tearful), really shouldn't .... [Nurse] said to me 'you know, you're very, very lucky, because you know, someone's watching over you ... everybody sort of says to me ... you are extremely lucky. I was talking to an ambulance driver on Sunday 'cos my mum was taken into hospital, and you know, she said to me 'it is so good' she said 'to see somebody who's actually had a cardiac arrest that's here to tell the tale" (42-57)[N08].* If others had not constantly reminded this patient of her close escape from death, she might have been able to overcome her trauma and move forward; however being constantly reminded that she was lucky to be alive had clearly not been helpful to her recovery.

Similarly, male non-shock patient was continuing to struggle with the knowledge that he had nearly died during a bout of ventricular tachycardia, which had left him feeling he should not be alive *"I shouldn't really be here I believe"* [N14] (750-751). This patient recounted the trauma of experiencing the narrow margin he believed delineated life and death: *"... Although I'm not a doctor, I know in my mind there was a very thin line between me being here now and not being here"* (398-400)[N14]. The patient associated the physical sensations he was feeling with those from an earlier medical procedure in which he had had to be defibrillated. Patient N14 believed the burn marks left on his chest by the defibrillator during a VT

Stimulation[39] procedure meant he must have received several defibrillation attempts: *"I think they had a job bringing me back cos I had burn marks where they tried to get me back and I heard the EP say to his colleague 'well done for that'. ... They left me just outside the theatre, well my heart was racing, hard to breathe, well I had the same feeling in the Gardens ... " (71-76)[N14].* Consequently, when he later becomes tachycardic, memories from the VT Stimulation procedure were brought to the fore and it was likely he catastrophised the sensations believing he was going to die.

The awareness of coming close to death is a recurrent theme found in many other studies, which also noted both positive and negative consequences of this awareness. For instance, Kamphuis et al. (2004) whose study only included participants who had experienced a cardiac arrest, found patients described 'meeting with death' as something that had happened without conscious awareness. Kamphuis suggested their patients were far from bleak, and had reframed death as something positive, no longer viewing death to be a threat. Williams et al. (2007) also found patients in their study viewed their 'death experience' to be so positive that it had been liberating and had encouraged them to enjoy the present including risk taking. However, the present study found that coming close to dying had not been a liberating experience but had increased the patient's awareness of the narrow line between life and death, leaving them feeling vulnerable.

First Order Theme: Vulnerability and Uncertainty

Living with uncertainty appears to be one of the most significant themes found throughout qualitative literature focussing on ICD patients and partners. It is of such significance that the theme has been incorporated into the titles of at least two studies ('Reconstructing unpredictability ...' Morken et al., 2009; 'Uncertainty is a major concern ...' Flemme et al., 2011). The theme Vulnerability and uncertainty relates to the cardiac event and after the ICD.

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[39] A Ventricular Stimulation Test is a procedure whereby the patient's heart rhythm is given an extra beat to see if the heart can correct itself unaided. If the heart fails to regulate the rhythm, the patient's heart will begin to fibrillate, the patient will lose consciousness and will need to be defibrillated into sinus rhythm.

The behaviours and cognitions reported by many patients suggested they felt vulnerable and uncertain after the implant. One female patient who had experienced a cardiac arrest was clearly feeling so vulnerable that she wanted to be stay within close proximity to the emergency services, without which she would have surely died from her cardiac arrest. This stark realisation resulted in her feeling immensely vulnerable when not within close proximity to an ambulance or hospital. This also led to her heightened vigilance for lifesaving resources that would 'save' her should she have another cardiac arrest: *"The first time we went away for a night was in December ... it was like ... a place where people have a retreat. ... And my first thought when I went in to the door was, 'there is no phone', so if I need someone, there's no phone ... so 'I wonder where the nearest ambulance station is'. Because, I mean the ambulance station is close here, but when I came out of hospital, Terry said 'we'll go for a ride in the car, and we went down the Gower, and my first thought was 'they'd never have got to me in time' because there just didn't seem anywhere where there was an ambulance station. So, I suppose, you do sort of thing to yourself 'where's the nearest hospital? You know ... is it accessible for somebody to get to you?" (117-132)[N08].*

The experience of the cardiac arrest had left female patient N08 with the belief that life was very uncertain, and there may not be time to make arrangements. Consequently, this patient demonstrated her vulnerability when she described her burial wishes to her husband. The theme of vulnerability however was not only relevant to patients who had arrested. A patient who had not experienced a cardiac arrest felt vulnerable after the cardiac event as she felt she no longer knew what events lay ahead for her: *"... It's got to me mentally, it does get to you, play with your mind. It makes me feel I don't know what's in front of me, I have three chances in life, that's how I see it. I had my first chance with leukaemia ... where the baby was concerned, I thought I was a goner, that was my second chance and then obviously my third chance has been getting through this" (66-69)[N18].*

Williams' et al (2007) also found patients did not want to venture too far from a hospital. This need to be near emergency services might suggest that these patients did not trust the ICD to be lifesaving and were still psychologically reliant on emergency services being close by. However, if this way of coping is left unchallenged, it could result in patients becoming fearful when venturing away from these resources, leading to a diminished quality of life.

Although, the ICD is in medical terms considered a straightforward procedure, it nevertheless appeared to be a traumatic time for the patient, which did not subside after the procedure. Patients reported that they had been told to 'live life as normal' on discharge from hospital, which often left patients feeling confused and bewildered. One female patient complained that she had felt 'abandoned' after being discharged: *"Cos it's like ... not that nobody cares but it's like you've a tooth out ... and it isn't really like you've had a tooth out ... it's something a bit bigger than that, do you know what I mean?" (429-432)[N07].* This patient recognised her need to acknowledge her feelings about the implant *"... I was quite looking forward to you coming and me being able to talk about it... Because when you first have it done, people are interested to know 'well, what have you got?'... but then, I suppose you just carry on .. So I was quite looking forward to just talking about it. Just acknowledging I had it done ..." (482-487) [N07].* Patient's description that the ICD implant procedure had been a major operation, illustrates the gravity that many patients attached to their procedure. Eckert and Jones's (2002) found a similar finding who also noted patient's realisation of a need to talk about their experience after going through this procedure.

Patients often complained they felt weak and unfit after their implant, which resulted in intense feelings of vulnerability to both the fear of shock as well as a fear being rendered helpless through fatigue. Williams et al. (2007) also documented these fears. Although most patients alleged they felt safer with an ICD, it appeared some patients were still fearful of whether or not it would fire when it was needed. Studies have not always used the term 'vulnerability' but have labelled the emotion/theme as anxiety or fear; Kamphuis et al. (2004) and McDonough (2009) used the term anxious to describe patients who were fearful relying on a technological device. Fears of 'will it work?', 'how will the shock be experienced?' were reported – hence a vulnerability that resulted from being dependent on technology to survive. The fear that the ICD might not fire when needed was an emotion expressed by one highly anxious individual in the present study who felt he would only be reassured that the device worked after it had tested. He reported: *"I went there once, after swimming once I can't remember how many months, about six months, four months, five months* *[to check] that the thing was firing properly. ... So I went and they gave me an anaesthetic and they tried it out and the shock was working"* [N11] (150-154).

Second Order Theme: Feelings of Loss

For many patients, feeling vulnerable and uncertain was associated with feelings of loss. Feelings related to loss found in this study included loss of past self, a loss of independence and a loss of dreams/goals. For the shock patients, loss was associated with disappointment, frustration along with undertones of anger.

First Order Theme: Loss of Identity

Feeling a loss for one's former self were reported when patients had had to make lifestyles changes in order to adjust to the ICD. This finding corroborates Doolittle and Sauve's (1995) finding that patients tended to focus on their life pre-ICD. Loss of past selves also resulted from being unable to participate in sports that patients had previously engaged in, which was a similar finding to Mert, Argon and Aslan's (2012) study. Many patients in this present study reported having had to make changes to their sporting pastimes and those who held positive attitudes towards the ICD appeared to report better outcomes from these changes. Male patient N03, was very positive in general about the device although he had been a competitive runner up until his cardiac event, and could no long run competitively. Rather than focus on his past self, this patient changed the focus of his running to achieve different future goals: *"... I've always said years ago, I won't run unless I can race, whereas it's the complete opposite now really, I'll run now just to keep fit ... it would be more for the ... not to actually race it but just to run it ... maybe I'd enjoy it more ... I'd be looking at the scenery more rather than the guy in front ... "(249-271)[N03][Male non-shock patient].*

Whereas some patients such as N03 had managed to negotiate a new self, other patients found this more difficult. Patient N10 had grown more and more resentful towards the limitations imposed on him by the ICD and blamed his present lack of fitness on the ICD: *"I used to be quite fit like, I used to go to boxercise, you know* *what I mean, and all that. I used to do a bit of boxing and all that, Gaelic football, you know what I mean, now I'm conscious of it ..." (88-91)[N10][Male non-shock patient].*

For others, a loss of their past self was simply the realisation that they were not the same person as they had been before the ICD: *"... (husband) he says ... 'you can't do this, you can't ... '.And I think I'm not an invalid, I'm not a cripple, I might have had a heart operation but I'm still me. But I'm not ... I don't feel the same person I was a year ago" (114-117)[N18] [Female non-shock patient].* This reaction to partner overprotection appears in Steinke's (2005) study; Steinke had found patients often reported to partners that they were not invalids when the partners were being overprotective. The loss of a past self suggests that patients appeared aware of their changed selves and needed time to come to terms with their new selves. This process appeared to be hindered by over protectiveness and by partners reminding them of their limitations.

Female shock patient S23 voiced disappointment at not being able to help her daughter look after her baby. For this participant, being a grandmother and taking care of her grandchildren were important to her identity as a mother and grandmother and her realisation that she could not continue in her role, made her feel a sense of loss: *"my confidence, it's knocked my confidence... I got a grandchild who's only two and a half ... I've always had the kids for my son to work. And I had the kids for my daughter to work ... I can't manage him [grandchild]. I can't get up and run around with him. And so I feel so disappointed I can't support her with the baby, like I have with everyone else" (627-633)[S23][Female shock patient].*

This shock patient's experience of loss was similar to that of non-shock patient N14, whose self-identity had been based on his ability to work. As reported by Williams et al. (2007) and McDonough (2009), patients need to be able to return to work, which for female shock patient S23 meant a return to looking after her grandchildren to relieve the burden of parenting from her children.

Male shock patient S05 also revealed the theme loss of identity. This theme could have been named 'loss of past self', however due to the impact this loss had had on the patient's identity, the term referring to identity seemed more appropriate. Being fit and athletic was important to patient SO5 and this appeared to define his identity;

he had always participated in sports and prided himself on his fitness. Therefore, to find he had lost his fitness after the device caused him concern and distress. His identity as an athlete was gone but he continued to compare himself to others, which resulted in him feeling more, distressed. *"I can [run] but it's not enjoyable 'cos it's a struggle ... it's hard to describe what the problem is, it's not a muscular physical thing, it's not as though I'm out of breath, it's as though I'm very, very unfit, that's how I feel. I never felt it before, it's horrible, it's not nice" (152-156)[S05][Male shock patient].* His loss resulted in him becoming frustrated.

First Order Theme: Loss of Goals/Dreams/Future self

Related to the loss of past self, was the loss of dreams and goals for the future. Although this could also have been labelled 'loss of control', the label loss of goals seemed more appropriate for this study's sample of patients. This particular type of loss appeared to be felt more if the goals/dreams had been job related as these usually had financial implications. Fridlund et al. (2000) also suggested a loss of work meant no money, which meant patients felt there was nothing to look forward to in the future resulting in the despair as some of the patients in the present study had felt. It is clear from the study's findings that the continued ability to achieve goals in life is important in the process of accepting the ICD. This suggestion strengthens the finding in Dickerson (2002) study, which found that being unable to achieve goals resulted in patients rejecting their device

In the present study, male non-shock patients N10 and N14 found their lost opportunity to achieve job-related goals affected their sense of self-worth and their mood. Palacios-Ceña et al. (2001) also found that patients felt depressed and worthless if they lost their jobs. This sense of worthlessness was often magnified if patients felt they were no longer employable: *"Disadvantages (of ICD) are I was going... well ahead in my career, especially at my age... I've achieved numerous certificates... To no avail now really 'cos I don't if I can get another job cos the way I feel and the defibrillator has to be renewed every four years doesn't it? ... if I'd be fortunate to have an interview with a college, I'd have to explain to them my condition, surely that would be a disadvantage, cos I have go this inser-insertion in me where if they were interviewing you, you haven't got one" (317-355)[N14][Male* *non-shock patient].* This finding was identical to a finding by Tagney (2003) who found patients felt employers would favour non-ICD recipients over them.

Patient N14's sense of identity had been based on being a hard worker, and when the ICD prevented him from carrying out this role, he perceived the ICD to be a stigma: *"you can go to a sort of club where other people have had it. ... like Alcoholics Anonymous, Defibrillators Anonymous ... whatever the word for it .... [crying]" (498-497)[N14][Male non-shock patient].* Williams et al. (2007) and McDonough (2009) also found a return to work was an important marker to a return to 'normal living'. Similarly, then when patients are not able to return to work and regain a normal life they can become depressed as Palacios-Ceña et al. (2011) had found in their study.

The patient's experience of loss through employment can depend on the type of job they held and the consideration and care shown by their employer. For instance, one non-shock patient who had a sympathetic employer was able to use position at work to get others to carry out jobs he could no longer do due to the ICD. He reported *"It's hard at work, I can't do certain things, you know, at the end of the day, if you're the boss, you've got the boys to mess around with the generator" (341-352)[N03][Male non-shock patient].* However, this line of action was not always an option for everyone. The sense of loss male non-shock patient N14 felt when he could no longer carry out his job was further compounded by his employer's harsh attitude: *"... When I spoke to the Director, he said 'I thought you'd be back in two weeks?' And I said 'it's a defibrillator' and he says 'yeah', you know. When I went back on the sick, you know I went in after eight weeks after a major operation... after the attack"* (506-509)[N14][Male non-shock patient].

Because patients felt they were living with uncertainty, they felt many dreams they held had been ruined. This loss of dreams was a very pertinent loss for one male patient who was finding it very hard to accept his ICD: *"... I was always going to use that HGV license as a backup... if I wanted to get out of work and work two or three days a week... so my whole lifestyle had to alter.... I got to re-evaluate everything like ... I'm still working as I am like ... but that's not very good neither like ... I was always going to fall back on driving ..' cos I love driving ... suddenly it's like somebody pulling the carpet from under your feet"* (216-242) [N10][Male non-shock patient]. Patient N10 spent a lot of time ruminating about his situation and his loss of future dreams. He felt anger and frustration and coped by blaming the doctor for not having properly informed him of other treatment options apart from the ICD. In turn, this anger resulted in him denying a need for the device. The futility of this coping strategy to alleviate his emotions resulted in this particular patient becoming very depressed. Dickerson (2002) and Fridlund et al. (2000) also documented a loss of dreams theme.

First Order Theme: Loss of Independence/Autonomy

Burke (1996) found that some patients had found new values in their lives because of the ICD. This was also true for some patients in this study. Those who had adjusted well to their device claimed that they had set themselves achievable goals in order to help them return to normal living: *"I can still run to a certain level, I just need to set myself another set of goals really"* (409-410)[N03][Male non-shock patient] and *"... I am definitely going to start back ... with my fishing now this year ... I feel as if I can do it now .. feel alright, feel good ... It's something I've always really enjoyed"* (167-170)[N06][Male non-shock patient}. Male non-shock patient N06 had been encouraged by his partner to remain as independent as possible. N06's coping style and sheer determination, which had been shaped through a childhood disability, helped N06 cope with his ICD. Williams et al (2007) found some patients demonstrated a strong, resilient streak similar to N06: *"... I'm nothing but determined ... I don't like having other people do things for me. I like to do things for myself ... I always have ... I've done things that doctors thought I wouldn't do, or shouldn't do ... But I've done them, I've just got on with it"* (473-540)[N06][Male non-shock patient].

Loss of independence was a theme found in studies by Tagney et al (2003), Bolse et al (2005) and Palacios-Ceña et al (2011). Often a loss of independence resulted from patients being overprotected by their partner, which appeared to be a common reaction by partners during the early days post-implant (Steinke, 2005). However, sometimes partners continued to overprotect, which made patients feel dependent on them. Patients in the present study were aware that their partners worried about them, which resulted in one male non-shock patient ensuring he was accompanied whenever he went out, just to prevent his wife worrying: *"I felt I'd lost a bit of* *independence really. I couldn't just go out running when I want to ... You know, I'd have to 'oh what you got on [wife] any chance you could come out with me now' ... [or] one of the kids would escort me on their bike you know, and .. before, I could say 'right I'm off' ... it wouldn't have bothered me if I'd gone by myself ... it was more cos [wife] felt a lot happier doing it*" (435-450)[N03][Male non-shock patient]. However, this had been a short-term strategy and he later began to go out alone and because of this was able to regain his former independence.

Sometimes patients concealed symptoms from their partner in an attempt to maintain independence. Concealment had first been a theme discovered by Tagney (2003). Female non-shock patient N17 had declared: "*... my husband is amazing ... always looks on the bright side, always happy ... but I'm aware that it's [ICD] preying on his mind ... he doesn't show it.. well if there was anything going on. If the heart was doing strange things, I wouldn't tell him at the time ... I might say something later" (194-209)[N17][Female non-shock patient].* Female patient N17 felt irritated that her husband was constantly checking on her and his overprotection contributed to the patient concealing symptoms.

Female non-shock patient N18 also felt that she had lost some independence as she felt she could no longer stand up for herself as she used to. This patient suggested that she used to have a lot of confidence when confronting aggressors, however with the ICD she now felt she had changed and could no longer verbally stand up for herself : *"I'm used to being independent and I feel I've lost my independence, ... Right at the minute there's a conflict going on with this particular girl in the street. And before, do you know, I would not give two monkeys whatsoever, I'd stand there and fill her gob completely and that was me. You know if you say to someone [the someone would say] 'that was the old 'N18', she's changed. She was always the type of person to put up with no shit. And I'm going to say it how it is, cos it's the truth, 'no, shit, she can stand up for herself ... and now I can't ... I have never, ever, ever, I've never been like that where other people have had to fight my battles..." (87-109)[N18][Female non-shock patient].*

The reluctance that patient N18 felt to stand her ground as she previously had stemmed from the fear that she might trigger the ICD: "*... I'm afraid I'm going to set myself off ... I'm afraid I could have an attack or have a shock, it will get too much* *for me that way ... I'm too afraid to go that extra mile, to stand my ground like I used to" (100-103)[N18].* Mert et al. (2012) had found a similar type of behavioural response when they reported a patient had refrained from quarrels and had remained unresponsive because of the fear of provoking a shock.

Patients who had received a shock also experienced a loss of independence. Male shock patient S01 found it difficult to accept that he would have to take medication for the rest of his life and blamed this on his personality-type. He reported that he was a Type-A[40] personality and as such did not like being reliant on anything: *"I still have a problem taking the tablets, I don't mean in actually swallowing them but I-it's the old Type-A person again see, I don't like being reliant on anything really"* (348-350)[S01][Male shock patient]. Although taking tablets was not related to the ICD per se, this example suggested that for many patients, the ICD comes in a package with a life-long regime of medication.

Similarly, male shock patient S15 was aware that he had become dependent on a machine but he was able to accept this as he realised that the ICD was there to safeguard his life, so although he experience a loss of autonomy, it was not perceived negatively: *"In some respects, you realise you've come dependent on a machine,. So things aren't of a natural process – I suppose if the machine breaks down, you're in trouble [laughs] but the monitor system and backup system is there, so everything is in order to actually safeguard your life"* (496-500)[S15][Male shock patient].

However, although S15 could accept being reliant on a machine, he was not happy being reliant on his wife. He found his loss of independence and freedom to come and go as he pleased difficult to accept: *"the fact I can't drive at the moment, means I'm limited ... if I suddenly feel like ... feel like going to [town] and going to a shop or something, I can't do so, unless [wife] takes me. That is a big, big thing"* (285-291) [S15]. Not being able to drive has been reported by other studies, such as James et al. (2001) as a source of conflict between partners. Although James et al. (2001) found patients took out their frustrations of not being allowed to drive on their partners, S15 appreciated that the situation was difficult for his wife and he empathised with her: *"... It's very, very difficult for her ... she comes down to [name*

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[40] Type A personality is defined as hard driving, persistent, involved in work, orientated towards leadership and achievement and having a sense of time urgency (Caplan & Jones, 1975).

of city] and visits me when I'm in hospital and she absolutely hates driving, she loathes it ... of course she has to do all the driving now – I'm back on the driving business aren't I? No, but she hates driving and I hate being a passenger, so it's not a very good combination. .. in some respects it's probably harder for her than for me" (367-377)[S15].

Shock patient S23 also found losing her independence or autonomy difficult to cope with, however although she was allowed to drive, she chose not to. She appeared to have lost all her confidence in her abilities as she reported a big contrast between her past and current lifestyle: *"I was so very independent, you know. Cos my husband worked away, he was only home weekends anyway ... I'd be out and about, and I'd drive up to London where he was working you know ... then suddenly nothing"* (407-408)[S23]. Her loss of self-confidence might have made worse by her family's over protectiveness: *"I can't go anywhere on my own. 'You can't go, you can't go on your own'. I mean my daughter ... and my son ... they'll say 'where's 'husband'?' – He's their step-father, and they'll say 'where's husband then, what's he doing leaving you on your own?' So, you've lost your independence as well"* (261-266)[S23], which led to her feeling like an invalid: *"I'm not an invalid, but it makes me feel like that"* (271)[S23].

First Order Theme: Loss of Confidence

This theme only appeared relevant to patients who had experienced an ICD shock. The revelation of the shock's unpredictability might have contributed to feelings of loss experienced by female shock patient S23. For instance, the unpredictability of the shock has been reported by other studies to lead to feelings of losing control (e.g. Morken et al., 2009; Dickerson, 2002 and Eckert et al., 2002). Female patient S23 asked herself 'why did that go off now?', which appeared to be a common response from participants after a shock. Patients needed to know why their device had fired and if the shock was not accounted for, the participant experienced a loss in confidence. The participant's loss of confidence could equally be attributed to them being unable to find a reason as to why they had been shocked and therefore their loss might have been attributed to a loss of health, loss of control or loss of being able to take life for granted. For instance, male shock patient S01 believed his device had fired due to his increased heart rate during a sexual encounter and as a result he was not worried about the firing; he merely assumed it was because his heart rate had increased to the extent that it was above the ICDs safety threshold. Consequently, he did not experience any loss in confidence, but he had later reported that if he could not have attributed the shock to an increased heart rate, he would have been extremely worried.

A loss of confidence was probably the most important emotional response experienced by two patients who could not account for the shock. Male shock patient S15 reported: *"My confidence suddenly went down ... It was the fact that my heart had gone into this rhythm and I hadn't been doing anything out of the ordinary. If I'd been wielding a pick axe or something like that, then I'd had said 'right the exertion had-it was my own stupid fault, it caused the heart to go like it is. But I'd actually spent the day doing very little, sitting around ... doing a bit of cooking which I'd hardly call strenuous. So, I couldn't understand why the heart had gone into this rhythm. Certainly to me there was no outward sign as to why this should happen and that's the thing that unnerved me a lot."* (213-226)[S15][Male shock patient].

After a shock was experienced, one male shock patient voiced a loss of confidence and control over his life and a loss of his future self. This patient's experience of a shock had not only knocked his confidence, but it had altered how he envisaged his future: *"...You have an image of what's going to happen in the future, as vague as that might be and with mine it was obviously going to be quite active. And then you have that futuristic view changed. ... if your active future is changed to sitting around in an arm chair all day, it might sound alright but when the reality is there, it does hit you and I think that's what happens to me every so often especially if I've done nothing but reading ... I think that image is becoming more concrete"* (385-396)[S15][Male shock patient]. Similar to the findings in this study, Morken et al. (2009) found patients felt a loss of control after they had experienced a shock. Also similar to Morken et al. (2009) was the finding that a few weeks after the shock, patients slowly re-built their confidence. His image of an inactive future would possible become more entrenched if he were to receive another firing from his device; as Morken et al. (2009) found, after a patient has rebuilt their confidence post-shock, their confidence was once more shattered when another shock was received and each time, it took longer and longer for patients to rebuild their confidence.

First Order Theme: Anxiety and Fear of Shock

Being apprehensive of an ICD shock appears to be a very common theme in qualitative literature although sometimes it has been identified as a loss of control (e.g. Eckert & Jones, 2002). This finding is important as studies (e.g. Burg et al. 2004; Kop et al. 2004) found that psychological distress increased the risk of a shock. The apprehension of receiving a shock was a common emotion felt amongst patients in the present study, but this apprehension almost turned into fear for two female non-shock patients who were not adjusting well to the ICD and were fearful of their device. For one patient, the fear stemmed from the memory of being shocked in hospital by an external defibrillator and remembering the feeling of her ribs being crushed: *"... I get sort of moments when I'm frightened of it [ICD], ... it's not so much in the body as having the first shock"* (86-90)[N16][Female non-shock patient]. This fear did not only stem from when patients received shocks in hospital as a similar dread was also experienced by a female patient who had not experienced defibrillation. However, her terror stemmed from a fear of the unknown: *".... most of the time-when I'm occupied, I forget it. But when I sit down quietly thoughts go round my head-it's always at the back of my mind ... that I don't know what's going to happen, how it will affect me, will it hurt, will there be more than one ..."* (363-371)[N17][Female non-shock patient].

In this study, when male non-shock patients spoke of their worry about a shock, they tended to speak in terms of the anxiety surrounding the medical cause of the shock, whereas the worry from female patients tended to focus on pain, and the concern about whether the ICD would work. Although the patient has an ICD, often they are still fearful of whether or not it will 'work' when needed. Kamphuis et al. (2004) and McDonough (2009) used the term 'anxious' to describe patients who were fearful relying on a technological device – 'will it work?', 'how will the shock be experienced?' – therefore feeling vulnerable because of having to be dependent on technology to survive.

Another reason for fearing a shock was the way the shock appeared to be appraised. Unsurprisingly one male non-shock patient was very fearful of receiving a shock, not because of the pain or the inconvenience it would cause but because of he believed that a shock would mean that his heart condition was worsening: *"... what would it mean? Um, it's a bit, dicey really, things are getting a bit dicey really, if it's got to that level (shock) really. The medicines are not doing their work ... and things are getting worse"* (216-219)[N11]. The present study found that having an in-depth understanding about the biology of the heart increased the feeling of vulnerability for patient N11. For instance *"I also didn't like the idea when I asked them ... the ca-wires go into the heart, how do they get to the ventricles, well they fit through the valves, well valves open and close so I know a bit about the heart .. a bit of science, I'm a science teacher so I found this a bit alarming, this wire going through the heart, from the top part to the lower part through the valves"* (126-136) [N11][Male non-shock patient]. This male participant's comment highlights how being informed can lead to increased fear.

The shock episodes experienced by the ICD patients who had received a shock varied greatly from patient to patient, therefore accordingly no one experience was relevant to all patients. None of the patients in the current research study had experienced multiple shocks[41]; however, male shock patient S05 experienced two shocks in short succession, which left him feeling very apprehensive: *"Two shocks ... I was trying to find somewhere to sit down and relax and of course the car was the obvious place ... and on the way to the car it hit me again .... I think for the week or two after that I was very apprehensive of it happening again"* (60-78) [S05][Male shock patient]. The finding that S05 felt nervous for a few days after experiencing a shock was also found by Kamphuis et al. (2004) who had reported patients felt uneasy for a few days after experiencing a shock because of the fear that their device might fire again.

Interestingly, although the ICD was implanted in the chest wall (see Figure 1.7), and the heart muscle received the electric shock, female shock patient described the shock as being like a blow to the head: *"... I thought I'd lose consciousness just before it [shock] went off or something you know, but it worked ... And it just felt like I'd been hit on the head with a hammer, literally. And I felt scared"* (186-189) [S23][Female shock patient]. Steinke et al. (2005) and Morken et al. (2009) also

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[41] Multiple shocks (shock storm) are frequent shocks experienced within a short period of time.

found patients described the shock as being like a blow to the head, for example "top of your head blown off" (Steinke et al., 2005) and "something hard on head" (Morken et al., 2009). However, for the majority of patients in the current study, the shock of the device was mainly felt in the chest with an intensity that was unexpected: *"I don't know how to describe it, it was more like being hit by a bus. Somebody said it would be like being hit in the back with a golf-club, but it was more than that, oh yeah, it was a wallop ... "* (242-145) [S01][Male shock patient]. And *"it was a much stronger impact than I expected. I thought it would have been far more concentrated here [points to heart], but in fact it went through me"* (260-262) [S05][Male shock patient].

For some patients, their apprehension and dread was possibly due to the distressing physical symptoms that signalled a prelude to shock. For instance, male shock patient S15 found the time leading up to the shock was worse than the shock itself: *"The horrible feeling just before the shock, shortly after it had happened, ... I would dread more than the actual shock itself.... Cos it was a grotesque feeling, the whole body seemed to go [shivers] ... I can't really describe it ... But it's just this horrible feeling before the actual shock itself.... I didn't like the feeling [of shock] but it's only seconds"* (239-248) [S15][Male shock patient]. This was a similar finding to Mert et al. (2012), who found some patients experienced a forewarning to an impending shock and who reported feeling hot, faint and nauseous prior to the shock.

This feeling of apprehension after experiencing a shock might have been because of the experience of shock or it might have been due to its perceived meaning. For example, female patient S23 believed that when she had a shock, it was because her heart had stopped: *"But when it [shock] happened .... And I felt scared ... I just felt stunned but then I thought it got to be my defib-defibrillator. And then I felt frightened that something else was going to happen. 'Why did that go off now?' 'Did my heart stop?'* (186-198)[S23][Female shock patient]. McDonough (2009) also found a simultaneous feeling of anxiety and fear during a shock firing. Other studies found that a shock was a reminder of illness and death (e.g. Morken et al., 2009 and Palacios-Ceña et al., 2011).

The shock experience made patients aware of its unpredictability as, for the majority of the patients, the shock had come most unexpectedly with surprising magnitude of power, for instance S05's assertion "it was a much stronger impact than I expected" (see S05's comment above). Female patient S23's experience of shock had reinforced its velocity, which made her apprehensive about driving: *"... I got this fear, cos it [shock] comes so sudden. How will I manage if I'm driving and then it goes off. You've only got like a 20-second warning or something.... You just feel extremely dizzy, you know that was me and you can feel it revving up in your shoulder and then bang – you know it felt like somebody had hit you with a hammer. How would I cope with driving. I've driven for a number of years ... driven lots of places but I just don't feel confident enough"* (167-175)[S23][Female shock patient].

First Order Theme: Pessimism

Patients who were not coping with their ICD expressed emotions of pessimism and negativity towards their ICD. Kamphuis et al. (2004) suggested that patients who have no complications during the first 6-months of their implant should report a decline in low mood by one-year. Nevertheless, at approximately 1-year some patients, who had not reported any complications with their device, still reported feeling low and two non-shock patients cried during the interview. Furthermore, one patient who had experienced complications after the implant (a displaced lead that resulted in further surgical procedure), reported a positive, high mood.

It appeared that patients who appraised their general situation negatively tended to show pessimism towards the ICD. Pessimism for female patient N17 was most likely a personality trait as she admitted she was a worrier by nature, and rather than consider the ICD as lifesaving as some patients had, she tended to focus on the fact that there was something wrong with her heart: *"... I suppose you're glad you've got it but then you think your heart can't be in a great state as you've got one, which obviously suggests that things will go wrong or can go wrong. It's going to be pretty serious. Well an optimist would say 'well I've got this now so I'll be fine', you know. And I think, I've got it because something's wrong – I'd rather not have it." (244-249)[N17][Female non-shock patient].*

Another patient's negativity appeared to stem from the negative impact the ICD had had so far on his life. This was the patient whose self-esteem was measured in terms of his achievements at work. The loss of employment, and feeling of shame because he had an ICD, might have contributed to this patient's depression. His feelings of depression were likely compounded further by the fact he was concealing his feelings from his partner in order to protect her. However, as Tagney (2003) suggested, patients who concealed feelings from their partners and reduced communication experienced increased pessimism.

Pessimism appeared to incorporate shame, and some patients felt they were a burden to their partner: *"I haven't been like this... it's just talking about it to you. ... It's all (begins to cry again) all my emotions, I keep to myself 'cos Meg's at work ... I'll be sitting in the garden, you think of things... Life ... I tend to keep things like this to myself... I don't want to worry my mother really, I don't want to worry Meg ... maybe I should have gone to ... it was in the booklet, you can go to a sort of club where other people have had it. I don't know ... like Alcoholics Anonymous, Defibrillators Anonymous" (470-495)[N14][Male non-shock patient].* The opportunity to talk and express feelings during the interview appeared cathartic for patients. It could be that feeling depressed led to reduced communication and unintentional concealment, but issue of concealment emerged as a possible predictor for depression and pessimism about the ICD.

Tagney et al. (2003) suggested that patients intentionally concealed shocks from partners to prevent the partner worrying. However, the present study found non-shock patients also concealed feelings from partners, although it cannot be determined if it was intentional or not but it did appear to result in the patient feeling increased isolation and desperation: *"... it's just talking about it to you... it's all (begins to cry again) all my emotions, I keep to myself 'cos Meg's at work ... I'll be sitting in the garden, you think of things... Life ... I tend to keep things like this to myself... "* (471-492)[N14][Male non-shock patient]. This emotion-focussed coping strategy of rumination was clearly not a helpful coping strategy: *"I don't want to sound like a Jonah, some days I can ... thinking 'what do you do? Got this (ICD), out of work' (cries)* (443-445) [N14][Male non-shock patient]. Feeling alone with the diagnosis and emotionally distant from partners through a breakdown of communication was also a recurrent theme found in other studies (e.g. Williams et al., 2007; Fridlund et al., 2000; Palacios-Ceña et al., 2011).

Female non-shock patient N16 had been defibrillated several times whilst she had been in hospital and was fearful of receiving a shock from her ICD. She was also depressed and pessimistic about life with an ICD. She described herself as a burden on her husband: *"And I've put a lot of stress through my husband, the children. My daughter, she phones everyday 'you all right mam? How you feeling today?' And if I say 'I'm not feeling too good today, she'll be back on the phone ... and I think oh, just leave me alone. ... But I've said to (husband) as well, 'I'll just go, live somewhere else' I feel like I'm a burden to him"* (341-347)[N16][Female non-shock patient].

Flemme (2011) reported that patients felt a burden when partners and families were overprotective. In the present study, the partner of female N16 had encouraged her to remain independent by making her travel to the shops every day to pick up essential shopping items such as bread, milk etc however, she still felt a burden. Her pessimism might have stemmed from her poor memory that had been severely affected by her multiple cardiac arrests. The patient explained how her poor memory was a major hindrance to her recovery and a constant source of frustration to her and her family: *"I'm completely frustrated when I can't remember ... I know it's frustrating for my husband, and you know my children.... But it's frustrating, before the hysterectomy they kept telling me everything was fine and there was nothing wrong. But something must have been wrong for that to happen [how does that make you feel?] Frustrated, angry"* (381-409)[N16][Female non-shock patient]. Kamphuis et al. (2004) suggested that a deterioration of cognitive abilities often led to irritation and anger. Whereas this patient alleged she did not act out her rage to others, she did vent her frustration and anger during the interview. She might have been unable to express feelings of fury, as she believed people expected her to be grateful for the ICD. Perhaps the conflicting emotions she felt only served to add to her frustrations.

It was evident that memory loss played a major limitation in some patient's lives. For example, activities involving social interaction requires thinking and concentration and if these are compromised, social interaction is hindered, which may have contributed to some patients feeling frustrated.

First Order Theme: Doubt and Regret having the ICD

Dickerson (2002) suggested that some patients felt they had no control over their lives, which also included the initial decision to have the implant. Furthermore, Dickerson (2002) and Palacios-Ceña et al.'s (2007) found that some of their participants believed there was no choice about whether or not to have the ICD. Both Palacios-Ceña et al (2007) and Dickerson (2000) suggested that there was often a dichotomy presented to patients 'do you want to live or die?' – In other words, if patients want to live, they should opt for the ICD. However, it might be that only once the device is implanted, that patients become aware of their limitations.

Notably, however, doubt and regret were only found in non-shock patients. In the present study, two patients (N10 and N14) who were struggling to come to terms with the ICD believed they did not have a choice about whether to receive the device and voiced that in hindsight they wished they had chosen not to have it. However, as patients in this study had experienced the same pre-ICD counselling as they were under the same health care system it could be suggested that N10 and N14 coped by blaming the doctor for their decision to accept the device, which was not a helpful strategy as it clearly did not appear to be helping them accept the ICD.

Dickerson (2002) suggested doctors tended to perceive death as a symptom to be treated. Palacios-Ceña et al. (2011) concurred with this and posited that the patient might sometimes be prepared to accept the risk of sudden death but a doctor was never prepared to accept this. The issue of accepting or rejecting the ICD as a treatment option has clinical implications for the counselling of pre-implant patients. Whereas from a medical perspective, there appears to be an assumption that most patients want an ICD as it can treat sudden cardiac death findings from this study and those of Palacios-Ceña et al. (2011) suggest this assumption is not necessarily true and some patients may benefit from a more thorough decision making process.

First Order Theme: Frustration at Others and Self

Two patients who were both male and both shock patients voiced much frustration. One patient voiced frustration with himself and his loss of fitness, whilst another patient voiced his frustration towards the concern shown to him by others. Patient

S05 had expected his level of physical fitness to be the same as it was before his cardiac event, and due to his loss in fitness, he found himself getting very frustrated with himself. Rather than try to build up his stamina slowly, he appeared to expect his fitness to have returned to normal and was perplexed that it had not: *"I find it frustrating. cos there I was in April playing rugby, full 40 minutes each way, full contact, running about and then bang, in June this happened and ever since, I struggle to run. I can run but not very far and not very fast, whereas before I used to enjoy running, I used to enjoy extending myself. I find it frustrating now. I can't experience that cos it's a struggle to run, so for whatever reason, I can't do it"* (117-123) [S05][Male shock patient].

Patient S15 highlighted the importance of allowing patients to retain as much independence as possible as imposed sanctions could lead to patients feeling frustrated : *"... the most difficult thing in actual fact, was people telling me to take it easy, including my wife. And everybody out of the best concern 'oh take it easy, don't do this and don't do that and sit down' ... that was frustrating, very frustrating, and just went against the grain, cos ... I just like being active"* (113-233) [S15][Male shock patient].

First Order Theme: Feeling Mortal

One of the shock patients had found the cardiac event (and presumably the ICD, although not specified) had increased his feeling of mortality. His raised awareness of his mortality led him to try to derive some benefit from the situation and he begun to reassess his life. Before the ICD, male shock patient tended to only focus on the future, but this changed after the implant. After the ICD, he was determined to enjoy the following ten years: *"How I view life? I've been more aware.... I have always worked for the future ... so with things as difficult as they have been in the past couple of years, I think I have become more aware of my age, not because of anything medical but 'lucky to get over that one' .... 'Come on, you're 66, let's do something positive over the next 10 years"* (601-609) [S01][Male shock patient]. Flemme et al. (2011) also found that patients became more reflective after a cardiac experience and began to re-evaluate goals. Williams et al. (2007) also found the increased feeling of mortality changed how patients viewed their lives; they found one patient began to take risks (although details of the risk were not specified) because they were determined to enjoy life in the here and now rather than worry about the future.

Another two shock patients also found their ICD had made them aware of their mortality, and rather than use that knowledge to capitalise on the present, both patients felt the ICD was a marker that their end was near. Male patient S15 found that his increased feeling of mortality made him grieve for his past life. By this he was able to come to terms with his present one. Similarly, female patient S23 felt the ICD was there as a standby, and that death was near: *".... I think a lot about dying, which I've never thought about before. I'm not scared to die because I believe in an afterlife and all that so I'm not scared. But it makes me think a lot about it like ... I can't get over the fact that this [ICD] is just there as a standby, it's like a marker to say 'right, you're nearing the end of your time"* (271-280)[S23][Female shock patient].

GENERAL DIMENSION: COPING WITH THE ICD

Second Order Theme: Problem Focussed Coping

Lazarus and Folkman (1984) suggested that problem-focussed coping strategies were more likely to be used when situations were appraised as being amenable to change. They suggested that problem-focussed coping included an objective, analytic process that was focussed primarily on the environment or included strategies that were directed inwards. Examples of strategies that focus on changing the environment or stressor include limiting activity and protective behaviours. In this study, patients employed a variety of strategies to help them cope with living with their ICD.

In the present study, it appeared that patients who were finding it difficult to cope with their ICD as well as patients who accepted their ICD and were 'getting on with life' often employed a problem-focussed approach. 'Getting on with it' or 'getting on with life' or 'incorporating uncertainty into life' was a notion often used by patients in this study. This notion commonly found in other qualitative literature albeit as a theme demonstrating a patient's acceptance of the device (e.g. Dickerson, 2002; Williams et al., 2007; McDonough, 2009; Flemme et al., 2011).

First Order: Limiting Activity

Some patients coped with their ICD by restricting or becoming more cautious in their physical and day-to-day activities. This study found two main reasons for why patients limited their behaviour. One was to avoid receiving a shock and the other was to avoid being alone in case they had a shock. Restricting behaviour in order to avoid the a shock was also a recurrent theme found in other studies (e.g. Flemme et al., 2011; Fridlund et al., 2011; Eckert & Jones, 2001; Palacios-Ceña et al., 2011); Steinke, Gill-Hopple, Valdez, & Wooster, 2005).

In this study, male patient N11 and female patients N17 and N19 had become more cautious when exercising or exerting themselves and consciously reduced activity when they felt their heart rate was beating fast. For example, N19: *"... two weeks ago I was going every day, just doing 30 minutes cardio a day and that was working up a sweat that was.... I know when I get the feeling enough is enough. And I don't push it too much, ... I can feel it in myself.... My heart beats fast, and then it can go like 'shaky' and that's when I stop ... I built it up slowly ... I just wanted to do something about my weight and feel better about myself"* (135-156)[N19][Female non-shock patient]. N19 gradually increased her exercise regime to maintain heart health and to feel better about herself. However, she was cautious about pushing her body too far at any one time.

Both N11 and N19 were also anxious when their heart rate was raised and similarly they both adopted problem-focussed coping strategies to deal with their anxieties. However, the underlying rationale for using restricting activity differed; whereas N19 wanted to increase heart health, N11 was fearful of provoking a shock. Male patient N11's belief that a shock would mean his heart condition was getting worse influenced his fear of receiving a shock: *"... I walk fast and sometimes if I'm late for something I'll run a bit... sometimes I'll go by train and sometimes if I leave the house a bit late, I'll run .. and sometimes I think 'I shouldn't be doing this', so I'm definitely watching my excesses .."* (303-307)[N11][Male non-shock patient] and similarly with female patient N17: *"... when I'm doing something strenuous, I keep telling myself 'you must pace yourself'. Cos if it starts-if it starts going too fast too quickly, there could be a problem, so you must pace yourself... If I feel a drag on my arm, my heart going a bit faster, then I think about it. If I walk too fast, which I tend to do, I have to tell myself to slow down. It's a conscious effort to do it"* (407-473)[N17][Female non-shock patient].

Male patient N14 who was also struggling to cope with his ICD limited his activity because of the fear that he may over exert himself and become too weak to call for help. Most of all, he feared being alone when experiencing a shock. N14 adopted a problem-focussed approach to cope with his feelings of fear and he made sure that he did not take long walks in solitary places. Although these seem sensible changes, when exploring his rationale behind the changes, it can be seen that N14 had catastrophised that he might be lost for days if he had a shock, which was highly unlikely given that he lived with his partner: *"... Other times you think about it (shock) more, whereas before I'd think nothing of walking ... especially at the weekend ... I love walking, I love nature, I'd walk miles.. I wouldn't do it now... as I explained to you, I did walk sort of back to my normal walking area but I felt absolutely knackered, sat down and thought 'oh God, how am I going to get back', there's no one in the woods ... if something did happen and that's why I take the phone .. I might not get found for a couple of days to tell you the truth, I am-I am not the same fit person I was ..." (697-710)[N14][Male non-shock patient].*

Therefore, although patient N14's caution could be considered sensible, the rationale behind the behaviour suggested that he was felt highly anxious and had catastrophised potential scenarios. However, catastrophising appears to be a cognitive coping style for this particular patient when faced with anxiety, which in turn led to a physiological response in his body: *"...before I had the defibrillator, there were times I had to sit in the car and take deep breaths but maybe it's to do with my condition .. I don't know. I was it (breathlessness) before but with this (ICD) it's a lot worse"* (597-600)[N14][Male non-shock patient]. It might be that he was experiencing symptoms of increased breathlessness, but it could also be that his breathlessness was due to his appraisal that the ICD was the cause of his symptoms. Despite patient N14's use of a problem-focussed strategy, his underlying emotions of fear and anxiety continued to remain high suggesting that employing only a problem focussed type strategy alone was not effective for all situations.

First Order Theme: Protective Behaviours

Another problem-focussed strategy adopted by patients was employing self-protective behaviours. A particular protective behaviour patients used was regularly checking their pulse rate. One patient who was particularly anxious about his arrhythmia constantly checked his heart rate when he engaged in exercise. This patient began to monitor his pulse rate to ensure it did not reach the threshold above which the ICD would fire: *"I do swimming, I measure my pulse now, which I never used to do ... say after 20 lengths"* (258-259)[N11][Male non-shock patient]. Flemme et al. (2011) reported an almost identical scenario as well as Fridlund et al. (2000). They found patients were unsure of how much activity could be carried out safely and often wore a pulse watch as a protective measure. These findings suggest that patients want to monitor their heart rate to ensure it does not exceed the defibrillator threshold rate, after which it is likely they would receive a shock.

First Order Theme: Re-assessing Role Identities

Male shock patient S15 and female shock patient S23 clearly showed that they had used the problem-focussed coping strategy of re-assessing roles within the home, including cleaning the home and driving in order to adjust to the ICD: *"We've swapped roles. I always did everything, you know he didn't even know how to switch on the washing machine ... I do what I can but I can't mop the floor or ... it makes me very tired to do stuff like that. So, he does a lot of cleaning and he learned to cook more. So it's sort of-we've split the role, if I can't do it, he'll do it. .... So the dynamics of the family have changed-he's looking after me more whereas I'd always looked after him ... he's very good 'you've always looked after me, it's my turn to look after you'* " (683-694)[S23]. However, patient S15 elaborated on how difficult and stressful it was for his wife, who had to drive despite hating driving and for himself, who presumably up to this point had always driven: "*... it's very, very difficult for her ... she absolutely hates driving. She loathes it ... and of course she* *has to do all the driving now ... she hates the driving and hate being a passenger so it's not a very good combination"* (367-375)[S15] [Male shock patient]. Therefore, although Hallas et al. (2010) posited that problem solving coping styles were positive, they might achieve a desired result, for example, getting from A to B in a car, but as coping strategies, they did not always alleviate stress.

Male shock patients S05 and S15 employed the problem-focussed coping strategy of taking precautions after their shock experience. Male patient S05 started to wear a safety harness when up a ladder after he had been astonished by the power of the shock: *"That morning [of shock] I was on a double extension ladder, fully extended, right to the top. And I was doing some work on a fascia board and if I'd had know the shock was a severe as it was, I wouldn't have been up there. It would have thrown me off easily. [Have you been up since?] I have but not so high and with a safety thing on and all sorts of other precautions"* (244-252)[S05][Male shock patient].

After his shock, male patient S15 began to carry a mobile phone when he went on a walk – however, he admitted that it was difficult to get a mobile signal in his area so the phone if needed would most likely be redundant. This suggested that although carrying a phone was clearly a problem-focussed strategy, it was likely that he carried the phone for emotional comfort and to keep his wife from worrying: *"I'm ok going for a walk, I'm building up now. I take a mobile phone with me, which is this area is probably more than useless really cos can't get the signals, so not really the best of things, but at least I got it there"* (296-299)[S15][Male shock patient].

Second Order Theme: Emotion-Focussed Coping

According to Lazarus and Folkman (1984), emotion-focussed coping strategies were more likely to be used when there it was appraised that nothing could be done to modify harmful, threatening, or challenging environmental conditions. This form of coping can take place as avoidant/restrictive behaviour, avoiding information, denial and distraction, blaming and venting, maintaining self-esteem, social comparison and acceptance.

First Order Theme: Avoidant/Restrictive Behaviour

Patients in this study who reported avoidant behaviours were generally those who were not coping well with their ICD, which immediately suggested that this coping strategy was not effective in relieving their anxieties. Avoidant behaviours might have been adopted with the aim that the behaviours would keep the patients safe: *"[it's stopped me from going abroad] in case something happens. Will there be people around who can help, will there be a specialist hospital somewhere, will there be someone there to, you know do something about it. Would I be on an aeroplane, you know 1000s of feet above the Atlantic ..." (385-388)[N17][Female non-shock patient].* Although the patient felt safer not travelling abroad, her fears about travel were unfounded and would remain unchallenged unless she flew on a plane. However, some types of avoidant behaviour were adopted for safety reasons, and could be considered appropriate precautions: "*... I used to do up other houses; you know I wasn't afraid of working... I'd be very reluctant to lift up a concrete lintel which I probably would have done on my own before ... or a boiler hanging on a wall, I wouldn't do that now"* (374-377)[N14][Male non-shock patient].

Avoiding sex was another avoidant behaviour, and this appeared to be a common issue for couples in this study as well as being a common finding in qualitative literature (e.g. Steinke, 2005; Tagney et al. 2003). Avoiding sex seemed more common during the early weeks post-discharge but for some couples the change in intensity and duration of their sexual activity remained reduced: *"I think we've got a good relationship as a couple ... don't have sex often ... both a bit wary, bit worried ... to tell you the truth .... If anything could happen I suppose (are you thinking of shock?) .. I do, but I don't mention it to Meg 'cos I don't want to worry ... but I do think about it (shock)* (263-278)[N14][Male non-shock patient].

Avoiding or restricting sexual activity appeared to be a common behavioural response to the fear of provoking a shock; however, this avoidance often resulted in patients feeling isolated and emotional distant from their partner at a time when patients perhaps needed more comfort and support. A good example of this in the present study was male patient N14 who felt emotionally distant from his partner but believed his relationship with his partner was good despite a reduction in sexual frequency and sexual intimacy since his ICD. His feeling of isolation and emotional distancing was further intensified when his partner moved into a separate bedroom. Palacios-Ceña et al.'s (2011) study also found evidence of emotional distancing due to a reduction in sexual intimacy and found patients reduced the frequency and intensity of having sex with their partner. However, similar to male patient N14, their avoidance of sexual intimacy resulted in their patients feeling emotionally distant to their partners.

Female patient N16 needed the physical intimacy of sex to prove to her that she was still desirable to her husband. Her partner's reluctance to engage in sexual intercourse through fear of triggering a shock, contributed to her feelings of depression and despondency with the ICD, despite the fact she understood his fear: *"... I think since I've had the ICD, he's very frightened ... my sex drive has gone higher ... but I think he's frightened that if he gets to intimate,... I just feel that he's-perhaps he's gone off me .... Once we talked and I said how I feel ... it's like 'I know you're there but I can't do the physical-since the ICD ... and it's 'what's the matter, you don't want me?' And he said I still love you and I do want you, but it's just times I'm frightened ... the shock, I think that's what he's frightened of. We have had intercourse since I had it fitted but it's not on a regular basis ... I think it's just me being paranoid"* (708-736)[N16][Female non-shock patient].

It was clear that avoidant coping, especially behavioural avoidant coping could negatively influence patient's quality of life. For shock patients, it was also clear that behavioural avoidance was maladaptive. For instance, female patient S23 had used to go out at weekends but since the ICD had avoided making these trips. She had used the explanation that her arrhythmia and her weight made her feel breathless and caused her to feel embarrassed. However, by staying indoors and not venturing out, it could be suggested that any weight issues that S23 has could be exacerbated by inactivity, thus this strategy had compounded her problem: *"We used to go out every weekend and we stopped doing that .... [why?] Well I had a problem with arrhythmia as well, about walking very far .. breathless ... Sometimes climbing the stairs is difficult cos I've put on weight. And my heartbeat was racing on and off. It was very unstable ... so it was like too much effort. And they I'd start worrying about would I be breathless, would I feel embarrassed you know"* (435-446) [S23][Female shock patient].

Male patient S01, had avoided going back into work, which had worried him, as he believed his self-reported Type A personality did not fit with avoidance behaviour. Therefore, although he was able to avoid stress, which he had attributed as being the cause of his illness, psychologically he remained worried: *"... Stress undoubtedly had affected me, and my son is having to shoulder it [family business] all now, which is still a stress. .... I haven't been in for 6-months now and I don't want to, which is a worry in itself because I've always been a Type-A person, get up and go for it"* (215-220) [S01][Male shock patient].

One shock patient reported that he had begun to engage in protective and cautious behaviour when swimming. Although some days he would push himself to swim a number of lengths, on other days he would not. The patient inferred that he was being careful and 'sensible', and it was as though he was congratulating himself on allowing himself to rest when as the Type-A personality he reported being, he would have a tendency to push himself. However, although S01 inferred it was caution driving his behaviour, it remained unknown whether this patient was really displaying avoidant behaviour: *"I don't think I've changed at all ... I love my golf, go down the driving range. ... I'm aware sometimes, I've been digging in the garden and all the rest of it 'I think I'll stop now'. ... I went swimming this morning ... I do a length, 25-metres without breathing. And .. some days that's easy and I'll do eight or 10 spaced out .... other days 'no, don't like it this morning'* (317-325)[S01][Male shock patient].

One important finding from the qualitative literature was that patients attempted to regain some control over the unpredictability of shocks, by avoiding and restricting activities that patients felt might be related to device firings. However, only two participants in the current study were found to use behavioural avoidant coping in order to cope with the ICD shock experience. For male patient S15, his reluctance to engage in golf was related to his loss of confidence after experiencing a shock. Although he had been a physically active man, and had regained some level of fitness after his ICD implant, the loss of confidence he had experienced after his shock had been so profound that he began to withdraw from activities: *"As I say, golf, I haven't played golf since this went off ...certainly initially it was the confidence thing. There are days when I can feel 'I don't fancy playing golf today anyway. I just don't feel up to doing things. .. the thing is, it could well be a kind of* *avoidance but it's bordering on the laziness 'oh I can't be bothered'. It's almost like a sort of depression, you know when you're depressed you just feel like doing nothing and it's that's kind of feeling in many ways"* (300-325)[S15][Male shock patient].

Immediately after his shock, male patient S15 stopped playing golf due to a loss in confidence but it might that from his avoidance of golf, which he professed to love, that the depression set in. It might also be that from feeling depressed, he began to avoid playing golf but his comments about a charity trip suggested that his depression probably followed his avoidant behaviour, as he was clearly worried about the shock: *"... We have a charity we support in Africa and over the last few years, we've been going ... to help with this charity.... We weren't going to cancel this until this went off and it's because this went off, we thought we'd not go ... we're not going ... where we go is a little island. By the time you get off that island, cross the water, get a vehicle the other side to take you to the nearest hospital- it's not much of a hospital, you wouldn't want to go there. You wouldn't even want to go to the toilet there let alone be a patient there ... the quickest is an hour and a quarter to get there ... Even after the ICD was put in, we still had it in mind to go there. It was after the shock, that we said no, can't go there, run this risk, not this time round"* (515-534)[S15][Male shock patient].

Clear evidence of avoidant behaviour came from male patient S01, who had experienced a shock during having sex with his wife. It was likely that this patient's acceptance of the shock (see Emotion-Focussed Coping below) was because he believed he knew the cause of the shock. Afterwards, he associated a shock with having sex and as a consequence was reluctant to have sex again and offered reasons as to why at his age, sex was no longer important. He used an analogy of sex being like drinking until being over the limit, thereby suggesting that his refrain from sex was logical. However, his analogy with alcohol might have been a form of denial, as he perhaps did not want to admit to himself that he was simply afraid: *"Yes probably. [when asked if the shock would stop him from having sexual intercourse again]. But because we're both 66 now, I don't think things are as important as they used to be. ... there are lots of other ways of showing affection than ... having to .. complete the event ... I mean it was definitely that, there's absolutely no doubt, it was definitely that [sex] that caused it. ... I think it would be very difficult to put that out* *of one's mind ... I mean if you knew one more drink would put you over the limit, you wouldn't have that drink, whatever the reason was"* (265-387) [S01][Male shock patient]. Kamphuis et al. (2004) who found there was uncertainty surrounding physical activity and future shocks reported similar instances of avoidant behaviour.

First Order Theme: Cognitive avoidance

Patients who appeared to be generally anxious about their health and their device restricted what they read about the ICD, or made sure they only listened to information that they could cope with, which Williams et al. (2007) also found in their study. By limiting what they read about the device allowed patients in the present study to avoid discordant information, however this study found, restricting or avoiding information did not always help relieve a patient from distress, which supports the notion that avoidance might be helpful short term but is not adaptive long term.

According to the monitor/blunting paradigm (Miller, Brody & Summerton, 1988), individuals have two alternative strategies for coping with an aversive event such as an arrhythmia or defibrillated shock), which are seeking information or avoiding information. The monitor/blunting paradigm conceptualised monitoring and blunting into coping dimensions or styles, suggesting individuals fall into the category of 'monitors' (seekers of information) or 'blunters' (avoiders of information) (Miller, et al., 1988). However, as it is a dimension or coping style, individuals are not usually dichotomised but fall somewhere along a continuum of monitoring behaviour (seeking information) or blunting behaviour (avoiding information). Unlike Lazarus's coping traits that implies an intraindividual stability of coping behaviour across a variety of stressful encounters, a coping style is a relatively stable individual approach to coping with stress defined as a repertoire of strategies available to cope with stressful encounters, specific to an individual (Heszen-Niejodek, 1997).

Previous research (e.g. Miller & Mangan, 1983; Ludwick-Rosenthal & Neufeld, 1993) found support that an individual's preferred coping style (i.e. blunting or monitoring) interacts with the level of information given, which in turn impacts on an individual's level of stress. Accordingly, information can have a stress-inducing affect when an individual has a monitoring style coupled with information being withheld or a blunting style coupled with too much information given. Similarly, a stress-reducing effect can be achieved when an individual with a monitoring style has been adequately informed or when 'blunters' are able to avoid information.

The present study found non-shock and shock patients who avoided or restricted their access to information about the ICD in an attempt to help manage their feelings about the ICD and could therefore be categorised as being blunters. One of the patients who used this coping strategy appeared to be coping well with her ICD, however the four others appeared fearful, uncertain, and in denial of their need for the device by restricting or avoiding device-related literature, which suggests that avoiding information was not their natural coping style. For example: *"Did I read it? (ICD literature) No. I'm terrible sometimes... Yes, of course I've read bits... I read before about the machine, I wanted to know what it did and I did all that, but I don't retain things... because I'm not interested" (336-339)[N04][Male non-shock patient].* The fact that this participant had previously said he had undergone a privately funded heart-bypass, rather than wait on an NHS waiting list, suggested that his explanation that he was 'not interested' was possibly not true and instead it could be proposed that he was in denial about needing the device.

Male patient N11 also restricted what he read about the device: *"I had a booklet, I did look in the booklet, and it did answer questions. But at the time 'I just want to get through this', I didn't really want to know too much really ... I didn't want to read about it a lot, I wanted to know the basic idea but I didn't want to label myself as something awful... I tried to shake it off in a way I suppose. That's what I tried to do"* (178-183) [N11][Male non-shock patient]. By restricting, what he read patient N11 was able to understand the basic concept of the ICD, whilst remaining distanced from what he was reading. However, this patient remained highly anxious, albeit coping well on a day-to-day basis with the ICD. Restricting what he allowed himself to read was not helping him fully adapt to his ICD, as he was not able to challenge fears about the device, which were often catastrophic and irrational: *"... I'm a little concerned that it might-I might precipitate this shock thing, which I don't want really to happen ... that's what would worry me, if I had this shock thing, other than when it was induced in a test .... [what would a shock mean to you?] ... it's a bit ... dicey really .... things are getting dicey really, if it's got to that level. .. the medicines are* *not doing their work ... and things are getting worse"* (209-219)[N11][Male non-shock patient]. If he had allowed himself to learn about the ICD he might have been able to challenge these beliefs, and he might have found comfort in knowing that his fears were unfounded.

It could be suggested that female patient N19 demonstrated a coping style of blunting as this type of avoidant coping appeared to be adaptive for her. She appeared to be coping well with the ICD and reported no device-related anxieties. However, she relied on her husband to become informed and to take on the responsibility for her safekeeping, something that he reported to find frustrating (see 'Frustration and Anger with the patient'). By relying on her husband to understand the ICD meant she was able to remain ignorant: *"Cos it doesn't affect me see? Day by day I just-I do go days without even thinking about it. ... I think I'm ignorant in a lot of ways, I think I should pay more attention but I just ...if (husband) wasn't there then I would have to think about it myself ... if I was on my own and I didn't have my husband. ... he'd ring the hospital and he'd want to know the ins and outs of everything, he did. So, I think if it wasn't for him, I'd be scared and I'd want to know a bit more but ... left-I put it all on him, I have"* (183-262)[N19][Female non-shock patient].

The admission that if it were not for her husband looking after her she would be forced to confront her condition, suggested that her tendency to avoid dissonant information was an adopted coping style rather than a trait. Although patient N19 was reluctant to be informed about the ICD, she had the knowledge that her husband was informed and knowledgeable; it also appeared that he had a trait coping style of monitoring (see 'Becoming Informed'). Therefore, she might have known from experience that her husband would search for any relevant information so she could remain ignorant. The suggestion that she realised that she has put this responsibility onto him however suggested that she might have felt some cognitive dissonance.

This might infer that deferring responsibility to the partner might be adaptive as a short-term coping strategy. It also infers that it is not adaptive long term as an adopted coping style, as it might lead to cognitive dissonance. However, as blunting appears to be coping style, patients have to weigh up whether the confronting their condition and taking responsibility for their welfare is worth feeling less cognitive dissonance. Avoiding information appeared adaptive for male patient S13, whose preferred coping style was to remain ignorant: [When asked if he had read the booklet on ICD] *"quite a bit of it, the wife probably read more than I did. I'll be honest, I didn't really want to know what was going on, I got to be truthful to you"* (415-416) [S13][Male shock patient].

First Order Theme: Denial, Distraction & Cognitive Disengagement

Male patient N10 was finding it very difficult to accept his ICD and expressed ambivalence about his need for an ICD: *"All of them had attacks or something like that like, so it was like a preventative measure (for me) like ... that brings me back to a sledgehammer to crack a peanut .. I just struggle with it.... It's just there, I don't see the purpose of it really .... from a medical point of view, I can see like, but from a personal point of view, an emotional point of view, and a physical point of view, I'm really struggling with it"* (71-108)[N10][Male non-shock patient]. Burke's (1996) suggestion that some patients need to experience a shock in order to resolve ambivalence and antipathy towards the ICD, was substantiated by N10: *"... my sister in-law said it might save your life. ...I know what they're trying to say ... just don't feel it probably won't be used ... maybe I'd feel different if I had an attack and it was used"* (166-173)[N10][Male non-shock patient].

Some patients explained that they believed they did not need the ICD but they had reconciled themselves to having the device by believing they were having it for the family's sake. For example, male patient N04 explained he had consented to have the device for the sake of his family. Patient N04 said: *"I'm not a worrier ... Probably my faith ... and that's why I said I probably wouldn't have had it done – I had it done cos of the family really ... more than me ... It's alright I don't even think about it to be honest with you ... very, very rare do I give it a thought .. When I have a twinge, I make it a little more comfortable, sometimes when I'm lying in bed, it's a bit uncomfortable, but apart from that I don't even know I've got it to be honest"* (78-86)[N04][Male non-shock patient]. Unfortunately, patient N04 had experienced some serious complications after his implant, which might have influenced his denial for a need for an ICD.

Distraction was closely related to denial in this study, as both were used to cognitively disengage from distress. Flemme (2011) found their participants used distraction to remove themselves from reality. Patient N11 used distraction to find some respite from his anxieties. He had been a previously fit, active man, and was able to find cycling an effective distraction. Cycling helped him - at least in the short term - to forget the threat from his ICD and his associated heart condition. He actively tried to engage in distraction as he recognised that it helped him cope: "*... well just carry on with everyday life, and you're busy doing other things and forget about it .... I totally forget about it I'm doing most things I do, even when I'm walking ... when I cycle around, I cycle fast and I feel 'yeah, I'm ok really"* (404-407)[N11][Male non-shock patient]. This strategy worked short-term to relieve his anxiety (whilst he was cycling), but it did not relieve him of his anxiety longer-term.

Denial and distraction were predominant coping strategies used by female patient S23, for whom the diagnosis of her illness and ICD implant had clearly been traumatic. Perhaps these strategies explained why this patient had sobbed throughout the interview.[42] The participant coped with her feeling of trauma by avoiding talking about her illness, dismissing others' concerns and trying to convince herself that the doctor had made a misdiagnosis. However, denial did not appear to be an adaptive strategy for longer-term. Her inability to deal with the shock of her diagnosis, and its threat to her children and grandchildren had resulted in constant intrusive distressing thoughts: *"I think at the time, I kept it down and then it keeps popping up. ... the shock of ... him telling me ... of realising my family might have it, my children, my grandchildren, so I coped by thinking, he might-he probably got this wrong, cos it made it easier ... [how long did you cope like that?] ... Oh I just kept it going cos it was easier. And if anybody asked I'd say 'oh well' you know, just get on with it, I'll be alright"* (104-116)[S23][Female shock patient]. Flemme et al. (2011) found a similar finding and reported that patients often try to suppress thoughts about their heart condition because they found the enormity of what was happening to them was too difficult to cope with.

Another coping style was to deny the seriousness of a situation by making jokes and being flippant. For instance male patient S01, who was the self-reported Type-A

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[42] In line with ethics, the patient had been asked if they would like to stop the interview but she had declined.

personality, asserted that he tended to joke in order to cope with stressful situations such as experiencing a shock: *"... we do talk things but I think the only way I can cope with it [shock during sex]... I mean there's the classic old joke 'what a way to go!' so the expression is, which again is how I've managed to cope with a lot of these things ... I do prefer to joke"* (297-305)[S01][Male shock patient]. However, his tendency to be flippant might have been a defence mechanism to cover his denial, as he also reported avoidant behaviours that showed he was actively engaged in avoidant behaviour (see above Avoidant/Restrictive Behaviour)

First Order Theme: Religious Coping

Male patient N04 and female patient N07 claimed they had a belief in God whom they believed ultimately controlled life: *"I have a faith, a really strong faith and I really believe that has kept me in good stead because I believe there is a time to be born and a time to die"* (142-144) [N07][Female non-shock patient]. Both patients were not afraid to die, and strongly believed that the time to die was ordained by God and not by doctors, thereby relinquishing the ICD of its life-saving properties.

Having a faith also appeared to help patients accept the ICD, because patients could hand their future over to a higher being. For the religious, life and death was ultimately in God's hands, which allowed the patient to be released from being reliant on the device to stay alive. For example, although male patients N04 and N11 both demonstrated a resigned acceptance to the ICD, non-religious N11 continued to express extreme anxiety whereas religious N04 expressed none. This was possibly because he had the certainty that his life would only last as long as God had ordained it to: N04 had said *"My faith makes a a big, big difference of course ... well, I know where I'm going ... the only sadness for me would be to leave my family, you know .. Obviously, nobody wants to do that... but I'm quite happy when the time comes, and that really has been my attitude I suppose. I don't care what they put in... whether it's a machine or whatever it is, I'm going to go as long as the Lord kind of wants me to go and that the end of it, and I'm content with that"* (316-330)[N04][Male shock patient]. Turning to God as ways of coping were also found in studies by Palacios-Ceña et al. (2011), Bolse et al. (2005) and Dickerson (2002).

First Order Theme: Blaming & Venting

Some patients used the interview process to vent their feelings about the ICD, the cardiac event and the frustration and anger they felt with their situation. As the sample was self-selected, it remains unknown whether the venting was intentional or pent up emotions were released during the interview. However, the fact that many patients appeared to be embarrassed when they broke down crying during the interview suggested that patients had unintentionally unleashed pent negative emotions.

It appeared that male patient N10 had vented frustration, annoyance, and anger at his situation on many occasions as his wife was able to corroborate these episodes of blaming and venting. He vented blame towards the doctor, which had been common amongst those who expressed antipathy towards the ICD. However, other patients did not commonly report his practice of constant venting and it was clear that venting and blaming was not helping patient N10 accept his situation. He refused to accept responsibility for making the decision to have the device and blamed the doctor that he had made it. This attribution of blame resulted in patient N10 becoming irreconcilable towards it. He was unable to accept it and had become depressed with his situation: *"I wouldn't have had it. I would take it out tomorrow ... but they said they can't do that ... I don't think I was given the right information ... like with my father like, he was given the option 'ok, we'll do it on increased medication'. Now I'm on Atenenol 50 and he's on Atenenol half that strength... And they said they can do it on medication... but I wasn't given that choice, or I might ... 'cos what happened was, Dr EP he tried to convince me really ..."* (112-124)[N10][Male non-shock patient].

First Order Theme: Maintaining Self-Esteem

Some patients in this study used positive distinctiveness as a way of maintaining their self-worth. Notably, most of those who used positive distinctiveness in this way had accepted and were coping well with their device. Accordingly, seeking distinctiveness might be an effective coping strategy for coping with an ICD.

One type of distinctiveness that patients appeared anxious to convey during the interview was that they were not the 'typical' heart condition patient. In other words, they were eager to put across that they were not responsible for their heart condition. For example, patient N11's use of 'pristine' as a descriptor to describe his arteries suggested his arteries were atypical of a heart condition caused by an unhealthy lifestyle: *".. I thought maybe one of my blood vessels here had blocked up .. they did all these tests, they said my arteries are pristine, which 'what a waste' I thought (small laugh)"* (365-368)[N11][Male non-shock patient]. Further evidence of distinctiveness by proclaiming a healthy lifestyle was sought from N08: *"I mean luckily I've never smoked and I've never drunk, so that baffled them for a start (laughs), 'cos that's normally one of the first things they ask ... 'Do you smoke? Do you drink?'... I said 'well I don't smoke, I don't drink, I don't drink tea or coffee so I've got no caffeine as such, you know ..."* (356-360)[N08][Female non-shock patient].

Male Shock Patient S01, who was a self-reported Type A personality, also wanted to convey that his arteries were in good condition. This had been a similar finding by another patient. In both cases, their explanation that their arteries were in good condition was almost defensive as if they anticipated that others would censure them for having 'furred up' arteries. They had been quick to disassociate themselves from the cardiac patient whose condition was due to an 'unhealthy' lifestyle. Accordingly they perceived themselves to be an 'atypical' cardiac patient, which helped them maintain their self-esteem: *"it was good to know that although I had a problem, if I'd also needed quadruple heart-by-pass as well cos I was all furred and clogged up-the fact that I wasn't, I've got you know, in very good nick, that was good you know. Yey! I'm pleased about that"* (620-624) [S01][Male shock patient].

First Order Theme: Social comparison

Similar to maintaining self-esteem was the coping strategy 'social comparison'. This coping strategy sometimes helped maintain self-esteem when used positively (downward comparison) but also caused distress when patients compared themselves negatively to others (upwards comparison). Patients who compared themselves positively against others generally found this comparison helped them cope with their ICD. Many patients through self-realisation, held the belief that they were safer than others were. This belief served to help patient cope with their ICD by facilitating acceptance: e.g. *"...I think the value of it is ... Knowing that I'm probably now in a better position that normal people are really ... if the same thing happened to Joe Bloggs ... say we were walking in some remote path ... the same thing happen to both of us .. I'd probably be the better off because I... got literally carrying around with me a paramedic ..."* (277-286)[N03][Male non-shock patient].

Williams et al. (2007) had found patients who made comparisons with war victims, which had helped them cope with their ICD. Coincidently, in this present study, a similar comparison had been made; Patient N11 compared himself favourably to child victim of War in Afghanistan. However, patient N11 did not find the positive evaluation helpful: *"(I tell myself) ... well, I could be dead, but I'm alive ... lucky to be here is the end result ... I could be in Afghanistan, a child bombed for no reason..."* (568-569)[N14][Male non-shock patient]. Patient N11 remained depressed, so although he tried to change how he appraised his situation, and tried to find comfort in his comparison, his mood remained the same. It could be that the comparison N11 made was not appropriate to his situation and if he had made an appropriate evaluation i.e. someone in his peer group or from an ICD support group, he might have felt comforted. Therefore, making a social comparison only appeared helpful if it was positive. If negative comparisons were made, they appeared only to further depress patients. For example, patient N16 not only compared herself to an ICD patient who was twenty years younger than herself but one who had also been a former athlete. Unsurprisingly, when she compared herself to the former athlete, it merely compounded her feelings of worthlessness and depression: *"I was reading the paper the other day about a woman, 30, she's had an ICD fitted. She's very fit and she's doing some marathon now .... you know, and I think 'my god, she's doing all these running and things"* (365-370)[N16][Female non-shock patient].

Patient S13 reported that Tony Blair (former UK Prime Minister), suffered from arrhythmias, which had helped him normalise and accept his symptoms: *"I've got an irregular heartbeat. And I'm told from the powers that be, that quite a few people go through life without having any problems whatsoever, named a few names, like Tony Blair and a few other people"* (22-25)[S13][Male shock patient]. The comparison made with a Prime Minister, would normally have been an upwards comparison, and would normally have made him feel worse. However because he had been told that the PM had the same cardiac condition as himself, the comparison made with a former minister served to make him feel better.

Flemme et al. (2011) found patients were often disappointed about having an underlying heart disease, which required the device and pharmacologic treatment. These feelings of disappointment were also found in the current study: *"I had always been very fit, played rugby only a couple of weeks before. I was a regular runner so I couldn't understand why my heart should be giving me problems when I had constantly been fit and active all my life"* (44-47)[S05]. In order to cope with his feelings of disappointment S05 continually compared himself to others. However, S05 made an upwards social comparison with his fiancée and other members of his sports club, which served only to make him feel worse. In a similar way to patient N11 who had compared himself unfavourably with a war-torn child, and patient N16, who had compared herself to an athlete twenty years her junior, patient S05 also used inappropriate people with whom to compare himself. For instance, his comparison with fellow rowers from a sports club, who were half his age, merely served to compound his disillusionment with his loss of physical fitness: *"Fiancée' started running when I started running and I should be able to comfortably beat her but she's leaving me behind, and that was worse in many ways. I used to go on the rowing machine, there was a competition, and people had to put their results in. And I was pushing myself as hard as I could and I went to look at the results and they were probably half my age mind, but even so, I was way out of it. And I thought 18-months ago, I would have done that easily"* (156-164)[S05].

After experiencing an ICD shock, he continued to make social comparisons with other ICD recipients. Downwardly comparing himself to others had made him feel more frustrated with his lack of fitness. In the same way, when he attended a support group meeting, his realisation that the cohort of shocked patients was very small caused him concern: *"[I'm] concerned that it should go off ... We went to an afternoon meeting, seminar with the arrhythmia nurses and other people who had these fitted. ...And in the room of about 30, 40 people only one person had it go off you know ... So for it to go off is obviously unusual and a bit concerning really"* (94-99)[S05][Male shock patient]. Accordingly, his concern was not that he had experienced a shock per se, but that the majority of others present at the meeting had *not* experienced a shock. This patient's coping style of comparing himself to others in order to ascertain how he measured up for fitness, heart health, and so forth, meant that he would need to seek out those ICD recipients to whom he could make downwards social comparisons in order to feel better.

Kamphuis et al. (2004) had found some patients were disappointed with their rate of their recovery and found their physical limitations difficult to accept, which was true for S05. Nonetheless, patient S05 found some comfort when he used an appropriate comparison; he compared his current stamina to his stamina after his implant, which was able to demonstrate to him that he his physical health and strength had improved. As patient S05 had a strong athletic identity, this was a helpful and appropriate comparison to make, and helped him to feel better about himself.

First Order Theme: Acceptance

The majority of patients in this study appeared to have accepted their ICD by one-year apart from non-shock patients N10 and N16, who were depressed and struggling with fears, ambivalence, anger and frustration. Acceptance had been achieved in several ways - a realisation that the ICD could be lifesaving, having trust in the medical team, resignation that there was no alternative treatment option available and through religious coping.

The majority of patients generally trusted their ICD to be a device that could save their life, which was a recurrent theme in other qualitative studies (e.g. Bolse et al., 2005; Flemme et al, 2011; Palacios-Ceña et al., 2011). For instance, patients N12 and N08 explained what many others had proposed: *"Well (ICD), it's just a precaution much as anything else ... just gives you peace of mind I suppose ... put it this way, I wouldn't be doing too much, so it's allowing me to get on with my life .. because if I am out in the garden doing some gardening and (wife) is not here, and something happens, at least if I black out this thing's going to come in and kick start me, which will give me time to get inside and phone for her"* (63-68)[N12][Male non-shock patient]. And *"... like I say, it's insurance, you've got it in case. Hopefully* *it doesn't have to be used but if it does it's there and it's got a job to do. Like I say, it's an amazing piece of technology."* (651-653) [N08][Female non-shock patient].

There appeared to be a subtle difference between accepting the ICD because there was no other treatment option available and accepting the device because it was what the patient wanted. This delineation is important; for example, patient N11's acceptance was one of a resigned acceptance rather than a joyful acceptance: *"... As for the ICD, well I suppose it's the essential friend, that's the way I look at it... not sure if it's a welcome friend but it's an essential friend .... "I still feel I'll never get completely used to the idea that I've got this thing really [arrhythmia] ...and this [ICD] is a permanent reminder of it but then it could have been lifesaving though so therefore be grateful"* (404-418) [N11][Male non-shock patient].

Whereas patient N11 demonstrated a resigned acceptance and remained anxious, patient N19 was clearly grateful to the ICD and felt lucky to have the device*: "It [ICD] hasn't really affected me really. I just carried on as normal and the scar doesn't bother me at all... I think about it all the time but .. very rarely I get upset through thinking about it, I'm just lucky"* (63-114)[N19][Female non-shock patient]. The difference in attitude towards having the ICD demonstrated that the motive underpinning the acceptance is important in determining whether it is an effective adaptive coping strategy. The ICD for patient N19 was part her 'new self' and belonged with her new identity: *"Yes I think about it [ICD] but .. I don't try and cover it up at all, it's part of who I am and it just doesn't bother me. I'll take anyone's hand, they'll say 'what's that lump' and I say feel it, you can touch it. But that doesn't bother me at all"* (68-71 [N19][Female non-shock patient]. Interestingly, patient N11 described the device as an essential friend who was sometimes unwelcome as a friend; a love-hate relationship, which has also been revealed as being so in the studies of Palacios-Ceña et al. (2011), and Dickerson (2002).

Burke (1996) suggested some patients perceived being 'normal' meant that they were no different at post from pre-implant but for others being 'normal' meant being aware of the changed identity and giving it value. In this present study, female patient N19 had fully accepted her ICD and embraced it into her new identity. She not only reported being confident with her body image, she had also chosen to wear a vest t-shirt for the interview, that clearly revealed the implant under her skin. In contrast, McDonough's (2009) found females reported choosing clothes that covered their incision cite, which suggests they were concerned about the scar and their body image.

Placing trust in the doctors or God also appeared to facilitate acceptance, and was a theme found in Palacios-Ceña et al.'s (2011) study. Patients who trusted their doctor's recommendation for an ICD appeared more readily to accept the ICD: e.g. *"... He [doctor] wouldn't have told me I needed an ICD if it wasn't necessary... so I was quite happy to have it implanted ...*" (227-229) [N06][Male non-shock patient]. Patient N06's simple faith in doctors meant he did not have to agonise over whether the ICD was an appropriate treatment option. This allowed him to focus on rehabilitation and getting on with life rather than ruminating about appropriateness of the initial decision to have one and the ensuing losses.

Similar to the non-shock patients, for whom the majority had accepted the ICD by one-year, four out of five shock patients appeared to have the same level of acceptance towards their illness and ICD. The one exception was male patient S05 who although had reported confidence in the surgeon, was not accepting of his illness but was looking for a cure. Therefore, he had not worked at trying to accept his illness or the ICD because he had focussed his attention to a stem-cell treatment, which he reported, would 'cure' his cardiac illness.

The ICD was likened to an insurance policy or a paramedic that was there as a protective measure. For instance: *"They tried to explain it to me, if I didn't have it, it was basically a matter of time. Now I've got it fitted and hopefully everything works tickety boo ... this thing will effectively stop my heart accelerating to explosion ... if there was nothing to control it, it could race into a self-destruct mode"* (146-152)[S13][Male shock patient]. Interestingly, patient S23, for whom family was important and who had a strong mother/grandmother role, had managed to reconcile herself to the ICD. She had managed this by having the belief that the ordeal of the ICD had been compensated by the fact her children and grandchildren would now be protected: *"And I kept saying 'well, it's just as well that they found out that I got it, so I can make sure my children and grandchildren are alright. And that was a sort of* *compensation thing for me. You know, they'd be ok, despite everything"* (301-305)[S23][Female shock patient].

Whereas patient S01 had joyfully embraced his ICD: *"I have no concerns at all. ... since it was sorted, and the euphoria of that probably hasn't gone away, it's still fantastic. ... I'm better now than I've been for years .. it was a constant worry, worry, worry and now it isn't and won't be unless something goes wrong and it goes off for no apparent reason."* (526-540)[S01][Male non-shock patient], patient S15 reported his acceptance was one of reluctance and resignation: *"Reluctance in the sense that you wouldn't have wanted to have it [ICD] in the first place but an acceptance with an overview of thinking it's there, it's going to be an aid obviously .... you don't want things to go wrong in the first place, so you certainly don't want to have something inside you that is there because you'd rather it wasn't there. I'd been living for 20 years after the heart attack, a normal life, I wanted that to continue but the fact this wasn't going to continue ... it's coming to terms-the actual coming to terms with didn't take long ... [what helped you come to terms with it?] Resignation ... just resigned to the fact that it was there"* (88-113) [S15][Male shock patient].

Some of the shock patients who used the emotion-focussed strategy of acceptance in the current study appeared to find their acceptance had perhaps been facilitated by the shock experience. Patient S01 perceived the ICD to be a 'good friend', and the shock was the 'good friend' fighting on his behalf when his life was in danger: *"It's sort of having a good friend I suppose it's nice to know it's there. ..... The fact there is a bully in the cupboard just in case and he's on my side, that's nice to know"* (354-360)[S01][Male shock patient].

Although waiting for a stem cell procedure, patient S05 found some acceptance simply because the ICD had kept him alive: *"well er, it's a good job I got it fitted or I'd be dead .. so I'm pleased in that respect"* (93-94)[S05][Male shock patient], and *"I suppose I'm lucky to have it fitted really aren't I because I would be dead otherwise"* (368-369)[S05][Male shock patient]. As he was holding onto the hope that he would be undergoing a novel medical procedure that would 'repair' his heart, he might have simply been grateful that the ICD had kept him alive for his next medical procedure.

One of the most dominant themes found for ICD non-shocked patients was the anxiety and fears surrounding the experience of a shock for the first time that had been based on fears of the unknown and the vicarious accounts of others. Therefore, it was somewhat surprising that only one shocked patient shared that he received some level of assurance once having experienced a shock: *"Initially going around in my mind was 'what the hell is it going to feel like if it goes off'. Now I've had a belt, I know what's going to happen. ... I know what to expect ... if I feel that belt, I will know something was not quite right and this thing has kicked in and sorted things out for me, hopefully.... I don't particularly want it again if I can avoid it, but now that I've had it, I know what to expect as appose to being in a situation of the unknown. There's nothing worse than not knowing.... Well now it's happened I know what it does-it immobilised me, it knocked me back into the –it really did"* (292-309)[S13][Female shock patient].

First Order Theme: Concealment

Female patient S23 had a strong role identity as a mother and grandmother as it was clear throughout the interview that she was very involved with her extended family as reported by her partner: *"she do worry about the kids too much. We got four grandchildren and 'why don't we take them with us?' Never mind if they are in school or not. Take them away for a week as soon as the weather breaks ... [why?] ... just to make sure they go on holidays, give them a break"* (324-333) [Male partner S23.1]. She might have concealed her thoughts and feelings to protect her family from any distress: *"... When I went back for my follow-up ... my daughter came with me because she was going to be tested and my husband was there. And they said are you alright about it [ICD?] But you don't actually want to say how you really feel, cos they [family] are worried enough as it is ... you know they got their own worries, so you got to feel 'oh don't worry, everything's going to be ok'. I didn't want my daughter-my daughter has got it [LQT], so I didn't want her worrying about it. So it was 'oh look at me, I'm doing fine, it's hasn't affected me really if it [ICD] comes to you, you'll be the same"* (128-145) [S23][Female shock patient]. Interesting, McDonough (2009) found that when patients realised their children might be affected, they reacted with fury. However, it seemed that patient S23 suppressed her feelings of fury and anguish and concealed them from others, which led her to feel depressed and weepy.

A further telling example from patient S23, which demonstrated her desire to protect her family, was *"It [ICD] saved my life. ... but it's also changed things (cries) ... I tried to keep it down you know, thinking 'don't worry about it', you can't live your life worrying all the time, but then to say it out loud makes it more real then ... But I don't want to talk to anybody [what about a nurse?] .. no, no, you tend to keep it all in then... I don't want my family to know how upset I am about it, because I think they got enough to deal with, watching me you know"* (586-613)[S23][Female shock patient]. Concealment was also reported by Flemme et al. (2011), who described how a patient kept hidden from his wife that he thought he might be about to have a shock, in order to prevent her from worrying.

SECTION 2: Qualitative Findings and Discussion for Partners

Participants included in this study comprised 11 females and 7 male and ranged in age from 30 to 68 years (mean age 54.89 years, standard deviation 11.92) (see Table 6.3). Partners represented a variety of educational and occupational backgrounds. Participants represented middle and working class occupations such as Company Director, Scientist, a retired Businessman, Company Owner, Support worker, retired Deputy Head Teacher, middle Management, retiree, Administrator, Nurse, a long-term sick, and one currently unemployed.

All but one couple had children ranging from a 1-year old, three year old, 13 year old, mid to late teenagers through to older married offspring with children of their own.

Table 6.3: Characteristics of Partners

Code	**Gender**	**Age**	**Indication for Partner's ICD Primary (P) or Secondary (S)**	**Time with ICD**
S01.1	Female	66	Sustained Ventricular Tachycardia Undiagnosed Cardiomyopathy (P)	≤ 1year
N03.1	Female	47	Sustained Ventricular Tachycardia (ARVC) (P)	≤ 1 year
N04.1	Female	65	Heart Failure (P)	≤ 1 year
S05.1	Female	40	Idiopathic Dilated Cardiomyopathy (S)	≤ 1 year
N06.1	Female	50	Out of Hospital Cardiac arrest - Myocardial Infarction (S)	≤ 1 year
N07.1	Male	65	Sustained Ventricular Tachycardia - Undiagnosed cardiomyopathy (P)	≤ 1 year
N08.1	Male	65	Out of hospital Cardiac arrest - Undiagnosed cause (S)	≤ 1 year
N10.1	Female	44	Hypertrophic Cardiomyopathy (P)	≤ 1 year
N11.1	Female	67	Sustained Ventricular Tachycardia - Enlarged heart (P)	≤ 1 year
N12.1	Female	60	Out of hospital cardiac arrest - Myocardial Infarction (S)	≤ 1 year
S13.1	Female	60	Sustained Ventricular Tachycardia Undiagnosed Cardiomyopathy (P)	≤ 1 year
N14.1	Female	56	Brugada Syndrome (S)	≤ 1 year
S15.1	Female	64	Heart Failure (S)	≤ 1 year
N16.1	Male	54	Multiple Cardiac Arrests during Routine operation (S)	≤ 1 year
N17.1	Male	57	Bundle Branch Block Syndrome (P)	≤ 1 year
N18.1	Male	30	Post Partum Cardiomyopathy (P)	≤ 1 year
N19.1	Male	30	Long QT Syndrome (S)	≤1 year
S23.1	Male	68	Long QT Syndrome (P)	≤ 2 years

Findings and Discussion *(See Appendix VII for the complete table of quotes and themes for the partners of patients)*

Table 6.4: *Hierarchical Development of the Raw Data, First Order, and Second Order Themes and General Dimensions*

Raw Data: Key Exemplar Quote	1st Order Themes	2nd Order Themes	General Dimension
"... I've actually said to her 'you don't know anything about it'. She was out, she don't know anything about it. When she woke up she was in hospital and she doesn't know about anything's that's happened. I find that really strange, although it happened to her, the trauma's left with me ..." (601-605) [N19.1]	Traumatised by Cardiac Event		Emotional Consequences
"... we were going to bed and he was getting up and he was making heavy breathing ... and I thought 'what's happening, something's happening' ... but it wasn't. He had a blocked nose, that's why he was breathing funny ... I was upstairs cleaning and she [daughter] said 'Mammy, you better get down, Daddy's not very well' ... and I thought 'it's a year now, oh no, not again ... here we go again'. And that's what's on my mind ... you fear the worst, it's constantly ..." (312-325)[N06.1]	Anxiety and Fear of a Repeat Cardiac Event	Anxiety and Fear	
"... it was difficult in the beginning to get the confidence and .. not understanding what it's there for but what it if goes off, what'll happen then, what, what ... you know, how's he going to feel, when is it going to happen?" (224-227)[N03.1]	Anxiety and Fear relating to the ICD and Shock		
"Since we started going to the EP, each realisation has perhaps brought us closer together, the fact that his heart is wearing out, ... his heart is wearing out so perhaps each individual step has brought us closer together ... not just the defib ... it brings an end to everything" (171-180)[S13.1]	Sadness relating to Partner's Mortality		
" ... the only I would query ... is the afterwards. You come home and you're on your own basically aren't you ... I'd just carry on and cope and then if I got a real question, I would ring them and ask them. But I did feel-it's like a cut-off, come home from hospital ... you just got to get on wi-with it ..." (127-149)[S13.1]	Feeling Abandoned/Ill-equipped		
"We've also got a lot of worries about [daughter], to think there's a 50 percent chance that daughter could have what [wife] has got ... well they said the only way to tell is a DNA test, which there is no funding for. And I say we'll pay for a DNA test, and they said you're not able to pay for it. And I thought what type of crazy place are we living in ... it just doesn't make sense to me ... they got a way of possibly preventing something with [daughter] ... but yet there's no funding for it ... it just doesn't	Frustration and Anger with the NHS	Frustration and Anger	

Raw Data: Key Exemplar Quote	1st Order Themes	2nd Order Themes	General Dimension
make any sense whatsoever ... and it is annoying cos there is something they can actually do but they don't" (655-680)[N19.1] "he was running along the Taff Trail ... on his own ... nobody around and I ... you talk to people afterwards who live along the Taff Trail or walk along it quite regularly, and they say they do find people just drop dead ... on the trail. And I'm thinking that could have been Tom and I'm thinking you knew of it, so why haven't you contacted us before now, you know. So I was frustrated and annoyed more than anything" (67-74)[N03.1]			
"I've tried to explain, 'no, you've got a better bloody chance than we have because you've got something to trigger your heart back ... And I don't know how to explain, I can't get through [how does that make you feel?] ... very frustrated. You know sometimes I just got to go out and take a walk and calm myself..." (74-86)[N16.1]	Frustration and Anger with the Patient		
[How did the shock make you feel?] "cross initially ... you know, flipping heck, that's another 6-months he's not going to be able to-to drive ... I wasn't worried because he-he was fine" (150-153)[S01.1]	Frustration with the Situation		
"... at the time I thought that it [relationship with partner] possibly could change, hugely ... and then when I read up on ICDs and all that, then I reassured myself ... " (64-66)[N14.1]	Becoming Informed	Problem-Focussed Coping	Coping with the ICD
" yes, [I ring her] to see if she's alright [every] five minutes, 10-minutes ... cos it's a worry. Even when she goes to the toilet ... now and again she's out there changing herself [stoma] and I'll go and say 'are you alright love'" (96-106)[S23.1]	Monitoring Patient		
"For Christmas I bought him a dog-tag (laughs). A heart-shaped dog tag, he'll kill me for it I know ... his name, ICD, and a telephone number" (251-253)[N03.1]	Protective Behaviours		
"... And I was ... there was a bit of 'crikey, this is my big, strong boy and he's supposed to be looking after me' and he has always looked after me, very well ... and the tables have turned you know. That was quite hard to come to terms with ... that was- although I would always look after him ... it changed my who perspective on our relationship" (55-60)[N14.1]	Re-assessing Role Identity and Control	Emotion-Focussed Coping	
"... we have come a little distant at times .... emotionally and physically. Physically more I think. First of all, it was fear, not so much now. I know straight afterwards I was very worried about ... triggering it" (267-275)[N19.1]	Being Cautious		

Raw Data: Key Exemplar Quote	1^{st} Order Themes	2^{nd} Order Themes	General Dimension
"I think what has helped is that we've continued to go to the support groups ... the support group is there for that type of thing you know, for people all in the same boat and you've got the partners there as well and you're just generally trying to help each other with that little bit of support ... and it's not just m-me ... I found them [support groups] very use- very, very good, in that it gives you that little bit of extra knowledge ... learning and listening to other people's experiences has given us a a bit of ... confidence" (146-177)[N03.1]	Seeking Reassurance and Control		
"When he came home from hospital ... I didn't cry in front of him ... my youngest son, he was with us all the time you know ... and he was on the phone all the time ... so I used to tell him how I felt ... I was crying all the time ... because I could see nothing was happening ... it was getting worse ... it was just really traumatic really" (181-190)[N04.1]	Frustrated Venting		
"We never talk .. Well, we talk about ... we laughed about it when he first had it done but I think as time's gone by .. it's a year now ... you just don't put it into your life .. We don't 'oh don't get him worked up, he might have a shock'... we don't do any of that" (258-262)[N04.1]	Denial/Cognitive Disengagement		
"Husband's cardiomyopathy, he's coping so well with it ... he does a lot of active outside work and even though he might be slower than he was ... he can still do it, which we've been told is fairly unusual. And we put it down to, he was very, very fit before he had the attacks, he used to play a lot of rugby and to his mindset 'I'm not going to be beaten by this'" (181-193)[S05.1]	Maintaining Self-Esteem		
"... I don't really tell [husband] about those [fears of him dying]. You know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful" (116-118)[S05.1]	Concealment		
"I am happy, I am so pleased that he's got this thing [ICD] ... I mean he could be in the situation that he had something like this [Brugada] and there was nothing they could have done, so great!" (509-512)[N14.1] "I think we're both sort of ... calm ... we deal with things, just get on with it really... I think in the early stages of these things, as with anything, you realise you're mortal ... And you somehow have to cope with that... and then you have to get on with your life because that's what you have to do, isn't it ... so, we're both on medication for life" (260-272)[N11.1]	Acceptance		

Raw Data: Key Exemplar Quote	1st Order Themes	2nd Order Themes	General Dimension
"We are Christians and we do believe ... we believe it's the Lord that done it [tested him through illness]. Cos we just feel that he was so, so bad that it was only the Lord that could help him ... I mean obviously he's still got the weak heart, and he's always going to unless he gets a transplant or the Lord gives him a new heart" (191-196)[N04.1]	Religious coping with illness		
"... the nurses, they're very good... But I do think they give them so many books to read ... and books make it for me more worrying, because there's too much information... don't ask me to say an example cos I've not looked at a book ... They've gone away [books have gone away]... We're getting on with our life. He has been told... he's to carry on as normal. So, if there is something he shouldn't do or can't do, we would be told" (244-280)[S01.1]	Cognitive Avoidant Coping	Mixed Avoidant Coping	
"We've refrained from it [sex] at the moment so that was probably about three weeks ago now.... I think knowing he had to stop four weeks driving again might stop [husband]... We sort of laughed about it. ... but that that's where it stayed at the moment... [refrained from sex because of not being allowed to drive not because of shock?] ... Yes [driving]... It's happened, I mean he had one [shock]... I was quite close to him and I felt it and .... that's fine... I say it's fine, but it was no big deal and I think it was a worry for [husband] really not me" (298-312)[S01.1]	Behavioural Avoidant Coping		

GENERAL DIMENSION: EMOTIONAL CONSEQUENCES

First Order Theme: Traumatised by Cardiac Event

Partners[43] who had witnessed their loved one having a sudden cardiac arrest (SCA[44]) or sudden cardiac death (SCD[45]) were often left traumatised by the events that had unfolded. This finding corroborates Doolittle and Sauve's (1995) suggestion that partners tended to focus on the cardiac event. The current study initially asked partners about the cardiac event, and it was clear for one patient that the horror of her husband's SCD had not diminished as she sobbed continually whilst recounting the event. The vision of her husband lying 'dead' in hospital was clearly still vivid in her mind and it was an image that she wanted members of her family to be protected from. She was so afraid that her husband might die again once home that she made sure she was the first to wake him from a period of sleep in case he had died: *"... my daughter, she turned to her little girl ... 'go and wake Dadu up' ... 'NO!' I said ... 'well he's been up there a while on his own ... and I'm petrified ... cos a lot of people have said 'you have a heart attack, you gone' when I see Sam on that [hospital] bed, there was nothing .. and I don't want my granddaughter to see it' (103-109)* [N06.1][Female non-shock patient].

The trauma experienced by partners also resulted in some of them feeling antagonistic towards the patient. Some partners who had witnessed the patient's cardiac arrest were resentful that they were left traumatised especially as their patient could not remember the event. Sometimes the partner complained that they felt the patient appeared to be too complacent about the cardiac event: *"... I've actually said to her 'you don't know anything about it', she was out, she don't know anything about it. When she woke up she was in hospital and she doesn't know about anything's that's happened. I find that really strange, although it happened to her, the trauma's left with me.. "* (601-605) [N19.1][Male non-shock partner].

Events surrounding the cardiac event often appeared to intensify the trauma felt by the partner. Male partner N19.1 believed that if he had not been near his young wife

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[43] To avoid confusion, participants who were patients (recipients of the ICD) will be referred to as 'Patient' and their partner will be referred to as 'Partner'

[44] Sudden cardiac arrest refers to when the electrical system within the heart malfunctions causing the heart to beat in such a way that no blood is pumped around the body.

[45] A sudden unexpected death caused by loss of heart function eg sudden cardiac arrest.

when she had her SCA, she would have died. His feelings of trauma extended to his daughter who was being bathed by his wife at the time of the arrest. His wife's sudden and unexpected cardiac arrest left him fearful for his daughter's wellbeing as well as fearing that he might have to raise his daughter by himself: *" I worry about her more than I do about me. I worry about my daughter as well, because she's so young, I do worry about (wife) being with her. Not all the time but .. [I: in what way?].. if anything happens to her. If anything happens to (wife) and I got a three-year old ... well (daughter) was there when it happened the first time, when she had the cardiac arrest. I just be worried about if anything happened to (wife) and the unit didn't go off or leaving a three year old on her own ... I know this sounds a bit ... but I do worry a bit about that" (241-257)[N19.1][Male non-shock partner].*

The accounts of partners N06.1 and N19.1 suggest that partners can be left with feelings of unresolved trauma from the patient's cardiac event and highlights the fact that the cardiac experience is not restricted to the patient. Helping the Partners of ICD recipients cope with this trauma highlights an area for further research.

Second Order Theme: Anxiety and Fear

First Order Theme: Anxiety and fear of a Repeat Cardiac Event

Anxiety and fear related to the cardiac illness or cardiac event was evident in partners, especially those who had been traumatised by their patient's sudden cardiac death experience. Partners were fearful that their loved one might experience a repeat cardiac event; the cardiac events had been unexpected and sudden, and had left them in shock by the unpredictability of life and death. In order to cope with the unpredictability and anxiety, partners became vigilant and watchful of the patient. Increased vigilance of bodily symptoms by both patients and partners appeared to be a common reaction to fear throughout qualitative literature. For example, Steinke et al. (2005) found partners were watchful of benign symptoms such as fatigue or shortness of breath, and often catastrophised, fearing these were warning symptoms of an impending cardiac death.

One partner who had been traumatised by her husband's sudden cardiac arrest, catastrophised normal everyday physical symptoms such as breathing heavily. She lived in constant fear that her husband was going to die: *"... we were going to bed and he was getting up and he was making heavy breathing .. and I thought 'what's happening, something's happening' .. but it wasn't, he had a blocked nose, that's why he was breathing funny ...I was upstairs cleaning and she [daughter] said 'Mammy you better get down, Daddy's not very well' ... and I thought 'it's a year now, oh no, not again ... here we go again' And that's what's in my mind .... You fear the worst, it's constant ..."* (312-325) [N06.1][Female non-shock partner].

Interestingly, her reference to the milestone of 'one-year' was another notion that was often referred to by both patients and partners, (e.g. partner N04.1: 258-259; partner N03.1: 351) and has been highlighted in several studies (e.g. Burke, 1996; Kamphuis et al., 2004; Flemme et al., 2005 and Morken et al., 2009). The importance of reaching the one-year milestone without receiving a shock was conspicuous but appeared to have no medical explanation (Dr Peter O'Callaghan, Consultant Cardiologist, Personal Communication, 15/01/2012). Therefore surviving to one-year with no shock or making it to one year after a cardiac arrest appears to be a self-made important milestone. Although Albarran et al. (2004) suggested that patients and partners might have been advised that appropriate or inappropriate shock firings were more common during the first six-months and were therefore more anxious during this time, this does not explain the first-year milestone.

Male partners N17.1 and N19.1, felt fearful when their patients mentioned ambiguous symptoms such as 'feeling funny'. These symptoms were usually perceived to be a threat to the patient's cardiac health or as a warning of an impending shock. In an attempt to reduce their anxieties two male partners resumed responsibility for their wife's health and safety. However, rather than alleviate their worries, this way of coping appeared to exacerbate their anxieties. For example, partner N17.1 was especially fearful for his wife's health and associated any benign illness to his patient's heart condition. The fear resulted in him taking responsibility for ensuring she kept well, which was clearly a worrisome burden: *"That's always the problem, cos any minor illness, well not minor illness, any illness ... any symptom, you attribute to something going wrong .... before the device had been fitted ... if you were ill, you were ill. But now if you're ill, is there an underlying reason why you're ill? And should I be doing something about it ... I feel responsible* *and that's my biggest bug bare really. I'm afraid of making the wrong decision. Or not making a decision when I should be making a decision"* (269-284)[N17.1][Male non-shock partner].

Partner N19.1 who was traumatised by his wife's sudden cardiac death had also taken over the responsibility for his wife's safety. He admitted that he felt he had no choice as his wife had become careless, forgetful and remiss in looking after herself. Partner N19.1 had feared not only could she die, but she was also putting his young daughter's life in danger. Similar to partner N17.1, these feelings of fear and anxiety were often exacerbated when the patient felt ill; however mild the symptom, the symptom was usually interpreted as a warning that something might be wrong with the heart: *"... 'She's [wife] is under the impression that she doesn't need it [ICD]. But like I said to her 'you went 28 years feeling fine', there's nothing to say that it won't happen again and ..... Some months I go without even thinking about it [ICD], and then at other times, I think well, especially if she feels unwell, you start thinking of it even more then"* (147-149)[N19.1][Male non-shock partner].

Partner N19.1 was a young father who's child was very young and as such he was very concerned about his daughter's welfare if her mother died. This has been highlighted in a previous study by Williams, Young, Nikoletti & McRae (2007), who found that partners with young children were concerned about their children's welfare as well as coping with the financial impact on the family especially if the patient was the sole provider for the family.

Interestingly, N19.1 had admitted that it was he and not his wife the patient, who had wanted to join in this study, as he wanted to talk about his situation and experience that he had been through. The need for partners to talk through their feelings was highlighted by Dunbar, Warner and Purcell (1993) and Eckert and Jones (2002). Findings from this study support their notion that partners have a great need to talk about the cardiac experience. A similar finding was also found by Albarran et al. (2004) who had found partners often felt 'left out' by health professionals when what they wanted was to be included in the discussions and explanations.

The partners of shocked-patients had held similar feelings of anxiety as the non-shock partners prior to the ICD shock. As partner S05.1 explained *"[The first 3-months] I suppose you have a worry when you hug people, you think 'what if it goes* *off and I feel it? [Were you worried about yourself?] Well I worried about husband, 'how would I cope if it went off? How would it affect us, you know, all rational, irrational fears I guess"* (310-317)[S05.1][Female shock partner]. Her anxiety also stemmed from the fear that the patient might die: *"...the first six months I was like, I was so scared, every time he felt dizzy, I thought he was going to collapse on me or die. I'd be like a cat, you know, if he said he felt unwell, I could feel my whole nervous system kicking in, adrenalin, and I'd be so anxious"* (229-232)[S05.1][Female shock partner].

This anxiety and fear of an imminent cardiac event appeared to be worse if the partner had been worrying for a long time prior to the ICD implant: *"I have been concerned for a number of years that something might happen. ... so if he stood like this (puts shoulders and head down) then I would begin to worry that something was occurring. So I used to worry and I probably still worry at the moment that something is going to-well I suppose I worry that the thing's not going to work ... I've been worried for such a while .. about these funny turns he was having. So .. I think when you've been doing that for a few years, it takes a little time to ... probably calm down about it."* (126-190)[S01.1][Female shock partner]. Interestingly, this was a similar response to non-shock female partner N06.1, who had catastrophised about everyday symptoms, fearing they meant her husband was about to die. Female partner N06.1 had also been worrying for a long time prior to the ICD implant, and although her worry had been more generalised worry, her strength of her emotional response to the ICD was similar to female shock partner S01.1.

Only shock partners were found to be anxious about the uncertainty of their futures. For instance, female partner S05.1 felt anxious about the unknown progression of the disease, which might have been due to her methodical and logical approach to problem solving and not being able to have information about the disease progression made her very anxious: *"it can't be cured. It can be controlled with drugs to ensure the heart doesn't work too hard ... every patient's different, you know some patients improve, some don't, some deteriorate quite rapidly, and the prognosis of the disease is very different between people ... so you never know how things are going to pan out"* (137-142)[S05.1][Female non-shock partner].

Male partner S23.1 who was 13 years senior to his wife had a different concern about the future. His worry stemmed from not knowing if he would be able to continue to care for his wife when he was older. This partner had been overprotective towards his wife, wanting to look after her in the way she had looked after him in the past. However, this had resulted in her feeling a loss of independence (see 'Loss of Independence/Autonomy'). Although he admitted he was a worrier by nature, their difference in age might have exacerbated his worries: *"Well I've always been a faffer and a worrier but I can take the worry side in my stride more or less [what do you worry about?] About how long she will last ... [she mentioned she was younger than you?] yeah, 13 years ... even more so. Alright I'm still fit .. But will I be fit enough in another five or six years to keep looking after her"* (249-261)[S23.1][Male shock partner].

Again, partners who were natural worriers or were anxious by nature worried more about their loved one. For instance, partner S15.1 who suffered from anxieties and self-confessed mental health issues found her anxieties had been made worse because her husband was not able to help her by being cheerful and positive. It is possible that her anxieties were for her own mental health rather than that of her husband although this could not be substantiated: *"... first it was hard, cos he was very down. ... it's me that gets down ... I'm cheerful and bubbly on the outside, 'husband's' not bubbly, he's very level. I am cheerful and bubbly but because I got anxieties, I can-I can put a falseness on you know to people, that I'm fine but I'm not ... I felt anxious about husband. I felt anxious that he was feeling sad"* (124-141) [S15.1][Female shock partner].

First Order Theme: Anxiety and Fear relating to the ICD and Shock

Anxiety relating to the ICD and its shock, including its unpredictability was another pertinent fear for many partners in the present study. Non-shock partners appeared to be living in wait for the shock to occur. For instance, partner N17.1 commented *" Given that we've been told that inevitably something is going to happen. She's got a 30% chance of it [shock] happening this year ... So, then you start thinking, well the odds are that something's got to happen eventually, you know. ... you're almost waiting really for something to happen in time. .... I think it has certainly affected us*

... made us think about .. how we live our lives and what we do. ... I'm not overly happy about 'wife' being on her own, cos the whole idea of this ICD is that at some stage this it going to kick in" (108-133)[N17.1][Male non-shock partner]. Eckert and Jones (2002) had similarly found that family members had felt helpless by the shock's unpredictability.

Also coupled with the unexpectedness of the shock firing was the anxiety of how the firing might affect their loved one. Male partner N17.1 was not helped when told that the shock would be 'frightening', which resulted in N17.1's increased vigilance and protectiveness over his wife. The following descriptor might have caused his tendency to catastrophise shock firings: *"You know we've been told that it's going to be a big wallop across the room and you just want to be there when it happens. ... I try to increase the amount of time I'm with her .... [Who told you wife could be blown across the room?] 'a nurse' ... The idea is-what happens is when this thing kicks, it could blow her across the room or something. ... Well perhaps I got it wrong, but I got the impression that when it does go, it's like a punch in the chest (smacks fist against hand), which in many instances could knock her-knock her down and frighten her - well they said it would be frightening, cos it would almost be like a punch in the chest"* (134-154)[N17.1][Male non-shock partner]. Eckert and Jones (2002) also cited that partners felt a need to be close by their loved ones in case of shock.

Increased vigilance and protectiveness appeared to be a common behavioural reaction by partners to the anxiety and fear of the unknown shock. However, partner N17.1's attempts to monitor and protect his wife resulted in him becoming more anxious when apart from her. The finding that partners increased their protection and vigilance over the patient because of a fear of shocks have been reported in other studies that have explored partner experiences such as Albarran, Tagney and James (2004) and Steinke, Gill-Hopple, Valdez, Wooster et al. (2005) . However, over protectiveness and increased monitoring was shown to be counterproductive for partner N17.1; his overprotectiveness merely resulted in provoking his wife's irritation, which she reacted to by concealing any symptoms from him. (See 'Loss of Independence/Autonomy'). The account from N17.1 also highlights how information from health professionals can be selectively processed and misinterpreted. It also emphasises the important role health professionals have in relaying information to patients and their families in unthreatening, neutral language to reduce the risk of messages being misconstrued.

Although partner S05.1 was not worried by her loved one's shock, the shock firing had made her feel very afraid. Her worry was that her husband would die, even if with an ICD shock. Her account was very similar to an explanation from a patient from Mert et al.'s (2012) study who had felt helpless and fearful during an episode of multiple shocks and reported wondering if their last breath would be their final one. Although partner S05.1's husband did not receive multiple shocks, she described the same feeling of helplessness and fear of death: *"... but because 'husband' described quite well how he felt before it went off, certain times he's felt unwell recently, I've thought is it going to go off .... [what do you do?] just be quiet for a while and see what happens, sit down, relax until he feels better again. It's like a dangling sword hanging over you waiting for it"* (324-333)[S05.1][Female shock partner].

Two other partners expressed anxiety and fear about the shocks. Female partner S15.1 was anxious that her husband had experienced a shock with no discernible cause: *"... when it actually went off, whether that was because the heart was feeling a bit stressed, I don't know, but when it went off he was doing nothing, which is a bit daunting. To be thinking well, you don't have to do something for your heart to go in the wrong rhythm"* (61-65)[S15.1][Female shock partner]. Her anxiety was similar to her partner's experience, whose confidence had been knocked because he could not attribute an explanation for their shock event.

Male partner S23.1, who was carefully monitoring his wife and being overprotective, felt anxious not because of the shock per se, but because he did not know how he was to respond to the shock: *"I knew it would kick start it back to life. But ... wasn't quite sure what the procedure would be from there on ... the worry was, what happens next after the box went off ... what to do when the box goes off. We had no .. didn't know what to do"* (54-73)[S23.1][Male shock partner]. When his wife had experienced a shock firing, he had taken her to hospital and reported feeling worried about what to do if another shock occurred. The fear that he did not know how to respond appropriately to a shock, might explain his over protectiveness and monitoring behaviour. Accordingly, he may have felt he needed to be present to protect her should she have a shock.

First Order Theme: Sadness relating to Patient's Mortality

One patient experienced post-traumatic growth from finding out about her husband's diagnosis and ICD implant. This partner was hoping for a reprieve in symptoms following an ablation[46] procedure, which doctors hoped would relieve the patient of his sustained VT. Her account was similar to an account by female partner N04.1, who had also become aware of her husband's mortality but continued to live in hope. However, their responses to their husband's diagnoses were starkly different. Whereas N04.1 displayed distress, S13.1 demonstrated a post-traumatic growth: *"Since we started going to the EP, each realisation has perhaps brought us closer together. The fact that his heart is wearing out, that's what they basically told him from the beginning, his heart is wearing out so perhaps each individual step has brought us closer together ... not just the defib ... it brings an end to everything"* (171-180)[S13.1][Female shock patient].

Partner S05.1 found that the shock reminded her that her husband had a life-threatening illness and that he was mortal: *"It's [shock] like a reminder that he has got a serious condition, it's more of a jolt in that way.... So, when it goes off, it makes you more aware of his mortality, that's it's a life threatening condition"* (128-133)[S05.1][Female shock partner]. This finding has also been found by Palacios-Ceña et al. (2011) and Morken et al. (2009) who found patients interpreted the shock to be a reminder of their illness and of their mortality.

First Order Theme: Feeling Abandoned/Ill-equipped

The theme 'feeling abandoned' was experienced by two partners of shock patients and was similar to the feelings of frustration and anger that had been voiced by non-shock partners (see 'Frustration and Anger with the NHS' below). For instance, female partner S13.1 felt she had been left to 'get on with it'. Partner S05.1 complained that she had felt dismissed: *"... they [surgeon] put one in then you go, so it's kind of, you know, the consultant said 'right, you can live a normal life now,*

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[46] A cardiac ablation is a procedure to destroy small areas of the heart that might be causing an arrhythmia. During the procedure small wires (electrodes) are placed in the heart and determine which area in the heart is causing a problem. An electrical current is sent to the problem area, creating a small scar that restores sinus rhythm, retrieved November, 2012 (http://www.nlm.nih.gov/medlineplus/ency/article/007368.htm

you're fine, off you go, kind of thing. It was all a bit kind of brusque and dismissive almost" (291-293)[S05.1][Female shock partner]. This theme has implications for clinical practice (See Implications to Nursing/Clinical Practice).

Second Order Theme: Frustration and Anger

First Order Theme: Frustration and Anger with the National Health Service

Frustration and anger towards the NHS is a theme that does not appear to have been mentioned in previous ICD qualitative literature. This might be because most studies have come from a nursing background and patients/partners might have been reluctant to complain about their health care in case it was compromised (suggestion supported by Wendy Churchouse, Specialist Arrhythmia Nurse, Personal Communication, 24/03/2012). Therefore, the fact that this study came from a psychological perspective and was separate to their nursing care, might explain why partners felt able to criticise and voice their anger and frustration with the NHS.

There were four main causes of partner frustration and anger identified in this study. The first cause of anger stemmed from the knowledge that their loved one could have died whilst they waited for results from cardiac tests and that the NHS had knowingly put their loved ones at risk of death. For example: *"... he was running along the Taff Trail ... on his own ... nobody around and I .... you talk to people afterwards who live along the Taff Trail or walk along it quite regularly, and they say they do find people just drop dead ... on the trail, and I'm thinking that could have been Tom and I'm thinking you knew of it, so why haven't you contacted us before now', you know. So, I was frustrated and annoyed more than anything"* (67-74) [N03.1][Female non-shock partner].

The second cause of anger identified was when loved ones were denied immediate medical treatment. Being put on a waiting list for an ICD, resulted in anger and indignation for one female partner: *"... We were quite happy to have it [ICD],... I said 'right ok, how long is this now, just a couple of weeks?' 'On dear me no, not till January'. I said 'excuse me, you've just told me that without this device you know ,, in so many words, he's not going to last?' 'Yes, well you know, we've got a list'. I wasn't happy about it and said 'you know, I don't think this is right. You're* *telling me that he needs this and he needs this as soon as possible and you're saying three months'.... he's worked in the pit and you know, he's paid in all his money, why shouldn't we have had it straight away, that was my belief anyway"* (70-91) [N04.1][Female non-shock partner].

The fact that N04.1 had been aware that her husband's health had been slowly deteriorating and she had failed to respond to the decline, might have contributed to this anger as she may have felt somewhat guilty that she had not been proactive. Her action of displacing blame and anger towards the NHS and away from herself, absolving herself of guilt meant she was able to maintain some sense of self-preserve: *"... I'm disgusted 'cos they probably could have found out before his heart got so weak ... We didn't find out till it was chronic heart failure .. We should have found out long before that but we didn't ....it wasn't until he couldn't breathe, they had to rush him in .. I thought I've seen this coming on' .. but I didn't know, I didn't know about it. So it could have been caught a lot earlier, so I mean I'm not happy about that ... "* (49-62)[N04][Female non-shock partner].

The third source of anger and frustration came from partners who found out the patient needed the ICD due to a genetic cardiac condition (e.g. cardiomyopathies and channelopathies, see Chapter 2), and as such children and other family members might also be at risk of sudden death. McDonough (2009) found participants in her study were also angry that their children might have inherited a life threatening cardiac condition, although McDonough failed to explain if the anger was voiced from patients or partners nor at what in particular the anger was directed. As McDonough's (2007) study was a US study with US laws governing genetic testing, her participants were allowed to be proactive in arranging for their children to be tested for a heritable condition.

The laws governing testing in Britain however are different to the US and partners with children who might have inherited a cardiac illness voiced much anger with the NHS. Partners perceived the NHS as being obstructive that was putting their children's lives at risk. It appeared that not only did the NHS not fund DNA testing, which would have given families some certainty about whether their child had inherited the gene but current British law governing genetic testing also prevented parents from funding their own test. Partner N19.1 described how he felt when he learned he was denied the right to pay for his daughter test: *"We've also got a lot of worries about [daughter], to think there's a 50 percent chance that [daughter' could have what [wife] has got. ... well they said the only way to tell is a DNA test, which there is no funding for and I said well I'll pay for a DNA test, and they said you're not able to pay for it. And I thought what type of crazy place are we living in ... it just doesn't make any sense to me ... they got a way of possibly preventing something with [daughter] .. but yet there's no funding for it ... it just doesn't make any sense whatsoever .... and it is annoying cos there is something they can actually do but they don't"* (655-680)[N19][Male non-shock partner].

The frustration and anger that partners vented during the interviews suggested that partners carry an extra burden of not just caring for their ICD-partner but if a heritable condition is involved then they also have to find ways to protect their children against the risk of sudden death. Although N19.1 reported that he had been advised by his Doctor to write to his MP to add weight to concerns about the right for DNA testing, he had not done so despite becoming very agitated during the interview. His inability to be proactive in getting his child's DNA tested, coupled with a lack of opportunity in which to vent his anger, might have resulted in him feeling a sense of powerlessness and learned helplessness.

This study's findings for heritable conditions has not been substantiated by other studies as developments in the understanding these conditions such as Brugada syndrome or Long Q-T syndrome are recent discoveries (Fowler, Cerrone, Napolitano, & Priori, 2012). This may explain why there is a dearth of literature focusing on the psychological adjustment to living with one of these conditions and suggests further research is needed in these areas.

The partners of shock patients also felt frustrated and angry towards the NHS. Female shock partner S05.1 found herself frustrated with the NHS system in a similar way to non-shock partner N19.1. Both had despaired at the haphazard treatment of a heritable cardiac illness. Both had raised the concern for children who might be affected and both were frustrated with the lack of information about the patient's illness: *"it's a bit fractured I have to say. Cardiomyopathy treatment is quite strange ... I would have thought you have a patient, get them on an ICD, stabilise them and then investigate what the causes are and go from there. There's* *two reasons ,,, it's good to be done early, secondly if it does look like it's genetic ... Husband has two children from his first marriage and they could .. be carriers of those genes .... so it does seem to be a bit haphazard the treatment I find .. I get frustrated, I feel not enough information is given to patients"* (162-177)[S05.1][Female shock partner].

Female patient S05.1 feelings of frustration were probably exacerbated by her natural coping style, which was to be organised, methodical and scientific in an approach to a problem. The NHS's seemingly haphazard treatment plan clearly angered her: *"I get frustrated. I feel not enough information is given to patients. I don't know if this is the scientist in me, but I almost want a flow chart with 'this is what he has, these are the possible reasons, this is what we're going to do for each one, and these are the outcomes. And we're going to follow this time-table'. But it doesn't happen like that"* (176-181)[S05.1][Female shock partner].

The last source of anger was evidenced in one patient who felt that the doctors had not taken her husband's symptoms seriously, and did not come up with a diagnosis but suggested that she should allow her spouse to 'relax': *"... they didn't come up with .. the diagnosis ... I feel quite strongly ... maybe I'm being hard on the doctors, maybe it was difficult to diagnose ... It was quite worrying. Because I went with him to one appointment .. I can remember saying to the doctor '.. he's having – what do I do when he does this?'... It was a worrying experience, very worrying, so it was really 'oh, he'll be fine, he'll be fine ... I was told .. it wasn't a problem. You know, 'let him relax, he'll be alright after a while'. ... Looking back on it, I'm probably more angry about it now, I mean it was very concerning every time it happened because it wasn't a very nice experience"* (41-102)[S01.1][Female shock partner].

First Order Theme: Frustration and Anger with the Patient

Some partners voiced much frustration with the patient and their unwillingness to accept the ICD. The partner's frustration was often borne from the fact that their loved ones did not share their beliefs that the ICD was a lifesaving device. Partner N16.1 voiced how he often became angry with his wife because she failed to see the simple saving benefit of the ICD. N16.1 failed to empathise with the emotional impact that the ICD had been having on his wife and subsequently he often went for a walk to calm his anger down: *"I've tried to explain, 'no, you've got a better bloody chance than we have because you've something to trigger your heart back .... And I don't know how to explain, I can't get through [how does that make you feel?] .. very frustrated. You know, sometimes I just got to go out and take a walk and calm myself ...* " (74-86)[N16.1][Male non-shock partner]. Although the walk helped him to calm down, partner N16.1 reported that his respite from anger was short-lived.

The frustration that partner N16.1 felt towards his wife might have been exacerbated by having to care for his wife. Before she had her ICD, she used to look after him as he had a bad spine and arthritis. Therefore, some of his frustration might be from feeling aggrieved that he was being made to relinquish his sick role identity: *"... she's a lot slower than what I am now [post-ICD]. Where I had the problem with arthritis and a bad spine ... it's all changed ... And I say 'come on! You should be jumping over your bloody head, you're six years younger than me"* (88-99)[N16.1][Male non-shock partner].

Albarran et al. (2004) had also found that some partners were less tolerant of taking on a caring role however rather than becoming angry and frustrated, participants in their study had become guilt-ridden and distressed. Interestingly, the patient of partner N16.1 had commented during her interview that she had always been the carer for everyone in the family, and now she felt it was her 'turn' to be cared for. Therefore, it might be that she also appeared reluctant to relinquish her newly acquired sick role. In addition, the reluctance of the patient or partner to relinquish their sick role identity might be a sign of marital discord, which might need to be addressed before the patient is able to accept the ICD.

Partner N10.1 also voiced anger and frustration towards her husband. However, it is possible her anger was displaced anger for she believed that her own father, who had died prematurely, might have been saved given the opportunity of an ICD. These feelings might have contributed to her lack of tolerance towards her husband's ambivalence and resentment towards his ICD: *"I really do thing that sometimes he's you know, just feeling a wee bit sorry for himself. ....If I had something, to be honest I'd just be glad somebody had saved me. I would have loved my father to have had it [ICD]"* (260-265) [N10][Female non-shock partner]. The finding that partners complained when patients felt sorry for themselves was also found in Williams et al. (2007) study. The evidence of misplaced anger suggests that when a family member develops an illness, this illness does not occur in isolation but can trigger feelings of resentment, anger and frustrations in other family members that might not hitherto ever be expressed impacting negatively on their mental health.

The anger and frustration felt by the two partners N10.1 and N16.1, in our study was probably not helped by the fact that their sleep was routinely disturbed because they had to wake up to calm their upset spouse. As the partners did not comment on the fatigue associated with interrupted sleep, their apparent acceptance of disturbed sleep highlights the unseen burden that some partners have to cope with. It appeared that female partner N10.1 was woken regularly during the night by her anxious husband: *"I think we're very lucky, very lucky you know ... We've perfectly healthy children, grandchildren. ... When he [Steve] worries, it worries me, 'cos I think that's like a strain ... that why I get him out of it quickly, if it's 4 o'clock in the morning, 2 o'clock, he will lie awake and stress himself out and things get worse .... If we chat for half an hour, he'll be snoring within 5 minutes an... And he'll be like 'oh thanks Mary for that', and I'll be like 'it's the truth Steve ... I've just told you what we actually have'.... I always think the worst thing that can happen is something happen to one of the children" (277-297) [N10.1].*

Similarly male partner N16.1 described how his nights were far from peaceful: *"She still has nightmares, we've got to separate the beds ... she's frightened of dying, she thinks she's going to die .. she was violent in bed .. she was sleeping and she was kicking and punching me and I said 'I can't cope with this ... but even though we're separated now, she still keeps me awake most nights .... . and sometimes she'll be crying in her sleep and then she'll wake up heavy breathing. I've got to wake up and sit with her, calm her back down, 'breathe normally, you're alright, nothing's going to happen, you're fine' (45-184)[N16.1]*

Male partner S23.1 was frustrated with his wife, as she would not appeal against her disability benefit application, which had been rejected. He seemed frustrated by his wife's attitude about the ICD, and her not wanting other people to know about it, and also by her refusal to contest: *"The only thing I had my hair off in the beginning and it's a bit worrying now ... she won't [apply for] disability. ... Well while she got the* *ileostomy and it's the pacemaker and defibrillator now and she still won't [apply for] get disability allowance ... I know [people] and they get it, her sister's got an ileostomy, she gets it. She won't appeal cos she's worried about people knowing [about ICD]* (285-291)[S23.1]. His frustration with her might have stemmed from his anxiety and fear that he might not be able to care for his wife in the future and his concealment of worry from her (see Concealment below). If his wife had a disability allowance, it might have taken the pressure off him to provide and look after her adequately as clearly this was troubling him (see Anxiety and Fear above).

First Order Theme: Frustration with the Situation

Male shock patient S05 and partner S05.1 were newlyweds and until the husband's diagnosis they had led very active lives: *"... we don't do as much cos 'husband's always tired ...I get a bit bored. You know, I wish we could do a few more things but I understand. I'm understanding that husband doesn't want to do it cos he's tired. It's his work you know ... and I say perhaps we ought to look at what you do ... and think about doing something else but he can't, he loves it. I think if he stopped doing what he enjoyed, that would be it ... that would take away any kind of purpose in life .... it would just be nice to do more things I guess"* (506-525)[S05.1][Female shock partner]. Her feelings of frustration were possibly pertinent because they were newlyweds and had expectations of an active future. She tried to overcome the source of her frustration by taking an active approach, i.e. asked her husband to change his job, but his refusal likely added to the futility of the situation. Although she feared of her husband dying, she concealed these fears and tried to be understanding with his decision to carry on working in a physically demanding job (see Concealment below).

Frustration due to a shock might have been more relevant to shock partners, as this meant the patient could not drive for 6-months. Partner S01.1's anger outburst at her husband's shock might have been because she had been trying desperately to return to normal, which included her husband being able to drive and be independent: [How did shock make you feel?] *"Cross initially ... you know, flipping heck, that's another 6-months he's not going to be able to-to drive ... I wasn't worried because he was-he was fine"* (150-153)[S01][Female shock partner].

GENERAL DIMENSION: COPING WITH AN ICD

Second Order Theme: Problem-Focussed Coping

Lazarus and Folkman (1984) suggested that problem-focussed coping strategies are more probable when situations are appraised as being more amenable to change. They suggested that problem-focussed coping includes an objective, analytic process that is focussed primarily on the environment or it can include strategies that are directed inwards. Examples of strategies that focus on changing the environment or stressor include monitoring patients, and protective behaviours.

First Order Theme: Becoming Informed

Becoming informed was an example of a problem-focussed strategy that aimed to change cognitive appraisal by becoming as informed as possible about the device their loved one's illness. This active way of coping generally brought reassurance: *"... at the time I thought that it (relationship with partner) possible could change, hugely ... and then when I read up on ICDs and all that, then I reassured myself .." (64-66)[N14.1]. And female partner N10.1: "... I've nothing but positive things [about the ICD]. Cos I've read up"* (130-131)[N10.1][Female non-shock partner].

Albarran et al. (2004) found partners needed more than technical information about the ICD in order to feel confident as the sole carer once the patient had returned home. Despite asking the nurse questions and trying to become as informed as possible about the device, partner N06.1 continued to worry, which suggests that becoming informed is not always sufficient for some partners to feel confident about the ICD and who may need extra support and reassurance. Feeling responsible for a partner's survival during a cardiac event was clearly overwhelming at times: *"Well I ask a lot of questions ... the nurse was good ... she explained about the box and this and that and you think 'right, ok that's what you do .. but you still worry ... I'm frightened in case I don't do the right thing"* (284-305)[N06.1][Female non-shock partner].

The gathering of as much information as possible was a coping style for partner N19.1: *"I'm a sort of information gatherer, if something's happening, I'll want to* *find out everything we can about it, which I found pretty difficult when it came to this ICD"* (167-170)[N19][Male non-shock partner]. This coping style of monitoring (see Miller, 1988) might have allowed his wife the freedom to adopt a blunting coping style approach as she knew her husband would tell her any important information (see 'Cognitive Avoidance' below). Case, Andrews, Johnson, & Allard (2005) posited that becoming informed reduced uncertainty, which in turn should reduce anxiety (thus having both an instrumental and emotional value). However, partner N19 remained anxious and mistrustful of the ICD, despite becoming informed. Lazarus and Folkman (1984) however suggested that people could become trapped in a cycle of information gathering and evaluating, which in some people could further exacerbate emotional distress.

The background of partner N19.1 might not have helped. Coming from a background, which involved having an in-depth knowledge of computers resulted in partner N19.1 realising how unreliable technology could be. This doubt in its reliability coupled with his coping style of information gathering possibly added to his mistrust of the device: *"... I think the biggest problem is that I tend to look at things on the net and stuff like that which I shouldn't .. so you don't always trust [the ICD] .. I know they have got a good success rate but still they're not [100% reliable]"* (119-122)[N19.1][Male non-shock partner].

His wariness was further heightened when his wife's leads moved and had to be re-aligned, which made him highly sensitive to any information surrounding defibrillator leads. *"The trouble is Medtronic were taken to court over their cables and this is the first thing that comes up when you put it in to search .... but it makes you think, how do they know they got it right now?"* (506-540)[N19.1][Male non-shock partner]. Therefore, although seeking information and being knowledgeable about a medical condition/device can be useful in allaying fears, it can also be counterproductive and add to partner fears instead of reducing them.

Only one shock partner engaged in becoming as informed as possible, which suited her coping style: *"My coping is I've got to know everything inside out ... I need to know things"* (359-366)[S05.1][Female shock partner]. Her coping style resulted in her becoming more informed as she learned about cardiomyopathies and the ICD from research publications and forum groups. This in turn helped her to feel more reassured about symptoms that her husband experienced, however this way of coping might also have exacerbated her feelings of frustration towards the NHS, who she felt were treating her husband in a haphazard manner (see first order theme: Frustration and Anger with the NHS above).

First Order Theme: Monitoring Patient

Female partner N06.1 and male partner N19.1 wanted to constantly monitor their patient's whereabouts and wellbeing when the patient returned home from hospital after their implant. The partner's need to monitor the patient may have arisen from the circumstances that had surrounded the patient's cardiac event as in both instances, N06.1 and N19.1's presence at the patient's SCD meant that the survived as the emergency services could be alerted. The presence of male partner N19.1 at the time of his wife's SCD was opportune, which might explain why he continued to check on her wellbeing. His monitoring behaviour peaked after his wife was discharged from hospital. Although his checking behaviours slowly decreased over the subsequent months, he continued to occasionally check on her to see if she is breathing: *"... when she first got home, I was still a bit .. I still am. Not so much leaving her on her own but I do actually check her occasionally, you know like prod her"* (25-27)[N19.1][Male non-shock partner].

Patient N06 had been implanted with his ICD for a year and his wife (partner N06.1) continued to check on him several times a day: *"... I'm frightened, I don't sleep .. because I'm watching him all the time ..."* (90-91)[N06.1][Female non-shock partner*]*. Partner N06.1 explained how her husband's SCD had occurred in the same year that she had experienced another extremely traumatic experience: *"... my brother .. he hung himself in my mother's house, and I had to cut him down ... so of course now I panic, I'm terrible ... I panic terrible and within a year you can say, ... I had two people dead on me that I couldn't understand"* (201-206)[N06.1][Female non-shock partner]. The fact both traumatic incidences had been sudden with no forewarning, it was possible that her urge to keep checking on her husband stemmed from a need to prevent another death: *"Dr said it won't prevent .. heart attack, ... it gives you a warning. ... so it's given you a warning, and that's what's put my mind at ease .. there'll be no going upstairs and finding your husband dead in bed"* (136-

142)[N06.1][Female non-shock partner]. However, despite her belief that the ICD would warn her if her husband needed help, she continued to remain fearful of finding him dead.

Accordingly, checking and monitoring behaviours of partners were often complex and were sometimes driven or being maintained by previous traumatic events. As the checking behaviour of partner N06.1 continued up to a year with no respite e.g. *"... I like him to go with the phone ... he goes to work every day and in between 10 and 12, he'll phone me ... Well if I don't hear from him, I panic .. I'll worry, I'll phone work and ask them 'is he alright?" (376-380)[N06][Female non-shock partner],* it is likely that her behaviour has become maintained by operant conditioning (see Skinner, 1948). For instance, when N06.1 checked on her husband and her anxiety decreased, the reduced anxiety acted as a negative reinforcement . Albarran et al. (2004) also found partners made sure they knew the exact whereabouts of the patient so they could be monitored, but found that the number of times checking occurred tended to decrease over time.

First Order Theme: Protective Behaviours

Mert, Argon, & Aslan (2012) suggested the partners in their study were more protective over the patient if the patient had experienced a SCD. However, this present study found that partners tended to become more protective of the patient after their implant whether or not a SCD had been experienced. This protective behaviour appeared to be a typical reaction especially in the first few weeks post discharge from hospital. One partner whose husband had experienced a bout of VT gave him an identity tag in case he collapsed: *"For Christmas I bought him a dog-tag (laughs). A heart-shaped dog tag, he'll kill me for it I know ... his name, ICD, and a telephone number ... "* (251-253) [N03.1][Female non-shock partner]. Another example from N06.1 demonstrated protectiveness: *I've bought him a jacket, and trousers and I told him 'you're not going (fishing) unless you're warm'. So he's had new waterproofs and I've bought him tidy boots for him to walk .. as long as he takes his phone with him .. it's just that little phone call, just knowing .. puts your mind at ease*" (413-424) [N06][Female non-shock partner].

The increase in protective behaviours might be explained by an increase in emotional closeness felt towards the patient by their partner after the cardiac event, which was reported by some partners. For instance partner N06.1 explained that her husband's cardiac arrest had changed her priorities: *"... it is a very big change ... for the better ... it has brought us closer ... as a family and as husband and wife ... before ... my children came first, and my husband came second .. but since the heart attack and this [ICD], he comes first ... my husband comes first, he's the most important ..."* (458-462)[N06][Female non-shock partner].

Partner N17.1 decided to take early retirement so he could increase the time he spent with his wife. However, he also wanted to increase the time he could spend protecting her: *"I'm not overly happy about [wife] being on her own. Cos the whole idea of this thing is that at some stage this is going to kick in ... so I suppose what I try to do is try to increase the amount of time I'm with her, rather than leave her on her own"* (132-139)[N17.1][Male non-shock partner]. Albarran et al. (2004) and Steinke et al. (2005) also found partners carried out protective behaviours in an effort to cope with their patient's illness and ICD.

However, the strategy of being protective and monitoring the patient, which was employed by a shock partner was clearly maladaptive both for him and his wife. For instance, partner S23.1 was so overprotective towards her that she had earlier complained about this, explaining that his over protectiveness had made her feel an invalid, which she had asserted she was not. Neither had it been an adaptive coping strategy for himself as he constantly worried about his wife, despite being overprotective and constantly checking on her every 5-10 minutes.

In turn, this approach to protect his wife was clearing slowly wearing him out and stopping him from engaging in his own hobbies as well as feeding his fears of not being able to cope in the future: [How do you feel about leaving wife on her own?] *"oh, very, very wary. If I do go up the shed, I got some old cars up there, I like to go and play with, but we got walkie-talkies. ... if I go up the shed for anything, even to get a stick of coal, I take the walkie talkie with me, so she can press the buzzer if she wants me like"* (88-92) [S23.1][Male non-shock partner]. And *" yes [I ring her] to see if she's alright [every] five minutes, 10 minutes ... cos it's a worry. Even when she goes to the toilet ... now and again she's out there changing herself [stoma] and*

I'll go and say 'are you alright love?" (96-106)[S23.1][Male non-shock partner]. However, it might be that her children were also feeding his fear as they were also overprotective and expected him to be with her at all times. The finding families used coercion to protect the patient was also found in the study by Albarran et al. (2004). They found partners had coerced family members into sanctioning restrictions on the patient.

Second Order Theme: Emotion-Focussed Coping

According to Lazarus and Folkman (1984), emotion-focussed coping strategies are more likely to be used when there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions. This form of coping can take place as reappraisal of identity and control, acceptance, or lessening emotional distress such as becoming cautious, seeking reassurance, venting and denial and religious coping.

First Order Theme: Re-Assessing Role Identity and Control

Some partners found they had to reassess their identities as husband and wife, and renegotiate roles that they had previously carried out before the patient's implant. Albarran et al. (2004) found that partners were determined to regain a sense of control and balance in their relationship, which was also supported in this study. For example, partner N03.1 was determined that family life would continue as before her husband's implant, which included going on a family caravan holiday that had been planned before the patient's cardiac event. Although the patient usually drove the towed caravan, the partner learned to carry out this task. Learning this new skill helped her feel empowered and gain some sense of control and mastery, helping her cope with her husband's ICD: *".. We booked a caravan holiday and Tom wanted to cancel it and I said no, and that I would tow the caravan .. Petrified of doing it, but I did it .. and cos I remember saying to him, what if it happened when we were away? You know, how would I get the caravan back. It was six-months of learning for both of us ... you know, I can do things as well as him, and he can do things as well as me, type of thing"* (736-742) [N03.1][Female non-shock partner].

Partner N14.1's role had also been challenged but like N03.1, she was also determined to adjust to her new role: *"... And I was think there was a bit of 'Crickey, this is my big, strong boy and he's supposed to be looking after me' and he has always looked after me, very well ... and the tables have turned you know. That was quite hard to come to terms with ... that was-although I would always look after him .. It changed my whole perspective on our relationship"* (55-60) [N14.1][Female non-shock partner].

Whereas N03.1 and N14.1 were willing to adopt a new caring role, male partner N16.1 resisted the change to his role and instead grew angry and resentful towards his wife (see first order theme: Frustration and Anger with the Patient, above). Partners N14.1 and N16.1 now had to take care of the patient, whereas before they had been the ones being cared for. Partner N14.1 was able to draw upon her knowledge of living with a chronic illness and was able to empathise with the patient. She allowed the patient peace and time to recuperate and adjust to his ICD: *"... I felt he needed time to heal himself up here [points to head]; which you do don't you, especially when you've always been very, very well. ... You've got to come to terms with it before you can go any further"* (538-541)[N14.1][Female non-shock partner]. However, although partner N16.1 also reported having personal experience of a chronic illness, he had resisted swapping care roles and at the same time was unwilling to give his wife time to adjust to her ICD.

First Order Theme: Being Cautious

During the first few weeks post-implant, partners were too frightened to engage in sex because of the fear of triggering the device. However, over time, the fear slowly dissipated and couples reported that they had managed to resume normal sexual relations. Although partner N16.1 was frustrated that his wife could not accept her ICD device, it was his wife had wanted to resume sexual relations with him. At first, he had refused to engage in sex, as he had been frightened that the device would fire through their mounting excitement: *"... [has ICD affected your relationship?] Yes, sex wise I was frightened to-to have sex, in the beginning because I thought all the excitement and everything is going to trigger the ICD off. But the Arrhythmia Nurse put us straight ... She said you're quite safe to have a normal sex life again. Cos Jean* *wanted sex all the time, and I was-I push her away... We're not back to normal but more sex, I have more of a sex drive than I had at the beginning, I was frightened to do anything"* (526-545)[N16.1][Male non-shock partner]. Even though partner N16.1 had been reassured by the nurse that sex was safe, one-year on, they had not managed to resume their normal sex life. This highlights the fact that at a time when patients may need physical intimacy, it can be the partner's fear of the device that prevents them from having sex. Steinke et al. (2005) had reported that some partners had drunk wine before sex to try to reduce the fear of triggering a shock therefore suggesting this type of fear from partners were not uncommon.

First Order Theme: Seeking Reassurance and Control

Some partners wanted emotional reassurance from other partners in similar situations to themselves. Many partners found reassurance when they attended a support group in which they were able to meet other partners of ICD patients. Partner N03.1 found attending support groups and hearing others talk about their loved one's ICDs helped her as she coped with her husband's ICD. She drew comfort from hearing other people talk about their experiences with the ICD: *"I think what has helped is that we've continued to go to the support groups. ... The support group is there for that type of thing you know, for people all in the same boat and you've got the partners there as well and you're just generally trying to help each other with that little bit of support .. and 'it's not just me.... I found them (support groups) very use-.. very, very good, in that it gives you that little bit of extra knowledge ... learning and listening to other people's experiences has given us a bit of .. confidence .. ... touch wood it won't go off, ... if you know that happened, it's normal then, it's a normal function ... it's the talking bit"* (146-180)[N03][Female non-shock partner]. By hearing stories, partner N03.1 was able to normalise shock firings, and she found comfort from hearing patients talk about their shock experience. Again, partner N03.1 reiterated what partner N19.1 had previously suggested; that partners have a need to talk about their experiences living with the ICD (see ' Traumatised by cardiac event' and 'Anxiety and fear of repeat cardiac event' above).

First Order Theme: Frustrated Venting

Partners N19.1 and N16.1 had vented their frustrations and anger with the patient and the NHS during the interview process (see 'Frustration and Anger with the Partner', and 'Frustration and Anger with the NHS' above). However, partner N04.1 used venting as a coping strategy when feeling hopeless and powerless to help her husband whom she feared was very poorly. She reported she used to cry all the time in the early days after her husband's implant, when she feared her husband was worsening. She used to vent her fears and worries at her youngest son over the phone in an effort to alleviate her fears: *When he came home from hospital ... I didn't cry in front of him .... my youngest son, he was with us all the time you know ... and he was on the phone all the time ... so I used to tell him how I felt ... I was crying all the time ... because I could see nothing was happening ... it was getting worse .. it was just really traumatic really"* (181-190)[N04][Female non-shock partner].

The fears that partner N04 had about her husband's heart condition might have been compounded by the way in which the doctor had broken the news. She had clearly been very distressed at the time, which might have caused her to perceive a higher level of threat when the doctor told them the diagnosis. Her heightened distress might have caused her to elaborate and catastrophise what the doctor was trying to convey: "*...they kept telling us that 'your heart is very, very weak' you know .. they didn't actually say .. 'you're going to die' like .. but they may as well cos that's what they kept on telling us, 'you're very, very weak', not 'you're just into heart failure' .. it was 'you're into* ***chronic*** *heart failure' ... "* (168-172)[N04.1][Female non-shock partner]. All though this highlighted how people elaborate messages when they are anxious and frightened, it also highlights how an elaborated message influences subsequent beliefs. This might have clinical implications; after hearing a diagnosis it is important to check that patients and families have processed accurate information about the illness.

First Order Theme: Denial/Cognitive Disengagement

Female partner N04.1 admitted that she and her husband no longer spoke about the ICD: *"We never talk .. Well, we talk about ... we laughed about it when he first had it* *done but I think as time's gone by .. it's a year now ... you just don't put it into your life .. We don't 'oh don't get him worked up, he might have a shock'... we don't do any of that"* (258-262)[N04][Female non-shock partner]. From her account that she no longer spoke of the ICD, it could be deduced that she had finally accepted it. However from her other behaviours such as avoiding reading information about the device (see 'Cognitive Avoidant Coping' below), it can be suggested that she might be in denial – she was enjoying her husband's 'good' health, and she was refusing to think about anything that might threaten this equilibrium. The cognitive emotion-focussed strategy of denial appeared to be adaptive for partner N04.1 in that it helped to manage her fears so that she could enjoy life again.

First Order Theme: Maintaining Self-Esteem

Maintaining self-esteem appeared adaptive and raised morale and positivity. Interestingly this way of coping was used by female partners S01.1 and S05.1, who earlier were the only two who had vented anger and frustration towards the NHS. Perhaps venting anger had led to feelings of solidarity and defensiveness on behalf of the patient, whose lives they felt had been put at risk: *"... luckily he's got a healthy heart, yes, well it's the electrics that-he had no clogging, his arteries were-didn't have any problems"* (72-78)[S01.1][Female shock partner]. And *"Husband's cardiomyopathy, he's coping so well with it ... he does a lot of active outside work and even though he might be slower than he was ... he can still do it, which we've been told is fairly unusual. And we put it down to, he was very very fit before he had the attacks, he used to play a lot of rugby and to his mindset 'I'm not going to be beaten by this"* (181-193)[S05.1][Female shock partner].

First Order Theme: Concealment

The emotion-focussed coping strategy concealment was used in order to protect the patient from worry but was clearly an unhelpful coping mechanism for partners. Concealment meant that partners did not express their fears to their loved ones, which if they had, might have changed the situation for them and their patient for the better. For instance, S05.1 concealed from her husband her fears about him dying:

"... I don't really tell 'husband' about those [fears of him dying]. You know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful" (116-118)[S05.1][Female shock partner]. However, if she had broached this worry with her husband, it may have encouraged him to be more careful at work and to delegate the more dangerous jobs to others rather than undertake all the workload on his own shoulders. This would have meant he would have a less physically demanding job, which might have made him less tired that was a source of distress to the partner.

In the same way, if partner S23.1 had expressed his fears that he may not be able to look after her in the future, it may have facilitated a conversation. In this conversation, the patient might have been able to express her feelings of loss and about feeling overprotected, which might have been cathartic for both: *"The defib's wonderful fair play .... There is an element of worry with it. I don't tell the wife to protect her more than anything. She'll say now and again 'you worried ain't you? 'oh yeah, a little bit' but I play it down"* (350-357)[S23.1][Male shock partner]. Therefore, although partners wanted to protect their loved ones from unnecessary worry, concealment appeared to lead them to overprotective the patient that was maladaptive to both patient and partner.

Partner S05.1 was a scientist and explained that she used rational logic as a coping strategy to reduce her worries about the ICD: *"... I don't really tell 'husband' about those [fears of him dying]. You know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful, so I keep it to myself and rationalise it away – he has the device, it works, it's been checked"* (116-119)[S05.1][Female shock partner]. However, this strategy did not appear to be adaptive, as partner S05.1 continued to be anxious. This highlighted how cognitions cannot easily be changed (see General Discussion)

First Order Theme: Acceptance

The significant majority of partners in this study were able to accept the reality of their situation by one-year post implant. This acceptance was achieved using various emotion-focussed strategies. The majority of partners found the ICD gave them reassurance and peace of mind, which was closely related to the belief that the ICD was lifesaving. Partner N14.1 reported: *"I was just very, very relieved with he finally got it sorted. I feel safe ... I just feel safer with it ... I feel happier now it's done"* (186-196) [N14.1][Female non-shock partner]. And from partner N08.1 *"... to me that's the only benefit (reassurance), that's all that matters, it's our insurance policy. There's no other tangible benefits, but I mean what other benefits do you want? That's the only one you want isn't it, she is no better or worse than she was before, it's just reassurance, that's the only benefit isn't it?"* (107-111) [N08.1][Male non-shock partner]. And: *" ... they (the surgeons) said it might happen again, but if it does then she's got this (ICD) and ... I'm not worried at all ... I just feel confident that if should something happen again, then, you know the device is there to shock the heart back ... "* (64-77) [N08.1][Male non-shock partner].

Shock partners also found the ICD gave them reassurance: *"The feeling that I've been given is that he is much better protected now than he was before, so therefore that's got to be good. So, I think you've got to from the initial being diagnosed then you've got a period of being worried about it all, and then you get through that and hope that everything will be ok"* 385-390)[S01.1]. Partners expressed gratitude to God and to the ICD its ability to shock someone back to life. For instance female partner revealed *"I think the ICD is nothing but positive. You can't get away from what you've got can you? You've got to be thankful you've got a device that can-it's ridiculously incredible!"* (322-324)[S15.1]

Partners were often the parent who had to explain the ICD to children, especially if the patient was hospitalised. Partner N03.1 had personified the ICD; although their children were teenagers, she believed it would help them accept the ICD. It also implied that that the ICD was going to be permanent fixture: *"..... It's a person. . .. it's a 24-hour paramedic .. it's there to save his life if it needs to go off' ... we call it CID, that' the only way we can accept it ... it's just an extra member of the family ... he's there as a 24-hour paramedic"* (118-135)[N03.1][Female non-shock partner]. Another female partner N10.1 had also chosen to personify the device but had simplified the ICDs lifesaving abilities to be a more age appropriate explanation for her young son. It appeared her strategy had been successful as he had been quite happy with his mother's explanation: *"My son was asking in the car what you were coming to see us about. ... and I explained to him about Daddy ... and God love him,* *he says 'but Mammy if he had a heart attack, that saves his life', and you know ... I said this .. is the basic honest truth"* (41-44) [N10.1][Female non-shock partner].

However, although male partner N18.1 did not find reassurance from the ICD, he could see immediate positive visual changes in his wife after it was implanted. He immediately attributed her improvement to the ICD, which helped him appraise the device positively: *"... she has come on since she's had it fitted, really, really well. She's a different person. If you'd seen her before her op, she was constantly pale, tired and drawn. Basically she looked like death warmed up like but when she had this done, I say even from the first day she home from hospital ... but the difference in her ... she was back to the old [wife]..."* (123-129)[N18.1][Male non-shock partner].

A shock partner also believed the ICD had given the patient a new lease of life. Female partner S13.1 explained how with the ICD she had been able to make plans to go on holiday with her husband, who was beginning to drive again: *"With the defib fitted, we were flying abroad, we were planning a couple of holidays. ... and we got the motor home, so he was driving, we were going places"* (201-203) [S13.1][Female shock partner]. Unfortunately, the patient S13 developed pneumonia, which impeded his recovery; nonetheless, the partner had perceived ICD as very positive

Whereas, N18.1 could see a physical improvement in his wife, female partner N14.1 was simply grateful to the ICD device which she believed would extend her loved one's life. She was also been grateful that there had been the technology to cope with her partner's illness. Her gratitude for the ICD might be due to her own experience of living with a chronic health condition for which there was no lifesaving technological device. She said *"I am happy, I am so pleased that he's got this thing [ICD] ... I mean he could be in the situation that he had something like this [Brugada] and there was nothing they could have done about it, so great!"* (509-512) [N14.1.][Female non-shock partner].

Three partners, including two non-shock partners and one shock partner demonstrated that they had a resigned acceptance to their situation. Therefore, although they had accepted the situation, it was because they felt there was no choice of treatment but the ICD: *"I think we're both sort of ... calm ... we deal with things, just get on with it really. ... I think in the early stages of these things, as with* *anything, you realise you're mortal ... And you somehow have to cope with that ... and then you have to get on with your life because ... that's what you have to do, isn't it ... so, we're both on medication for life"* (260-272) [N11.1][Female non-shock partner].

Female partner S05.1 found she had accepted the device but only due to becoming normalised to it over time. Accordingly, she did not perceive the device positively but rather she had learned to accept the ICD merely by becoming used to it. When asked what had changed after six months, she had replied *"...I got used to it, that's all it was, just got used to the fact he was dizzy and what it meant. It didn't mean he was going to collapse, it was part of his treatment"* (237-239) [S05.1][Female shock partner]. And, *"I've known 'husband' more with the ICD than I've known him without it, so it's get-you kind of get normalised don't you?"* (525-527)[S05.1][Female shock partner].

One benefit perceived by shock partners was that the shock demonstrated to them that the ICD worked, which gave them some reassurance. Before the shock, partner S05.1 had been sceptical about whether the device would fire when needed and now she felt reassured: *".[husband] has described it as being punched in the back very hard. I guess one thing is that it works, which in a strange twisted way is kind of good. It was there to do the job, so that makes you feel safer in some respects"* (321-324)[S05.1][Female shock partner]. Similarly, partner S23.1 was also reassured that the ICD would be able to bring his wife back to life: *"Well it's reassuring if she does pass out, it will kick her back to life"* (195-196)[S23.1][Male shock partner]. For female partner S13.1, she simply believed that her husband was only alive because of the ICD: *"He's still here, otherwise he wouldn't be"* (114)[S13.1][Female shock partner].

First Order Theme: Religious Coping with Illness

Partner N04.1 used her faith in God to help her cope with her husband's illness. She believed God was testing her husband's faith: *"We are Christians and we do believe ... we believe that it's the Lord that done it [tested him through illness] 'cos we just feel that he was so, so bad that it was only the Lord that could help him. ... I mean* *obviously he's still got the weak heart, and he's always going to have unless he gets a transplant or the Lord gives him a new heart"* (191-196) [N04][Female non-shock partner]. Despite her belief in God and the belief that only He could help save her husband, she nonetheless she had vented her anguish to her son rather than to God, which would be a more likely scenario given her religious beliefs. Her reluctance to vent to God might have been due to several reasons. Firstly she might have doubted God could save her husband, secondly she might have feared that God did not intend to save her husband or more likely the third was that if she vented her fears to God she might be forced to face up to the seriousness of her husband's illness. Her use of denial and cognitive avoidance supported this third suggestion. However, she might well have been unaware of deliberately trying to avoid thinking about her husband's illness in which case her denial was acting more as a defence mechanism. Religious coping for partners does not appear to have been cited before, although it has been cited before as a common coping strategy used by patients in studies by Dickerson (2002) and Palacios-Ceña et al (2011).

Second Order Theme: Mixed Avoidant Coping

At times partners demonstrated a mixture of avoidant type coping in order to avoid facing up to adverse aspects of the ICD. Partners engaged in cognitive avoidance to avoid listening to disconcerting information that might make them feel threatened or took steps to avoid certain behaviours in an attempt to control their anxiety.

First Order Theme: Cognitive Avoidant Coping

Male partner N16.1 and female partner N04.1 both displayed a mixture of cognitive and behavioural avoidant coping. Unsurprisingly, it was female partner N04.1 who engaged in denial and venting (see 'Frustrated Venting and Denial' above), who attempted to avoid distressing information about the ICD and its ability to fire: *"I'll be honest with you .. I put that [shocks] to the back of my mind, because ... if I thought about it .. I don't think I would cope ..."* (256-257) [N04.1][Female non-shock partner]. Cognitive avoidance was used by partners, which appeared to lead to incorrect information. Again, this highlighted the way that partners elaborated messages about illness threats: *"The thinking is at the time, we didn't want to know ... too much you know., ... because ... I mean when me and my son went in, we listened to the doctors ... you sort of look at each other and think, they're not saying .. that it's so .. 'You can go anytime' she said. You don't want to talk about it but that's how we felt, that they were in so many words were saying to us* (409-414) [N04][Female non-shock partner].

In a similar way partner, N16.1 also avoided thinking about the negative aspects of the ICD. Although previously he had expanded on the positive aspects of the device, and vented his frustration that his wife would not accept it, it was evident that he coped with any adversity in life through avoiding disconcerting information, and therefore this was probably his coping style: *"... ... When she started working in the shop, her husband put her down ... and then when she got out of that marriage and came with me ... they offered her the Assistant Managers [job] and she was like 'on no I can't. And I say why can't you do it? Go for it, the sky's the limit, you can do anything you want to .... And that's the same in everything, the ICD, I don't want to know the negatives about it, if there is any, ... All I want to know if the positives"* (323-331)[N16.1][Male non-shock partner]. Whether this way of coping was adaptive for these partners is debatable; partner N04.1 appeared to continue to be anxious despite avoiding noxious stimuli and partner N16.1's refusal to dwell on any negative aspect of the ICD might have contributed to the frustration he felt towards his wife who spoke openly of her fears.

Cognitive avoidance was also evident in shock partners. Unlike female partner S05.1 who was frustrated by the lack of information about her husband's illness, female partner S01.1 chose to remain as uninformed as possible. She had not read any of the literature given to her, and reported that she had put the unread ICD booklets away in a drawer as soon as she had got home. Maybe her refusal to even have the booklets out on show, demonstrated her desire to get on with a normal life. Interestingly, she had been uncomfortable throughout the interview, and explained that she tried not to think about the ICD *"I don't think about it"* (367-368)[S01.1][Female shock partner]. Her cognitive avoidance was helping her to cope with the ICD and therefore this explained why she was initially reluctant to take part in the interview: *"... the nurses .. they're very good .. but I do think they give them so many books to read .. and books make it for me more worrying, because there's too* *much information ...don't ask me to say an example cos I've not looked at a book, one of those booklets. They've gone away [books have been put away]... We're getting on with our life. He has been told .. he's to carry on as normal. So, if there is something he shouldn't do or can't do, we would be told"* (244-280)[S01.1][Female shock partner].

Female partner S13.1 reported a cognitive-type avoidant coping, by simply refusing to think about the shock. It might be that she realised that the device had to fire or else her husband would have died (see emotion-focussed coping above): [when asked if she thinks about the shock] *"I don't think. I'd worry too much"* (99)[S13.1][Female shock partner]. Another possible reason for her avoiding thinking about the shock in order to reduce worrying was that her husband had experienced the shock whilst he had been in hospital and she had not been present. A similar explanation was offered by Albarran et al. (2004), who suggested partners felt upset that they had not been present at the time of the shock, but had ultimately felt relief that it had worked.

First Order Theme: Behavioural Avoidant Coping

Male partner S23.1 experienced a lot of anxiety about his wife; he was afraid to leave her on her own, he did not know what to do if she had a shock and he feared he might not be able to look after her when he got older. In order to cope with his worries, he reported to drink sherry at night: [To stop worrying*] "I'll have a glass of sherry in the night. But I can't have too much in case I got to drive 'er or in case something happens like ... But I know when her son is home, I might have .... a bottle of sherry a night ... I'm quite alright after drinking a bottle of sherry, I like I don't get 'fall-y' over ... I can't afford to get 'fall-y' over in case something happens"* (124-139)[S23.1][Male shock partner]. What was pertinent about his drinking was that he limited his drinking so that he could be alert in case something untoward happened to his wife, which suggested that he lived with a constant awareness that his wife's life could be in danger.

Female partner S01.1 explained how her and her husband had refrained from sex after her husband had received a shock whilst having sex, which she had also felt:

"We've refrained from it [sex] for the moment so that was probably about three weeks ago now... I think knowing he had to stop four weeks driving again might stop 'husband' ... We sort of laughed about it ... but that's where its stayed at the moment ... [refrained from sex because of risk of not being allowed to drive not because of shock?] .. yes [driving] ... it's happened, I mean he had one [shock] ... I was quite close to him and I felt it and ... that's fine ... I say it's fine, but it was no big deal and I think it was a worry for 'husband' really, not for me " (298-312)[S01.1][Female shock partner]. Interestingly, she suggested that her husband had probably been more concerned about the shock, whereas her husband reported that the shock had probably been more traumatic for his wife. Both suggested they had laughed about it, which was likely a common response for patient S01. However, it did not seem to be a likely response for partner S01.1. In both cases, the laughter might have been a defence mechanism. Although laughing about something undermined the seriousness of the situation, interestingly, they had not attempted to have sex for three weeks.

Their abstinence from sex might be because patient S01 had believed his wife had been hurt during the shock: *"I can't see that [wife] would want to run that risk anyway because it sort of-certainly wasn't pleasant. And I mean it says in the book 'would your partner feel a tingle?' Blinking heck it was more than a tingle"* (391-395)[S01][Male shock patient]. Steinke et al. (2005) found patients were worried about hurting the partner, whereas partners were reluctant to initiate sex. In addition, they suggested that partners reacted to the patient's experienced of shock. Accordingly, their abstinence might be due to the patient believing his wife did not want sex because the shock hurt, and the partner feeling too afraid to initiate sex as she was worried that the shock was unpleasant for her husband.

Next:

Chapter 7 – Qualitative Study: General Discussion and Implications to Clinical/Nursing Practice

Part 2

Chapter 7

QUALITATIVE STUDY: GENERAL DISCUSSION AND IMPLICATIONS TO CLINICAL/NURSING PRACTICE

SECTION ONE: *General Discussion: Patients and Partners*

- *Summary of Key Findings*
- *How the Findings Informed the Development of the Complex Intervention*
- *Limitations of study*

SECTION 2: *Implications to Clinical/Nursing Practice*

SECTION ONE: General Discussion: Patients and Partners

The aim of the qualitative study was to explore how patients and partners coped with the emotional consequences to a life-threatening diagnosis, the ICD device and the defibrillated shock. The population of patients recruited included many that had previously been physically healthy. The realisation that they had been or were at risk of a sudden cardiac death and needed an ICD often came to them as a shock. Even for those patients who had suffered a previous cardiac illness such as a myocardial infarction, their need now for an ICD appeared to be met with disappointment and anxiety.

Previous qualitative studies have tended to combine the findings of participants with no experience of shock with those who have had an experience of a shock. This has meant that the influence of shock on participant's emotions and coping with an ICD was often unclear. To rectify this shortcoming, the findings clearly labelled those findings from 'shock' participants and the findings of the shock-cohort were compared to the non-shock-cohort to identify what similarities and differences existed. These findings were then examined to see how they can be related to psychological theory. A cognitive-emotional-coping framework, with particular reference to Smith and Lazarus's Appraisal theory and model of emotion was used (see Smith & Lazarus, 1990, 1993; Smith, 1990; Lazarus, 1991, 1993).

The cohorts of patients and partners[47] between them shared some themes whereas other themes were only pertinent to one cohort (patient or partner). In general, patients and partners experienced similar emotional consequences to the cardiac event such as feeling traumatised, and appeared to have similar anxieties and fears relating to the ICD and its ability to shock. Similarly, patients and partners used similar problem- and emotion-focussed coping methods such as using protective behaviours, avoidant behaviours, venting and acceptance. However, the cohort of patients alone elicited themes such as feeling vulnerable and uncertain, feeling loss, pessimism and regret about having the ICD. Likewise, the cohort of partners also elicited themes only pertinent to them, such as experiencing feelings of frustration and anger at the NHS and at the patient, and utilised unique coping methods such as monitoring the patient and information gathering, which were not used by the patient.

Smith and Lazarus's theory of appraisal and model of emotion (see Smith & Lazarus, 1990, 1993; Smith, 1990, Lazarus, 1991, 1993) was used to help explain the study's findings. Smith and Lazarus's model of emotion suggested that specific appraisals led to specific emotions evoked. These emotions were proposed to have an adaptive function and a direct implication for how people subsequently coped (Smith, 1991; Smith and Lazarus, 1993). Lazarus (1991, 1993), Smith, and Lazarus (1990) examined emotions at two levels. The first level was the individual's appraisal of the situation using singular components of appraisal. The second level took in a broader perspective that captured the central essence of the theme or 'core relational theme', which was proposed to predict the emotional reaction. Support for the importance of appraisal in determining emotion, which was a central tenet to Smith and Lazarus's model of emotion, was found in the themes that emerged from these findings.

Participants who had had a cardiac arrest usually found the event a distressing experience. Non-shock patients as well as shock/non-shock partners appeared to have been traumatised by the cardiac arrest event. The emotional consequence of

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[47] Unless specified 'patient and partner' refer to both shock and non-shock cohorts of participants

'trauma'[48] can be explained by Smith and Lazarus's appraisal theory. As patients were unconscious during the cardiac arrest, appraisals of the event were made after its occurrence. These appraisals were often created from the witnessed accounts of others, who were sometimes quick to emphasise the patient's narrow escape from death. Appraisals made were of threat to life, which if occurred again, might result in death. Partners too suffered from trauma as they had often witnessed the cardiac arrest and realised how quickly, easily and unexpectedly their loved one might have died. For partners, the cardiac arrest was often combined with feelings of helplessness, as the event unfolded. Although Smith and Lazarus did not suggest a core relational theme for trauma, the findings in this study suggested that trauma might be perceived as an exaggerated or extreme form of anxiety.

As the cardiac event experienced had been both sudden and unexpected, with a real threat to life, patients and partners felt a magnified vulnerability and uncertainty about the patient's life at risk. Lazarus and Smith's model of emotion proposed that core relational themes uncertainty and vulnerability led to feelings of anxiety and as such, it could be suggested that in extreme cases, these could result in feelings of trauma. Further evidence that trauma appears to be a similar emotional response to anxiety can be found when taking into account the individual components of Smith and Lazarus's appraisal theory – both have the same motivationally relevant, motivationally incongruent and low/uncertain emotion-focussed coping potential. The fact that feelings of trauma persisted in participants a year after the cardiac death, suggested that that participant's perceived threat to life persisted over time.

The most noticeable themes that were absent from the shock-patient subgroup but were present in the non-shock patient subgroup were 'trauma', and 'vulnerability and uncertainty'. This did not imply that shock patients did not experience trauma, but merely that their focus of distress tended to be the defibrillator shock rather than the initial cardiac event that pre-empted their need for the device. However, as the interviews had been carried out specifically with the aim of finding out about living and coping with the ICD shock, this might have accounted for this particular finding. In the same way, feeling vulnerable and uncertain might be similar to feeling anxious and fearful of the shock. The non-shock patients focussed on the unpredictability of

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[48] Please note that in this discussion the theme trauma represents an emotional consequence of extreme anxiety rather than the DSM-IV-TR criteria of post-traumatic stress disorder.

the shock, which was a fear of an unknown quantity. The shock-patients were also anxious and fearful because they had had a shock, which was an aversive experience.

The experience of a shock appeared to affect the subgroup of shock-partners in a similar way to the initial cardiac event. For instance, after a patient had a cardiac arrest, partners were left with a raised awareness of their loved one's mortality. However, for shock-partners, this heightened awareness of the fragility of life was reinforced after the ICD had fired. Accordingly, although the themes 'trauma', 'vulnerability and uncertainty', 'anxiety and fear' differed by name, they nonetheless comprised the same individual appraisal components. For example, they all comprised the individual components of goal relevance, goal incongruence, along with a low or uncertain emotion coping potential. Because of this, participants had emotions that shared the core-relational theme of fear-danger.

The feelings of trauma experienced by participants might also be explained using Leventhal, Deifenback and Leventhal's (1992) self-regulatory model of illness and illness behaviour. In this dual-processing model, any symptom (e.g. increased heart rate) has a subjective response (e.g. anxiety), which elicits an appropriate coping response. The coping response is monitored and if deemed unsuccessful, it is altered. Both this model and that of Smith and Lazarus proposed an explanation for an emotional consequence to an event. However whereas Smith and Lazarus's model of emotion highlighted the importance of appraisal in producing emotions, Leventhal et al.'s self-regulatory model suggested it was the coping method employed by the individual in response to an event that determined the emotional consequence. Participants in this study might still have felt traumatised because they failed to alter how the cardiac arrest was appraised.

Patients and partners also shared general anxieties and fears towards the ICD and its potential to shock. From participant's accounts, it appeared that having an ICD was reassuring as a life-threatening arrhythmia could be terminated by a shock. Therefore, anxiety relating to the ICD appeared to be counter intuitive. However, according to Smith and Lazarus' appraisal theory of emotion this anxiety was predicted as anxiety is evoked in situations where the core relational theme is an ambiguous threat. The notion of living with an ambiguous threat is applicable to the ICD population, as the shock delivered by the device was often perceived as threatening. The device's ability to shock with no forewarning compounded its ambiguity. Indeed, the uncertainty surrounding how and when a shock would be received appeared to dominate the thoughts of many participants in this study. Therefore, it was not a surprising finding that patients felt anxious living with the uncertainty of a shock.

Lazarus and Smith's appraisal theory (see Smith & Lazarus, 1990, 1993; Smith, 1990, Lazarus, 1991, 1993) suggested that the emotion generated from appraisals had an adaptive function. In the case of anxiety, the proposed adaptive function was to motivate an individual to move away from the threat. As patients were not able to eliminate the threat (i.e. they could not control when a defibrillated shock might occur) they tended to engage in strategies to minimise the threat of a shock. For example, female patient N17 and male patient N11 believed that physical activity might make their heart rate go too fast, so they restricted physical activity.

According to Smith and Lazarus, anxiety is likely to continue if the threat is motivationally relevant and incongruent coupled with a low/uncertain emotion-focussed coping potential. It could therefore be predicted that no matter how hard the patients engaged in problem focussed coping strategies to reduce their anxiety; these anxieties would persist until they could be managed emotionally. Conversely, the emotion focussed coping strategy of avoiding threatening information, appeared to be maladaptive. Patients often appeared to remain anxious despite avoiding information. This gives support for Lazarus's proposal (see Lazarus 1991) that appraisal generation control was often a mixture of conscious and unconscious appraisals – i.e. by avoiding the threat, the threat still exists in the subconscious. Therefore, with the threat still present in the subconscious, it was still able to evoke feelings of anxiety.

Whereas patients often responded to their anxieties and fears by limiting exercise, partners tended to respond to their fears by adopting protective behaviours and monitoring the patient. The partner behavioural response of being protective was sometimes perceived by patients as being *overprotective* and in some cases this meant some patients concealed symptoms. Being overprotective appeared to compound feelings of anxieties and increased existing feelings of loss in patients. As can be seen, it was common for patients and partners to experience more than one emotion at any given time; emotional responses often exist in parallel as the person-situation is usually multi-faceted. In the case of participants in this study, they were often faced with competing demands. For example, having an ICD might mean a patient is not allowed to drive, which might result in them being unable to return to work. This could lead the patient to feel frustrated and angry, whilst their loss of a work identity can simultaneously result in other feelings of loss and might result in sadness and anger.

Patients' feelings of anxiety were sometimes found to be associated with feelings of loss - a loss of their previous self and independence when they had felt invincible and certain about life. Lazarus and Smith's model of emotion, posited an appraisal of loss should lead to feelings of sadness, whose important appraisal components were found in appraisals made by 'sad' patients in this study. For instance, male patients N10 and N14 felt losses that were motivationally very relevant and motivationally incongruent. These patients also felt they had low problem focussed coping potential coupled with a low future-expectancy. The study found that as well as leading to sadness, feelings of loss were sometimes associated with feelings of depression and negative emotions. However, it might not be the feelings of loss that influenced the depressive feelings of patients but maladaptive coping strategies used to deal with these losses.

'Loss' appears to be a common feeling amongst the chronically ill. For instance, Charmaz (1983) analysed interviews taken from the chronically ill (including various diagnoses such as cardiovascular disease, diabetes, cancer, and multiple sclerosis to name a few) and found 'loss' was a common feeling in the chronically ill. However, Charmaz suggested that the feelings of loss resulted from how people coped. Charmaz (1983) suggested that the chronically ill suffered from a loss of self because they led restricted lives, experienced social isolation, felt discredited and devalued and felt a burden to others coupled with a sense of uselessness. This study's findings resonated with those of Charmaz (1983) in that these findings found evidence of the ideology Protestant Work Ethic held (see transcripts N14 and N10). For both of these patients, having an ICD had meant their work ethic's values of independence and hard work could not be maintained. Because they could not return to work, they had a diminished sense of self.

Accordingly, for those patients whose sense of identity was shaped by their occupation, the inability to return to 'normal' i.e. return to work, seriously impacted on their sense of self. Charmaz (1983) posited that unless new selves, new forms of actions, and new lives evolved, people would continue to have a diminished self-concept. This notion was supported by this study in which some of the patients (see N10 and N14), appeared to have a diminished sense of self after realising their losses. Conversely, N03 appeared to adapt his coping in order to experience positive affect, which partly supported Leventhal et al.'s (1992) self-regulation theory. Hence, it might not be the appraisal of loss that led to feeling depressed, but the maladaptive coping strategy that was employed to deal with losses. However, the findings of N10 and N14 did not fully support Leventhal et al.'s theory, who posited that people would alter coping strategies if appraised to be maladaptive, as these patients did not try to change their coping. Instead, they ruminated and vented. These coping strategies merely appeared to compound their sense of loss and increase feelings of negative affect.

Scheier and Carver (1992) emphasised the importance of goals and proposed that when people believed their goals were attainable, they would experience positive affect. They suggested that positive affect, which included pride, gratitude and simple relief (depending on the type of challenge faced) would be felt if the challenge was successfully achieved. Likewise, Scheier and Carver (1992) suggested an inability to attain a goal (or face a challenge) would give rise to negative affect, which encompassed feelings such as shame, anger and resentment. Scheier and Carver's suggestion that positive affect followed attainable goals might explain the positive affect experienced by male patient N03. Male patient N03 realised that although he could not run competitively anymore, he could set himself a new set of goals, which allowed him to challenge himself. In the same way, Scheier and Carver's (1992) model can be used to explain why male patients N10 and N14 experienced negative affect after relinquishing all future goals. It was not necessarily the loss of the goals that predicted their negative mood but their failure to find new goals and ways to be challenged.

The depression experienced by male patient N10 might not have been because he did not feel challenged. According to Lazarus and Smith, the depression might also be explained through N10's blaming of others. Lazarus and Smith posited that the core relational theme for anger should be a 'demeaning offense against me and mine' (Lazarus, 1999 p.96) or 'other-blame' (Smith, 1990). For instance, N10 believed the ICD device was unnecessary and he blamed others for the fact that he had accepted having an ICD, accordingly fulfilling the core relational theme of blaming others. According to Smith (1990), blaming others should result in anger, and this coupled with the ineffectual coping of venting that was used to deal with this anger might have led to feelings of depression – in turn suggesting that feelings of depression appear to be more relevant to the theory of coping than the theory of emotion.

Partner's behavioural response of overprotecting the patient might be due to partners feeling emotionally ill-equipped. Partners felt uncertain about the ICD shock and the fact that they could not control what happened to the patient. The behavioural response by partners can be explained using Smith and Lazarus's model of emotion; partners experienced motivationally relevant and incongruent appraisals coupled with low/uncertain emotion-focussed coping potential. Therefore, in order to cope with their low emotion-focussed coping potential, partners tended to engage actively in problem-focussed coping, some of which were adaptive such as taking protective measures, but also some, which were maladaptive such as overprotecting the patient. Some partners experienced the emotion of anger, which again was line with the Lazarus' appraisal theory; anger was voiced by the partners who were both frustrated and who blamed others for their situation.

The desire to return to 'normal living' appeared to be the primary motivation for partners. This desire was hindered if the patient did not cooperate with or share their motivation. When patients struggled with negative or ambivalent feelings, partners sometimes reacted with annoyance and frustration. Partners often only focussed on the reassurance given to them by the ICD. In some cases, the patient recognised their partner was frustrated with them, which further compounded their distress. Also relevant to partners of patients who had been diagnosed with a channelopathy or genetic cardiomyopathy, were feelings of frustration and anger towards the NHS. This appeared to be a unique theme and which to my knowledge, has not been reported elsewhere in the qualitative literature.

There were differences between patient and partner in relation to the initial decision to have an ICD. Patients who appeared to be struggling to cope with the ICD experienced regret and doubt at the decision to have the ICD. Notably this was found in those who were experiencing anger and sadness. However, all partners, including those whose patient was struggling with the ICD, were simply grateful to the life saving properties of the device and were grateful to the medical professionals. This gratitude can be explained using Smith and Lazarus' appraisal theory, as it suggested the emotional response to giving others credit was gratitude. Interestingly, the proposed adaptive function for this positive emotion is to reinforce pro-social behaviour in others. In this instance, this was found; partners were grateful to the medical team, and for the ICD, and this was expressed by the partner's positive appraisal of the device.

Patients used a combination of problem-focussed and emotion-focussed strategies whereas partners used these as well as mixed avoidant coping strategies at times. Using mixed avoidant type coping, partners were able to avoid certain dissonant aspects of the ICD. There was no one obvious coping strategy that appeared superior to other strategies but it was clear that 'venting' was detrimental in the short-term and long-term mental health of the patient. It was also clear that some ways of coping were clearly more adept than others at helping participants adapt to the ICD depending on how long the participant had been living with the ICD. For example, it could be suggested that emotion-focussed avoidant or denial coping in patients might initially be more effective than information seeking in helping participants cope with a diagnosis, as it protected against unmanageable feelings.

The findings from this study suggested that if denial type coping was allowed to persist, it could eventually lead to feelings of guilt and helplessness in participants. For instance, guilt was experienced by patients who continually refused to take responsibility for their well-being and who instead placed this responsibility onto their partner. As well as this leading to guilt (having transgressed a moral imperative - see Lazarus, 1999, p.96), the partner was left feeling frustrated and angry towards the patient. However, unlike Leventhal et al.'s (1992) self-regulatory model suggested, patients and partners did not appear to purposely appraise emotional outcomes and adapt coping behaviours accordingly. This is not to say it did not happen, but if it did, then these findings suggested that this process was more likely carried out on a more subconscious than conscious level of appraisal.

Apart from a few notable cases, most patients and all of the partners in this study had accepted the ICD by the one-year post implant milestone. Patients who were still struggling to accept the ICD at one-year, appeared to have a heightened awareness of physical discomfort from the implant and elaborated on its discomfort and ensuing distress. This particular finding is perhaps best explained by previous research by Leventhal, Hansell, Diefenback, Leventhal, Glass, (1996) who found that negative affect (NA), including anxious affect (AA) and depressive affect (DA) were predictive of increased physical symptom reporting. While state NA can incorporate a range of emotions, including anger, sadness and fear, trait NA like neuroticism was found to affect the perception, interpretation and reporting of symptoms (Morrison & Bennett, 2012).

Accordingly, although from the data it cannot be determined whether patients held traits such as neuroticism, findings in this study suggested that patients who were especially fearful or saddened by the ICD, tended to report a higher number of physical symptoms from the ICD. In terms of perceptual style, Williams (2006) suggested neurotics and those high in trait NA are more introspective, and attend more negatively to somatic information, and thus tend to perceive more symptoms. However, this may not be purely psychological as Williams (2006) suggested that neurotics also have a greater physical reactivity to stress. Therefore the physical symptoms reported by patients who were finding it hard to cope, might have had a physiological cause as well as a psychological basis; however, neither proposition can be determined from this study's data.

Interestingly, the two shock-patients who were waiting in hope for a further medical procedure to 'cure' them of their arrhythmia did not mention any discomfort from the ICD. This finding suggested that the initial primary appraisal might have influenced how well the patient tolerated the device, which can be explained using Smith and Lazarus's theory of appraisal. For instance, the two patients who were living in hope of a further 'curative' medical procedure might have appraised the device differently to others who did not have this hope. For the two 'hopeful' shock-patients, the device might not have been perceived as being relevant for the future survival. Rather, they believed the ICD was a temporary solution. Accordingly, the ICD had no goal relevance and as such, their awareness of the device's discomfort was minimal.

The shock-patient subgroup's ways of coping with the defibrillated shock experience did not appear to differ too much from the non-shock patient subgroup's way of coping with the *threat* of shock. Both non-shock and shock-patients used a mixture of emotion- and problem-focussed and avoidant-type coping strategies in an attempt to try to regain some control over their lives. For instance, a shock patient who had been shocked during sex used avoidant behaviour as he associated sex with a real threat of shock. According to Lazarus (1983) and Hallas, Burke, White & Connolly (2010) (who used Lazarus' 1983 definition of problem-focussed coping behaviour) this avoidant strategy should have been adaptive. The shock patient and his wife gave explanations as to why they were avoiding sex, such as offering their age as a reason. However, it was clear that their reason for not having sex was the fear of another shock and is best explained using Mowrer's (1943) behavioural theory of avoidance. This theory suggested that the avoidant behaviour (avoiding sex) was acting as a negative reinforcement (reduced anxiety), which was protracting the avoidant behaviour (see Chapter 4 for a full explanation of this theory). Therefore, in some way, this behaviour could be labelled adaptive as the couple experienced reduced anxiety and found other ways to show affection to each other.

According to Mowrer, the only way this conditioned response could be extinguished would be for the couple to have sex and experience no shock. Therefore, this behaviour was also maladaptive because until the couple engaged in sex, this fear would not be extinguished. This problem-focussed approach was hence both adaptive and maladaptive. It was adaptive as it prevented anxiety about a raised heartbeat and the couple found other ways to show their affection to each other, but it was also maladaptive because until the couple engaged in sex, this fear would not be extinguished. The importance of engaging in sex even if it was associated with a shock was evidenced in Steinke et al. (2005). They found patients recommended resuming sex as soon as possible after a shock in order to avoid potential negative effects on the relationship.

Other coping strategies appeared to have the capacity to be adaptive as well as maladaptive depending on how it was used. For instance, emotion-focussed coping was found to be both adaptive and maladaptive. For example, social comparison was used by the shock-patient subgroup, which had resulted in them feeling worried and despondent when used downwardly, but had led to feelings of encouragement when used upwardly.

Sometimes a coping style prevented people from coping adaptively. For instance, the shock-cohort had experience of shock and thus had 'proof' that the device worked. One female shock partner could not understand that now having 'proof' the ICD worked, this knowledge failed to reduce her anxiety. Having a 'scientific' coping style, where logic was used to counter fear, she remained anxious despite reminding herself of the ICD's attributes as well as confirmation that the device was working. The inability to use rational logic to reduce anxiety was also explained by Smith and Lazarus's appraisal theory. The shock-partner's core relational theme of danger/threat was causing her to feel anxious. However, her anxiety was being sustained by the following independent appraisal components: the shock was relevant to her wellbeing, it posed a threat and she was unsure she had the emotional reserves to cope.

Incidentally, her inability to reduce her anxiety through rational thought processes can also be explained using the S-REF (Wells, 2000) model of processing. According to this model, the ICD was perceived as a stressor to be processed. In this instance, anxiety was sustained because of how the stressor was being processed. In other words, the anxious partner was processing the stressor in an 'object' mode rather than a 'metacognitive' mode. Accordingly, the thoughts of 'my partner has the ICD' 'the ICD works' 'the ICD's been checked' were unsuccessful facts to counter threatening facts. As such the S-REF activity continued, sustaining distress. If she had allowed herself to think about how she was thinking about her thoughts, she might have moved into a metacognitive mode of thinking, and consequently she might have been able to reconcile the threatening thoughts.

Although there were many similarities in themes between the shock and non-shock subgroups, there were also instances in which a theme was found that only related to one of the subgroups. One major difference between the subgroups was the experience of a shock. After the shock experience, patients felt a profound loss in confidence. Previous qualitative studies (see Morken et al. 2009; Dickerson, 2002; Williams et al. 2007) asserted that after a SCA or SCD occurred, it had taken a while for patients to regain any confidence. These confidence levels were slowly restored over time; however, whatever level of confidence had been restored was quickly lost after another defibrillated shock was experienced.

A theme that was unique to the non-shock cohort was 'doubt and regret having the ICD'. This theme was found in some non-shock patients (e.g. N04, N10) who had been sceptical of their need for the device (90-92: N04 and 177-180: N10). The experience of a shock from the ICD created a shift in belief about the necessity for the ICD. Whereas non-shock patients believed the ICD was an insurance policy, and as such might never be used, after a shock, this belief could no longer be upheld. This theme was most likely absent in the shock-patient cohort because the device had fired, and thus had removed any lingering doubt that the ICD might be a redundant treatment option. For some of the shock patients, the shock signified to them that their heart was failing. This might well hold some truth depending on the patient's underlying cardiac condition. For a heart failure patient, this stark realisation made him alter his expectations for the future, which left him feeling sad and despondent.

In summary, there were many similarities between the shock and the non-shock cohort. For instance, there were similarities in the response to the ICD, how a shock was appraised and the need to try to gain some control over their lives. However, there were also a few major differences. For instance, the shock subgroup of patients knew what it was like to experience a shock, thus dispelling the unknown uncertainty surround a shock. The feeling of uncertainty was supplanted by feelings of apprehension and dread. In addition, an acute loss of confidence was felt after a shock occurred, especially if the cause of the shock was unknown. The findings also suggested that when patients negatively appraised the ICD and had faulty beliefs about the device, it often led to emotional distress. This emotional distress needs to be reduced. Emotional distress such as increased anxiety and depression were not only found to negatively impact on participant's well-being but also appeared to be associated with avoidant behaviour. This meant that there was no opportunity for participants to 'test out' the faulty beliefs and so the wrong beliefs remained unchallenged. Furthermore, findings from previous studies (e.g. Lampert et al. 2002, 2004) have shown that increased emotional distress can lead to an increased risk of an arrhythmia, which reinforces the importance to lower a patient's distress. Accordingly, a psychological intervention, which changes appraisals, and gives patients coping strategies to cope with their emotions could be instrumental in helping both patients and partners cope with the ICD device.

Summary of Key Findings

- Patients and partners experienced trauma related to the cardiac event.
- Patients and partners had a high level of distress relating to the ICD and its ability to shock.
- Patients felt vulnerable, uncertain, had feelings of loss, felt pessimistic and experienced doubt and regret about having agreed to have an ICD.
- Partners experienced feelings of anger and frustration towards the patient especially if the patient was finding it difficult to accept the ICD.
- Patients and partners used a combination of coping strategies to cope with their emotions: protective behaviours, avoidant behaviours, venting and acceptance.
- Although there was no one coping strategy that was superior to others in helping patients and partners adjust to the ICD, frustrated venting and blaming was clearly very unhelpful.
- Partners tended to closely monitor the patient, which resulted in the patient concealing symptoms from the partner and feeling a loss of independence.
- Concealing thoughts and emotions from each other, led to patients and partners feeling isolated.
- The experience of a shock tended to reinforce feelings of vulnerability, especially if the circumstances that triggered the shock could not be accounted for.
- Patients, whose self-identity was strongly formed by their occupation, found not being able to return to work seriously impacted on their sense of self.
- Remote monitoring did not appear to be an issue for participants.

Unique Finding from this Study

- Partners felt anger and frustration towards the NHS, especially if the patient was diagnosed with a familial cardiomyopathy.

How the Findings Informed the Development of the Complex Intervention

The general findings from the qualitative study provided some evidence for the need for a psychological intervention for ICD patients. The findings were used to inform the quantitative phase of the MRC (2008) guidelines for developing a complex intervention.

- Patients needed to know what physical sensations to expect during the first few weeks. Common misunderstanding and inappropriate expectations identified were addressed in an education section such as informing patients that most patients feel weak after their ICD and lack stamina.
- Patients needed guidance on building up their stamina. The intervention included a graded exercise programme to help patients slowly build up their stamina safely.
- Patients had many anxieties, worries and fears. As high levels of distress can increase the risk of an arrhythmia, the intervention included a section to help patients challenge worries and fears and offered strategies to help patients cope with anxiety.
- Returning to work and 'normal living' was important for patient's sense of identity. The intervention included a section to help patients keep active and return to 'normal' living.
- Many patients and partners were pre-occupied with fears about a shock. The intervention included a section to help patients cope effectively with an ICD shock.
- Patients who had a positive appraisal about the ICD appeared to be coping better compared to those who negatively appraised their device. When describing the device, the intervention always framed the ICD in a positive light.

(See Chapter 8 for a detailed description of the Intervention)

Limitations of Qualitative Study

1. Patients were accessed through the Arrhythmia Specialist Nurses who assessed their suitability for the study. This was a major limitation as patients were first 'screened' by nurses to be suitable participants. The screening of patients meant that the sample was biased. Patients who may have been extremely anxious or had issues about their treatment might not have been invited by the nurses to join the study. Accordingly, the sample might not have included very anxious participants. However, one advantage of using Specialist Arrhythmia Nurses to invite patients onto the study was that they offered legitimacy to the study.
2. Finding patients who had received a defibrillated shock from their ICD had proved problematic; therefore, two of the participants from the shocked group (patient and partner) had their ICD for ≤ 2 year rather than ≤ 1 year as per the non-shock groups of patients and partners. Therefore, they had had longer to adjust to their ICD before being interviewed.
3. The participants were self-selected. It became clear during the recruitment process that often the couple had put themselves forward as participants because one-half of the couple had very much wanted to talk about their experience. This finding suggests that there is a need for some patients and partners to talk about their experience of the cardiac event and adjusting to the ICD. This might be more pertinent for those couples for whom communication between them has decreased after the implant. Again, this meant the sample of participants was biased, as there might have been a patient/partner who wanted to take part but their partner/patient refused. As participants were self-selected, it is therefore unlikely that couples who were currently engaged in avoidance and denial as coping strategies during the recruitment phase, volunteered to take part in this study.
4. Only couples were invited to join the study. Although the study was interested in how the dyadic relationship between patient and partner influenced their coping, this meant that the experiences of patients who lived alone (e.g. single, divorced, widowed) were not reported. The experience of living alone with an ICD might be very different to the experience of living with someone, and these differences might be explored in another study.

5. In line with PhD research, it was not necessary for another researcher to validate the rigour and transparency of the method used to find themes. However, if a full Framework Method analysis had been used, it would have made the process of coding and finding themes transparent.

Section 2: Implications to Nursing/Clinical Practice

1. More Support Needed for Partners

Some partners need reassurance that the Arrhythmia Specialist Nurse is there to support them as well as the patient; many partners reported that they had wanted to speak to the Arrhythmia Nurses about their worries about the ICD and their loved one, but held the belief the Nurse's role was only for the patient. Furthermore, partners sometimes complained of feeling left out of their loved one's treatment.

From this study, it was clear that many partners reported feeling extremely anxious about the patient's heart health, and which they often felt responsible for, especially if the cardiac event had involved a SCA/SCD. Partners who had witnessed their loved one's SCA/SCD were often still distressed at one-year post implant by their experience. This high level of distress and anxiety had often resulted in partners becoming overprotective towards the patient, which had become counterproductive for both of them. At one-year, partners still exhibited high levels and anxiety, and the losses that many partners felt after the implant were compounded by feeling overprotected.

It might therefore be helpful to partners or the primary care-giver to be given a private consultation with the Arrhythmia Specialist Nurse during which they can voice their private fears and concerns.

2. Pre-ICD Counselling: do all Patients *really want* an ICD?

Some patients expressed doubt and regret in having the ICD device. These patients tended to rationalise the decision to have an ICD as being for the sake of others (e.g. their partner, their children). This finding suggests that some patients may have felt 'obliged' to have an ICD for the sake of others. However, notably this finding was only pertinent to those patients struggling to accept their device.

Therefore, patients perhaps need to rationalise why they are having the ICD before their implant and how are going to reconcile themselves with this reasoning post-implant. It is suggested that patients write a list of reasons as to why they want an ICD, which could be used later to reflect upon if patients find themselves struggling to accept the device.

3. The Need for a Follow-up Appointment at 2-week Post-Discharge

Patients might benefit from a follow up appointment with a health professional during the second week of being discharged from hospital as many patients reported the period between discharge and the six-week follow up appointment was too long. A follow up session during the second week post-implant would provide the patient with an opportunity for reassurance that their wound was healing correctly, that the ICD was in the appropriate place and to answer any lingering or new concerns may arise.

It was clear from the interviews that before the ICD implant, the emphasis for patients and partners were to ensure life, and it was only after the implant that worries and concerns about living with the ICD became pertinent. A two-week interval from discharge to follow-up is sufficient to allow patients and families the time to think about longer-term needs/concerns, which prior to the implant had not been anticipated.

4. Elaboration and Selection of Information from Health Professionals

It is important that health professionals are careful in what information/message they are giving to the recipient and the language that they use to relay these messages. It was clear from this study, that patients and partners often selected and elaborated messages from Health Professionals, which often resulted in information received as threatening, and was often misconstrued and inaccurate. Of note, it was found that informing patients who survived a sudden cardiac arrest that they were 'lucky' to be alive merely compounded their feelings of vulnerability to a repeat event.

Therefore, it is suggested that patients and partners are asked to repeat what information/message they think is being given, to ensure that the correct information/message has been relayed. In addition, health professionals need to use language that is benign and non-threatening and to refrain from advising patients that they were 'lucky' to survive a cardiac arrest/death.

5. The need for a Written Structured Guide on Living with an ICD

It is recommended that this population of patients receive a self-help coping booklet that will help them adjust to living with an ICD. One reason for this suggestion is that this study found evidence that coping with the ICD and patient's subsequent quality of life was not determined by clinical factors such as the severity of an underlying heart condition, but by the individual's appraisal of the cardiac illness and the ICD, their emotional responses to these appraisals and the coping strategies adopted. A further reason is that patients reported that when they were discharged, they had been told to return to 'living their lives as normal', which was advice they found impossible to follow without any formal instruction, guidance or support.

Ideally, this self-help coping booklet should comprise psychosocial aspects of living with an ICD, including how to challenge negative appraisals and a table of typical post-implant worries and concerns reported by patients and partners. The qualitative phase found that patients who were very distressed engaged in avoidant behaviours. This meant that patients often did not have the opportunity to 'test out' an incorrect belief, which if tested, might have reduced their levels of emotional distress. It is also important to target distress as anxiety has been shown to increase the risk of a shock (see Burg et al. 2004 and Kop et al. 2004). The booklet should also include an exercise plan to help guide patients how to become more physically active. This is not a new recommendation as Dougherty (1997), Tagney et al., (2003), and Zayac and Finch (2009), have all suggested the need for a post-implant intervention/care plan.

Some patients reported concerns about the extent to which the ICD protruded and therefore it would be helpful if the booklet included photos of ICD implants in various body shapes for patients to make comparisons with their own body shape. Although patients are given information about the ICD and its size before their implant during their pre-counselling session, many patients appeared distressed post-implant by its size and its position in the chest wall, suggesting that the time they were given this information was not appropriate. Providing photos was an idea initially recommended by Vazquez Sowell, Kuhl, Sears, Klodell et al (2006).

6. Insufficient Anaesthesia Used during Implant Procedure

Some patients reported feeling considerable pain during the implant procedure. They reported that the area where the incision was made had not been sufficiently anesthetised or the anaesthetic had worn off too soon. This had resulted in them feeling considerable pain on the initial incision and the stitching up of the wound. The patients reported that due to the effects of the sedation, they had felt unable to make their distress known and to raise the alarm. This is an important issue as it could have implications when the procedure needs to be repeated (e.g. lead displacement, box change). (See Appendix V: N19 33-41 and N16 451-461).

Next:

Chapter 8 – Psychological Coping Interventions and the Brief Psychological Coping Study Intervention

Part 3

Chapter 8

PSYCHOLOGICAL COPING INTERVENTIONS AND THE BRIEF PSYCHOLOGICAL COPING STUDY INTERVENTION

***SECTION ONE**: Previous Psychological Interventions for ICD Patients*

- *Previous Psychological Interventions for ICD Patients*
- *Rationale for the Brief Psychological Coping Intervention*
- *The Creation of the Brief Psychological Coping Intervention*

***SECTION 2:** the Brief Psychological Coping Intervention Booklet: Getting on with Life: learning to live with your ICD*

- *Critique of Intervention*
- *Testing the Intervention*

SECTION ONE: Previous Psychological Interventions for ICD Patients

Over the past 10 years, six studies have reported interventions delivered in the first few weeks after an ICD implant, in which one of their main aims was to reduce anxiety and/or depression in ICD patients, (see Table 8.1).

The majority of interventions reported here (see Table 8.1), used a telephone component. Frizelle et al.' (2004) intervention was a group-based cognitive behavioural rehabilitation programme delivered 10 x 2-hour weekly meetings over the course of 6-weeks. Participants were randomised to an immediate-treatment group or a waiting-treatment group. All participants were assessed prior to the intervention, immediately after the course of treatment and 3-months after their treatment ended. Participants were requested to practice relaxation and a home-based exercise programme daily. At week 9 (of 12-weeks), participants were contacted by telephone to reinforce the intervention and to discuss any issues that may have arisen from the home-based exercises. At the end of the immediate-treatment group's programme, results showed a significant difference between the two groups. Whereas there was very little improvement in depression, anxiety and ICD concerns scores in the waiting-treatment group, the immediate-treatment group had improved scores. At the end of 3-months following treatment, scores showed a significant reduction in anxiety, depression and ICD Concerns in both the immediate and treatment groups.

One issue with a group intervention is that patients have to travel to the venue to receive the CBT rehabilitation programme. Indeed, Frizelle et al. (2004) found 26% of the total ICD cohort wanted to join the study but were unable to attend due to transport difficulties. One way around this issue is to deliver the intervention over the telephone or to use a written intervention. Five studies reported using the telephone to deliver their intervention (Dougherty, Lewis Thompson, Baer et al., 2004; Dougherty, Thompson, & Lewis, 2005; Lewin, Coulton, Frizzelle, Kay et al., 2007; Dunbar, Langbert, Reilly, Viswanathan et al., 2009; Crössman, Schulz, Kühlkamp, Ritter et al., 2010; Irvine, Firestone, Ong, Cribbie, et al., 2011). See Table 8.1 for a description of these studies.

Dougherty et al.'s (2004 and 2005) studies reported the short- and long-term outcomes of a nursing intervention based on social cognitive theory. Participants were randomised to an intervention- or routine care group. The intervention consisted of a booklet about surviving a sudden cardiac arrest and weekly telephone support from an expert cardiovascular nurse. Participants were asked to read the booklet during the first week after their hospital discharge. The telephone calls made by the nurses were structured and patients needed to refer to the study booklet during the call. The intervention group could also make free phone calls to their expert nurse and were given a 24-hour pager for out of hours. Compared to the control group at 1-month, the intervention group reported fewer physical symptoms but this did not significantly reduce their health care usage. The benefits for the intervention group over the control group from 6- to 12-months however included significantly reduced anxiety, fewer physical concerns and a reduced fear of dying.

Dunbaret al.'s (2009) study was a psycho-educational intervention providing education and symptom management training (SMT), and cognitive techniques to improve coping and illness appraisals. The study design included one control and two intervention groups. One intervention group consisted of telephone-led counselling sessions and the other was a support group. Both intervention groups received the same content of the intervention. The SMT took place when participants were still in their acute-care setting prior to hospital discharge (see Table 8.1 for details of SMT). The cognitive skills were given at 2-3 months after the implant, and participants received a booster session during the fifth month after their implant.

Dunbar et al.'s (2009) psycho educational intervention was effective in significantly reducing anxiety early in recovery, with the greatest decrease in scores occurring at 3-months post-implant. The largest effect size between groups was at 3-months. Lower levels of clinical anxiety persisted over time in the intervention group, but statistical significant differences were not retained, and there were no group differences at 6- or 12-months. The results showed that the chance of having depressive symptoms was reduced by the intervention. The chance of having depressive symptoms at 12 months was lower for the intervention groups (telephone group= 13%, support group= 17%) compared to the control group (=31%).

Two recent studies (Crössman et al., 2010 and Irvine et al., 2011) reported that their intervention improved psychological outcomes for particular groups of ICD patients. Crössman et al.'s (2010) intervention consisted of a 20-page psycho-educational/coping booklet and monthly phone calls, (see Table 8.1 for details). Crössman et al. (2010) reported no significant differences in psychological outcomes between the intervention and the control group. However, they identified that age was a moderator; older participants in the intervention group (aged over 65-years) reported that their levels of anxiety were worse at 6-months whereas younger (under 65-years) reported improved levels of anxiety.

Irvine et al. (2011) conducted a CBT intervention based on the cognitive theory of anxiety. The intervention included a booklet and a CD with exercises based on mindfulness and relaxation. Intervention participants also received eight telephone-counselling sessions. The study reported that post-traumatic stress disorder and avoidance symptoms for men and women both significantly improved from baseline to 6-months and baseline to 12-months. The study also found women reported significantly reduced depressive symptoms from baseline to 6-months and baseline to 12-months.

The ICD-Plan, devised by Lewin et al. (2007), is currently the only psychological written intervention for ICD recipients in the UK, although it is a literature-based intervention, it does rely on some telephone support by nurses. This intervention consists of four booklets, and a CD with progressive relaxation exercises. Lewin et al. (2007) reported that the intervention group had significantly improved physical health, but although this group had reduced depression and anxiety and increased quality of life, these improvements were not significant. The ICD Plan was criticised by some British Heart Foundation Specialist Arrhythmia Nurses for being too 'heavy', and saturated with too much information[49]. Further shortcomings of the this intervention includes its cost; cardiac health care professionals need initial training to deliver the intervention by a clinical psychologist and nurses would require up to one-hour additional patient contact time over 12-weeks following discharge, therefore using limited time and financial National Health Service resources[50].

The shortcomings of the psychological interventions for ICD patients thus far have included issues with travel, a heavy reliance on nursing telephone support and costs incurred by training nurses to deliver the intervention. Self-help leaflet-based interventions based on psychological theory have found to be effective in helping patients cope with distress. For example, a study was carried out by Lancastle and Boivin (2008) who tested the efficacy of a leaflet based brief coping intervention on women who were undergoing fertility treatment. On the day of embryo transfer, they randomised 55 women to receive a positive reappraisal coping intervention (PRCI) or a positive mood intervention (PMI). Both of these conditions consisted of women reading 10 statements daily from a card. Compared with the PMI, the PRCI was rated by the women as being helpful. The PRCI helped the women feel more positive, which helped them cope with the strain of waiting for pregnancy results.

Another example of a leaflet-based coping intervention was one by Bennett, Phelps, Brain, Hood et al. (2007). They randomised patients waiting for cancer genetic risk assessment to receive a written self-help intervention or routine literature. They found that the intervention significantly helped reduce distress in patients who were moderately distressed at baseline.

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[49] Feedback from University Hospital of Wales and Manchester Royal Infirmary have the ICD Plan but choose not to use it as it has too much information for patients to cope with (personal communication with Arrhythmia Specialist Nurses, 2010).

[50] Each set of books that made up the ICD Plan cost £12.15 per patient (2007 prices) (see Lewin, et al, 2007)

As well as in leaflet form, self-help interventions can be delivered via web-based learning. A good example of one study that used a website to deliver a self-help intervention was the Electronic Targeted Intervention for Psoriasis (eTIPS) study by Bundy, Pinder, Bucci, Reeves, et al. (2013). This study tested the efficacy of an electronic CBT intervention for patients with mild to moderate psoriasis. Although this study was not comparable to the present research in terms that psoriasis is not a cardiac condition, it was comparable in so far as distress can trigger a psoriasis flare (Bundy et al, 2013), and distress can trigger an ICD shock. Bundy et al. (2013) suggested that the psoriasis population was a difficult-to-reach medical population, and the ICD population can also be defined as 'difficult-to-reach' albeit likely for different reasons. The travel limitations experienced by ICD population can make them difficult to reach as they cannot easily travel to places for group interventions. As well as being suspended from driving for 6-months after their implant, qualitative studies have found that patients are often wary of using public transport in case they have a shock (e.g. Eckert & Jones, 2002, McDonough, 2009).

Bundy et al.'s (2013) study randomised participants to an intervention or a wait-list condition group. The study found that an electronic CBT intervention resulted in a significant difference in scores for anxiety between the intervention and the wait-list condition (in favour of the intervention group). In addition, the intervention group reported an improved quality of life. However, a weakness with this study was that it had a high attrition rate. Furthermore, the intervention group appeared to have a higher attrition rate compared with the control group: 43% vs. 23%. In addition to a high attrition rate, the study acknowledged that symptoms of psoriasis might improve depending on the season. Accordingly, one group might have received the intervention in a season that ameliorated psoriasis, whilst another group might have received the intervention during a season, in which the severity of psoriasis often worsened. The design of the study, which included a wait-group condition could not control for the variation in seasons.

The advantages of an electronic intervention over a booklet are that because it is web-based it is likely to be more cost-effective and it can be updated or amended without wastage. Albarran et al. (2004) suggested that ICD patients might benefit from a web-based intervention. They suggested the benefits would be that ICD patients would not have to travel to receive the intervention, the intervention would be accessible to the whole family and not just the patient and a new patient could access it immediately. However, the mean age of patients in the eTIPS study was 45 years, which was younger than the average age of an ICD patient. It might be that older patients may prefer a booklet rather than a web-based intervention, which requires some knowledge of and access to a computer.

Table 8.1: Previous Psychological Interventions Published 2003-2013

Author (date) Country of origin	Sample	Study Design	Type of Intervention	Duration of Intervention	Main Outcomes
Dougherty, Lewis, Thompson, Baer & Kim (2004) USA	Secondary prevention patients only Intervention = 84 Control= 84	RCT	Nursing Intervention Intervention used a booklet 'Sudden Cardiac Arrest: A Survivor's Experience', nursing telephone support and a nurse pager Intervention aimed to provide knowledge and behavioural skills to manage ICD recovery, increase self-efficacy to deal with illness demands, and reduce emotional arousal and anxiety. Delivered by weekly 20- minute structured phone calls from an expert cardiovascular nurse	2-months	Short-term Follow-up At 1-month: Measures used: Patients concerns Assessment Short-form Health Survey State-Trait Anxiety Index Centers for Epidemiologic Studies-Depression Intervention group had significant reduction in physical symptoms and fears relating to ICD
Dougherty, Thompson, Lewis (2005) USA	Continued study from above		As above		Long-term Follow-up 6- to 12-months: Compared to the control group, the intervention group had significantly reduced anxiety, physical concerns and fear of dying
Frizelle, Lewin, Kaye, Hargreaves, et al. (2004) UK	Secondary prevention patients only Intervention = 12 Wait group = 10	RCT	Cognitive-behavioural rehabilitation programme Group CBT programme delivered weekly for 2h Programmed included: a 10-minute home exercise plan devised in consultation with a physiotherapist, coping and avoidance behaviour, tape with muscle relaxation	6 weeks	Outcomes at 12-weeks: Intervention group had significantly reduced HADS-anxiety, HADS-depression and ICD concerns

Author (date) **Country of origin**	**Sample**	**Study Design**	**Type of Intervention**	**Duration of Intervention**	**Main Outcomes**
			exercises, breathing techniques, and weekly goal setting. Educational sessions were given on the model of anxiety, phobia and panic, the ICD, and electrocardiogram follow-ups.		
Lewin, Coulton, Frizzelle, Kaye & Cox **(2009)** **UK**	Intervention = 71 Control = 121	Clustered RCT using 6 centres	The ICD Plan The ICD Plan consists of 4 booklets: Before your Implant, For the Relative or Carer, When you get Home, and The Plan (goal setting) The ICD Plan also includes a relaxation CD, and 3 CBT self help telephone calls at weeks 1,3 and 6	3-months	Measures used: Short-Form Health Survey Hospital Anxiety and Depression Scale Seattle Angina Questionnaire subscale (physical limitations) Outcomes at 6-months: Intervention group had significantly improved physical health but no significant effect on depression, anxiety or QoL
Dunbar, Langbert, Reilly, Viswanathan et al. (2009) **USA**	N= 246 randomised to individual care, group care (both intervention groups) or routine care (control group)	RCT	Psycho-educational Intervention The intervention was delivered via 4 x 60 minute individual telephone counselling sessions or 4 x 2-hour group sessions Initial symptom management training (symptoms associated with incision, device-site pain, sleep disturbance, ICD shock, returning to activities) was given to participants on acute ward prior to discharge All intervention patients phoned one week after discharge to remind them to use symptom management techniques	2-months	3- and 12-months: Telephone intervention and group intervention: Lower levels of clinical anxiety in the intervention group compared to the control group. But no group differences at 6- and 12-months Reduced depressive symptoms in intervention groups: at 12-months, chance of depressive symptoms 17% support group, 13% telephone group and 31% for control

Author (date) Country of origin	Sample	Study Design	Type of Intervention	Duration of Intervention	Main Outcomes
Crössman, Schulz, Kühlkamp, Ritter et al. (2010) Germany	Secondary Prevention Patients only Intervention = 56 Control = 63	RCT	CBT Intervention 20-page booklet describing medical and technical aspects of the ICD, the psychological process of post-implant adjustment, and coping with anxieties Monthly telephone counselling calls aimed to reduce avoidance behaviour (encourage activity), reduce cognitive bias (presenting the ICD as an emergency backup), reduce anxiety (increasing self-efficacy by explaining typical post-implant experiences) and to identify resources for patients who continue to have ICD issues	6-months	Outcomes at 6-months: No significant differences between groups Young patients improved in HADS-anxiety whilst those over 65 worsened
Irvine, Firestone, Ong, Cribbie, et al. (2011) Canada	Only patients with hypertrophic cardiomyopathy included Intervention = 96 Control = 97	RCT	CBT intervention An intervention which included a therapist's manual, a psycho-educational booklet for patients, CD with mindfulness-based exercises and a progressive muscle relaxation exercise and 8 telephone counselling sessions	6-months	Outcome at 12-months: Intervention group had significant improvement in PTSD total (IES-R) and avoidance symptoms. Women had significantly reduced depressive symptoms

HADS = Hospital Anxiety and Depression Scale. PCA= Patient Concerns Assessment. STAI = State-Trait. Anxiety Inventory. BDI-II = Beck Depression Inventory II. QoL = Quality of Life. IES-R = Impact of Events Scale – Revised. PTSD = Post Traumatic Stress Disorder.

The Rationale for the Brief Psychological Coping Intervention booklet (see Appendix XIX: Brief Psychological Coping Intervention Booklet)

The shortcomings of the psychological interventions for ICD patients discussed earlier included issues with travel, relying on nurses to deliver telephone support to patients and the costs incurred by training nurses to deliver the intervention. Currently, hospitals[51] around the country give an information pack to the ICD patient on their discharge from hospital after their ICD implant. This information generally consists of advice on driving regulations from the Driver and Vehicle Licensing Agency (DVLA) and generic educational literature. The generic information provided tended to be in booklet form and was either the British Heart Foundation's (BHF) "Implantable Cardioverter defibrillators" or the Arrhythmia Alliance: The Heart Rhythm Charity's (AA) "ICD Patient Information". Occasionally Health Trusts included literature on healthy eating[52] and alcohol intake.[53] Primarily the information pack is designed to educate patients about the structure of the cardiac system, arrhythmias and the function of the ICD.

From the feedback from various hospitals around the country (see footnote 49), there appeared to be a clear need for a written brief psychological intervention that could be delivered with the minimum of cost and time to NHS resources. The brief psychological coping intervention for ICD patients, (which will subsequently be referred to as 'study intervention') was devised to meet this need. The study intervention was informed from the findings of the qualitative study (see Chapters 6 & 7), from an ICD literature review (see Section 1, Chapter 3), advice from expert forums such as ICD patient support groups, and from evidence-based psychological theories.

As a significant minority of ICD patients in the qualitative study had reported problems with their memory, the study intervention was written in a simple, straightforward manner to meet the needs of those patients who had limited cognitive resources. Moreover, previous evidence has suggested that most health information is too complex for the average reader (e.g. Davis, Crouch, Wills, Miller, Abdehou,

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[51] Liverpool Heart & Chest Hospital, Wythernshaw Hospital, Manchester Royal Infirmary, Bristol Heart Institute, John Radcliffe in Oxford, St Barts, St Georges and St Mary's in London, University Hospital of Wales, Morriston Hospital in Swansea, and Ninewells Hospital in Dundee, Scotland.

[52] E.g. University Hospital of South Manchester and Liverpool Heart & Chest Hospital

[53] E.g. Liverpool Heart & Chest Hospital

1990; Jubelier, 1991; Cooley, Moriarty, Berger, Selm-Orr, et al., 1995). For instance, Davis et al. (1990) found that there was a gap of five years between patient reading levels and the comprehension levels required by written patient materials.

Beck's (1976) cognitive theory of anxiety proposed that anxious patients often 'misread' information for threat messages. Therefore, the intervention was written clearly with an emphasis on the positive aspects of the ICD (the gains rather than the losses) to prevent patients from feeling threatened. The findings from the qualitative study also revealed that the emotions that patients experienced had often been influenced by their appraisal of the ICD, which had in turn influenced the coping strategies they chose to adopt. This outcome suggested that targeting cognitions and behaviours would provide the most benefit to patients and which could be adapted from effective interventions that were already in existence to help people cope with a chronic illness.

The study intervention was based on cognitive and behavioural theories as many studies found that a cognitive behavioural intervention helped reduce anxiety in ICD patients (e.g. Frizelle et al. 2004; Lewin, Coulton, Frizzelle, Kaye, et al., 2007). Cognitive theory was used to restructure cognitions and to help patients challenge negative automatic thoughts, and behavioural theory was used to teach distraction and relaxation skills. Interventions that included exercise training were found to be more effective in reducing depression (e.g. Frizzelle, Lewin, Kaye, Hargreaves et al., 2004; Pedersen, van den Broek, & Sears, 2007). Accordingly, in order to maximise the effectiveness of the study intervention, an exercise component to complement the cognitive and behavioural theories was included.

The study intervention is a home-based intervention and uses similar evidence-based psychological cognitive and behavioural coping strategies to those used in the *ICD Plan* (to see a copy of the study Intervention as given to patients, see Appendix XIX). However, significant changes were incorporated into the design of the study intervention. These addressed the shortcomings of the *ICD Plan* that had been highlighted by Arrhythmia Specialist Nurses (see footnote 47). In summary, the study intervention was designed to be simple, straightforward and to meet the needs of those patients with limited cognitive resources. The design took into consideration the limited time and financial resources realistic of today's National Health Service by producing one booklet that had reduced the length and depth of the *ICD Plan* making it economically sustainable. The fact that nurses do not need to be trained to administer the study intervention means the intervention can be administered easily, which will potentially result in more patients having access to the intervention.

The Creation of the Brief Psychological Coping Intervention booklet: *Getting on with Life: Learning to live with your ICD*

Primarily the study intervention was devised to be a simply written intervention to help patients cope psychologically with their ICD. However, in addition, the booklet also aimed to help ICD patients cope with living with a chronic cardiac condition. Findings from the qualitative study revealed that patients often restricted their level of activity after they were given a diagnosis of a chronic cardiac condition (see Chapters 6 and 7). This restriction in activity can result in a gradual decline in physical health. In order to prevent Patients' health from further deteriorating, patients with a chronic heart condition need to keep physically active. In addition to keeping active, some patients might need to target other risk factors such as making dietary changes and stopping smoking.

Patients have to cope with the significant emotional distress that often results from being diagnosed with a chronic illness (see Chapters 6 and 7). A number of interventions exist to help individuals and their families cope with a chronic illness. These include educational interventions such as providing relevant information (e.g. a leaflet/booklet), cognitive and behavioural interventions such as stress-management training and metacognitive interventions such as mindfulness and distraction. These interventions were adapted and modified to be appropriate to the needs of ICD patients, and which together comprised the study intervention.

SECTION 2: The Brief Psychological Coping Intervention Booklet: Getting on with Life: Learning to live with your ICD

Chapter Details (see Appendix XIX: Brief Psychological Coping Intervention Booklet)

The Brief Psychological Coping Intervention booklet: Getting on with Life: Learning to live with your ICD included the following chapters and activity aids:

Chapters:

1. *Introduction*
2. *Common concerns*
3. *Keeping active*
4. *Getting to sleep at night*
5. *Learning to relax*
6. *Coping with worries*
7. *Planning a shock strategy*

Activity Aids:

1. *Exercise diary*
2. *Activity planner*
3. *Changing worries chart*

Chapter 1: Introduction

This chapter introduced the reader to the booklet. The reader was advised that they might wish to read particular chapters rather than the whole booklet. A key message in the introduction was that not all patients would feel they need the booklet's support to return to normal living, but that the booklet was there for those who were feeling uncertain about living with their ICD. Patients in the qualitative study had complained that on discharge from hospital after their ICD implant, they had often been left with a 'what *am I supposed to do now?'* feeling. The reader was advised that there were two accompanying booklets with 'Learning to Live with your ICD' in the Getting on with Life series. The additional booklets 'Stopping Smoking' and

‘Eating Healthily, were also sent out to patients along with a CD that played three relaxation therapies (see Appendices XX and XXI to see the additional booklets). The additional booklets and the CD were *not* subject to evaluation in the pilot randomised control trial.

Chapter 2: Common Concerns

People with a chronic illness can experience high levels of suffering; for instance in relation to ICD patients, up to 23 percent experience high levels of psychological distress (Hoogwegt, Kupper, Theuns, Zijlstra et al., 2012). Dunbar, Dougherty, Sears, Carroll et al.’s (2012) scientific statement suggested that this distress could be reduced with an educational intervention that gives patients information including the nature and treatment of their disease, how to cope with the disease and treatment and how to change behaviour in order to reduce the risk of disease progression. For instance, Dougherty, Lewis, Thompson, Baer et al. (2004) found a telephone educational intervention delivered by expert nurses resulted in decreased ICD related physical symptoms[54] and anxiety.

This chapter focussed on providing an educational intervention to present the patient with accurate and relevant information. This chapter was primarily based on Beck’s (1976) cognitive theory of anxiety, in which it was suggested that anxious patients tend to misinterpret benign information as threatening messages. Therefore, this chapter provided accurate information to address common ICD-related worries that had been expressed by patients in the qualitative study (see Chapters 5-7).

Further support for an educational element to the intervention came from Sears, Vazquez, Matchett, & Pitzalis (2008) who suggested that ICD patient information was an essential component to reduce distress as many ICD-specific concerns could be traced to having a poor understanding of the device. This was added specifically as Sears et al. (2008) suggested that patients might also benefit from psycho-social education about everyday functioning with the device, such as what common

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[54] Physical symptoms were found to be a measure of patient distress and antipathy towards the ICD in the qualitative study (see chapter 6).

feelings and concerns might be experienced by patients on discharge, and was a need reported by patients in the qualitative study (see chapters 6 and 7).

Table 8.2: Extract from the Table of Common Concerns in Learning to Live with your ICD: Self-Management Recovery Programme for ICD Patients. (See Appendix XIX Chapter 2 for the full table).

Here were some common worries about ICDs, and the facts behind them:

I will be really worried if I get a shock from my ICD, because it means my heart condition is getting worse	*Not necessarily. You may receive a shock for a number of reasons. Don't forget, the ICD is just doing what it is supposed to do. But if you are worried by a shock, contact your Arrhythmia Nurse*
I'm worried a shock will damage my heart	*This is an extremely common worry. No, shocks do not damage the heart in any way!*
My ICD feels to be moving around a bit. I am worried the leads/wires could become dislodged	*The feeling that an ICD is moving around is quite common. Your ICD is just settling into your chest. The wires are securely fastened and is it highly unlikely they will become dislodged. Also they come in varying lengths - so if you're very big, you'll have a longer lead than if you're very small. A suitable length lead is fitted in you with enough length to allow you plenty of 'give' for when you stretch*
The ICD sticks out so much – much more than I thought it would – maybe something is wrong	*The ICD may take up to a year to sink in and how much it sinks depends on the build of your body; if you have little fat, it may show more. Some people use their 'bump' as a 'party piece' and even show off their scar!*

Chapter 3: Keeping active

This chapter was based on Cognitive theories of Depression (Abramson, Seligman & Teasdale, 1978; Beck 1976), Appraisal Theory of Emotion, and Coping Theory (e.g. Smith and Lazarus, 1990). Physical activity and exercise training have important roles for ICD patients in helping them take control of their heart condition by increasing their self-efficacy and perceived outcome expectancies that they will become fitter with the reduced likelihood of receiving a shock (Dougherty, 2006; Arrhythmia Alliance, 2008). A review by Pedersen, van den Broek, & Sears (2007) that examined psychological interventions for ICD patients suggested that exercise training should be a major treatment component. They found that interventions, which had a combination of cognitive behavioural therapies with exercise training, produced the largest effect sizes for changes in anxiety and depression (e.g. Chevalier, Cottraux, Mollard, Nan Yao, et al., 2006; Frizelle, Lewin, Kaye, Hargreaves et al., 2004; Kohn, Petrucci, Baessler, Soto et al., 2000).

However, in practice, it might be unrealistic and to expect patients to adopt an exercise regime when hitherto it had not been part of their lifestyle. What might be more sustainable long term is to empower patients, i.e. equip them with the skills required to adopt an 'active' lifestyle doing 'normal' everyday activities. Dougherty (2006) and Arrhythmia Alliance (2008) posited that patients gained the greatest benefit from exercise that was similar to normal everyday activity.

The section of the intervention that focussed on helping patients keep active was based on social cognitive theory, and included goal setting. In order to translate the behavioural intention into actual exercise behaviour, patients were encouraged to form implementation intentions. This concept derived from the model of action phases (Gollwitzter, 1990) which stated that achieving a behavioural goal was dependent on a motivational phase, in which intentions are formed, and a volitional phase in which intentions are realised. The motivational phase comprised beliefs about how desirable or possible was a potential intention was, whereas the volitional phase comprised processes that would increase the likelihood of this action by emphasising the production of action plans. Therefore, implementation intentions provided a framework to conceptualise how intentions would be translated into actions (Albery & Munafò, 2008). For instance, the study intervention encouraged patients to think about when they would exercise (e.g. first thing in the morning after breakfast), where (e.g. to the shops and back) and how (e.g. make sure that they do not plan anything else to do that day before the exercise).

Findings from the qualitative study (see Chapters 6 and 7) suggested that patients who had previously been fit and active were disappointed with their lack of physical strength and fitness after the ICD. Therefore for this cohort of patients, the study intervention gave assurance that their changed physical status was 'normal' along with the encouragement that their fitness would gradually improve over time, and the exercise plan could be used as a training diary to increase their stamina.

Chapter 4 and Chapter 5: Getting to sleep at night and Learning to relax

These chapters were based on Stress-Management Training and a Relaxation Intervention. According to Lazarus and Folkman (1984), the key tenet of stress is how an event (external or bodily reaction) is appraised rather than the event per se. For example, an ICD battery change procedure might be perceived to be stressful to some individuals but not to others depending on how the procedure has been appraised. Stress-management training generally comprises interventions based on cognitive and behavioural theories of stress and teaches individuals how to cope with stress using coping strategies such as relaxation training and cognitive restructuring, which appear to be effective. For example, Sears, Vazquez Sowell, Kuhl, Kovacs et al. (2007), carried out an ICD shock and stress management programme and found anxiety was reduced in those who received education and cognitive-behavioural interventions.

Muscle Relaxation Training

The basic therapeutic claim of muscle relaxation therapy (MRT) is that tense, stressed and anxious individuals can find relief from distress and psychological arousal by learning to reduce muscle tension (Conrad & Roth, 2007). A theoretical rationale for MRT is than an important element of psychological distress is the activation of the stress response that is initiated after a stressor has been appraised as stressful (Conrad & Roth, 2007). This appraisal combined with sensory information triggers autonomic responses (see ANS below), which according to Morrison & Bennett (2011) can be regulated by relaxation.

The Autonomic Nervous System (ANS)

The autonomic Nervous System (ANS) regulates and co-ordinates important bodily activities including blood pressure but its main function being to keep a constant internal body environment (homeostasis) when internal or external changes occurs (Andreassi, 2007). A number of brain areas control the ANS, including the hypothalamus, which has links to the cortex and limbic systems of the brain that are involved in processing cognitive and emotional demands, which allows the ANS to respond to psychological factors such as raised anxiety, as well as physical demands placed on the body (Morrison & Bennett, 2011).

The ANS comprises the sympathetic nervous system (SNS) and the parasympathetic nervous system (PNS). According to Andreassi (2007), the SNS generally controls activities that can be mobilised simultaneously during stressful situations by the release of adrenaline and noradrenaline (Morrison & Bennett, 2011), (known as the 'fight-or-flight' response [Cannon, 1915] or 'stress response'). The sympathetic release of adrenaline that increases autonomic responses, such as increased heart rate, increased blood pressure, increased blood sugar, enhanced blood flow to the voluntary muscles, decreases blood flow to internal organs and increases sweating. The rapid heartbeat and extra glucose bring extra nutrition and oxygen to the muscles, whereas the increased muscle tension prepares the individual for running or physical defence. The sympathetic response to threat is adaptive as the shortness of breath induces rapid breathing, hyper-oxygenating the blood and secretion of adrenaline into the blood enables it to clot faster if injury occurred.

The activities under PNS control are also adaptive to its basic functions of rest, repair, and relaxation of the body and restoration of energy stores (Andreassi, 2007). According to Andreassi (2007), the PNS is dominant during eating, sleeping and sexual activity. Some of the PNS activities include the stimulation of salivary secretions, digestive secretions in the stomach, pupil restriction and increased blood flow to the genitalia during sexual excitement. Although both systems have contrasting functions, they tend to act together with reciprocity in order to keep the body in homeostasis. The activity in each of the organs depends on the relative activity in the SNS and PNS; when activity in the SNS dominates, the body is activated and the when PNS is dominant, the body is resting and relatively inactive (Morrison & Bennett, 2011).

How Relaxation Helps

Jacobson (1934a, 1934b) developed a method of progressive muscle relaxation that was based on the theory that a psychobiological state called neuromuscular hypertension was the basis for a variety of negative emotional states and psychosomatic diseases (Conrad & Roth, 2007). Jacobson asserted that relaxing muscles would lead to the mind being relaxed (Conrad & Roth, 2007). Jacobson's (1938) deep muscle relaxation technique, involves alternatively tensing and relaxing muscle groups in the body in an ordered sequence. Over time, the emphasis of practice shifts towards relaxation without prior tension, or relaxing specific muscle groups while using others in order to lower physiological arousal and reduce a stress-response, or the likelihood of ANS activity (stress-response) (Morrison & Bennett, 2011)

Relaxation has been suggested as being adaptive in more ways than merely reducing a stress response. For instance, metacognitive therapy (Wells, 2000) suggested relaxation could be used to divert attentional resources because relaxation required considerable attentional resources. Therefore, according to metacognitive therapy, training in relaxation skills might provide new coping strategies for responding to threat. Relaxation might reduce S-REF activity (see chapter 4) by: (i) the reduction of worry/perseverative processing; (ii) the reduction of physiological arousal, which would enable more valuable processing resources to become available; (iii) the provision of alternative strategies for guiding processes in stressful situations and (iv) weakening the activity of lower-level (automatic) processing that generates intrusive thoughts (Wells, 2000). Accordingly, relaxation techniques might provide a means of disrupting maladaptive S-REF perseveration. If relaxation was practised in object mode, in which the individual has little meta-awareness and the individual's goal is to escape from or reduce a non-existent threat, then the individual's negative beliefs about the threat would not ultimately be modified and relaxation might not be adaptive in this circumstance. However, if the aim of relaxation is to reduce physiological arousal or to have 'time-out' from worry, then it would be adaptive (see also Metacognitive Therapy – Mindfulness and Distraction below).

The study intervention taught patients to recognise symptoms of stress, for example patients were taught to be aware of tension; whether they had hunched, tense shoulders or they were holding their hands in a fist. The intervention provided patients with written instructions in how to carry out Jacobson's (1934) progressive muscle therapy and was provided with a CD with verbal instructions. In addition to instructions on how to relax, patients were encouraged to think about when they would practice relaxation skills, where they would carry out these skills, and how they would carry them out. For instance, patients were taught to think about possible disruptions that might occur during their relaxation therapy such as being disturbed by a phone-call. This additional instruction was based on social cognitive theory and the process of implementation intentions (Gollwitzer, 1999), which suggested that making plans linked critical situations to goal-directed responses. For instance, "when it's 5 o'clock, I will practice relaxation on the bedroom floor, with my phone switched to silent". Gollwitzer (1999) suggested that when the individual noticed it was 5 o'clock, the situational cue would elicit the goal-directed response to initiate the intended behaviour.

Chapter 6: Coping with Worries

This chapter was based on Metacognitive Theory: Mindfulness and Distraction (Wells & Matthews, 1994, 1996) and Cognitive theory: Cognitive Restructuring and Challenging Negative Automatic Thoughts (Beck, 1976). Morrison and Bennett (2011) defined a psychological model of stress as being a psychological transaction between a stimulus event (e.g. ICD implant) and the cognitive and emotional characteristics of the individual. Central to this model was appraisal, which underlies all cognitive theories of stress. For instance, Smith and Lazarus's (1993) theory of appraisal highlighted that it was the appraisal of an event that led to distress rather than its objective assessment, and Beck (1976) suggested it was the cognitive response to an event rather than the event per se that led to feelings of distress (see Chapter 4). These theories, based on schema theory, suggested that an individual's beliefs and appraisals need to be modified to reduce distress, which includes changing/challenging the behaviour that maintains the maladaptive cognitions (Wells, 2000).

The study intervention encouraged patients to challenge their appraisals and cognitions using cognitive re-structuring. Firstly, individuals were encouraged to identify and challenge the accuracy of their thoughts. For instance, in line with an ICD patient, catastrophic thoughts of a worsening heart might be identified when the hospital technician typically remained silent whilst a patient's device was being interrogated[55]. In this instance, the patient would be encouraged to think about their thoughts in the following way:

- "What other points of view are there?" e.g. - maybe the technician is concentrating
- "What would someone else think here?" e.g. - maybe they would think the technician is merely focusing on the job in hand
- "Could I be mistaken in the way I am thinking?" e.g. - just because someone is silent, it does not mean they are worried or concerned
- "Am I thinking straight?" e.g. - I am anxious and I need reassurance. This is why his silence is making me feel worried

Using the same example scenario, the individual would also be encouraged to think about the reality of the situation:

- "What are the facts here?" e.g. – I am well. My medication is effective because my doctor said so. I am back at work. The technician has not said anything is wrong"
- "What is the evidence for my worries?" i.e. – "There is no evidence!"

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[55] The term 'interrogating' refers to downloading the stored data from the ICD device. The cardiac electrophysiologist and a trained technician or nurse typically carries out the interrogation. Interrogation of the cardioverter-defibrillator is performed by communicating via electromagnetic coupling with a donut-shaped electrode that is placed over the device and attached to a programmer, which is specific to the device of each manufacturer. Interrogation allows the physician to determine which electrical therapy has been given and when they were received. Lead integrity and battery status are also checked (Groh, Foreman & Zipes, 1998).

Metacognitive theory (Wells, 2000) suggested that psychological distress was due to S-REF activity, which included the maladaptive processing of information (see chapter 4). The theory further suggested that a trigger for the activation of maladaptive processing was heightened self-focussed attention and perseverative forms of appraisal and coping, such as worry and threat monitoring. The S-REF model suggested that coping strategies that strengthened alternative plans for dealing with thoughts (e.g. detached mindfulness), increased the flexibility of control over attention, interrupted rumination, and reduced self-focussed attention would be effective in reducing psychological distress.

According to Wells (2000), the experience of being distracted referred to the often-involuntary capture of attention by task-irrelevant stimuli. For example, if a doorbell rings during a 'worry episode', the worrier may become shortly distracted from worrying. Accordingly, individuals could use active and volitional distraction as coping strategies by focusing attention away from threat or emotion. The study intervention offered the reader both cognitive and behavioural distraction methods. One cognitive distraction task included counting to 50 whilst imagining the numbers in their head. Behavioural distraction tasks included talking to someone about anything other than the worry on their minds or focusing hard on the plot whilst watching a film or listening to the radio. Patients were encouraged to write down suitable distraction tasks for the day and for the night as talking to someone might not be an appropriate distraction coping task in the middle of the night.

However, distraction coping might not be suitable as a long-term solution but be more adaptive as a short-term respite from distress. Consistent with the S-REF framework, distraction diverts attention away from processing threat and emotion, thereby reducing distress temporarily by preventing the activation of fear and anxiety. However, whilst attentional strategies, such as distraction, might reduce the intensity of arousal or distress, they do not allow the individual to access information that could disconfirm negative beliefs. For example, if an individual believed high arousal was potentially harmful, attentional strategies might prevent them from experiencing disconfirmatory information. Therefore, distraction and control strategies may prevent long-term reduction in fear, since fear-related propositions remain unmodified. Likewise, these avoidance behaviours (distraction) might be maintained by Mowrer's (1947) two-process behavioural model, which suggested avoidance was maintained due to operant conditioning of the fear response (see chapter 4).

According to Wells (2000), meditational types of intervention can be used to reduce distress in some individuals. However those individuals whose S-REF processing was characterised by hypervigilence for bodily sensations and catastrophic misinterpretation of such sensations might not benefit from meditation that uses heightened body focus attention. Meditations that use a heightened body focus strengthen hypervigilence and does not contain information that could correct faulty catastrophising appraisals. Conversely, some procedures such as meditation-based strategies involving heightened body-focussed attention could strengthen self-focussed processing tendencies and therefore maintain or strengthen individual susceptibility to S-REF activation. For example, the panic patient who misinterprets a racing heart as a sign of an imminent heart attack may benefit less from a meditation in which the individual focuses on bodily sensations than those individuals who do not show bodily hypervigilence. Overall, the S-REF model implied that 'mindful' procedures that relied on non-self focussed strategies and achieved attentional control might be particularly useful in the general treatment of a range of disorders – as a prerequisite or component of knowledge modification (Wells, 2000).

Mindfulness training is a meditative procedure based on the programme of Kabat-Zinn (1990), and involves focusing attention on breathing and letting go of thoughts as they occur, followed by redeployment of attention on breathing. In everyday practice of mindfulness, focusing on breathing is used as an anchor for bringing attention back to the 'here and now' whenever attention is diverted to other streams of thoughts or general lack of awareness. By engaging in mindful meditation, appraisals and cognitions are disengaged with in order to block ruminative thinking and allow individuals to be aware of their thoughts without being overwhelmed by them.

The intervention offered patients a brief introduction to the concept of mindfulness, giving examples of how to practice being 'mindful'. For instance, whilst out walking, they were encouraged to think about how they were feeling, whether they were waking quickly, whether they felt cold or hot, how it felt when their feet hit the ground and what were other people around them doing. The aim of the 'mindful' section of the intervention was for patients to become less focussed on their worries (although these worries would still exist in the background), due to their attentional resources being used in 'mindful' activities, which would result in the emotional impact of these worries being reduced. According to Wells (2000), by teaching patients skills in mindfulness, this also increases their attentional flexibility, which should help patients increase their attentional control over negative affective experiences.

Chapter 7: Planning a Shock Strategy

This chapter on planning a shock strategy was developed to help patients devise an action plan to be followed if a shock was experienced. This was included based on the rationale that although patients could not control the occurrence of a shock, they can control how they react to the shock. Sears, Shea and Conti (2005) suggested that if patients made a plan in how to respond to a defibrillated shock, this would reduce the anxiety and uncertainty that surrounded the event and help them cope more effectively post-shock.

The decision to include a chapter labelled 'Planning a Shock Strategy' was also based on Smith and Lazarus' appraisal theory of emotion. The core emotional theme for anxiety and sadness (related to depression) included low emotion and problem coping potential. As ICD patients (and their partners) were concerned about what to do in the event of a shock, the intervention included advice to plan what to do in the event of the shock to increase the patient's perceived coping potential.

Activity Aids: Exercise Diary, Activity Planner and Changing Worries Chart

An exercise diary and an activity planner, which related to Chapter 3: Keeping active, were included at the end of the booklet. Based on social cognitive theory in particular goal setting (Gollwitzer, 1990), patients were encouraged to plan an exercise regime that would help them slowly but steadily increase their stamina. In this chapter, patients were also encouraged to include pleasurable activities each day, which would also help them build up their stamina and help them to return to 'normal' living.

A changing worries chart that related to chapter 6: Coping with worries, was also included at the end of the booklet. Based on Beck's (1976) cognitive theories to restructure and challenge negative automatic thoughts, patients were guided to identify worries and to write down realistic responses to them.

Patients were advised that they might photocopy the exercise diary, activity planner and the changing worries chart if they so wished to.

External Critique of intervention

Committee members from a local ICD support group, who had had their ICD for a varying number of years, reviewed the intervention. From this feedback, changes deemed appropriate were made to the intervention before the study began. The Arrhythmia Specialist Nurses at the University Hospital of Wales (UHW) and Morriston Hospital reviewed study intervention as well as the Consultant Cardiac Electrophysiologists from University Hospital of Wales and Morriston Hospital to ensure that all the medical information was correct.

Testing the Intervention

In line with MRC (2008) guidelines, a pilot randomised control trial (RCT) was carried out to test the efficacy of the intervention. In addition to finding out if, the intervention helped reduce psychological distress, the pilot RCT was interested in identifying possible risk factors for increased anxiety and depression. The reason for this is that there was contradictory evidence in the literature as to whether age and gender were risk factors for increased anxiety and depression (e.g. Hamilton & Carroll, 2004; Bilge, Ozben, Demircan, Cinar et al., 2006)(see Section 3, Chapter 3). This study was also interested in whether any particular cardiac illness was a risk factor for increased anxiety and depression as the ICD patient cohort in this study represented a wide range of different cardiac illness.

With regard to coping, this study was interested in whether Type-D personalities tended to use a particular type of coping. Denollet (2005) posited that type-D personalities were 'distressed people'; however, findings from Pedersen, Middel and Larsen (2002) suggested that type-D people might experience distress because of the way they cope rather than because they were *distressed* people per se (see Section 3, Chapter 3). The pilot RCT was also interested in whether different cardiac illnesses, age and gender were predictors of particular types of coping.

Next:

Chapter 9 - Pilot Randomised Control Trial: Brief Psychological Coping Intervention for ICD Patients

Part 3

Chapter 9

PILOT RANDOMISED CONTROL TRIAL: BRIEF PSYCHOLOGICAL COPING INTERVENTION FOR ICD PATIENTS

This chapter describes the pilot randomised control trial that was carried out to evaluate the effectiveness of the brief psychological coping intervention.

***SECTION ONE**: Pilot RCT Study*

- *Aims 1*
- *Aim 2*
- *Methods (participants)*
- *Sample Size*
- *Materials and Measures*
- *Recruitment*
- *Analyses Aim 1*
- *Analyses Aim 2 (2.1 and 2.2)*
- *Results (Sample Characteristics)*
- *Results for Aim 1*
- *Key Findings for Aim 1*
- *Discussion for Aim1*
- *Results for Aim 2*
- *Discussion for Aim 2*
- *Key Findings for Aim 2*

SECTION 2:

- *General Discussion*
- *Critique of Pilot RCT*
- *Feedback on the Intervention Booklet*
- *Limitations to the Pilot RCT*
- *Recommended Changes to the Design of the Study*
- *Recommended Changes to the Written Intervention*
- *Recommended Changes to the Delivery of the Intervention*

SECTION ONE

A pilot randomised control trial (RCT) was carried out in line with the developmental process of the Medical Research Council's 'Developing and Evaluating a Complex Intervention' guidelines (MRC, 2008). The pilot RCT had two aims:

- **Aim 1**

  The main aim was to determine the effectiveness of the brief psychological coping intervention in comparison to existing information booklets used in routine care.

- **Aim 2**

  Aim 2.1 One aim was to find the significant predictors of key emotional outcomes (anxiety and depression), and key coping outcomes (confrontational, acceptance-resignation and avoidant) by examining their variances using predictor variables from the general theoretical framework of Lazarus and Folkman (1984).

  Aim 2.2 Another aim was to find the demographic and clinical risk factors for the key outcomes.

METHOD

Participants

Participants who were eligible for the study were recruited from the University Hospital of Wales (UHW), Cardiff, Morriston Hospital, Swansea and the Bristol Heart Institute, Bristol.

Participants were included if they were aged 18 and over. No upper age limit was applied. Participants must have been having their ICD fitted for the first time. Participants were excluded if they were having a box-change (replacement battery) or a replacement ICD because their ICD had been recalled. Participants were also excluded if they were waiting for a heart transplant or a coronary artery by-pass or had severe psychiatric or psychological health issues. Participants who could not read English were also excluded.

The NHS Research Ethics Committees of participating hospitals approved the study. The study was conducted in according with the World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects (2003). Ethical and Research and Development approval was initially gained for Cardiff and Swansea. However, recruitment was slow and the study subsequently widened its geographical area to include Bristol.

SAMPLE SIZE

This study was a pilot randomised control trial. The aims of this study were to identify effect sizes, participant uptake and to determine the likely attrition rate of participants in order to estimate the acceptability of the intervention and estimate the sample size needed for a fully powered randomised controlled trial.

MATERIALS AND MEASURES

Contents of Envelope given to Participants (see Appendices)

An envelope was given to participants. Each envelope contained a Participant Information Sheet, a Participant consent form, a Questionnaire of measures, and a form to collect demographic and contact details. See samples of materials used in the following appendices:

Appendix VIII	Participant Information Sheet
Appendix IX	Sample Participant Consent Form
Appendix X	Psychological Measures Questionnaire
Appendix XI	Sample form used to collect the Demographic/Contact details

Each participant was randomised to an intervention or control group using a computer algorithm. Covering letters were sent out at 3- and 6-months[56] with the patient's name entered in the salutation. See samples of materials used in the following appendices:

Appendix XII	Letter of Introduction to Ward Sisters
Appendix XIII	Sample Participant Information Sheet used by Bristol Heart Institute[57]
Appendix XIV	Computer Algorithm used in the study
Appendix XV	Covering letter sent at 3-months
Appendix XV I	Reminder letter sent to participants after 2-weeks
Appendix XVII	Process measures sent to participants in the Intervention group at 3-months
Appendix XIX	Brief Psychological Coping Intervention

Psychological Measures Used in the Questionnaire

A questionnaire was given to participants at baseline and at 3- and 6-months. The questionnaire consisted of 10 separate validated measures (see sample questionnaire Appendix X). The measures chosen for the questionnaire assessed participants' beliefs about the ICD and their cardiac illness, levels of anxiety and depression, ways of coping, and levels of activities and exercise. The questionnaire also included two measures, which were not validated namely the Positive ICD Beliefs questionnaire and the Behaviour questionnaire, (see Detailed Description of the Measures used in the Study Questionnaire below). The same measures were used baseline, and 3- and 6-months.

At baseline, participants filled in a form giving demographic information (name, address, date of birth, contact phone number and marital status) (see Appendix XI).

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[56] The 3- and 6-month covering letters were identical apart from the wording to reflect the time since the participant's implant.

[57] Bristol Heart Institute participants received all their study materials (apart from the psychological measures questionnaire), with the BHI logo inserted.

Patient notes were used to find patients' clinical characteristics. A checklist was used to find the relevant clinical information (see Figure 1).

<table>
<tr><td colspan="4">Pack Number:</td><td colspan="3"></td></tr>
<tr><td colspan="4">Name of patient:</td><td colspan="3">ICD or CRT-D</td></tr>
<tr><td colspan="4">Secondary</td><td colspan="3"></td></tr>
<tr><td colspan="4">Primary</td><td colspan="3"></td></tr>
<tr><td colspan="4">If Heart Failure - NYHA class 1 – 4</td><td colspan="3"></td></tr>
<tr><td>Previous /
known</td><td>MI</td><td>CABG</td><td>PCI</td><td colspan="2">Angina</td><td>Valvular disease</td></tr>
<tr><td>DCM /</td><td>HCM</td><td>ARVD</td><td>Restricted CM</td><td>Long QT</td><td>Short QT</td><td>Brugada</td></tr>
<tr><td colspan="4">Other Unclassified</td><td colspan="3"></td></tr>
<tr><td colspan="4">Receiving psychotropic medication prior to implant</td><td>Yes</td><td colspan="2">No</td></tr>
</table>

Figure 9.1: A sample of the checklist table used to report participants' clinical characteristics

Detailed Description of Measures used in the Study Questionnaire (in the order they appeared in the questionnaire)

ICD-Concerns Questionnaire (ICD-C) (Frizelle, Lewin, Kaye, Moniz-Cook, 2006)

The ICD-Concerns Questionnaire was developed to measure the extent and severity of concerns of patients with an ICD. The concerns in this measure had been identified by Frizzelle and colleagues from interviews with ICD patients and from a literature search that documented the psychological sequelae of an ICD implant. The questionnaire assessed perceived limitations due to the ICD using 11-items[58] (e.g. *'I am worried about ... Not being able to work/take part in activities/hobbies because I*

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[58] Item 20 of the ICD-C was omitted in this study as it was repetitious of item 4.

have an ICD'). The measure included 8-items to measure device-specific concerns (e.g. *'I am worried about .... Problems occurring with my lead'*). The items were rated on a 5-point response scale ranging from *'0-Not at all worried'* to *'4-Very worried'.* The total ICD concern was the sum of the factors (perceived limitations and device-specific concerns). No cut-off point was suggested. However, high scores suggested higher perceived limitations and a higher number of device-related concerns. The total score for the measure used in this study ranged from 0 to 76.

According to Frizelle et al. (2006), the ICD-Concerns Questionnaire had an acceptable internal consistency, with a Cronbach alpha coefficient of .94 for the total scale and .94 for perceived limitations and .92 for device-specific concerns. In the current study, the Cronbach alpha was .93 for the total scale and .87 and .85 for device-specific concerns and perceived limitations respectively.

Impact of Events Scale (IES) (Horowitz, Wilner & Alverez, 1979)

The IES is an instrument that measures subjective distress related to a specific event. In this study, the event was *'living with the ICD device'.* The scale measured the frequency of intrusive thoughts with 7-items (e.g. *'I think about the ICD when I don't mean to'*) and avoidant behaviour using 8-items (e.g. *'I try not to think about the ICD'*). The response scale used was *'1-not at all'* to *'4-often'.*

The totals of the subscale scores were the mean of the item scores, which ranged from 1 to 4 for avoidance and 1 to 4 for intrusive thoughts. The split-half reliability of the total scale was high (r=.86). According to Horowitz et al. (1979), the intrusion and the avoidance subscales were also high with Cronbach alpha coefficients of .78 and .82 respectively. In the current study, the Cronbach alpha coefficients were .85 for intrusion and .83 for avoidance.

This measure was shown by Horowitz et al. (1979) to have a good test-retest reliability of .79 for the avoidance subscale and .89 for the intrusion subscale and was therefore suitable to be used in a repeated measures design.

Florida Patient Acceptance Survey (FPAS) (Burns, Serber, Keim, & Sears, 2004)

The FPAS is a measure to assess the level of patient acceptance to a cardiac-device such as the ICD. Patient acceptance was defined by Burns et al. (2004) as the psychological accommodation and understanding of the advantages and disadvantages of the device, the recommendation of the device to others, and the derivation of benefit in terms of biomedical, psychological and social functioning. Patient acceptance was theorised to be a device-specific component of the construct of quality of life (Burns et al., 2004).

The questionnaire comprised 18-items and assessed four factors on a continuum. Factors measured were Return to Life (4-items e.g. *'I have returned to a full life'*), Device-related Distress (5-items e.g. *'It is hard for me to function without thinking about my device'*), Positive Appraisal (4-items e.g. *'I would receive this device again'*) and Body Image Concerns (2-items e.g. *'I feel less attractive because of my device'*). The items were rated on a 5-point response scale ranging *from '1- Strongly disagree'* to *'5-Strongly agree'*, and higher total scores indicated higher acceptance towards their device. The total scores for the individual factors ranged from 4 to 16 (return to life and for positive appraisal), 5 to 20 (device-related distress) and 2-8 for body image concerns. The total FPAS score = (sum of subscale scores /15) x 100.

According to Burns et al. (2004), the FPAS demonstrated good internal consistency, with a Cronbach alpha coefficient of .84 for the total FPAS. For the individual subscales, Burns et al. found a Cronbach alpha coefficient of .89 for Return to Life, .79 for Device-related Distress, .82 for Positive Appraisal and .74 for Body Image Concerns. In the current study, the Cronbach alpha coefficient for the FPAS total was .86. The Cronbach alpha coefficients for the subscales in the current study were .70 (Return to Life), .84 (Device-related Distress), .83 (Positive Appraisal) and .80 (Body Image Concerns).

Positive ICD Beliefs Questionnaire (measures level of positive appraisals about the ICD) (Not validated)

There was not a valid measure that assessed the set of positive or negative beliefs held by ICD patients so this 24-item measure was created for this purpose. This beliefs measure was based on Frizelle et al.'s (2006) ICD Concerns questionnaire[59], which measures worries about perceived limitations and device specific concerns. Whereas worries do not necessarily require evaluation and are not value-laden, beliefs like appraisals are based on evaluation and are value-laden. Accordingly, this measure was devised to measure positive beliefs/appraisals in order to test Lazarus' theory that appraisals influence emotions.

The Positive ICD Beliefs Questionnaire comprised 24 items. The measure was evaluated positive beliefs (11-items e.g. *'I am lucky to have the ICD'*), self-efficacy (5-items e.g. *'I feel more in control of my life with an ICD'*) and treatment efficacy (8-items e.g. *'The ICD will fire when it needs to'*). The response scale used was a 4-point scale ranging from *'0-no, not at all' to 4-definitely'*. The total score was the sum of item scores, which could range from 22 to 88. Higher scores indicated a set of more positive ICD-related beliefs.

The measure was initially piloted with patients attending a cardiac outpatient's clinic to ensure face validity. In the current study, the Positive ICD Beliefs Questionnaire had good internal consistency with a Cronbach alpha coefficient of .86.

ICD Behaviour Questionnaire (measures avoidant behaviour relating to normal everyday activities (Not validated)

This questionnaire was developed specifically for this study as there was not a measure to assess the changes in participants' 'normal' daily activities (e.g. visiting places, engaging in social activities) after an ICD.

This 22-item measure was designed to measure beliefs about the self and coping in relation to daily activities (6-items). The measure used six items to assess levels of

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[59] Permission to adapt the ICD-Concerns measure was given by Prof Bob Lewin (personal communication, 16th February 2011).

avoidant and restrictive physical behaviours (e.g. *I tend to avoid certain situations'*) and 10- items to assess levels of engagement with social activities (e.g. *I regularly take part in exercise or social activities that increase my heart rate'*). A 5-point response scale was used, which ranged from *1-totally disagree* to *5-completely agree*. The total score was the sum of item scores, and ranged from 22 to 110. High scores reflected a more active, daily lifestyle.

The measure was initially piloted with patients attending a cardiac outpatient's clinic to ensure its face validity. In the current study, the ICD Behaviour Questionnaire had good internal consistency with a Cronbach alpha coefficient of .89.

Medical Coping Modes Questionnaire (MCMQ) (Feifel, Strack & Nagy, 1987a)

This measure was based on Feifel and colleague's clinical experience and their empirical findings that suggested that there were three major styles of coping. The modes of coping were taking direct action (confrontational); avoiding the stressor (avoidance); and accepting the stressful situation without attempting to alter it (resignation-acceptance).

The measure comprised 19 items that measured three ways of coping. Confrontational coping had 8-items e.g. *'How much do you want to be involved in decisions regarding your treatment?'* Avoidant coping had 7-items e.g. *'In conversations about your condition, how often do you find yourself thinking about other things?'* and Acceptance-Resignation coping had 4-items e.g. *'How often do you feel that you don't care what happens to you?'* The responses were rated using a response scale, which ranged from *1-4*. Total scores for confrontational coping ranged from 8 to 32. The total score for avoidant coping ranged from 7 to 28 and for acceptance-resignation coping ranged from 4 to 16. Higher scores indicated more confrontational/avoidant/acceptance-resignation coping used.

Each item had individual responses, which either measured the frequency of a mode of coping or the extent to which the participant used a mode of coping. In the current study, participants were asked to relate the questions to how they were coping with their situation.

According to Feifel et al. (1987b), the Medical Coping Modes Questionnaire has a moderate internal consistency, with Cronbach alpha coefficients of .70 for Confrontation, .66 for Avoidance and .67 for Acceptance-resignation. In defence of the low Cronbach alpha coeffiencients, Feifel et al. (1987) suggested that because participants might use more than one coping mode, this might have reduced the use of alternative responses within the same coping mode. In the current study, the Cronbach alpha coefficients were .64, .63 and .78 for confrontation, avoidance and acceptance-resignation respectively.

Leisure time Exercise Questionnaire (adapted from Godin's leisure time exercise questionnaire) – Godin & Shephard (1985) and Exercise Diary

The Godin Leisure-time Exercise measure assesses leisure-time exercise behaviour. This measure was chosen as Godin and Shepherd (1985) posited that the outcomes from this measure could be used to examine changes in behaviour following an intervention to improve health and fitness. The questionnaire assessed exercise in terms of metabolic equivalents (METs). A MET is defined as the resting metabolic rate, that is, the amount of oxygen consumed at rest, approximately 3.5 ml O_2/kg/min. As such, work at 2 METs requires twice the resting metabolism or 7 ml O_2/kg/min (Jetté, Sidney, Blümchen, 1990).

Participants were instructed to indicate how many times a week they engaged in strenuous, moderate and mild exercise for more than 15 minutes during the day. Participants were given examples of each; e.g. strenuous = running/jogging; moderate = fast walking, easy cycling; mild = yoga, golf. A total weekly score of units was derived by summing the reported weekly frequency of participation in each of the three intensity levels multiplied by the corresponding MET value (3= mild exercise, 6= moderate exercise, and 9= strenuous exercise.)

Godin and Shepherd (1985) proposed that this questionnaire was reliable, valid and easy to complete without any detailed checking needed by professional staff. However, the current study found that participants consistently failed to understand how to complete Godin's measure correctly. In particular, they had difficulty with the instruction which asked them to change a number of minutes of a total activity into blocks of 15 minutes.

An exercise diary subsequently superseded this measure. The exercise diary[60] has a simple table format so participants can record how many minutes a day they engage in three levels of exercise. There were three tables with different general levels of exercise. One table was labelled 'How many minutes did you exercise STRENUOUSLY each day?' The second table was labelled 'How many minutes did you exercise MODERATELY each day?' and the third table 'How many minutes did you exercise MILDLY each day?' Underneath each instruction, examples of types of exercise were given to demonstrate the different intensities of exercise. For instance, examples of exercise given to demonstrate strenuous exercise were running and jogging. Examples given for moderate exercise were fast walking and easy swimming, and for mild exercise were easy walking and bowling.

Participants simply had to write down the total number of minutes in which they engaged in the three levels of exercise each day during the previous week. The total score for each level of exercise was found by totalling the number of minutes from Monday to Sunday.

Brief Illness Perception Questionnaire (B-IPQ) (Broadbent, Petrie, Main, & Weinman, 2006)

The B-IPQ was designed to quickly assess the cognitive and emotional representations of an illness and was based on Leventhal's self-regulatory model (1984) (Broadbent, et al., 2006). Leventhal's model proposed that situational stimuli (e.g. symptoms) generated cognitive and emotional representations of the illness, which were useful to predict coping (Moss-Morris, Weinman, Petrie, Horne, et al., 2002).

The Brief IPQ has nine single item scales with wording that can be altered to represent a particular illness/condition. Where the word *'illness'* was used in the original Brief IPQ, the current study replaced this word with the term *'heart*

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[60] The exercise diary was not used until permission to use it was received from R&D, UHW, which meant patients (35 at baseline, and 16 at 3-months) were not tested with this measure.

condition'. Five items assessed cognitive illness representations (consequences, timeline, personal control, treatment control and identity e.g., *'How much control do you feel you have over your heart condition?'*). Two items assessed emotional representations (e.g., *'how concerned are you about your heart condition'*). One item assessed illness comprehensibility (*'how well do you think you understand your heart condition'*). Moss-Morris, Weinman, Petrie, Horne et al., (2002) suggested that 'illness coherence' measured a type of meta-cognition, which reflected the way in which participants evaluated the coherence or usefulness of their illness representation. All the items except the causal question were rated using a 0-10 response. The items 3, 4 and 7 were reversed scored.

The causal representation was assessed using an open-ended response item, which asked participants to list the three most important causal factors in their illness.

According to Broadbent et al. (2006), Pearson correlations demonstrated that the Brief-IPQ had significant test-retest reliability and was therefore suited to a repeated measures design. In the current study, test-retest scores were not taken because the study design was a randomised control trial.

Type-D Personality: DS-14 (Denollet, 2005)

The DS 14 was used to assess Type-D personality, which was developed using cardiac patients (Denollet, 2005; Pedersen, van den Berg, Erdman, van Son, et al., 2009). The DS-14 scale assessed negative affect (NA) using 7-items, e.g. *'I take a gloomy view of things'* and social inhibition (SI) using 7-items e.g. *'I would rather keep people at a distance'*.

Items were answered using a 5-point response scale ranging from *0-false* to *4-true*. Total scores ranged from 0 to 28 for the SI subscale and 0 to 28 for the NA subscale. A standardised cut-off of ≥10 on both sub-scales was used to identify those with a Type-D 'distressed' personality (Pedersen et al., 2009). Denollet (2005) proposed the personality trait constructs of NA and SI should remain stable over time and should be independent of changes in mood.

The temporal stability of Type-D personality in this study was confirmed by the means of test-retest correlations, which were r = .77 for NA and r = .65 for SI. According to Denollet (2005), the DS-14 had good internal consistency with a Cronbach alpha coefficient of .88 for NA and .86 for SI. In the current study, the Cronbach alpha coefficient for NA and SI was .82 and .71 respectively.

Profile of Moods-Short-Form (POMS-SF) (Shacham, 1983)

According to Shacham (1983) the original version for the Profile of Mood States (POMS; McNair, Lorr & Doppelman, 1971) used to assess transient, distinct mood states was too onerous for very ill patients to complete due to its length. Shacham scaled the POMS down from 65 items to 37 items, and named it the POM-Short-Form. The POM-SF was shown to provide the same information as the POMS and hold the same internal consistency but could be administered more easily to patients who were in considerable pain or who were stressed due to its shorter length (Shacham, 1983; Curran, Andrykowski & Studts, 1995).

The POM-SF has 37-items rated on a 5-point response scale that ranged from *'1-not at all'* to *'5-extremely'*. The POMS-SF consisted of six factors; five factors measured a negative mood state and one factor measured a positive mood. The negative mood state factors were tension-anxiety (6-items e.g. '*Nervous*'), anger-hostility (7-items e.g. *'Bitter'*), fatigue-inertia (5-items e.g. *'Weary'*), depression-dejection (8-items e.g. *'Hopeless'*) and confusion-bewilderment (5-items e.g. *'Forgetful'*). The positive mood state factor was vigour-activity (6-items e.g. *'Full of "pep"'*). The total mood state was calculated by the total of the non-vigour items (tension, anger, fatigue, depression and confusion) minus the total of the vigour items. Total scores (non-vigour minus vigour) ranged from 25 to 149. There was no cut-off score but higher scores indicated a more negative mood state.

According to Shacham (1983), the POMS-SF had good internal consistency, with a Cronbach alpha coefficients of .80 (Tension-Anxiety), .91 (Depression-Dejection), .90 (Anger-Hostility), .87 (Vigour-Activity), .87 (Fatigue-Inertia) and .819 (Confusion-Bewilderment). In the current study, the Cronbach alpha coefficients were .89 (Tension-Anxiety), .89 (Depression-Dejection), .90 (Anger-Hostility), .89 (Vigour-Activity), .89 (Fatigue-Inertia) and .65 (Confusion-Bewilderment).

Quality of Life (EQ-VAS) (EuroQol Group, 2011)

The EuroQol Group (which encompassed networks in England, Finland, the Netherlands, Norway and Sweden) met to test the feasibility of jointly developing a standardised non-disease specific instrument for evaluating health-related quality of life.

The EQ-VAS records the respondents' self-rated health on a vertical visual analogue scale, which looked like a ladder. It has a vertical line from the top of the page to the bottom, which is divided into 10 'steps'. The top of the 'ladder' was labelled '100' and beside the number had the statement 'best imaginable health state'. At the foot of the 'ladder' was a label with '0' and the statement 'worst imaginable health state' beside it. The steps were not numbered apart from a midway mark, which was labelled 50. Participants were asked to indicate (drawing a line or putting a cross) on the 'ladder' at the point at which they imagined their current health state. Participants did not have to keep to the incremental steps, which were unlabelled but went up in units of tens. For instance, participants could mark anywhere on the ladder (e.g. at 25 or 63).

Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)

Symptoms of anxiety and depression were measured using the HADS, which was specifically devised for physically ill patients (Zigmond & Snaith, 1983). The HADS has been used before with cardiac patients (Bambauer, Locke, Aupont, Mullan et al, 2005 et al., 2005; Herrman, 1997). In addition, Dunbar et al. (2012) in a scientific review suggested that the HADS measure was more sensitive to detecting changes in anxiety and depression in ICD patients compared to other measures of anxiety/depression (e.g. the State-Trait Anxiety Inventory, Spielberger, 1983).

The HADS is a 14-item self-report questionnaire. It consisted of a 7-item anxiety subscale (e.g. *'I get a sort of frightened feeling as it something awful is about to* *happen'*) and a 7-item depression subscale (e.g. *'I have lost interest in my appearance'*). Items were scored on a 4-point response scale ranging from *0-3.* Possible total scores ranged from 0 to 21 for the depression subscale and 0 to 21 for the anxiety. There was no specific cut-off score, but a cut-off ≥8 on both the anxiety and depression subscale of the HADS was suggested to indicate possible levels of clinical anxiety and depression (Zigmond & Snaith, 1983).

In Herrmann's (1997) review, the Cronbach alpha coefficients ranged from .80 to .93 for anxiety and .81 to .90 for the depression subscales. In the current study, the Cronbach alpha coefficient was.80 for anxiety and .81 for depression subscales. Herrmann (1997) found the mean correlation between anxiety and depression subscales in 18 studies to be r=.63, which was similar to the finding in this study, which was r=.64.

PROCEDURE

Setting up the study

The Arrhythmia Specialist Nurses liaised with their Cardiac Ward Sister. The Arrhythmia Specialist Nurse for each hospital informed the Cardiac Ward Sister that a researcher would be recruiting patients who were going to be fitted with an ICD. The Arrhythmia Specialist Nurse gave the Cardiac ward nurse a letter that explained the study and outlined the criteria of participants (see Appendix XII). The letter requested for a duty nurse to approach a patient (identified by the criteria), to ask if they would consent to speaking with the researcher[61].

Participant allocation to Control and Intervention Condition

Before recruitment commenced, a computer algorithm was set up to generate two numbers (0, 1) randomly in blocks of six. A table was produced from these numbers

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[61] [This part of the recruitment procedure was requested by Nic Drew, R&D, UHW (Ref: RD 111498) and this recruitment procedure was adhered to for the initial introduction to patients for both Morriston and UHW]. BHI patients were recruited by their Arrhythmia Specialist Nurse.

to allocate participants to the control group (0) or the intervention group (1) (see Appendix XIV). Envelopes containing a questionnaire, a participant information sheet, a consent form and a demographic form were numbered beforehand. An envelope was given to the participant by the researcher. At this point, the participant and the researcher were blind to which group the participant would be allocated to. When the consent form, questionnaire and demographic form had been completed and returned to the researcher in a sealed envelope, the researcher cross-checked the number on the envelope with the computer algorithm to identify if the participant belonged to the control or the intervention group. The participant remained blind to the group they were allocated.

Recruitment

There were two recruitment procedures for participants. One was for in-patients who were admitted to hospital after their cardiac event. The other recruitment procedure was for participants who were elective[62] patients. These patients were usually admitted to hospital on the evening before their ICD implant.

Recruitment for participants who remain in-patients whilst waiting for their ICD implant

1. The Arrhythmia Nurse Specialist (at each hospital) was contacted weekly to learn of any newly admitted patients or if any patients (currently undergoing tests) were going to be fitted with an ICD. The researcher was given the name of the patient and the ward onto which the patient had had been admitted.

2. If the patient consented to speak with the researcher, the researcher introduced herself to the patient. The patient was given a Participant Information Sheet to read[63]. The patient was informed of the following:

    2.1. The researcher's background and the aim of the study. This was verbally explained to the patient: i.e., the researcher was a PhD student who was

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[62] Elective patients were primary prevention patients, who were going to have an ICD because they had an increased risk of sudden cardiac arrest.

[63] All participants were given identical materials, however all the materials used by Bristol had the University Hospitals Bristol electronically printed onto the letterhead.

carrying out a study to compare the efficacy of two booklets that helped people to cope with their ICD.

2.2. If they volunteered to take part in the study, they would be randomised into a group comparing one of two booklets.

2.3. The study required them to fill in a questionnaire before their ICD procedure, which was to be handed back to the researcher or given to one of the nurses on the ward in a sealed envelope before their implant.

2.4. They would receive a follow-up questionnaire at 3-months and at 6- months after their ICD implant. At each follow up, they would be asked to fill in a similar questionnaire and return it to the researcher in a SAE envelope that would be provided.

2.5. Assurance that their consent to take part was voluntary; they did not have to take part or give a reason to explain their decision.

2.6. The terms and rights as research study participants, which covers informed consent, their right to withdraw, confidentiality, and anonymity of results.

  2.6.1. It was explained that they were free to withdraw at any time; however, all of their data collected to date might be kept.
  2.6.2. It was explained that data would be anonymised immediately and no one apart from the researcher and her supervisors will be able to identify them from their data.
  2.6.3. It was explained that their scores on the measures would not be passed on to their medical team (Arrhythmia Specialist Nurse, cardio-electro physiologist)
  2.6.4. Patients were told that consent to participate would involve permitting the researcher to access medical information specific to their cardiac illness.

3. Patients were told that they would receive a set of booklets in the post during the second week of them returning home after their implant. (See Appendix XIX for a sample copy of the intervention).

4. After the researcher explained the study to the patient, the patient was asked if they would like to take part in the research. If the patient was happy to join the study, they were asked to fill in the consent form. When the consent form was completed and collected, the researcher gave the participant the psychological questionnaire to fill in. Instructions on how to fill in each measure in the questionnaire was written at the top of each page. Participants were advised to fill in the questionnaire without giving each question too much thought.

5. The participant was asked if they would like the researcher to stay whilst they completed the form or whether they would prefer to fill in the questionnaire in private or at a time that was more convenient for the participant.

6. If the participant requested that the researcher stay whilst they filled out the form, the researcher took the questionnaire away when it was completed, along with the additional forms (consent form and demographic information form). If the participant wanted to fill out the questionnaire in private or at a different time, the researcher asked the participant to put the questionnaire and other documents (consent form, demographic form) into the envelope provided. The participant was asked to ensure they sealed the envelope and to give it to one of the ward nurses. The ward nurse would forward the envelope to the Arrhythmia Nurse and the researcher would collect it from the Arrhythmia nurse.

7. After the participant had consented to join the study by completing the consent form, the participant's clinical details, GP name and contact details were retrieved from the participant's medical notes.

Recruitment for Elective Patients

Elective patients were patients who had been identified as having an increased risk of a sudden cardiac arrest. The consultant usually informs these patients that they are advised to have an ICD. At an ICD counselling session, the Arrhythmia Specialist Nurse spends time with the patient discussing the device. The Nurse explains how the ICD works, where it is inserted, and what the patient must do/avoid doing after the implant procedure. For example, patients are advised that they must not raise the arm (nearest to the ICD) above their shoulder for 6-weeks. Patients are informed of driving restrictions after the implant and about an ICD shock. At the end of this counselling session, patients are given generic educational literature about the ICD and they are usually advised to think about whether they wanted to go on the waiting list for a device.

Elective patients were recruited after they received their ICD counselling session. Elective patients were given an envelope (containing a participation information sheet, a consent form, a demographic form and a questionnaire) at the end of their counselling session along with a brief covering letter explaining the study. The Arrhythmia Nurse briefly told the patient about the study. The Nurse told the patient that if they would like to take part in the study, they were to bring in the completed forms that were enclosed in the envelope when they were admitted for their ICD implant procedure. Booklets were sent out to participants following their implant.

Data collection at 3- and 6-months for both Inpatients and Elective Patients

1. Before sending out questionnaires at 3- and 6-months, the patient's GP was contacted by phone to find out if the participant was deceased.

2. At 3- and 6-months post-implant, participants were sent a psychological questionnaire (for either 3-months or 6-months as appropriate) with a covering letter to remind the participant about the study. A stamped addressed envelope was included. At each time point, the participant was asked to complete the questionnaire and return it to the researcher in the stamped addressed envelope provided.

3. Note: Participants in the intervention group were sent an extra form to complete at 3-months, which informed the researcher if the participant had read the intervention (see Process Measures, Appendix XVII).

4. An independent assessor[64] examined the 3-month data collection for the first 30 participants (15 controls + 15 interventions) to ensure there were no anomalies to cause concern. The Research and Development committee requested that preliminary data be screened to ensure participants in the treatment arm were not being negatively affected by the intervention (See Appendix XVIII to see the letter sent to Professor Bisson[65] outlining the results from the independent assessor).

5. If the questionnaire were not returned after two weeks, participants were followed-up with a reminder and another questionnaire.

ANALYSES

Aim 1

This aim examined the effectiveness of the brief coping intervention. In order to evaluate the effectiveness of the intervention, the mean scores for appraisals, emotions and ways of coping of the intervention and control group were taken at baseline, 3-months and 6-months and were compared. Although randomisation took place, there might have been differences in scores at baseline that influenced the scores at 3-months or 6-months. Therefore, differences between the groups at baseline were adjusted by analysis of covariance (ANCOVA) in order to control for these differences.

Pre-Implant to 3-Months

A series of one-way ANCOVAs were conducted to examine between-groups scores for each measure. The independent variable was the type of intervention (i.e. brief psychological coping intervention or routine literature). The dependent variable (DV)

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[64] Professor K. Vedhara

[65] In 2012, Professor Jonathan Bisson was the Chair of the Cardiff and Vale Research Review Service

was the score at 3-months. Participants' baseline scores were used as the covariate in each analysis. For example, if the DV was the level of depression measured by the HADS depression score at 3-months, the covariate for this DV would be the HADS depression score at baseline. This study focussed on effect size rather than significant *p* values. This was because the sample size anticipated was going to be too small to evidence a statistical significant difference between the two groups but the effect size would be unaffected by the size of the sample.

The hypotheses for the 3-month results were:

> **Hypothesis $_1$** – there would be meaningful[66] between-group effect sizes with the intervention group having more positive scores than the control group in relation to ICD-beliefs and illness-related appraisals at 3-months.
>
> **Hypothesis $_2$** – there would be meaningful between-group effect sizes with the intervention group reporting lower levels of depression and anxiety compared to the control group at 3-months.
>
> **Hypothesis $_3$** – there would be meaningful between-group effect sizes with the intervention group using more problem-focussed coping and less emotion-focussed coping. In addition, the intervention group would have greater acceptance towards their ICD and would be taking more exercise compared to the control group at 3-months.

Pre-Implant to 6-Months

A series of one-way ANCOVAs were conducted to examine the between-group scores at 6-months. Each individual measure identified a belief about the ICD or cardiac illness, an emotion, a type of coping, the level of acceptance to the ICD or a participant's level of exercise.

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[66] In this study, meaningful was defined as at least a small to medium effect size (Cohen, 1992).

The independent variable was the type of intervention (i.e. brief psychological coping intervention or routine literature). The dependent variable was the score at 6-months. The participants' baseline score was used as the covariate for each analysis. For example, if the DV was the level of depression measured by HADS depression at 6-months, the covariate for this DV would be the HADS depression score at baseline.

The hypotheses for results at 6-months were:

Hypothesis $_4$ – there would be meaningful between- group effect sizes with the intervention group having more positive scores than the control group, in relation to ICD-beliefs and illness-related appraisals at 6-months.

Hypothesis $_5$ – there would be meaningful between-group effect sizes with the intervention group reporting lower levels of depression and anxiety.

Hypothesis $_6$ – there would be meaningful between-group effect sizes with the intervention group using more problem-focussed coping, less emotion-focussed coping. In addition, the intervention group would have greater acceptance towards their ICD and would be taking more exercise compared to the control group at 6-months.

Aims 2.1 and 2.2:

Aim 2.1: The first aim was to find the significant predictors of key emotional outcomes (anxiety and depression), and key coping outcomes (confrontational, acceptance-resignation and avoidant) using predictors from the general theoretical framework of Lazarus and Folkman (1984).

Aim 2.2: The second aim was to find the demographic and clinical risk factors for these key outcomes.

Bivariate Correlations

At the outset, in order to find out the level at which variables correlated with each other, a series of bivariate correlations were carried out between the theory-led predictors for the key emotional and the key coping outcomes.

The series of bivariate correlations were conducted to examine the association between the predictor variables. In other words, bivariate correlations were conducted between the mean scores of emotion (anxiety and depression) taken at 3-months with ICD-beliefs and cardiac illness-related appraisals taken at 3-months. Then, another series of bivariate correlations were carried out with the mean scores for each key coping outcome (confrontational, acceptance-resignation, avoidance) at 3-months with the mean scores for ICD-beliefs and cardiac illness-related appraisals and emotions (anxiety and depression). The series of bivariate correlations were repeated using the mean scores at 6-months.

A further series of bivariate correlations were carried out using demographic and clinical variables with the mean scores of the key emotional and key coping outcomes at 3- and 6-months.

Hierarchical Regressions

After the bivariate correlations were conducted, a series of hierarchical regression analyses were carried out to determine the significant independent variables for the key emotion and key coping variables. For each outcome variable, two contemporaneous regressions (3- and 6-months) were carried out. In each regression, 3-month predictor variables[67] were used to explain 3-month outcomes and 6-month predictor variables used to explain 6-month outcomes. Each regression involved a two-block entry process.

In these regressions, theoretically relevant psychological variables were entered into Block 1 as the study wanted to know how much of all the variance was explained by psychological independent variables. For instance, for one of the key emotional

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[67] In this study, 'predictor' does not infer causality but is a description of a variable that might explain some variance.

outcomes, depression, Lazarus' theory-led predictors would be appraisals. Demographic and clinical characteristics were entered into Block 2 to see if they explained any of the variance left after Block 1.

Scores from the bivariate correlations were used to select independent variables for entry into the regression. Pallant (2010) suggested that the correlation between a predictor variable and the dependent variable must be at least .3, (see Pallant, 2010, page 158). Accordingly, in Block 1, psychological independent variables were only considered for entry into the hierarchical regression if they had a correlation of *at least .3* with the outcome variable.

Guidelines from Pallant (2010) to prevent multi-co linearity were used. In order to prevent multi-co linearity, Pallant suggested that each predictor variable must not correlate too strongly with other predictor variables entered into the same regression analysis. Pallant suggested that in order to prevent multi-co linearity, this correlation should not exceed .7. In line with the number of participants, the regressions could use a maximum of eight independent variables. Many independent variables appeared to be highly correlated (more than .7) with each other, for example, the Positive ICD Beliefs Questionnaire and the ICD-Concerns Questionnaire. Therefore, this guideline was helpful in reducing the number of independent variables that could be considered in order to achieve linearity. In these cases, the variable with the highest correlation with the dependent variable was chosen.

Block 2 demographic and clinical characteristics independent variables also had to be correlated with the outcome variable. Therefore, the scores from the bivariate correlations were also used to determine which independent variables to include into Block 2 of each regression. The study was interested in age and gender as risk factors for increased anxiety and depression at 3- and 6-months. For the key coping outcomes, this study was interested to find out if age, gender, having a Type-D personality, and clinical characteristics predicted a particular way of coping.

Independent variables were only entered into Block 2 if they *significantly* correlated with the dependent variable *by at least .1.* Unlike the psychological independent variables, the correlation between them and the outcome variable did not have to reach .3. No correlations between individual predictor variables were carried out for demographic and clinical variables in Block 2 as each variable clearly defined a unique construct.

Note: The hierarchical regression used was a modified version used by Bennett, Lowe and Honey (2003). In this version, the residual variance from Block 1 was saved and formed the outcome variable for Block 2. The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model. For instance, if Block 1 accounted for 70% of the variance, the total variance left to be explained in Block 2 would be 30%. For example, if the residual for Block 2 was .12 the variance explained would be .12 x 30, which would be 3.6. Therefore, in this instance, the total variance provided by the model would be 70% and 3.6% = 73.6%.

The following hypotheses were tested using a series of bivariate correlations and hierarchical regressions:

Hypothesis $_1$ - At 3- and 6-months after the ICD implant, concurrent illness and ICD-related beliefs would explain a significant percentage of variance in levels of anxiety.

Hypothesis $_2$ - At 3- and 6-months after the implant, concurrent illness beliefs and ICD-related beliefs would explain a significant percentage of variance in the levels of depression.

Hypothesis $_3$ - At 3- and 6-months after the implant, concurrent illness beliefs, ICD-related beliefs, and levels of anxiety and depression would explain a significant percentage in variance in coping with the ICD using confrontation.

Hypothesis $_4$ - At 3- and 6-months after the implant, concurrent illness appraisals, ICD-related beliefs, levels of anxiety and depression would explain a significant percentage of variance in coping with the ICD using acceptance-resignation.

Hypothesis $_5$ - At 3- and 6-months after the implant, concurrent illness appraisals and ICD-related beliefs, levels of anxiety and depression would explain a significant percentage of variance in coping with the ICD using avoidance (behavioural avoidance and cognitive avoidance).

RESULTS

SAMPLE CHARACTERISTICS: Recruitment, Demographic and Clinical Characteristics of Participants

Of the initial 99 patients included at baseline, 72 patients (71.28 %) completed the study at the 3-month follow-up. Reasons for not completing the study at 3-months included withdrawing from the study (n = 5), not responding at 3-months (n = 19), ICD postponed (n = 1), and not having an ICD (n = 2).

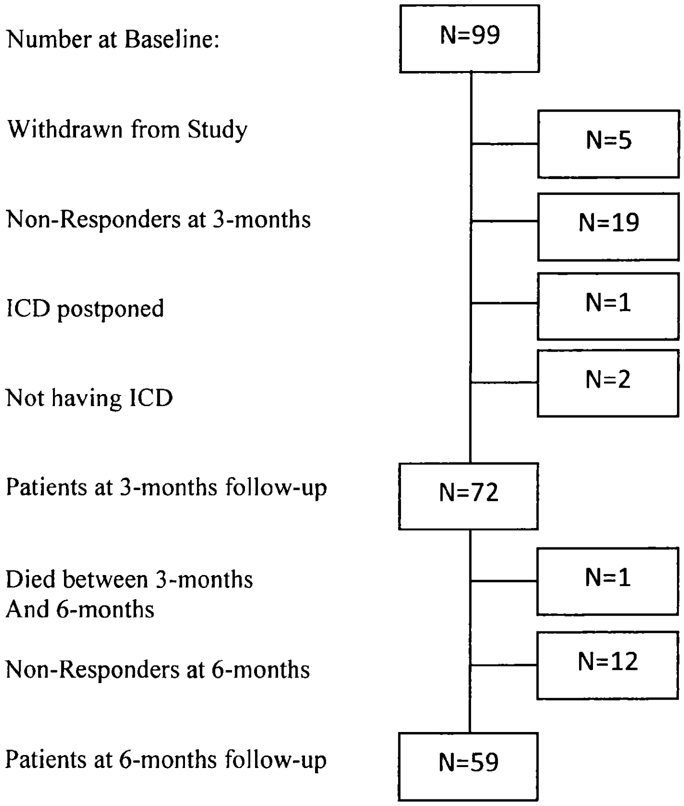

Figure 9.2: Flowchart of Participants Recruited

Demographic characteristics were obtained from a self-report questionnaire, which had asked patients their date of birth, their gender and marital status. The researcher knew the name of the regional hospital and details about whether the patient was an in-patient or elective patient during recruitment. The sample was 86% male (n=85) and 14% female (n=14) with a mean age of 62 years. Demographic details are summarised in Table 9.1.

This was a slightly older population than the patients recruited in the earlier qualitative study, which had a mean age of 57 years compared to 62 years in the Pilot RCT. The large majority of patients were recruited from Welsh regional hospitals, with approximately twice as many in-patients recruited as elective patients (n=67 to n=32). Most patients lived with an intimate partner (n=78 compared to n=21), and the majority of the couples were married.

Table 9.1: Baseline demographic characteristics of participants recruited

		Total N (%)
Participants Recruited at Baseline		99
Gender	Male	85 (85.9)
	Female	14 (14.1)
Age	Mean Age Years	61.76
	SD	13.92
Type of Patient	In-Patient	67 (67.7)
	Elective	32 (32.3)
Regional Hospital	UHW[68]	66 (62.6)
	Morriston Hospital	31 (31.3)
	BHI[69]	6 (6.1)
Group Allocated	Intervention	47 (49)
	Control	52 (51)
Marital Status	Married	66 (66.7)
	Divorced	6 (6.1)
	Widowed	9 (9.1)
	Living with partner	11 (11.1)
	Civil partnership	1 (1)
	Single	6 (6.1)
Type-D Personality		32 (32.3)

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[68] University Hospital of Wales
[69] Bristol Heart Institute

Clinical characteristics of patients were obtained from the Arrhythmia Nurse Specialist and from medical records. Over half of the sample (n=58) had a clinical diagnosis of heart failure (NYHA classes 1-3) and over half the sample had a previous myocardial infarction (MI) (n=54) or angina (n= 88). Just under a third of patients had undergone a percutaneous coronary intervention (or coronary angioplasty 'stent') (n=28).

Table 9.2: Clinical characteristics of participants recruited into the study

		Total N (%)
Heart Failure NYHA	No NYHA	41 (41.4)
	NYHA Class 1	21 (21.2)
	NYHA Class 2	13 (13.1)
	NYHA Class 3	24 (24.2)
History of an MI	No MI	54 (54.5)
	History of MI	45 (45.5)
History of Angina	No Angina	88 (88.9)
	History of Angina	11 (11.1)
History of CABG, PCI or Valve Replacement	None	71 (71.7)
	PCI/CABG/Valve	28 (28.3)
Cardiomyopathy	No Cardiomyopathy	62 (62.6)
	ARVC	3 (3.0)
	LQT/SQT	2 (2.0)
	Brugada	2 (2.0)
	Dilated	24 (24.5)
	Restrictive	1 (1.0)
	HCM	0 (0)
	Unclassified	5 (5.1)
Clinical indication for having a defibrillator	Primary	44 (44.4)
	Secondary	54 (55.16)
Type of defibrillator	ICD	77 (77.6)
	CRT-D	22 (22.2)
Taking Psychotropic medication	No medication	88 (88.9)
	Taking medication	11 (10.1)

Two-thirds of patients had no evidence of a familial cardiac illness (n=62), however over half of those who were diagnosed with a cardiomyopathy had been diagnosed with dilated cardiomyopathy, (closely associated with heart failure, see Chapter 2). Four patients had a channelopathy (see Chapter 2) and five patients had an unclassified cardiomyopathy. Over two-thirds of patients recruited received an ICD device (n=77) as opposed to under a third who received a CRT-D[70] device (n=22). The majority of patients (n=89) were not on psychotropic medication prior to this study.

Baseline Demographic Characteristics of Participants Randomised into the Intervention and Control groups

Table 9.3: Demographic characteristics of participants in randomised groups

		Control Group N (%)	**Intervention Group N (%)**
Participants Recruited	Total Baseline	51	48
Gender	Male	43 (84.3)	42 (87.5)
	Female	8 (15.7)	6 (14.3)
Age	Mean Age Years	60.82	62.75
	SD	12.93	14.98
Type of Patient	In-Patient	34 (66.7)	33 (68.8)
	Elective	17 (33.3)	15 (31.3)
Regional Hospital	UHW[71]	36 (69.2)	26 (55.3)
	Morriston Hospital	12 (23.1)	19 (40.4)
	BHI[72]	4 (7.7)	2 (4.3)
Marital Status	Married	34 (66.7)	32 (68.1)
	Divorced	4 (7.8)	2 (4.3)
	Widowed	4 (7.8)	5 (10.6)
	Living with partner	5 (9.8)	6 (10.6)
	Civil partnership	1 (2)	0
	Single	3 (5.9)	3 (6.4)
Type-D Personality		19 (36.5)	13 (27.7)

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[70] Unfortunately, a large national randomised control trial coincided with a significant period of recruitment at University Hospital of Wales, Cardiff. Accordingly, the current study stopped recruiting potential CRT-D participants at this site.

[71] University Hospital of Wales

[72] Bristol Heart Institute

Participants were randomised into an intervention (n=47) or a control group (n= 52). Each group appeared to have a comparable number of participants that shared similar demographic characteristics (see Table 9.3). Differences between the demographic characteristics between participants randomised to the control and intervention groups were examined using an independent t-test (for ages) and a series of Chi-square for independence for gender, in-patient, and Type-D.

The results found no significant differences in mean age, gender distribution or the frequency of a Type-D personality between the two groups. Although a Chi-square could not be carried out for 'marital status' due to cells having a cell count that was lower than five (Chi-square assumption violated), the marital status of patients appeared similar between the two groups. Of note, 10 participants in the intervention group did not have the support of an intimate partner compared to 11 participants in the control group.

Baseline Clinical Characteristics of Participants Randomised into the Intervention and Control groups

Each group appeared to have a comparable number of participants that shared similar clinical characteristics (see Table 9.4). A series of Chi-square for independence tests were carried out to detect if there were any significant differences in the categorical variables between the participants randomised to the intervention and the control group. No significant differences in clinical characteristics were found between the two groups. A Chi-square could not be carried out for 'cardiomyopathy' due to cells having a cell count that was lower than five (Chi-square assumption violated). However, the two treatment groups had a similar proportion of participants with a cardiomyopathy.

Table 9.4: Clinical characteristics of participants in randomised groups

		Control Group N (%)	Intervention Group N (%)
Heart Failure NYHA	No NYHA	23 (45.1)	18 (37.5)
	NYHA Class 1	12 (23.5)	9 (18.8)
	NYHA Class 2	5 (9.8)	8 (16.7)
	NYHA Class 3	11 (21.6)	13 (27.1)
History of an MI			
	No MI	28 (54.9)	26 (54.2)
	History of MI	23 (45.1)	22 (45.8)
History of Angina			
	No Angina	48 (94.1)	40 (83.3)
	History of Angina	3 (5.9)	8 (16.7)
History of CABG, PCI or Valve Replacement	None	36 (70.6)	35 (72.9)
	PCI	15 (29.4)	13 (27.1)
	CABG	0	0
Cardiomyopathy	Valve Replacement	0	0
	No Cardiomyopathy	30 (58.8)	32 (66.7)
	ARVC	3 (5.9)	0
	LQT/SQT	1 (2.0)	1 (2.1)
	Brugada	0	2 (4.2)
	Dilated	14 (27.5)	10 (20.8)
	Restrictive	1 (2.0)	0
	HCM	0	0
	Unclassified	2 (3.9)	3 (6.3)
Clinical indication for having a defibrillator	Primary	20 (39.2)	24 (50.0)
	Secondary	31 (60.8)	24 (50.0)
Type of defibrillator	ICD	43 (84.3)	34 (70.8)
	CRT-D	8 (15.7)	14 (29.2)
Taking Psychotropic medication	No medication	43 (84.3)	45 (93.8)
	Taking medication	8 (15.7)	3 (6.3)

Baseline Mean Scores for Participants Randomised into the Intervention and Control Groups

Participants were randomised to an intervention (n=47) or a control group (n=52). Each group appeared to have comparable psychological measures at baseline. Differences between key psychological and exercise scores at baseline between the two groups were determined by a series of independent-samples t-tests.

There was no significant difference between the control and the intervention group:

- Profile of Moods-SF total scores: t (94) = -.528, p=.599.
- Hospital Anxiety and Depression Scale – Subscale Depression: t (95) = -.648, p=.519.
- Hospital Anxiety and Depression – Subscale Anxiety: t (95) = .911, p=.364
- ICD-Concerns Questionnaire: t (95) = 1.121, p=.265
- ICD BELIEFS Questionnaire: t (96) = -.398, p = .692
- BEHAVIOUR Questionnaire: t (95) = 1.494, p=.134
- Brief Illness Perception Questionnaire subscales:
  - Consequences: t (90) = -1.180, p = .241
  - Timeline: t (90) = .954, p = .343
  - Personal Control: t (90) = -.985, p= .327
  - Treatment Control: t (90) = .065, p= .948
  - Identity: t (90) = -.543, p= .588
  - Concern: t (89) = .728, p= .468
  - Comprehension : t (89) = -1.032, p= .305
  - Emotional Response: t (89) = -.505, p= .615

- the Impact of Events Scale subscales:
  - Avoidant: t (95) = .545, p= .587
  - Intrusive: t (95) = -.042, p= .966

- Medical Coping Modes Questionnaire:
  - Avoidant: t (93) = -1.062, p= .291
  - Acceptance-resignation: t (93) = -.130, p= .897
  - Confrontational: t (93) = .820, p= .414

- Florida Patient Acceptance Survey: t (95) = .008, p=.994
- Strenuous Exercise: t (64) = -1.488, p = .115
- Moderate Exercise: t (64) = -.505, p = .615
- Mild Exercise: t (63) = .362, p = .719

SHOCKS

A very low number of participants reported shocks at the 3- and 6-month follow-up. At 3-months, three participants had experienced shocks.[73] At 6-months, five participants experienced shocks after the 3-month follow-up. In the control group, three participants experienced one shock, and one participant experienced three shocks. In the intervention group, one participant had two shocks.

PARTICIPANT BIAS

A series of Chi-square for independence tests were carried out to detect if there were any significant differences in the categorical variables between the participants who were non-completers (only filled in baseline measures), half-completers (only filled in baseline and 3-month measures) and full-completers (filled in baseline, 3-month and 6-month measures). The cell count was lower than five for the following demographic and clinical categories: gender, type of patient, regional hospital, marital status, heart failure, and history of angina, CABG, PCI, or Valve replacement, cardiomyopathy, and type of defibrillator. As the cell count was lower than five, the low frequency count meant the Chi-square assumption was violated. A Fisher's exact test could have been conducted to assess the significant difference between the proportions of the two groups with a low frequency count (see Routledge, 2005). However, Fisher's exact test is generally carried out on a 2x2 contingency table and therefore it was not appropriate to conduct this test.

Two Chi-square analyses were conducted on two variables in which the assumption was not violated. A Chi-square for independence indicated no significant association between Clinical indication for having a defibrillator and non-completers, half-completers and full completers: χ^2 (2, n = 99) = 1.93, p = .38, *Cramer's V* = .14. However, a Chi-square for independence indicated there was a significant association between participants with a history of MI and non-completers, half-completers and full completers: χ^2 (2, n = 99) = 6.07, p = .048, *Cramer's V* = .23.

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[73] It was not known if more than one shock indicated consecutive shocks or indicated shocks on separate occasions.

A one-way between-groups analysis of variance was conducted to explore the baseline scores of the age of the patient and status of non-completers, half-completers and full completers. There was a statistically significant difference at the $p < .05$. level for age and completer status: F (2, 96) = 7.87, p = .001. The effect size, calculated using eta squared, was .14, which is a large effect. Post-hoc comparisons using the Tukey HSD test indicated that the mean age of participants who were non-completers (mean = 53.14, S.D. = 17.69) was significantly different from the mean age of participants who were full-completers (mean age = 65.42, S.D. = 10.24). There were no other statistically significant differences between mean baseline scores of measures and non-completers, half-completers and full-completers (see Table 9.5).

Table 9.5: Mean Baseline Scores for Participants who were Non-Completers (only completed baseline measures). Participants who were Half-Completers (completed baseline and 3-month measures) and Participants who were Full-Completers (completed measures at baseline, 3-months and 6-months)

Name of Measure	Construct of Measure	Baseline Score (Non-Completers: 0-mths) Mean Scores (S.D.)	Baseline Score (half-completers: 3-mths) Mean Score (S.D.)	Baseline Score (full-completers: 6-mths) Mean Score (S.D.)
ICD Concerns Questionnaire	Level of ICD-related concerns. A higher score indicates higher perceived limitations and more ICD-concerns	20.52 (10.60)	21.46 (13.01	24.65 (15.87)
Positive ICD Beliefs questionnaire	The level of positive beliefs held about the ICD. A higher score indicate a higher level of positive beliefs	77.45 (12.47)	74.00 (10.76)	75.82 (13.39)
Brief Illness Perception Questionnaire – Consequences	Measures perception of how much the underlying cardiac illness affects patient's lives. A higher score reflects higher negative affect	7.00 (2.33)	6.69 (3.22)	6.20 (2.87)
Brief Illness Perception Questionnaire – Timeline	Measures perceived longevity of cardiac illness. A higher score reflects longevity	9.47 (1.17)	8.15 (3.24)	8.50 (2.69)
Brief Illness Perception Questionnaire – Personal control	Perception of control over cardiac illness. A higher score reflects less[74] control	6.11 (2.83)	5.31 (2.53)	5.50 (2.70)
Brief Illness Perception Questionnaire – Treatment control	Measures the extent to which patients believe the ICD can help their cardiac illness. Higher score reflect more negative[75] beliefs	1.63 (1.98)	1.93 (2.36)	1.92 (2.68)

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[74] This item was reversed so that a *higher* score reflected *less* control.

[75] This item was reversed so that a *higher* score reflected more *negative* beliefs

Name of Measure	Construct of Measure	Baseline Score (Non-Completers: 0-mths) Mean Scores (S.D.)	Baseline Score (half-completers: 3-mths) Mean Score (S.D.)	Baseline Score (full-completers: 6-mths) Mean Score (S.D.)
Brief Illness Perception Questionnaire - Identity	Measures the frequency of abnormal cardiac rhythms. Higher score reflects more rhythms experienced	3.05 (3.54)	2.62 (2.81)	3.70 (3.45)
Brief Illness Perception Questionnaire - Concern	Measures patient's level of concern about cardiac illness. Higher scores reflect more concern	7.84 (2.29)	7.00 (2.97)	7.51 (2.72)
Brief Illness Perception Questionnaire – Illness comprehension	Measures the level of patient's understanding about their cardiac illness. Higher scores reflect less[76] understanding	2.21 (2.42)	3.46 (3.41)	2.42 (2.46)
Brief Illness Perception Questionnaire - Emotional response	Level of negative emotion experienced towards the patient's cardiac illness. Higher scores reflect more negative emotion	5.37 (3.34)	5.00 (3.42)	5.04 (3.10)
Florida Patient Acceptance Survey (FPAS) Total	Measures the level of patient acceptance towards the ICD. A higher score indicates a higher level of acceptance	78.58 (12.32)	79.74 (12.76)	72.29 (17.27)
FPAS subscale – Return to Life	Patient's belief that they have returned/will able to return to a full life. A higher score indicates a more positive belief held by patients in their ability to return to a full life	67.81 (19.58)	68.27 (21.57)	59.38 (23.44)
FPAS subscale – Device-related Distress	Level of ICD-device related distress. A higher score indicates less distress experienced	78.25 (17.79)	74.23 (17.66)	72.66 (24.69)
FPAS subscale – Positive Appraisal	Level of positive appraisal towards the ICD. A higher score reflects a higher positive regard towards the ICD	91.56 (10.59)	91.83 (12.07)	79.98 (25.57)

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[76] This item had been reversed so that a *higher* score reflected *less* understanding

Name of Measure	Construct of Measure	Baseline Score (Non-Completers: 0-mths) Mean Scores (S.D.)	Baseline Score (half-completers: 3-mths) Mean Score (S.D.)	Baseline Score (full-completers: 6-mths) Mean Score (S.D.)
FPAS subscale – Body Image Concerns	Concerns about the body because of the ICD. A higher score reflects less concern	74.40 (27.24)	92.31 (15.76)	81.84 (22.81)
Type D personality Scale – Negative Affect	Measures patient's level of negative affect. A higher score indicates a HIGHER level of negative affect	9.05 (5.07)	12.08 (6.40)	10.25 (5.65)
Type D personality Scale – Social Inhibition	Measures degree of social inhibition. A higher score indicates a higher level of social inhibition	7.38 (5.59)	8.00 (5.60)	8.78 (5.56)
Profile of Moods Short Form TOTAL	Measures an overall level of low mood. The higher the score, the lower the mood	46.85 (21.74)	42.54 (20.22)	43.84 (23.95)
Profile of Moods subscale - Depression	Subscale that measures depression. A higher score indicates a higher depressed mood.	13.30 (6.27)	12.23 (4.30)	13.55 (6.36)
Profile of Moods subscale - Vigour	Subscale that measures positive mood. A higher score reflects a better mood	11.50 (4.61)	15.00 (7.08)	13.95 (5.47)
Profile of Moods subscale - Anger	Subscale that measures levels of anger. Higher scores indicate a higher level of anger	12.05 (6.34)	11.85 (7.03)	11.14 (5.50)
Profile of Moods subscale - Tension	Subscale that measures tension. Higher scores a higher level of tension	13.55 (5.67)	13.69 (5.95)	12.73 (5.41)
Profile of Moods subscale - Confusion	Subscale that measures confusion. Higher scores reflect a higher level of confusion/uncertainty	8.65 (3.48)	9.69 (4.23)	8.97 (3.26)

Name of Measure	Construct of Measure	Baseline Score (Non-Completers: 0-mths) Mean Scores (S.D.)	Baseline Score (half-completers: 3-mths) Mean Score (S.D.)	Baseline Score (full-completers: 6-mths) Mean Score (S.D.)
Profile of Moods subscale - Fatigue	Subscale that measures tiredness/fatigue/weariness. Higher scores indicate more fatigue	10.80 (3.74)	10.08 (2.93)	11.84 (5.44)
Hospital Anxiety and Depression Scale - Anxiety	Measures level of anxiety currently experienced. A higher level indicates a higher degree of anxiety felt	6.25 (3.48)	5.85 (2.88)	6.69 (3.99)
Hospital Anxiety and Depression Scale – Depression	Measures level of depression currently experienced. A higher score indicates a higher level of depression	4.90 (4.32)	5.23 (3.42)	4.81 (3.85)
Impact of Event Scale - Intrusion	Frequency of intrusive thoughts about the ICD. A higher score indicates a higher frequency of intrusive thoughts	11.25 (4.27)	11.69 (4.07)	12.27 (4.73)
Impact of Event Scale - Avoidance	The frequency of engaging in avoidant behaviours in order to cope with the ICD. higher score indicates a higher frequency of avoidant behaviours used	13.20 (5.43)	13.77 (5.25)	13.47 (4.55)
Medical Coping Modes Questionnaire – Confrontation	Measures a confrontational way of coping. Higher scores reflect more use of confrontation coping	19.10 (3.43)	20.38 (4.21)	18.84 (2.84)
Medical Coping Modes Questionnaire – Avoidance	Measures an avoidant way of coping. Higher scores reflect more avoidance used	11.65 (2.28)	11.15 (3.34)	11.87 (3.11)
Medical Coping Modes Questionnaire – Acceptance-Resignation	Measures acceptance-resignation way of coping. Higher scores reflect more use of acceptance-resignation	6.55 (2.28)	7.23 (2.39)	6.68 (1.95)

Name of Measure	Construct of Measure	Baseline Score (Non-Completers: 0-mths) Mean Scores (S.D.)	Baseline Score (half-completers: 3-mths) Mean Score (S.D.)	Baseline Score (full-completers: 6-mths) Mean Score (S.D.)
Exercise Measure - Strenuous	Measures number of minutes per week that the participant strenuously[77] exercised	15.88 (52.09)	55.63 (104.93)	30.61 (100.41)
Exercise Measure- Moderate	Measures number of minutes per week that the participant engaged in moderate[78] exercise	29.65 (66.93)	103.75 (143.62)	50.24 (90.65)
Exercise Measure- Mild	Measures number of minutes per week that the participant engaged in mild[79] exercise	197.94 (237.52)	178.13 (270.77)	266.71 (545.46)
Behaviour Questionnaire	Measures level of typical active everyday behaviour. A higher score indicates a higher level of active daily behaviour	69.21 (19.21)	81 (20.89)	73.98 (14.94)

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[77] Strenuous exercise = exercise resulting in a very fast heart beat

[78] Moderate exercise = exercise resulting in a fast heart beat

[79] Mild exercise = exercise resulting in little or no increase in heart beat

ANCOVA RESULTS Aim 1

ICD Concerns Questionnaire:

Table 9.6: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention (n=33)	F (df=1, 69)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control (n=32) Intervention (n=26)	F (df=1, 56)	p	Partial Eta² (size of effect)
ICD Concerns Questionnaire	Control: 24.88 (16.10) Intervention: 23.39 (14.82)	Control: 18.90 (15.53) Intervention: 17.82 (15.88)	.016	.899	.000	Control 19.72 (17.96) Intervention 16.07 (15.83)	.336	.565	.006

A higher score indicates higher perceived limitations and more ICD-concerns

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Positive ICD Beliefs Questionnaire

Table 9.7: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention (n=31)	F (df=1, 68)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control (n=31) Intervention (n=28)	F (df=1, 58)	p	Partial Eta² (size of effect)
Positive ICD Beliefs questionnaire	Control: 75.36 (12.56) Intervention: 75.29 (13.92)	Control: 71.23 (13.09) Intervention: 76.55 (13.76)	4.240	.043	.060 (Medium)	Control: 72.16 (13.32) Intervention: 77.21 (13.52)	1.961	.167	.033 (Small-medium)

The level of positive beliefs held about the ICD. A higher score indicate a higher level of positive beliefs

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Brief Illness Perception Questionnaire (IPQ-B)

Table 9.8: Baseline, 3-month and 6-month mean scores. F. P. Partial Eta^2 Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=38) Intervention (n=31)	F (df=1, 67)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control (n=31) Intervention (n=26)	F (df=1, 55)	p	Partial Eta^2 (size of effect)
Brief Illness Perception Questionnaire – Consequences	Control: 5.68 (3.02) Intervention: 6.97 (2.76)	Control 5.53 (2.78) Intervention: 5.06 (2.96)	3.458	.067	.050 (Medium)	Control: 5.31 (2.70) Intervention: 5.36 (2.66)	.471	.496	.009 (Small)
Brief Illness Perception Questionnaire – Timeline	Control: 8.61 (2.64) Intervention: 8.23 (2.99)	Control: 9.03 (2.17) Intervention: 8.79 (2.22)	.072	.789	.001	Control: 8.91 (1.80) Intervention: 8.96 (1.91)	.036	.849	.001
Brief Illness Perception Questionnaire – Personal control	Control: 5.13 (2.46) Intervention: 5.87 (2.91)	Control: 6.00 (2.56) Intervention: 4.70 (3.12)	4.602	.036	.065 (Medium)	Control 5.09 (2.54) Intervention 5.39 (2.63)	.062	.804	.001
Brief Illness Perception Questionnaire – Treatment control	Control: 1.87 (2.79) Intervention: 1.68 (2.10)	Control: 2.90 (2.78) Intervention: 1.58 (2.36)	7.215	.009	.99 (Medium-Large)	Control: 2.28 (2.26) Intervention: 1.21 (1.64)	2.613	.112	.046 (Small-medium)

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=38) Intervention (n=31)	F (df=1, 67)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control (n=31) Intervention (n=26)	F (df=1, 55)	p	Partial Eta^2 (size of effect)
Brief Illness Perception Questionnaire - Identity	Control: 3.32 (3.31) Intervention: 3.81 (3.57)	Control: 1.45 (2.10) Intervention: 1.79 (2.80)	.320	.574	.005	Control: 2.34 (2.80) Intervention: 2.07 (2.45)	.027	.869	.001
Brief Illness Perception Questionnaire - Concern	Control: 7.59 (2.80) Intervention: 7.32 (2.76)	Control: 5.95 (3.05) Intervention: 5.48 (3.49)	.008	.929	.000	Control: 6.31 (3.12) Intervention: 5.50 (3.55)	.118	.733	.002
Brief Illness Perception Questionnaire – Illness comprehension	Control: 2.19 (2.50) Intervention: 2.81 (2.77)	Control: 2.28 (2.35) Intervention: 3.00 (3.10)	1.039	.312	.016 (Small)	Control: 3.06 (2.94) Intervention: 3.14 (2.38)	.383	.539	.007
Brief Illness Perception Questionnaire - Emotional response	Control: 4.81 (3.29) Intervention: 5.27 (3.03)	Control: 4.70 (3.44) Intervention: 4.22 (3.75)	1.233	.271	.019 (Small)	Control: 4.66 (3.34) Intervention: 3.54 (3.37)	1.984	.165	.036 (Small-medium)

Consequences: Measures perception of how much the underlying cardiac illness affects patient's lives. A higher score reflects higher negative affect
Timeline: Measures perceived longevity of cardiac illness. A higher score reflects longevity
Personal Control: Perception of control over cardiac illness. A higher score reflects less control
Treatment Control: Measures the extent to which patients believe the ICD can help their cardiac illness. Higher score reflect beliefs that are more negative
Identity: Measures the frequency of abnormal cardiac rhythms. Higher score reflects more rhythms experienced
Concern: Measures patient's level of concern about cardiac illness. Higher scores reflect more concern
Comprehension: Measures the level of patient's understanding about their cardiac illness. Higher scores reflect less understanding
Emotional Response: Level of negative emotion experienced towards the patient's cardiac illness. Higher scores reflect emotion that is more negative

Florida Patient Acceptance Survey (FPAS)

Table 9.9: Baseline, 3-month and 6-month mean scores. F. P. Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	**Baseline Mean Score (S.D.)**	**Mean Scores at 3-months (S.D.) Control (n=39) Intervention (n=33)**	**F (df=1, 70)**	**p**	**Partial Eta² (size of effect)**	**Mean Scores at 6-months (S.D.) Control: (n=31) Intervention (n=28)**	**F (df=1, 57)**	**p**	**Partial Eta² (size of effect)**
Florida Patient Acceptance Survey (FPAS) Total	Control: 72.99 (16.81) Intervention: 73.64 (16.64)	Control: 71.63 (15.81) Intervention: 73.18 (17.83)	.203	.654	.003	Control: 67.71 (17.36) Intervention: 76.67 (15.02)	5.407	.024	.088 (Medium-large)
FPAS subscale – Return to Life	Control: 59.29 (24.16) Intervention: 61.55 (21.99)	Control 55.47 (24.52) Intervention: 56.82 (24.80)	.066	.798	.001	Control: 55.08 (24.92) Intervention: 52.90 (23.17)	.311	.580	.006
FPAS subscale – Device-related Distress	Control: 71.54 (19.14) Intervention: 73.79 (22.45)	Control: 70.50 (19.31) Intervention: 73.33 (22.45)	.362	.550	.005	Control: 66.88 (24.65) Intervention 74.29 (21.07)	2.034	.159	.035 (Small-medium)

Name of Measure	Baseline Mean Score (S.D.)	Mean Scores at 3-months (S.D.) Control (n=39) Intervention (n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Mean Scores at 6-months (S.D.) Control: (n=31) Intervention (n=28)	F (df=1, 57)	p	Partial Eta^2 (size of effect)
FPAS subscale – Positive Appraisal	Control: 83.49 (23.19) Intervention: 80.11 (25.51)	Control: 79.22 (22.66) Intervention: 84.26 (24.26)	.026	.873	.000	Control: 71.09 (32.76) Intervention: 89.06 (13.88)	7.474	.008	.118 (Medium-large)
FPAS subscale – Body Image Concerns	Control: 83.01 (21.55) Intervention: 84.47 (22.54)	Control: 79.06 (27.79) Intervention: 79.92 (31.86)	.024	.878	.000	Control: 75.78 (26.36) Intervention: 92.86 (16.47)	10.210	.002	.154 (Large)

Total: Measures the level of patient acceptance towards the ICD. A higher score indicates a higher level of acceptance
Return to Life: Patient's belief that they have returned/will able to return to a full life. A higher score indicates a more positive belief held by patients in their ability to return to a full life
Device-Related Distress: Level of ICD-device related distress. A higher score indicates less distress experienced
Positive Appraisal: Level of positive appraisal towards the ICD. A higher score reflects a higher positive regard towards the ICD
Body Image Concerns: Concerns about the body because of the ICD. A higher score reflects less concern

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

EuroQoL

Table 9.10: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta^2 Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control: (n=39) Intervention (n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control: (n=31) Intervention:(n=28)	F (df=1, 58)	p	Partial Eta^2 (size of effect)
Euro Quality of Life	Control: 59.03 (22.48) Intervention: 59.52 (23.47)	Control: 64.82 (19.64) Intervention: 61.24 (20.86)	.006	.417	.010 (Small)	Control: 63.09 (17.70) Intervention: 61.25 (21.21)	.160	.690	.003

The EuroQoL measures patient's health-related quality of life. A higher score indicates a higher HR-QoL.

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Behaviour Questionnaire (not validated)

Table 9.11: Baseline, 3-month and 6-month mean score. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention (n=32)	F (df=1, 69)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control: (n=31) Intervention (n=28)	F (1, 58)	p	Partial Eta² (size of effect)
Behaviour Questionnaire	Control: 78.63 (16.84) Intervention: 73.25 (18.62)	Control: 71.40 (16.84) Intervention: 67.88 (18.62)	.196	.660	.003	Control: 71.72 (15.01) Intervention: 66.86 (18.41)	.508	.479	.009 (Small)

The non-validated Behaviour Questionnaire measures level of typical active everyday behaviour. A higher score indicates a higher level of active daily behaviour

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Type-D Personality Questionnaire

Table 9.12: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score	Mean Score at 3-months (S.D.) Control (n=39) Intervention (n=33)	F (df=1, 69)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control: (n=31) Intervention:(n=28)	F (df=1, 57)	p	Partial Eta² (size of effect)
Type D personality Scale – Negative Affect	Control: 10.77 (5.67) Intervention: 10.36 (6.27)	Control: 12.10 (6.45) Intervention: 10.73 (6.85)	.594	.444	.009 (Small)	Control: 12.63 (7.61) Intervention: 10.04 (6.27)	2.839	.098	.048 (Small-medium)
Type D personality Scale – Social Inhibition	Control: 8.69 (5.09) Intervention: 8.13 (6.00)	Control: 8.63 (5.65) Intervention: 9.25 (5.75)	1.017	.317	.015 (Small)	Control: 8.94 (5.31) Intervention: 8.71 (6.24)	.039	.845	.001

Negative Affect: Measures patient's level of negative affect. A higher score indicates a HIGHER level of negative affect
Social Inhibition: Measures degree of social inhibition. A higher score indicates a higher level of social inhibition

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Hospital Anxiety and Depression Scale

Table 9.13: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta^2 Group results from the one-way between groups ANCOVA

Name of Measure	**Baseline Mean Score**	**Mean Scores at 3-months (S.D.) Control (n=39) Intervention (n=33)**	**F (df=1,68)**	**p**	**Partial Eta^2 (size of effect)**	**Mean Scores at 6-months (S.D.) Control: (n=31) Intervention:(n=28)**	**F (df=1,57)**	**p**	**Partial Eta^2 (size of effect)**
Hospital Anxiety & Depression Scale: ANXIETY	Control: 6.72 (3.59) Intervention: 6.52 (4.08)	Control: 5.93 (3.59) Intervention: 5.55 (4.68)	.021	.886	.000	Control: 6.19 (4.11) Intervention: 5.14 (4.35)	.195	.661	.003
Hospital Anxiety & Depression Scale: DEPRESSION	Control: 4.56 (3.59) Intervention: 5.27 (4.08)	Control: 5.10 (3.36) Intervention: 4.73 (3.94)	1.468	.226	.021 (Small)	Control: 4.91 (3.60) Intervention: 4.82 (4.00)	.175	.678	.003

HADS ANXIETY measure levels of current anxiety. A higher level indicates a higher level of anxiety
HADS DEPRESSION measures current levels of depression. A higher score indicates a higher level of depression experienced

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Profile of Moods Questionnaire (Short Form) (POMS-SF)

Table 9.14: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention:(n=33)	F (df=1, 70)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control: (N=31) Intervention:(N=28)	F (df=1, 57)	p	Partial Eta² (size of effect)
Profile of Moods Short Form TOTAL	Control: 40.00 (21.97) Intervention: 44.81 (24.06)	Control: 41.65 (25.43) Intervention: 40.28 (29.42)	.181	.672	.003	Control: 42.97 (24.28) Intervention: 39.61 (27.16)	.824	.368	.015 (Small)
Profile of Moods subscale - Depression	Control: 12.54 (5.51) Intervention: 13.94 (7.00)	Control: 13.63 (5.86) Intervention: 13.52 (7.48)	.109	.742	.002	Control: 14.25 (6.82) Intervention: 12.46 (6.61)	2.099	.153	.036 (Small-medium)
Profile of Moods subscale - Vigour	Control: 15.49 (6.21) Intervention: 12.55 (4.72)	Control: 15.90 (5.74) Intervention: 14.79 (5.36)	.017	.896	.000	Control: 15.28 (4.61) Intervention: 14.68 (5.79)	.026	.873	.000
Profile of Moods subscale - Anger	Control: 11.51 (6.05) Intervention: 10.79 (5.80)	Control: 11.93 (5.66) Intervention: 11.73 (6.40)	.151	.698	.002	Control: 11.59 (5.01) Intervention: 10.54 (5.77)	.739	.394	.013 (Small)

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention:(n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control: (N=31) Intervention:(N=28)	F (df=1, 57)	p	Partial Eta^2 (size of effect)
Profile of Moods subscale - Tension	Control: 12.62 (5.26) Intervention: 12.94 (5.97)	Control: 11.38 (5.71) Intervention: 10.94 (5.81)	.424	.517	.006	Control: 11.53 (4.50) Intervention: 10.89 (5.65)	.253	.617	.004
Profile of Moods subscale - Confusion	Control: 8.69 (3.22) Intervention: 9.24 (3.63)	Control: 9.50 (3.74) Intervention: 9.58 (4.62)	.028	.869	.000	Control: 9.47 (4.17) Intervention: 8.39 (3.10)	1.023	.316	.018 (Small)
Profile of Moods subscale - Fatigue	Control: 10.95 (5.10) Intervention: 11.94 (5.44)	Control: 11.13 (5.15) Intervention: 11.09 (5.65)	.001	.979	.000	Control: 11.41 (4.29) Intervention: 12.00 (6.01)	.251	.616	.004

POMS TOTAL: Measures an overall level of low mood. The higher the score, the lower the mood
POMS Depression: Subscale that measures depression. A higher score indicates a higher depressed mood.
POMS Vigour: Subscale that measures positive mood. A higher score reflects a better mood
POMS Anger: Subscale that measures levels of anger. Higher scores indicate a higher level of anger
POMS Tension: Subscale that measures tension. Higher scores a higher level of tension
POMS Confusion: Subscale that measures levels of confusion. Higher scores reflect a higher level of confusion/uncertainty
POMS Fatigue: Subscale that measures tiredness/fatigue/weariness. Higher scores indicate more fatigue

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Impact of Events Scale (IES)

Table 9.15: Baseline, 3-month, 6-month mean scores. F, P, Partial Eta^2 Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (N=39) Intervention (N=32)	F (df=1, 69)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control: (n=32) Intervention:(n=26)	F (df=1, 57)	p	Partial Eta^2 (size of effect)
Impact of Event Scale - Intrusion	Control: 11.96 (4.57) Intervention: 12.00 (4.54)	Control: 11.41 (3.86) Intervention: 11.67 (5.55)	.014	.908	.000	Control: 10.97 (4.23) Intervention: 10.61 (4.38)	.417	.521	.007
Impact of Event Scale - Avoidance	Control: 13.71 (5.11) Intervention: 13.17 (4.44)	Control: 13.49 (4.92) Intervention 12.33 (4.93)	1.207	.276	.017 (Small)	Control: 13.78 (5.11) Intervention: 12.57 (4.72)	1.273	.264	.022 (Small)

IES Intrusion: Frequency of intrusive thoughts about the ICD. A higher score indicates a higher frequency of intrusive thoughts
IES Avoidance: The frequency of engaging in avoidant behaviours in order to cope with the ICD. A higher score indicates a higher frequency of avoidant behaviours used

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Medical Coping Modes Questionnaire

Table 9.16: Baseline, 3-month and 6-month mean scores. F, P, Partial Eta² Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control (n=39) Intervention (n=31)	F (df=1, 68)	p	Partial Eta² (size of effect)	Mean Score at 6-months (S.D.) Control (n=31) Intervention:(n=26)	F (df=1, 55)	p	Partial Eta² (size of effect)
Medical Coping Modes Questionnaire – Confrontation	Control: 19.03 (3.26) Intervention: 19.13 (3.15)	Control: 19.13 (3.18) Intervention: 19.70 (3.89)	.932	.338	.014 (Small)	Control: 17.42 (2.72) Intervention: 17.75 (2.91)	1.020	.317	.019 (Small)
Medical Coping Modes Questionnaire – Avoidance	Control: 11.33 (3.03) Intervention: 12.32 (3.21)	Control: 12.41 (3.51) Intervention: 13.18 (3.64)	.233	.631	.003	Control: 15.860 (.471) Intervention: 15.04 (3.26)	2.171	.146	.039 (Small-medium)
Medical Coping Modes Questionnaire – Acceptance-Resignation	Control: 6.82 (1.68) Intervention: 6.74 (2.24)	Control: 7.31 (2.19) Intervention: 7.00 (2.62)	.217	.643	.003	Control: 7.32 (2.44) Intervention: 7.39 (2.75)	.103	.750	.002

Confrontation: Measures a confrontational way of coping. Higher scores reflect more use of confrontation coping
Avoidance: Measures an avoidant way of coping. Higher scores reflect more avoidance used
Acceptance-Resignation: Measures acceptance-resignation way of coping. Higher scores reflect more use of acceptance-resignation

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Exercise Diary Questionnaire

Table 9.17: Baseline. 3-month and 6-month mean scores. F. P. Partial Eta^2 Group results from the one-way between groups ANCOVA

Name of Measure	Baseline Mean Score (S.D.)	Mean Score at 3-months (S.D.) Control: (n=25) Intervention:(n=19)	F (df=1, 42)	p	Partial Eta^2 (size of effect)	Mean Score at 6-months (S.D.) Control: (n=22) Intervention:(n=15)	F (df=1, 35)	p	Partial Eta^2 (size of effect)
Exercise Measure - Strenuous	Control: 21.21 (61.88) Intervention: 61.58 (135.12)	Control: 18.97 (55.39) Intervention: 54.80 (103.39)	.005	.944	.000	Control: 54.35 (169.39) Intervention: 89.43 (324.94)	.678	.416	.020 (Small)
Exercise Measure-Moderate	Control: 46.36 (85.29) Intervention: 70.00 (116.76)	Control: 53.91 (83.16) Intervention: 85.20 (196.42)	.003	.954	.000	Control: 85.13 (121.37) Intervention: 106.07 (247.01)	.010	.920	.000
Exercise Measure- Mild	Control: 291.12 (1061.53) Intervention: 229.16 (400.44)	Control: 404.06 (944.34) Intervention: 227.56 (354.68)	.399	.531	.013 (Small)	Control: 203.55 (309.08) Intervention: 188.75 (326.46)	1.501	.229	.042 (Small-medium)

Strenuous exercise: Measures number of minutes per week that the participant strenuously exercised. Strenuous exercise is exercise that results in a very fast heart beat.
Moderate exercise: Measures number of minutes per week that the participant engaged in moderate exercise. Moderate exercise results in a fast heart beat.
Mild exercise: Measures number of minutes per week that the participant engaged in mild exercise. Mild exercise results in a little or no increase in heart beat.

S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

In the current study, cardiac illness causal factors reported by the Impact of Events Scale were later categorised from participants' responses (see Table 9.18). Only the first causal factor was put into the table. The factors were categorised in line with the seven most commonly reported causal factors. The most commonly reported causal factors were Smoking, work related stress, poor diet, alcohol, general stress, family history or genetics, previous illness, lack of exercise. Eight participants did not know the cause of their cardiac illness and 14 reported miscellaneous causes such as 'lack of knowledge'.

Table 9.18: Causal factors reported by Participants relating to their Cardiac Illness

Causal Factor	**Number of Participants**
Smoking	20
Work Related Stress	11
Poor Diet	9
Lack of Exercise[80]	9
Alcohol	8
General Stress	7
Family History/ Genetics	7
Previous Illness	6
Unknown Causes	8
Other	14

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[80] 'Lifestyle' was reported as Exercise

RESULTS: AIM 1

Finding out the Efficacy of the Intervention using ANCOVAs

The main aim of the pilot RCT was to test the efficacy of the study intervention by examining whether the intervention group reported statistically superior outcomes to the control group.

The following hypotheses had been predicted:

> **Hypothesis $_1$** – there would be meaningful[81] between-group effect sizes with the intervention group having more positive scores than the control group in relation to ICD-beliefs and illness-related appraisals at 3-months.
>
> **Hypothesis $_2$** – there would be meaningful between-group effect sizes with the intervention group reporting lower levels of depression and anxiety compared to the control group at 3-months.
>
> **Hypothesis $_3$** – there would be meaningful between-group effect sizes with the intervention group using more problem-focussed coping and less emotion-focussed coping. In addition, the intervention group would have greater acceptance towards their ICD and would be taking more exercise compared to the control group at 3-months.
>
> **Hypothesis $_4$** – there would be meaningful between- group effect sizes with the intervention group having more positive scores than the control group, in relation to ICD-beliefs and illness-related appraisals at 6-months.
>
> **Hypothesis $_5$** – there would be meaningful between-group effect sizes with the intervention group reporting lower levels of depression and anxiety.

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[81] In this study, meaningful was defined as at least a small to medium effect size (Cohen, 1992).

> **Hypothesis $_6$** – there would be meaningful between-group effect sizes with the intervention group using more problem-focussed coping, less emotion-focussed coping. In addition, the intervention group would have greater acceptance towards their ICD and would be taking more exercise compared to the control group at 6-months.

To test these hypotheses a series of one-way between-groups ANCOVA was conducted on adjusted means to examine the differences in scores in appraisals, mood and coping variables between the two groups at 3-months and 6-months. The adjusted mean scores were used to ensure that differences in scores at baseline did not influence scores at 3-months and 6-months. (See Appendix XXII for a Table of adjusted mean scores).

Note: the scores indicating which group had higher (or lower) scores related to unadjusted means. However, ANCOVA analyses to find effect sizes were carried out on *adjusted* means.

Hypothesis $_1$ - Appraisal Variables at 3-months

Hypothesis $_1$ was supported. Hypothesis $_1$ stated that there would be meaningful[82] between-groups effect, with the intervention group reporting a higher level of positive ICD- and illness-related beliefs compared to the control group.

The mean scores reported by the Positive ICD Beliefs questionnaire indicated that the intervention group had a higher level of positive ICD-beliefs compared to the control group. There was a meaningful medium between-groups effect size that reached statistical significance to $p<.05$ ($F=4.240$, $df= 1, 68$, $\eta\rho^2 = .060$, $p<.05$). (See Table 9.7)

Items from the B-IPQ that measured participants' beliefs in relation to their cardiac illness indicated that the intervention group reported a greater sense of personal control over their illness compared to the control group (see Personal Control, Table

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[82] In this study, meaningful was defined as a small to medium effect size (Cohen, 1992)

9.8). There was a medium between-groups effect size that was statistically significant ($F=4.602$, df= 1, 67, $\eta\rho^2 = .065$, $p<.05$). In addition to personal control, B-IPQ scores that related to treatment control indicated that the intervention group reported a greater sense of treatment control. There was a large effect size that was statistically significant ($F=7.215$, df=1, 67, $\eta\rho^2 = .099$, $p<.01$) (see Treatment Control, Table 9.8). The B-IPQ score that related to perceived consequences to the cardiac illness indicated that the intervention group had been less affected compared to the control group (see Consequences, Table 9.8). There was a medium between-groups effect size, which was not statistically significant ($F =3.458$, df=1, 67, $\eta\rho^2 = .050$, $p>.05$).

Hypothesis $_2$ - Emotional outcome Variables at 3-months

Hypothesis $_2$ was not supported. Hypothesis $_2$, which stated that there would be meaningful between-groups effect sizes with the intervention group reporting better emotional outcomes than the control group, was not supported. The questionnaires that measured mood (the B-IPQ item to measure emotional response, the DS14-negative affect subscale, the HADS-anxiety and depression-subscales, the POMS depression-subscale and the POMS-total scale) indicated that no meaningful between-groups effect sizes were reported. (See Table 9.8, Table 9.12, Table 9.13, and Table 9.14)

Hypothesis $_3$ - Ways of Coping, Exercise and Patient Acceptance Variables at 3-months

Hypothesis $_3$ was not supported. Hypothesis $_3$, which stated that there would be a meaningful between-groups effect size with the intervention group reporting scores that reflected they used more problem-focussed coping (confrontational coping) and less emotion-focussed coping (avoidant, and acceptance-resignation coping) than the control group, was not supported in this study.

Hypothesis $_3$ which stated that there would be a meaningful between-groups effect size at 3-months with the intervention group reporting scores that indicated they had a greater acceptance towards their ICD and engaged in more exercise than the control group was not supported.

Hypothesis $_4$ - Appraisal Variables at 6-months

Hypothesis $_4$ was supported. Hypothesis $_4$ which stated there would be a meaningful between-groups effect size with the intervention group reporting mean scores that indicated they had a higher level of positive-ICD and illness-related beliefs at 6-months compared to the control group was supported. The mean scores reported on the Positive ICD Beliefs Questionnaire, the B-IPQ item for treatment control, and the FPAS subscales that related to positive-ICD appraisal and body image concerns supported this hypothesis.

At 6-months, the mean scores reported on Positive ICD-Beliefs Questionnaire indicated that the intervention group had a greater level of Positive ICD Beliefs compared to the control group. There was a small-medium between-groups effect size that was not statistically significant (F=1.961, df= 1, 58, $\eta\rho^2 = .033$, $p>.05$) (see Table 9.7). The scores on the B-IPQ treatment-control item also showed a small-medium between groups effect size that was not statistically significant (F=2.613, df= 1, 55, $\eta\rho^2 = .046$, $p>.05$) (see Treatment Control, Table 9.8).

The mean scores on the FPAS positive appraisal-subscale indicated that the intervention group had a higher level of positive beliefs in the ICD compared to the control group. There was a medium-large between-groups effect size in favour of the intervention group, which was statistically significant to $p<.01$ (F=7.474, df= 1, 57, $\eta\rho^2 = .118$, $p<.01$) (see Table 9.9).

The mean scores reported by the intervention group on the FPAS body image concerns[83] subscale indicated that they had fewer ICD-body-related concerns compared to the control group. There was a large between-groups effect size, which was statistically significant to $p<.01$ (F=10.210, df= 1, 57, $\eta\rho^2 = .154$, $p<.01$) (see Table 9.9).

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[83] The FPAS subscale was named 'Body Image Concerns'. However, the statement items reflected appraisals rather than worries.

Hypothesis $_5$ - Emotional outcome Variables at 6-months

Hypothesis $_5$ was partially supported. Hypothesis $_5$ that stated that there would be meaningful between-groups effect sizes with the intervention group reporting less depression and less anxiety was partially supported in this study. The hypothesis relating to depression was supported but the hypothesis relating to anxiety was not supported.

The measures that supported the hypothesis relating to depression were the negative affect subscale of the DS14 (see Table 9.12), the depression-subscale of the POMS-SF (see Table 9.14) and the B-IPQ item that measured emotional response (see Emotional Response, Table 9.8). At 6-months, the intervention group reported scores that indicated they felt less depressed compared to the control group. At 6-months, the scores on the DS14-NA indicated a small-medium between-groups effect size ($F=2.839$, $df= 1, 57$, $\eta\rho^2 = .048$, $p>.05$). The scores on the POMS depression-subscale indicated a small-medium between-groups effect size ($F=2.099$, $df= 1, 57$, $\eta\rho^2 = .036$, $p>.05$). The B-IPQ emotional response item revealed a small-medium between-groups effect size ($F=1.984$, $df= 1, 55$, $\eta\rho^2 = .036$, $p>.05$).

Hypothesis $_6$

Ways of Coping Variables at 6-months

Hypothesis $_6$ in relation to coping was partially supported. Hypothesis $_6$ stated that there would be meaningful between-groups effect sizes with the intervention group reporting that they used more problem-focussed coping (confrontation-type coping) and less emotion-focussed coping (avoidant and acceptance-resignation-type coping) than the control group. Only the avoidant-subscale of the MCMQ supported this hypothesis.

The mean scores on the avoidant-subscale of the MCMQ indicated that the intervention group used less avoidant-coping than the control group. There was a small-medium between-groups effect size ($F=2.171$, $df= 1, 55$, $\eta\rho^2 = .039$, $p>.05$) (see Table 9.16).

Exercise at 6-months

Hypothesis $_6$ in relation to exercise was partially supported. Hypothesis $_6$ stated there would be meaningful between-groups effect sizes with the intervention group reporting scores that indicated they were engaging in more exercise than the control group. The intervention group reported mean scores, which suggested they were taking part in more strenuous and moderate exercise at 6-months compared to the control group. The intervention group also reported a score, which suggested they were taking part in less mild exercise compared to the control group.

However, the ANCOVA (on the adjusted mean) found there was a small-medium between-groups effect size for mild exercise ($F=1.501$, df= 1, 35, $\eta p^2 = .042$, $p>.05$). This suggested that taking into account baseline scores, the intervention group had increased their levels of mild exercise more than the control group. The weekly mean number of minutes of mild exercise from baseline had increased more in the intervention group than in the control group.

Patient Acceptance Variables at 6-months

Hypothesis $_6$ in relation to patient acceptance was supported. Hypothesis $_6$ stated there would be a meaningful between-groups effect size with the intervention group reporting scores that indicated they had a greater acceptance to their ICD compared to the control group.

The mean scores on the total FPAS at 6-months indicated that the intervention had a greater acceptance towards their ICD compared to the control group. There was a medium-large between-groups effect size, which was statistically significant ($F=5.407$, df= 1, 57, $\eta p^2 = .088$, $p<.05$) (see Table 9.9).

Summary of Key Findings for Aim 1:

Key Findings at Three-Months

The ANCOVA results showed that in comparison to the control group, the intervention group **significantly:**

1. Scored more highly on the Positive ICD Beliefs Questionnaire (see Table 9.7).
2. Believed they had a greater sense of personal control over their cardiac illness (see Personal Control, B-IPQ, Table 9.8).
3. Believed that the ICD could help their cardiac illness (see B-IPQ, Treatment Control, Table 9.8).

There was one **medium effect size**, which suggested the difference between the groups might not have been significant (possibly because of a small sample) but was nevertheless **meaningful**[84]**:**

4. The intervention group reported less negative affect from the cardiac illness (see B-IPQ Consequences, Table 9.8).

Key Findings at Six-Months:

The ANCOVA results showed that in comparison to the control group, the intervention group **significantly:**

1. Scored more highly on the ICD acceptance measure (see FPAS total, Table 9.9).
2. Scored more highly on the FPAS Positive Beliefs-subscale (see FPAS positive appraisal, Table 9.9).
3. Reported fewer ICD-related body-image concerns (see FPAS body image concerns, Table 9.9).

There were some **small-medium effect sizes**, which suggested the differences between the groups might not have been significant (possibly due to a small sample) but were nevertheless **meaningful**[85]**.** In comparison to the control group:

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[84] A small-medium or larger effect size (Cohen, 1992)

[85] A small-medium or larger effect size (Cohen, 1992)

4. The intervention group reported a higher positive belief that the ICD could help their cardiac illness (see B-IPQ Treatment Control, Table 9.8).
5. The intervention group reported lower levels of depression (see B-IPQ Emotional Response Table 9.8; Type-D Negative affect, Table 9.12; and POMS-depression subscale Table 9.14).
6. The intervention group reported less ICD-related distress (see FPAS device-related distress, Table 9.9).
7. The intervention group reported using less avoidant coping (see MCMQ avoidance, Table 9.16)

DISCUSSION – Aim 1

The first aim of this study was to determine if the brief psychological coping designed to help patients cope with their ICD, was helpful for patients. The study tested the efficacy of the intervention compared to routine literature in a pilot randomised control trial. Overall, the intervention group appeared to report better scores compared to the control group and in some measures statistical significance was reached. One reason that significance was not reached in other measures might have been due to the low number of participants recruited. Accordingly, this discussion is based on effect sizes rather than *p* values unless stated.

One inference that can be made from the results of the analyses of covariance (ANCOVAs) is that the psychological intervention appeared to be effective in helping patients adapt to their device. The intervention group reported results showed they had generally improved more than the control group and in some cases meaningful effect sizes were achieved, some which reached statistical significance. The intervention group reported greater positive appraisals about the ICD compared to the control group. The intervention group also reported a lower level of depression compared to the control group at 6-months. In addition, they appeared to have used less avoidant coping and to have taken part in more mild exercise more than the control group.

An inference from the mean scores of measures relates to the practical implications for education and patient aftercare. The B-IPQ items ‘concern’ and ’comprehension’ showed that the intervention group reported scores that indicated that they felt *less affected* by the consequences of their cardiac illness compared to the control group, whilst simultaneously reporting that they *understood less* about their condition (see Table 9.8). This was a similar finding by Marke and Bennett (2012), who found a positive association between illness comprehension and PTSD symptoms.

The analyses were cross-sectional and as such the cause and effect could not be established. However, several explanations for an association between illness comprehension and concern about cardiac illness can be put forward. One explanation might have been that feeling less distressed resulted in patients not needing to know a lot about their condition. Another possible explanation is that the intervention helped patients to focus on coping with the ICD rather than dwell on their illness. This focus might have diverted attentional control to something that was positive or portrayed positively (i.e. the ICD). Accordingly, the intervention group may have avoided thinking and learning about their cardiac illness and were instead actively confronting the realities of living with their ICD or CRT-D. Another likely explanation was that the intervention group felt they had a good understanding of their ICD and in comparison to their knowledge of the ICD, they felt they had less of an understanding about the cardiac illness.

Some more inferences from the ANCOVAs can be made. Evidenced by effect sizes, the meaningful differences between the control and intervention groups appeared to vary. For instance, the between-group effect sizes for the Positive ICD Beliefs Questionnaire and the B-IPQ item to measure treatment control appeared to be larger at 3-months than at 6-months. The scores on the Positive ICD Beliefs Questionnaire reported by the intervention group at 3-months (see Hypothesis $_1$ - Appraisal Variables at 3-months) and the B-IPQ treatment-control item appeared to stabilise at 3-months as no increased meaningful changes were noted at 6-months. This suggested that the gains in positive ICD-beliefs by the intervention might have reached a ceiling effect by 3-months.

In contrast, the scores for the total FPAS that measured patient acceptance and the exercise diary that measured mild exercise did not appear to have any meaningful between-group differences until 6-months. The finding that the between-group effect sizes for exercise and patient acceptance occurred after a meaningful between-group difference for positive ICD-beliefs, suggested that increased exercise and patient acceptance to the ICD might have been associated with the patient holding more positive ICD beliefs. The notion that the psychological intervention appeared to be effective in helping patients accept their device and doing more exercise has a theoretical inference as these association can be explained using Lazarus' theoretical framework.

Lazarus' theoretical framework (see Smith & Lazarus, 1990, 1993; Smith, 1990; Lazarus 1991, 1993) suggested that appraisals influence emotion and together appraisals and emotion influence coping. According to Folkman and Lazarus (1998), coping is a mediator of emotion. However, their theory is bi-directional. Accordingly, once coping is achieved, appraisals and emotions do not cease to be influenced. Rather, the individual re-appraises their well-being to see if it has improved. The outcome of this re-appraisal re-informs emotions and coping. Hence, the more positive belief in the device over time, evidenced by the intervention group might have influenced their emotional state. This might also explain why the depression scores reported by the intervention group were lower than those reported by the control group. Patient's improved mood might have in turn influenced ICD acceptance and taking part in exercise.

The general improvement in mood found in the intervention group can also be explained by other theories. For instance, Abramson, Seligman, and Teasdale's (1978) model of human helplessness depression and Beck's (1967, 1983, 1976) cognitive diathesis-stress theory of depression and negative automatic thoughts are also able to explain the better mood reported by the intervention group. Abramson et al.'s (1978) model posited that individual differences influence levels of depression. They posited that they influence depression by increasing the likelihood of the individual making internal, stable and global attributions about negative events. Furthermore, the individual would hold more negative beliefs about the consequences of these negative events. Abramson et al. (1978) also suggested that depression was likely to occur if a *desirable* outcome was *unlikely* or an *undesirable* outcome was *likely*. Because the intervention included activities, such as strategies to cope with worries, strategies to increase stamina, and strategies for coping with a defibrillator shock, which aimed to increase a participant's sense of mastery and control, the inclusion of these might explain some of the intervention group's improved mood.

The intervention also included information and activities to challenge distorted cognitions and address negative attributions. These were a table of common concerns and an activity to challenge the accuracy of worries/thoughts. The intervention's inclusion of an activity to address negative thoughts might also offer an explanation as to why there was a meaningful difference between the intervention and control group in levels of depression. The intervention group reported a depression score that indicated they were less depressed compared to the control group

The general improvement in scores reported by the intervention group can also be explained by Wells' (2000) meta-cognitive theory. The nature of the brief psychological intervention provided the intervention group with a ‘plan of action’ to follow, which might have helped focus patient’s minds on ‘getting on with normal daily life’. According to Wells and Matthews (1994, 1996), psychological distress was caused by the activation of the S-REF configuration. This activation can be reduced by changes made to meta-cognition, which for example, might be facilitated by adaptive coping. In relation to depression, Wells and Matthews’ (1994, 1996) model posited that depression was caused by a failure to achieve an important goal. The intervention booklet not only provided patients with a structured plan to follow, but also included tips on setting realistic goals and on ways to overcome obstacles to goal setting. These strategies for patients to follow outlined in the intervention, might also help explain why the intervention group reported lower levels of depression compared to the control group.

The finding that the control group engaged in more mild exercise at 3-months than intervention group might have been because they were trying to ‘get back to normal’. A finding from the qualitative study suggested that some patients were frustrated with feeling so unfit after their implant so it is likely that some patients might have tried to regain their stamina as quickly as possible. The control group’s higher level of exercise at 3-months might therefore have been due to an overactive rest-cycle coping response. On the other hand, the intervention, which taught patients the importance to *gradually* increase their daily exercise, might be why they reported to be exercising less than the control group at 3-months.

The overactive rest-cycle coping response can ultimately result in patients doing less exercise as they become over-tired and give up exercising. It is likely that the control group were engaging in this overactive rest-cycle coping response as results suggested they were doing twice as much mild exercise at 3-months compared to how much mild exercise they were doing at 6-months.

It is not easy to compare this intervention’s efficacy with other interventions that have previously been devised for ICD patients. One reason for this is that studies testing ICD interventions differed considerably in sample size (see Table 8.1) and used different standardised measures to this study. However, one study that was similar to this study because it used the HADS was a study by Frizelle et al. (2004). They reported that their intervention group had significantly reduced depression and anxiety at 3-months compared to its scores at baseline. Unlike this study, their study did not adjust by analysis of covariance participant's corresponding baseline scores. In addition, the baseline scores reported suggested that their cohort of participants might have been less anxious and depressed before the intervention, compared to the current study. For instance, Frizelle et al. (2004) reported a HADS mean score of 4.32 for anxiety and 3.05 for depression (for their total cohort). The current study found the mean HADS baseline score of both groups (the intervention and the control group) was 6.57 for anxiety and 4.92 for depression, which suggested that initially this study's participants had higher levels of psychological distress compare to Frizelle et al. (2004).

In Frizelle et al.'s (2004) study there was less potential for changes in levels of depression and anxiety compared to this study as their participants initially had lower levels of depression and anxiety at baseline. However, the lower levels of anxiety in Frizelle et al.'s (2004) study might have increased participants willingness and ability to engage in an intervention and might have increased their preparedness for living with the ICD. Although the intervention group in this study reported reduced levels of depression after the intervention, unlike Frizelle et al. (2004), they did not report any meaningful improvement in anxiety. One explanation might be that participants' initial high levels of anxiety might have prevented them from being receptive to the intervention.

The intervention study by Lewin et al. (2009) also used the HADS and like this study, they adjusted by analysis of covariance corresponding baseline scores. Similar to this study, at 6-months the scores reported by Lewin's (2009) intervention group did not indicate significantly improved levels of anxiety and depression. Although at 6-months, their HADS scores indicated that their intervention group had lower levels of anxiety and depression than this study, their control group also reported lower levels of anxiety and depression. This finding might suggest that they used participants who had lower baseline scores for anxiety and depression. It might also suggest that the techniques used by the control group appeared helpful to patients. Abrahams (NICE, 2014) highlighted the importance of finding out what happens to the control group.

A systematic review by Magyar-Russell, Thombs, Cai, Baveja et al. (2011), that examined the prevalence of anxiety and depression in ICD patients found sample size could affect the prevalence reported. They reported that studies with samples over 200 generally reported a lower prevalence rate for anxiety and depression compared to studies with smaller samples. The authors did not offer an explanation for this finding however one explanation might have been that the statistical accuracy of prevalence rates differed according to sample size. For instance, it appeared that the studies in their review, with larger sample sizes tended to have narrower confidence intervals (CI) compared to those studies with smaller sample sizes. For example, the study by Kapa, Rotondi-Trevisan, Mariano, Aves et al.'s (2010) had a sample size of 223. At 12-months, Kapa et al. (2010) reported prevalence rates of 15% (HADS-anxiety ≥8, CI: 11-20) and 11% (HADS-depression ≥8, CI: 8-16). However, Frizelle et al. (2004) who had a much smaller sample size of 22, found prevalence rates of 33% (HADS-anxiety, ≥ 8, CI: 16-53) and 25% (HADS-depression ≥ 8, CI: 13-48), which had considerably wider confidence interval ratios.

The sample size in the current study was possibly not helped by its attrition rate, which was considerably higher in this study than in those of Frizelle et al. (2004) and Lewin et al. (2009). In this study, the attrition rate was 39.2% (control) and 41.7% (intervention), compared to Lewin et al. (2009) who lost 21.46% (control) and 25.35% (intervention). Frizelle et al.'s (2004) study only lost one participant (control) due to death. Their reduced attrition rate might have been due to the fact they had more personal contact with the participant; NICE (2014) suggested that person delivering the intervention might be one of two main factors that make an intervention effective.

To sum up, the intervention group appeared to show more improvement compared to the control group after their ICD implant although these findings need to be interpreted with caution (see Limitations of Pilot RCT, page 412). Adjusted by analysis of covariance for corresponding baseline scores indicated that at 3-months, participants in the intervention group had some superior scores which were statistically significant compared to the control group (a higher level of positive ICD-related beliefs, a greater sense of personal control over the illness, a greater belief that the ICD could help the illness). There was also a meaningful difference between-group[86] with the intervention group reporting scores that indicated they felt less negative affect from their cardiac illness.

At 6-months, in comparison to the control group, the intervention group again had some superior scores, which were statistically significant (greater acceptance to their ICD, fewer ICD related body-image concerns and a higher level of positive ICD-related beliefs). There were also meaningful effect sizes between-groups at 6-months, which suggested that the intervention group had benefitted from the intervention (greater belief that the ICD could help the cardiac illness, lower level of depression, less ICD-related distress and less avoidant coping).

One way of trying to understand how this intervention appeared to benefit patients was to try to explain its findings using psychological theory. For instance, Lazarus' appraisal theory of emotion, suggested appraisals and mood influence each other. As the intervention positively framed the ICD device, this might explain why the intervention group generally reported superior scores. The intervention also included activities to increase a participant's sense of mastery and challenge cognitions, which according to Abramson's et al. (1978) model of human helplessness and Beck's (1967, 1983, 1976) cognitive diathesis-stress theory of depression should reduce depression.

One way of testing if the results from this study supported Lazarus' framework was to examine the predictor variables of emotions and coping. Using Lazarus' framework, regression analyses needed to be conducted to determine whether appraisals were predictor variables of anxiety and depression and if appraisals and emotions were predictor variables of coping. The predictor variables for emotions and coping cannot be deduced from ANCOVA analyses, but are explored below in regression analyses for Aim 2.

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[86] Medium effect size (see Cohen, 1992)

REGRESSION RESULTS Aim 2

Finding the Predictor Variables[87] for anxiety, depression, confrontational, acceptant-resignation and avoidant coping

Aim 2.1 was to find the significant predictors of key emotional outcomes (anxiety and depression), and key coping outcomes (confrontational, acceptance-resignation and avoidant) using the theoretical variable predictors from the general theoretical framework of Lazarus and Folkman (1984). Aim 2.2 was to find the demographic and clinical risk factors for the key outcomes. This section first reports the correlations of predictor variables with outcome variables. Next, this section reports the hierarchical regressions that were used to examine if theory-led predictor variables were significant in explaining some of the variance in the key outcomes.

Hierarchical regressions were used so that the theoretically relevant predictor variables could be entered first into Block 1, followed by other potential predictors relating to demographics and clinical characteristics in Block 2. The psychological predictor variables were chosen based on the theoretical framework of Lazarus and Folkman (1984), Smith, and Lazarus (1991). Therefore, predictor variables for anxiety and depression were appraisals (i.e. ICD beliefs, concurrent cardiac illness beliefs) and predictor variables for coping were appraisals and emotions. A secondary aim was to determine which demographic/clinical characteristics might be risk factors for increased anxiety and depression at 3- and 6-months and which might predict specific types of coping.

The following hypotheses were tested:

> **Hypothesis $_1$** - At 3- and 6-months after the ICD implant, concurrent illness and ICD-related beliefs would explain a significant percentage of variance in levels of anxiety.
>
> **Hypothesis $_2$** - At 3- and 6-months after the implant, concurrent illness beliefs and ICD-related beliefs would explain a significant percentage of variance in the levels of depression.

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[87] In this study, 'predictor' does not infer causality but is a description of a variable that explains some variance.

Hypothesis $_3$ - At 3- and 6-months after the implant, concurrent illness beliefs, ICD-related beliefs, and levels of anxiety and depression would explain a significant percentage in variance in coping with the ICD using confrontation.

Hypothesis $_4$ - At 3- and 6-months after the implant, concurrent illness appraisals, ICD-related beliefs, levels of anxiety and depression would explain a significant percentage of variance in coping with the ICD using acceptance-resignation.

Hypothesis $_5$ - At 3- and 6-months after the implant, concurrent illness appraisals and ICD-related beliefs, levels of anxiety and depression would explain a significant percentage of variance in coping with the ICD using avoidance (behavioural avoidance and cognitive avoidance).

NOTE: The R^2 (total variance of Blocks 1 and 2) displayed in the following hierarchical regressions required proportional adjustment in order to calculate the total variance explained by the full model. For instance, in this instance, Block 1 accounted for 52% of the variance, so therefore the total variance left to be explained in Block 2 was 48%. The residual for Block 2 was .132. Therefore, the variance explained by Block 2 was .132 x 48, which was 6.34%. For that reason, in this instance, the total variance provided by the model was 52 + 6.34 = 58.34%.

ANXIETY – Testing Hypothesis $_1$

Anxiety at 3-Months

Bivariate correlations were conducted to explore the associations between the psychological predictor variables (measured at 3-months) and levels of anxiety (measured at 3-months). The outcomes revealed that some of the cardiac-illness appraisals had a significant positive correlation with anxiety. These were B-IPQ items measuring consequences and comprehension. This finding offers some support for the finding reported in Aim 1. The B-IPQ items 'concern' and 'comprehension' showed that the intervention group reported scores that indicated that they felt *less affected* by the consequences of their cardiac illness, whilst simultaneously reporting that they *understood less* about their condition (see Table 9.8).

The results of the Pearson's *r* bivariate correlations are displayed in Table 9.19. Bivariate correlations explored the relationships between the predictor variables at 3-months. Correlations revealed that the Positive ICD Beliefs questionnaire and the ICD-concerns Questionnaire had a significant negative correlation of -.740. They were considered to achieve co-linearity and therefore a decision to use the Positive ICD Beliefs questionnaire was made. The decision to use this measure was because it was based on the ICD-Concerns Questionnaire but targeted *beliefs* rather than *worries* or *concerns.* The B-IPQ item personal control over the cardiac illness was not strongly associated with anxiety. This was surprising as Lazarus had suggested an appraisal component of anxiety was low emotion-focussed coping potential (see Chapter 4), and accordingly it had been anticipated that there would be a significant negative correlation.

Table 9.19: Pearson's correlations showing concurrent associations between cardiac-condition appraisals and ICD-related appraisals with anxiety at 3-months

Appraisal Predictor Variables at 3-months	Anxiety (HADS) 3-months
Cardiac illness-related Appraisals at 3-months	
B-IPQ – consequences	**.551****
B-IPQ – Timeline	.291*
B-IPQ – Personal Control	.213
B-IPQ – Treatment Control	.130
B-IPQ – Identity	.172
B-IPQ – Comprehension	**.476****
ICD-related Appraisals at 3-months	
Positive ICD Beliefs questionnaire – total	**-.662****
ICD-concerns Questionnaire – total	.778**
FPAS – Positive Appraisals	**-.341****
FPAS – Body Image Concerns	-.254*

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. **In Bold: predictor variables entered into the regression**

Bivariate correlations revealed that age and cardiomyopathy variables measured at baseline, were significantly correlated with anxiety scores at 3-months. There was a significant negative correlation between age and anxiety and a significant positive correlation between cardiomyopathy and anxiety. The Pearson's *r* correlations for age and the clinical characteristics are displayed in Table 9.20.

Table 9.20: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina, myocardial infarction with anxiety at 3-months

Demographic & Clinical Predictor Variables at Baseline	Anxiety (HADS) 3-months
Demographic Characteristics	
Age	**-.370****
Gender	.103
Clinical Characteristics	
Heart failure	-.022
Cardiomyopathy	**.249***
Angina	.228
Myocardial Infarction	-.228

Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. **In Bold: predictor variables entered into the regression

The 3-month scores of the following psychological variables were entered into Block 1 (in the order they appear in the table). These were the B-IPQ items measuring consequences and comprehension, the Positive ICD Beliefs questionnaire, and the positive appraisal subscale of the FPAS at 3-months. The demographic variable 'age' (age of patient) and the clinical variable 'cardiomyopathy' (patient having a clinical diagnosis of a type of cardiomyopathy), were entered into Block 2. Table 9.21 displays the results of the hierarchical regression analysis for the associations of the psychological predictors, demographic and clinical predictors of anxiety at 3-months.

The variance explained for anxiety in the Lazarus and Smith model was 52%, F=19.667, p<.001. An additional 6.34% was explained by age and having a cardiomyopathy (F=6.239, p<.01). The total variance explained after adjustment = 58.34%. See Table 9.21. The first part of hypothesis$_1$ was supported as some of the appraisals explained a significant percentage of variance in anxiety at 3-months. The age of the patient and the status of cardiomyopathy were found to be significant risk factors of increased anxiety at 3-months.

Table 9.21: Hierarchical regression analysis: anxiety at 3-months with appraisals, demographic and clinical characteristics as predictor variables

	Predictors of Anxiety at 3-months	
Predictors	ΔR^2	β
Block 1	**.520****	
B-IPQ item 1 – Consequences		.276**
B-IPQ item 7 – Comprehension		.273**
Positive ICD Beliefs questionnaire		-.353**
FPAS – Positive Appraisal		-.088
Block 2	**.132****	
Age		-.283*
Cardiomyopathy		.230*

Total Variance after adjustment = 58.34%

N = 72

*p<.05. ** p<.01. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey.

Anxiety at 6-months

Bivariate correlations were carried out to explore the associations between the psychological predictor variables (measured at 6-months) and levels of anxiety (measured at 6-months). Some of the cardiac illness-related appraisals had a positive significant correlation with anxiety. These appraisals were the B-IPQ items measuring consequences, timeline, and identity. The ICD-related appraisals from the Positive ICD Beliefs questionnaire and the body image subscale of the FPAS had a significant negative correlation with anxiety and the ICD-Concerns Questionnaire had a significant positive correlation. The Pearson's *r* correlations are display in Table 9.22.

Bivariate correlations explored the relationships of the predictor variables with each other. Correlations revealed that the Positive ICD Beliefs questionnaire and the ICD-concerns Questionnaire were highly correlated (-.718). They were considered to achieve co-linearity and therefore a decision to use the Positive ICD Beliefs questionnaire was made. The decision to use this measure was because it was based on the ICD-Concerns Questionnaire but targeted *beliefs* rather than *worries* or *concerns.*

Table 9.22: Pearson's correlations showing concurrent associations between cardiac-condition appraisals and ICD-related appraisals at 6-months with anxiety at 6-months

Appraisal Predictor Variables at 6-months	Anxiety (HADS) 6-months
Cardiac illness-related Appraisals	
B-IPQ – consequences	**.535****
B-IPQ – Timeline	**.314***
B-IPQ – Personal Control	.099
B-IPQ – Treatment Control	**.382****
B-IPQ – Identity	.339**
B-IPQ – Comprehension	.250
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.647****
ICD-concerns Questionnaire – total	.721**
FPAS – Positive Appraisals	-.144
FPAS – Body Image Concerns	**-.381****

Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. **In Bold: predictor variables entered into the regression

Bivariate correlations revealed there was a significant negative correlation between age and anxiety, which suggested that the younger the patient, the higher the level of anxiety (see Table 9.23).

Table 9.23: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with anxiety at 6-months

Demographic & Clinical Predictor Variables at Baseline	Anxiety (HADS) 6-months
Demographic Characteristics	
Age	**-.395****
Gender	.087
Clinical Characteristics	
Heart failure	170
Cardiomyopathy	.200
Angina	.242
Myocardial Infarction	-.185

Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. **In Bold: predictor variables entered into the regression

The following psychological predictor variables were entered into Block 1 of the hierarchical regression (in the order they appear in the table). These were B-IPQ items measuring consequences, timeline, and treatment control, the Positive ICD Beliefs questionnaire and the body image concerns subscale of the FPAS. Although B-IPQ identity (item 5), significantly correlated with anxiety, it was excluded. The main reason for this was that the wording in the questionnaire alluded to the number of arrhythmias experienced and therefore this item did not reflect 'appraisal' but evidence of symptoms. The demographic variable 'age' was entered into Block 2. Table 9.24 displays the results of the hierarchical regression analysis for anxiety at 6-months.

The variance explained for anxiety using predictors from Lazarus and Smith's model was 48.2%, F=11.987, p<.01. An additional .57% of the model was explained when age was added to the overall model (F.386, p>.05). The total variance explained after adjustment = 48.77%[88]. The second part of hypothesis$_1$ was supported as some of the appraisals explained a significant percentage of variance in anxiety. The age of the patient was not found to be a risk factor for increased anxiety at 6-months.

Table 9.24: Hierarchical regression analysis: anxiety at 6-months with appraisals, demographic and clinical characteristics as predictor variables

	Predictors of Anxiety (HADS) at 6-months	
Predictors	Δ R^2	β
Block 1	**.482****	
B-IPQ – Consequences		.261**
B-IPQ – Timeline		.162
B-IPQ – Treatment Control		.046
Positive ICD Beliefs questionnaire		-.432**
FPAS –Body Image Concerns		-.101
Block 2	**-.011**	
Age		-.621

Total Variance after adjustment = 48.77

N = 60

*p<.05 ** p<.01. HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey.

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[88] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

DEPRESSION – Testing Hypothesis $_2$

Depression at 3-months

Bivariate correlations were carried out to explore the associations between the psychological predictor variables (measured at 3-months) with levels of depression (measured at 3-months). The results are displayed in Table 9.25. The bivariate correlations revealed that some of the cardiac-condition related appraisals had significant positive correlations with depression. These were the B-IPQ items measuring consequences, timeline, and comprehension. Interestingly, similar to anxiety, it appeared that having a greater understanding of the cardiac illness was associated with feeling depressed.

Correlations relating to ICD-related appraisals revealed that the Positive ICD Beliefs questionnaire and the body image concerns subscale from the FPAS had a significant negative correlation with depression. The ICD-Concerns Questionnaire had a significant positive correlation with depression.

Bivariate correlations explored the associations of the psychological predictor variables using Pearson's correlations. Correlations revealed that the Positive ICD Beliefs questionnaire and the ICD-Concerns Questionnaire were highly correlated (-.740). They were considered to achieve co-linearity. A decision to use the Positive ICD Beliefs questionnaire was made. The decision to use this measure was because it was based on the ICD-Concerns Questionnaire but targeted *beliefs* rather than *worries* or *concerns.*

Table 9.25: Pearson's correlations showing concurrent associations between appraisals with depression at 3-months

Appraisal Predictor Variables at 3-months	Depression (HADS) 3-months
Cardiac illness-related Appraisals	
B-IPQ – consequences	**.577****
B-IPQ – Timeline	**.310****
B-IPQ – Personal Control	.166
B-IPQ – Treatment Control	.157
B-IPQ – Identity	.068
B-IPQ – Comprehension	**.367****
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.625****
ICD-concerns Questionnaire – total	.731**
FPAS – Positive Appraisals	-.257*
FPAS – Body Image Concerns	-.137

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. **In Bold: predictor variables entered into the regression**

Bivariate correlations revealed that only angina significantly correlated with depression at 3-months.

The Pearson's *r* correlations for all the demographic and clinical characteristics suggested there was a significant positive correlation between angina and depression. The Pearson's *r* correlations for all the demographic and clinical characteristics are displayed in Table 9.26.

Table 9.26: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with depression at 3-months

Demographic & Clinical Predictor Variables at Baseline	Depression (HADS) 3-months
Demographic Characteristics	
Age	-.209
Gender	.208
Clinical Characteristics	
Heart failure	.079
Cardiomyopathy	.071
Angina	**.333****
Myocardial Infarction	-.042

Correlation is significant at the .01 level (2-tailed). *Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. **In Bold: predictor variables entered into the regression

The following psychological predictor variables were entered into Block 1 of the hierarchical regression (in the order they appear in the table). These were the B-IPQ items that measured consequences, timeline and comprehension and the Positive ICD Beliefs questionnaire. Although the FPAS positive appraisal was significantly correlated with depression, Pearson's *r* did not reach .3 and so was omitted. The clinical variable 'Angina' was entered into Block 2 of the regression. Table 9.27 displays the results of the hierarchical regression analysis for depression at 3-months.

The psychological predictor variables explained 47.5% of the model of depression at 3-months, F=16.609, p<.01. The cardiac illness 'angina' explained a further 8.7% of the variance (F= 14.717, p<.01). The total variance after adjustment = 56.22%[89]

The first part of hypothesis $_2$ was supported as some of the appraisals significantly explained some of the variance in depression at 3-months. A clinical diagnosis of angina was a risk factor for depression at 3-months.

Table 9.27: Hierarchical regression analysis: depression at 3-months with appraisals and clinical characteristics as predictor variables

	Predictors of Depression (HADS) at 3-months	
Predictors	ΔR^2	β
Block 1	**.475****	
B-IPQ – Consequences		.338**
B-IPQ – Timeline		.137
B-IPQ – Comprehension		.159
Positive ICD Beliefs questionnaire		-.332**
Block 2	**.166****	
Angina		.422**

Total Variance after adjustment = 56.22%

N = 72

*p<.05 ** p<.01. HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey.

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[89] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

Depression at 6-months

Bivariate correlations were carried out to explore the associations between the psychological predictor variables (measured at 6-months), with levels of depression (measured at 6-months). The results are displayed in Table 9.28. The bivariate correlations revealed that some of the cardiac illness-related appraisals significantly correlated with depression. These were the B-IPQ items measuring consequences, timeline, treatment control, and identity.

The Positive ICD Beliefs questionnaire and the ICD Concerns Questionnaire also significantly correlated with depression. However, they were highly correlated with each other and considered to achieve co-linearity (-.718). A decision to use the Positive ICD Beliefs questionnaire was made. The decision to use this measure was because it was based on the ICD-Concerns Questionnaire but had been targeted *beliefs* rather than *worries* or *concerns.*

Table 9.28: Pearson's correlations showing concurrent associations between appraisals at 6-months with depression at 6-months

Appraisal Predictor Variables at 6-months	Depression (HADS) 6-months
Cardiac illness-related Appraisals	
B-IPQ – consequences	**.623****
B-IPQ – Timeline	.266*
B-IPQ – Personal Control	.244
B-IPQ – Treatment Control	**.374****
B-IPQ – Identity	.306*
B-IPQ – Comprehension	.133
ICD-related Appraisals	
Positive ICD BELIEFS questionnaire – total	**-.623****
ICD-concerns Questionnaire – total	.678**
FPAS – Positive Appraisals	-.086
FPAS – Body Image Concerns	-.201

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. **In Bold: predictor variables entered into the regression**

Bivariate correlations revealed that age, heart failure and having had a previous myocardial infarction was significantly associated with depression at 6-months. There was a significant negative correlation between age and depression, which suggested that the younger the patient, the more likely they were to have higher levels of depression. There was a significant positive correlation between heart failure and depression and having had an MI and depression. The Pearson's *r* correlations for all the demographic and clinical characteristics are displayed in Table 9.29.

Table 9.29: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with depression at 6-months

Demographic & Clinical Predictor Variables at Baseline	Depression (HADS) 6-months
Demographic Characteristics	
Age	**-.292***
Gender	.067
Clinical Characteristics	
Heart failure	**.256***
Cardiomyopathy	.068
Angina	-.068
Myocardial Infarction (MI)	**.366****

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). HADS = Hospital Anxiety and Depression Scale. **In Bold: predictor variables entered into the regression

The following psychological predictor variables were entered into Block 1 of the hierarchical regression (in the order they appear in the table). These were the B-IPQ items that measured consequences and treatment control and the Positive ICD Beliefs questionnaire. The demographic age variable (age of patient), having a clinical diagnosis of HF (NYHA classes 1-3), and a clinical diagnosis of a previous MI were entered into Block 2 of the regression. Table 9.30 displays the results of the hierarchical regression analysis for depression at 6-months.

The psychological predictor variables explained 50.6% of the model of depression at 6-months, F=21.177, $p<.01$. The demographic variable age and the clinical variables HF and MI explained an extra 5.1% of the variance (F=3.247, $p<.05$). The total variance explained = 55.7%[90].

The second part of hypothesis$_2$ was supported as there some of the appraisals explained a significant percentage of variance in depression at 6-months. The only risk factor identified for depression at 6-months was a clinical diagnosis of heart failure (NYHA classes 1 to 3).

Table 9.30: Hierarchical regression analysis: depression at 6-months with appraisals and clinical characteristics as predictor variables

	Predictors of Depression (HADS) at 6-months	
Predictors	Δ R^2	β
Block 1	**.506****	
B-IPQ - Consequences		.431*
B-IPQ - Treatment control		.064
Positive ICD Beliefs questionnaire		-.384**
Block 2	**.103**	
Age		.029
HF		.367**
MI		-.208

Total Variance after adjustment = 55.7%
N = 60

*p<.05 ** p<.01. HADS = Hospital Anxiety and Depression Scale. B- IPQ = Brief Illness Perception Questionnaire. HF = Heart Failure. MI = Previous history of MI.

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[90] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

COPING

Coping at 3-months using CONFRONTATION – Testing Hypothesis $_3$

Bivariate correlations were conducted to explore the associations between coping using confrontation at 3-months, and appraisals and emotions measured at 3-months. The POMS-SF subscale 'vigour' was the only variable that was significantly correlated with confrontational coping at 3-months.

Table 9.31: Pearson's correlations showing concurrent associations between appraisals and emotions at 3-months with CONFRONTATION coping anxiety at 3-months

Appraisal and Emotion Predictor Variables at 3-months	Confrontation type Coping (MCM) 3-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	.045
B-IPQ – Timeline	.197
B-IPQ – Personal Control	.012
B-IPQ – Treatment Control	-.026
B-IPQ – Identity	-.137
B-IPQ – Concern	.077
B-IPQ – Comprehension	-.076
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	-.021
ICD-concerns Questionnaire – total	.004
FPAS – Positive Appraisals	-.013
FPAS – Body Image Concerns	-.023
Emotions	
Anxiety (HADS)	.011
Depression (HADS)	.031
Depression TOTAL (POM-SF)	.067
Depression subscale (POMS-SF)	.090
Tension (POMS-SF)	.163
Anger (POMS-SF)	.186
Confusion (POMS-SF)	.202
Vigour (POMS-SF)	.256*
Fatigue (POMS-SF)	.106
Negative Affect (DS14)	.043
B-IPQ – Emotional Response	.041

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. MCM = Modes of Coping Measure. **In Bold: predictor variables entered into the regression.**

According to Lazarus' theory, appraisals and emotions should have influenced coping. Therefore, it was surprising that no appraisals significantly correlated with this type of coping. The B-IPQ item measuring perceived personal control was predicted to have been highly correlated with this type of coping as a high level of personal control might help facilitate confrontation. The Pearson's *r* correlations for appraisals and emotions are displayed in Table 9.31.

Bivariate correlations revealed that there was a significant negative correlation between age and confrontation coping at 3-months (see Table 9.32). This suggested that the younger the patient, the more likely they were to use confrontation-type coping.

Table 9.32: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with CONFRONTATION type coping at 3-months

Demographic & Clinical Predictor Variables At baseline	Confrontational Coping (MCM) 3-months
Demographic Characteristics	
Age	**-.418****
Gender	.093
Type D	-.070
Clinical Characteristics	
Heart failure	.015
Cardiomyopathy	.019
Angina	.066
Myocardial Infarction	-.067

**. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed).
In Bold: predictor variables entered into the regression

A hierarchical regression could not be carried out. The POMS subscale for Vigour was significantly correlated with this type of coping. However as the Pearson's *r* correlation did not reach the minimum associated strength of .3, it was omitted.

Coping at 6-months using CONFRONTATION

Bivariate correlations were conducted to explore the associations of confrontation type coping at 6-months, with appraisals and emotions measured at 6-months. Some appraisals that had not been significantly associated with confrontational coping at 3-months were significantly associated at 6-months. The Pearson's *r* correlations for appraisals and emotion variables are displayed in Table 9.33.

Table 9.33: Pearson's correlations showing concurrent associations between appraisals and emotions at 6-months using CONFRONTATION type coping at 6-months

Appraisal and Emotion Predictor Variables at 6-months	Confrontation type Coping (MCM) 6-months
Cardiac illness-related Appraisals	
B-IPQ - Consequences	**.432****
B-IPQ – Timeline	.273*
B-IPQ – Personal Control	-202
B-IPQ – Treatment Control	.028
B-IPQ – Identity	.165
B-IPQ – Comprehension	-.090
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	-.251
ICD-concerns Questionnaire – total	.296*
FPAS – Positive Appraisals	.055
FPAS – Body Image Concerns	-.233
Emotions	
Anxiety (HADS)	.279*
Depression (HADS)	.239
Depression TOTAL (POMS-SF)	.240
Depression subscale (POMS-SF)	.236
Tension (POMS-SF)	.182
Anger (POMS-SF)	.133
Confusion (POMS-SF)	.181
Vigour (POMS-SF)	-.131
Fatigue (POMS-SF)	**.302***
Negative Affect (DS14)	.243
B-IPQ – Emotional Response	**.449****
B-IPQ – Concerns	**.466****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. MCM = Modes of Coping Measure. **In Bold: predictor variables entered into the regression**

Bivariate correlations of the demographic and clinical predictor variables with confrontational coping at 6-months revealed that only age was significantly associated (see Table 9.34). Similar to the findings at 3-months, age of patient was negatively correlated with confrontational coping. This meant that the younger the patient, the more likely they were to use confrontation-type coping. Coping using confrontation-type coping was expected to be significantly negatively correlated to having a Type-D personality. However, the association between these two variables was very weak (-.022).

Table 9.34: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with CONFRONTATION type coping at 6-months

Demographic & Clinical Predictor Variables at Baseline	Confrontation type Coping (MCM) 6-months
Demographic Characteristics	
Age	**-.450****
Type-D	-.022
Gender	.096
Clinical Characteristics	
Heart failure	.070
Cardiomyopathy	-.007
Angina	.150
Myocardial Infarction	-.030

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes Questionnaire. **In Bold: predictor variables entered into the regression

Table 9.35 displays the results of the hierarchical regression analysis for finding the predictors of coping using confrontation at 6-months. The B-IPQ items to measure consequences, concerns and emotional response and the fatigue POMS subscale were entered into Block 1. (in the order they appear in the table). The demographic age variable was entered into Block 2.

The variance explained for coping using confrontation with the psychological predictors from the Lazarus and Smith's model was 21.3%, F= 4.929, p<.01. An additional 4.3% was explained by the age of the patient (F= 4.399, p<.05). The total variance explained after adjustment = 25.6%[91]

These finding did not support the second part of hypothesis$_3$, appraisals (beliefs about the consequences of the cardiac illness) and emotions did not explain a significant percentage of variance in confrontation-type coping at 6-months. The age of the patient however did explain a significant percentage of variance in confrontation-type coping.

Table 9.35: Hierarchical regression analysis: CONFRONTATION type coping at 6-months with emotions and demographic characteristics as predictor variables

	Predictors of Confrontation type Coping at 6-months (MCM)	
Predictors	Δ R^2	β
Block 1	**.213****	
B-IPQ - Consequences		.145
B-IPQ - Concern		.241
B-IPQ - Emotional response		.197
POMS-SF Fatigue		.014
Block 2	**.055***	
Age		-.268*

Total Variance after adjustment = 25.6%

N = 60

*p<.05. ** p<.01. MCM = Medical Coping Modes Questionnaire. POMS-SF = Profile of Moods Questionnaire (short form). B-IPQ = Brief Illness Perception Questionnaire. HADS = Hospital Anxiety and Depression Scale

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[91] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

Coping using ACCEPTANCE-RESIGNATION at 3-months – Testing Hypothesis $_4$

Bivariate correlations were conducted to explore the associations between acceptant-resignation coping and appraisals and emotions. The correlations revealed that the Positive ICD Beliefs questionnaire had a significant negative correlation with acceptance-resignation type coping. The ICD-Concerns Questionnaire and B-IPQ items measuring consequences, timeline and comprehension had a significant positive correlation with acceptance-resignation type coping. The HADS depression and anxiety subscales, the total POMS-SF and all its subscales and the B-IPQ item to measure emotional response and concerns were positively correlated to coping using acceptance-resignation. The Pearson's *r* correlations are displayed in Table 9.37.

Bivariate correlations explored the associations of the psychological predictor variables using Pearson's correlations. Correlations revealed that the Positive ICD Beliefs questionnaire and the ICD-Concerns Questionnaire were highly correlated (-.740). They were considered to achieve co-linearity. A decision to use the Positive ICD Beliefs questionnaire was made. The decision to use this measure was because it had been based on the ICD-Concerns Questionnaire but created to target *beliefs* rather than *worries* or *concerns.*

Many emotions were significantly associated with acceptance-resignation type coping at 3-months. Due to the number of participants in the study, a maximum of eight independent variables could be entered into the regression (see Cohen, 1992). Therefore, further correlations were conducted to explore the associations between the emotional variables in order to help determine which should be entered into the regression. Correlations revealed that several of the emotional outcomes had high correlations with each other and considered to achieve co-linearity. These were the HADS-A, HADS-D, DS14-NA, total POMS-SF and B-IPQ emotional response (see Table 9.36). In order to maintain consistency with the rules about which variables should be entered into the regression, a decision was made to use HADS-A based on the finding that this subscale measure had the strongest correlation with acceptance-resignation type coping. In addition, HADS-A was not too strongly correlated with the B-IPQ emotional response item, which was also strongly correlated with acceptance-resignation type coping.

Table 9.36: Summary of inter correlations of emotional predictor variables that were so strongly correlated, they were considered to achieve co-linearity at 3-months

Measure	HADS-A	HADS-D	DS14-NA	POMS-SF	POM-DEP	POM-ANG	POM-CON	POM-TEN	B-IPQ-emo
HADS-A	1	.811**	.740**	.832**	.804**	.726**	.694**	.802**	.658**
HADS-D		1	.683**	.877**	.837**	.694**	.716**	.764**	.646**
DS14-NA			1	.702**	.685**	.549**	.585**	.625**	.628**
POMS-SF				1	.947**	.841**	.836	.867**	.723**
POM-DEP					1	.831**	.817**	.811**	.680**
POM-ANG						1	.638**	.775**	.544**
POM-CON							1	.747**	.661**
POM-TEN								1	.661

** = p<.01. HADS-A = Hospital Anxiety and Depression Scale – anxiety subscale. HADS-D = Hospital Anxiety and Depression Scale – depression subscale. DS14-NA = Negative effect subscale of DS14 (Type D personality measure). POMS-SF = total Profile of Moods Scale. POM-DEP = Profile of Moods depression subscale. POM-ANG = Anger subscale of the Profile of Moods Scale. POM-CON = Confusion subscale of the Profile of Moods Scale. POM-TEN = Tension subscale of the Profile of Moods Scale. B-IPQ-emo = Emotional response item on the Brief Illness Perception Questionnaire

Table 9.37: Pearson's correlations showing concurrent associations between appraisals and emotions with ACCEPTANCE-RESIGNATION type coping at 3-months

Appraisal and Emotion	Acceptance-Resignation type Coping (MCM)
Predictor Variables at 3-months	3-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	**.613****
B-IPQ – Timeline	.267*
B-IPQ – Personal Control	-.253*
B-IPQ – Treatment Control	.179
B-IPQ – Identity	.226
B-IPQ – Comprehension	**.351****
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.671****
ICD-concerns Questionnaire – total	.660**
FPAS – Positive Appraisals	-.182
FPAS – Body Image Concerns	-.143
Emotions	
Anxiety (HADS)	**.660****
Depression (HADS)	.556**
Depression TOTAL (POMS-SF)	.566**
Depression subscale (POMS-SF)	.551**
Tension (POMS-SF)	.506**
Anger (POMS-SF)	.428**
Confusion (POMS-SF)	.465**
Vigour (POMS-SF)	-.463**
Fatigue (POMS-SF)	.531**
Negative Affect (DS14)	.498**
B-IPQ item 8 – Emotional Response	**.532****
B-IPQ item 6 – Concern	**.587****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. MCM = Medical Coping Modes. **In Bold: predictor variables entered into the regression**

There was a significant negative correlation between age and acceptance-resignation type coping (see Table 9.38). This suggested that the younger the patient, they more likely they were to engage in this type of coping.

Table 9.38: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with ACCEPTANCE-RESIGNATION type coping at 3-months

Demographic & Clinical Predictor Variables at Baseline	Acceptance-Resignation type Coping (MCM) 3-months
Demographic Characteristics	
Age	**-.295***
Type-D	.174
Gender	.023
Clinical Characteristics	
Heart failure	-.038
Cardiomyopathy	.038
Angina	.062
Myocardial Infarction	-.143

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes. **In Bold: predictor variables entered into the regression

Table 9.39 displays the results of the hierarchical regression analysis for finding the predictors for acceptance-resignation type coping at 3-months. The variance explained by the psychological variables was 53.9%, F=14.039, p<.01. An additional .092% was explained by age (F= .852, p>.05). The total variance explained after adjustment = 53.99%[92].

These findings partially supported the first part of hypothesis$_4$ as although appraisals explained a significant percentage of the variance in acceptance-resignation type coping at 3-months, emotional variables did not.

Table 9.39: Hierarchical regression analysis: ACCEPTANCE-RESIGNATION type coping at 3-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Acceptance-resignation type coping at 3-months (MCM)	
Predictors	Δ R^2	β
Block 1	**.539****	
B-IPQ – Consequences		.250*
B-IPQ – Comprehension		.057
Positive ICD Beliefs		-.324*
HADS - Anxiety		.207
B-IPQ – Concern		.043
B-IPQ – Emotional response		.064
Block 2	**-.002**	
Age		-.113
Total variance after adjustment = 53.99%		
N = 72		

*p<.05. ** p<.01. MCM = Medical Coping Modes. B-IPQ = Brief Illness Perception Questionnaire. HADS = Hospital Anxiety and Depression Scale

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[92] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

Coping using ACCEPTANCE-RESIGNATION at 6-months – Testing Hypothesis $_8$

Bivariate correlations were conducted to explore the correlations between acceptant-resignation coping at 6-months with appraisals and emotions measured at 6-months. These Pearson's *r* correlations are displayed in Table 9.41.

Correlations revealed that the Positive ICD Beliefs questionnaire was highly correlated with the ICD-Concerns (-.718). They were considered to achieve co-linearity. The Positive ICD Beliefs questionnaire was chosen for entry into the regression. The decision to use the Positive ICD Beliefs questionnaire was made based on the fact that this measure had been created from the ICD Concerns Questionnaire but had been created to reflect *beliefs* rather than *worries* or *concerns.*

Many of the measures of emotion were highly correlated with acceptant-resignation coping. However, due to the number of participants a maximum of eight variables could be entered as independent variables in the hierarchical regression (see Cohen, 1992). Further correlations were conducted to explore the strength of association between the emotions (see Table 9.40). This would help decide which emotional variables to use in the regression. The measures of emotion that were highly associated with each other were the total POM-SF, the HADS subscales, the DS14-NA and the B-IPQ emotional response item. The depression subscale of the HADS was chosen as it was most strongly correlated with acceptance-resignation type coping. Individual POMS scores (apart from POMS depression subscale) did not correlate too highly with HADS depression, so POMS Anger, POMS Tension, POMS Fatigue, and POMS Confusion were also chosen to be independent variables for Block 1.

Table 9.40: Summary of inter correlations of emotional predictor variables that were strongly correlated with each other at 6-months and considered to achieve co-linearity

Measure	HADS-A	HADS-D	DS14-NA	POMS-SF	POM-DEP	POM-ANG	POM-CON	POM-TEN	B-IPQ-8
HADS-A	1	.792**	.818**	.774**	.720**	.617**	.610**	.738**	.763**
HADS-D		1	.748**	.802**	.742**	.564**	.606**	.647**	.709**
DS14-NA			1	.784**	.775**	.641**	.602**	.678**	.777**
POMS-SF				1	.930**	.843**	.809**	.891**	.650**
POM-DEP					1	.773**	.757**	.803**	.659**
POM-ANG						1	.653**	.902**	.511**
POM-CON							1	.682**	.525**
POM-TEN								1	.582**

** = p<.01. HADS-A = Hospital Anxiety and Depression Scale – anxiety subscale. HADS-D = Hospital Anxiety and Depression Scale – depression subscale. DS14-NA = Negative effect subscale of DS14 (Type D personality measure). POMS-SF = total Profile of Moods Scale. POM-DEP = Profile of Moods depression subscale. POM-ANG = Anger subscale of the Profile of Moods Scale. POM-CON = Confusion subscale of the Profile of Moods Scale. POM-TEN = Tension subscale of the Profile of Moods Scale. B-IPQ-8 = Emotional response item on the Brief Illness Perception Questionnaire

Table 9.41: Pearson's correlations showing concurrent associations between appraisals and emotions with ACCEPTANCE-RESIGNATION type coping at 6-months

Appraisal and Emotion Predictor Variables at 6-months	Acceptance-Resignation type Coping (MCM) 6-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	**.747****
B-IPQ – Timeline	.278*
B-IPQ – Personal Control	.287*
B-IPQ – Treatment Control	.316*
B-IPQ – Identity	.300*
B-IPQ – Comprehension	.230
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.554****
ICD-concerns Questionnaire – total	.573**
FPAS – Positive Appraisals	.020
FPAS – Body Image Concerns	-.240
Emotions	
Anxiety (HADS)	.591**
Depression (HADS)	**.649****
Depression TOTAL (POMS-SF)	.511**
Depression subscale (POMS-SF)	.510**
Anger (POMS-SF)	.341**
Tension (POMS-SF)	**.364****
Confusion (POMS-SF)	**.457****
Vigour (POMS-SF)	-.371**
Fatigue (POMS-SF)	**.457****
Negative Affect (DS14)	.570**
B-IPQ – Emotional Response	.657**
B-IPQ – Concern	**.519****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes. B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form.
In Bold: predictor variables entered into the regression

The age of the patient was significantly negatively correlated with acceptance-resignation type coping at 6-months. This suggested that the younger the patient, the more likely they were to use this type of coping. The demographic and clinical variables are displayed in Table 9.42.

Table 9.42: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with ACCEPTANCE-RESIGNATION type coping at 6-months

Demographic & Clinical Predictor Variables at 6-months at 6-months	Acceptance-Resignation type Coping (MCM) 6-months
Demographic Characteristics	
Age	**-.314***
Type-D	.182
Gender	-.133
Clinical Characteristics	
Heart failure	.042
Cardiomyopathy	.087
Angina	.033
Myocardial Infarction	-.099

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes. **In Bold: predictor variables entered into the regression

Table 9.43 displays the results of the hierarchical regression analysis for acceptant-resignation coping at 6-months. The variance explained for acceptance-resignation type coping using predictors from the Lazarus and Smith model was 59.1%, F= 12.965, p<.01. An additional 1% was explained by the age of the patient (F= .417, p>.05). The total variance explained after adjustment = 59.51%[93].

These findings partially supported the second part of Hypothesis $_4$ as appraisals (belief about the consequences of cardiac illness) explained a significant percentage of variance in acceptance-resignation-type coping. However, no emotional outcome, demographic or clinical variable explained a significant percentage of acceptance-resignation type coping at 6-months.

Table 9.43: Hierarchical regression analysis: ACCEPTANCE-RESIGNATION type coping at 6-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Acceptance-resignation type coping at 6-months (MCM)	
Predictors	Δ R^2	β
Block 1	**.591****	
B-IPQ - Consequences		.528**
B-IPQ - Concerns		-.023
POMS – confusion		.102
POMS – tension		-.122
POMS – fatigue		.038
HADS – depression		.210
BELIEFS		-.184
Block 2	**-.010**	
Age		-.085

Total Variance after adjustment = 59.51%

N = 60

*p<.05. ** p<.01. MCM = Medical Coping Modes. B-IPQ = Brief Illness Perception Questionnaire. POMS = Profile of Moods Questionnaire (short form). ICD-C = ICD Concerns Questionnaire. HADS = Hospital Anxiety and Depression Scale

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[93] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

BEHAVIOURAL AND COGNITIVE AVOIDANT coping at 3-months – Testing Hypothesis $_5$

The Medical Coping Modes (MCM) avoidant coping subscale and the Impact of Event Scale (IES) – avoidant coping subscale both measured avoidant coping. Correlations revealed that the two measures were not so highly correlated (.544, p<.01) that they would achieve co linearity. As they were not too strongly correlated, this also suggested that they measured different constructs of avoidance. The questions in the MCM questionnaire appeared to relate to behavioural avoidance, whereas the questions in the IES questionnaire appeared to relate to cognitive avoidance. Consequently, regression analyses were conducted to find predictors for both types of avoidance.

Behavioural AVOIDANT coping at 3-Months: Behavioural type avoidance measured using the Medical Coping Modes Questionnaire

Bivariate correlations were carried out to explore levels of association between MCM avoidant coping (measured at 3-months), appraisals, and emotions (measured at 3-months). The Pearson *r* correlations are displayed below in Table 9.44.

The correlations revealed that the Positive ICD Beliefs questionnaire had a significant negative correlation with MCM behavioural avoidant coping. The ICD-Concerns Questionnaire and B-IPQ items measuring consequences and comprehension had a significant positive correlation with MCM behavioural avoidant coping. The HADS depression and anxiety subscales, the total POMS-SF and all its subscales and the B-IPQ item to measure emotional response and concerns were significantly positively correlated to this type of coping.

The Positive ICD Beliefs questionnaire and the ICD-concerns questionnaire were strongly associated with each other and considered to achieve co-linearity (-.740). The Positive ICD Beliefs questionnaire was chosen for entry into the regression. The decision to use the Positive ICD Beliefs questionnaire was made based on the fact that this measure had been created from the ICD Concerns Questionnaire and had been created to reflect *beliefs* rather than *worries* or *concerns.*

There were many variables of emotion that were significantly stronger related to MCM behavioural avoidant coping. Due to the number of participants in the study, a maximum of eight independent variables could be entered into the regression (see Cohen, 1992). Therefore, further correlations were conducted to explore the associations between the emotional variables in order to help determine which should be entered into the regression. Correlations revealed that several of the emotional outcomes had high correlations with each other and considered to achieve co-linearity. These were the HADS-A, HADS-D, DS14-NA, total POMS-SF and B-IPQ emotional response (see Table 9.36). A decision to use HADS depression was made as it had the strongest correlation with this type of coping MCM avoidant coping. The DS14 negative affect measure and the B-IPQ items that measured emotional response and concerns were also chosen for entry into the regression as they were not too strongly correlated with HADS depression or each other.

Table 9.44: Pearson's correlations showing concurrent associations between appraisals and emotions at 3-months with MCM-AVOIDANT coping at 3-months

Appraisal and Emotion Predictor Variables at 3-months	Avoidant Coping (MCM) 3-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	.358**
B-IPQ – Timeline	.179
B-IPQ – Personal Control	-.018
B-IPQ – Treatment Control	-.151
B-IPQ – Identity	.144
B-IPQ – Comprehension	.306**
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.354****
ICD-concerns Questionnaire – total	.552**
FPAS – Positive Appraisals	-.207
FPAS – Body Image Concerns	-.111
Emotions	
Anxiety (HADS)	.566**
Depression (HADS)	**.571****
Depression TOTAL (POMS-SF)	.566**
Depression subscale (POMS-SF)	.466**
Tension (POMS-SF)	.546**
Anger (POMS-SF)	.503**
Confusion (POMS-SF)	.391**
Vigour (POMS-SF)	-.197
Fatigue (POMS-SF)	.443**
Negative Affect (DS14)	**.379****
B-IPQ – Emotional Response	**.508****
B-IPQ – Concern	**.529****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. MCM = Modes of Coping Measure. **In Bold: predictor variables entered into the regression**

The demographic predictor variable gender was significantly correlated to MCM behavioural avoidant coping. Patients who were female, were more likely to use this type of coping. The Pearson's *r* correlations of the demographic and clinical variables are displayed in Table 9.45.

Table 9.45: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with MCM-AVOIDANT coping at 3-months

Demographic & Clinical Predictor Variables at Baseline	Avoidant Coping (MCM) 3-months
Demographic Characteristics	
Age	-.130
Type-D	-.028
Gender	**.435****
Clinical Characteristics	
Heart failure	-.105
Cardiomyopathy	-.027
Angina	.227
Myocardial Infarction	-.120

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes. **In Bold: predictor variables entered into the regression

Table 9.46 displays the results of the hierarchical regression analysis to find predictors of MCM-avoidant coping at 3-months. The variance of the model of a behavioural type avoidance explained using the psychological predictors from the Lazarus and Smith model was 34%, F= 7.888, p<.01. An additional 16.1% was explained by gender (F=13.838, p<.01). The total variance explained by the regression after adjustment = 55.26%[94].

These findings did not support hypothesis$_5$, as neither appraisals nor emotions explained a significant percentage of variance in (behavioural) avoidant coping. However, gender was a significant risk factor; being female increased the use of behavioural-type avoidance coping at 3-months.

Table 9.46: Hierarchical regression analysis: MCM-AVOIDANT coping at 3-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Avoidant coping at 3-months (MCM)	
Predictors	ΔR^2	β
Block 1	**.340****	
Positive ICD Beliefs questionnaire		.056
HADS Depression		.391
DS14 – negative affect		-.127
B-IPQ – Concern		.241
B-IPQ - Emotional response		.211
Block 2	**.161****	
Gender		.416**
Total variance after adjustment = 55.26 %		
N = 60		

*p<.05. ** p<.01. MCM = Medical Coping Modes Questionnaire. B-IPQ = Brief Illness Perception Questionnaire. POMS = Profile of Moods Questionnaire (short form). HADS = Hospital Anxiety and Depression Scale. DS14 = Type D personality questionnaire.

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[94] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

Cognitive AVOIDANT coping at 3-months: Cognitive type avoidance measured using the Impact of Events Scale

The Impact of Event Scale (IES)-avoidant coping subscale measured avoidant coping. Correlations revealed that the measure was not too highly correlated with the Medical Coping Modes Questionnaire subscale that also measured avoidance (.544, p<.01, which suggested that they measured different constructs of avoidance. The questions in the IES measure for avoidant appeared to measure *cognitive* type avoidance.

Bivariate correlations were conducted to explore the associations between psychological variables (measured at 3-months) and IES-avoidant coping (measured at 3-months) which are displayed in Table 9.47. Correlations to explore the relationships between psychological variables found there were many that were too high and considered to show evidence of co-linearity. The Positive ICD Beliefs questionnaire and ICD-Concerns Questionnaires, which measured appraisals, were strongly correlated (-.740). The decision to use the Positive ICD Beliefs questionnaire was made. This was based on the fact that this measure had been created from the ICD Concerns Questionnaire and had been created to reflect *beliefs* rather than *worries* or *concerns.*

The inter-correlations for the emotional outcome predictors that were highly correlated so that they were considered to achieve co-linearity are described in Table 9.36. Those that were most strongly correlated with IES avoidant coping were entered into Block 1 of the regression model. To limit the total number of psychological variables to five (as there were three demographic and clinical variables to take into consideration), the highest five that were too strongly correlated with each other were chosen for entry into the hierarchical regression.

Table 9.47: Pearson's correlations showing concurrent associations between appraisals and emotions at 3-months with IES-AVOIDANT coping at 3-months

Appraisal and Emotion Predictor Variables at 3-months	Avoidant Coping (IES) 3-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	**.328****
B-IPQ – Timeline	.248*
B-IPQ – Personal Control	.016
B-IPQ – Treatment Control	.273*
B-IPQ – Identity	-.011
B-IPQ – Comprehension	.294*
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.620****
ICD-concerns Questionnaire – total	.680**
FPAS – Positive Appraisals	-.350**
FPAS – Body Image Concerns	-.261*
Emotions	
Anxiety (HADS)	.618**
Depression (HADS)	**.504****
Depression TOTAL (POMS-SF)	.444**
Depression subscale (POMS-SF)	.475**
Tension (POMS-SF)	.500**
Anger (POMS-SF)	.402**
Confusion (POMS-SF)	.409**
Vigour (POMS-SF)	-.192
Fatigue (POMS-SF)	.330**
Negative Affect (DS14)	.429**
B-IPQ – Emotional Response	**.488****
B-IPQ – Concern	**.502****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. IES= Impact of Events Scale. **In Bold: predictor variables entered into the regression**

Two demographic variables, age and gender significantly correlated with IES-avoidant coping. There was a significant positive correlation between age and IES-avoidant coping. This suggested that the older the patient, the more likely they were to use this type of coping. The clinical variable 'heart failure' was also significantly correlated and therefore was entered into Block 2 of the regression. The Pearson's *r* correlations of the demographic and clinical variables are displayed in 9.48.

Table 9.48: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with IES-AVOIDANT coping at 3-months

Demographic & Clinical Predictor Variables at Baseline	Avoidant Coping (IES) 3-months
Demographic Characteristics	
Age	**.324****
Type-D	.144
Gender	**.283***
Clinical Characteristics	
Heart failure	**-.258***
Cardiomyopathy	.156
Angina	.012
Myocardial Infarction	-.225

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). IES = Impact of Events Scale. **In Bold: predictor variables entered into the regression

Table 9.49 displays the results of the hierarchical regression analysis for IES-coping at 3-months. The variance of the model of IES-avoidant coping using the psychological predictors from the Lazarus and Smith model was 46.5%, F=12.813, p<.01. An additional 8.9% (F= 3.223, p<.05) was explained by age, gender and heart failure. The total variance explained by this regression after adjustment = 51.26%[95].

These findings supported this part of hypothesis$_5$. Positive beliefs (appraisals) and emotional response (emotion) about the cardiac illness significantly explained a percentage of variance in IES-avoidant coping at 3-months. Having HF (NYHA 1 to 3) was a risk factor for cognitive avoidance at 3-months.

Table 9.49: Hierarchical regression analysis: IES-AVOIDANT coping at 3-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Avoidant coping at 3-months (IES)	
Predictors	ΔR^2	β
Block 1	**.465****	
B-IPQ - Consequences		-.325*
B-IPQ - Concerns		.254
B-IPQ - Emotional response		.311*
Positive ICD Beliefs questionnaire		-535**
HADS – depression		-.045
Block 2	**.089**	
Age of Patient		.-.090
Gender		.181
Heart failure		-.292*
Total variance after adjustment = 51.26%		
N = 60		

*p<.05. ** p<.01. IES=Impact of Events Scale. B-IPQ = Brief Illness Perception Questionnaire. POMS = Profile of Moods Questionnaire (short form). ICD-C = ICD Concerns Questionnaire. HADS = Hospital Anxiety and Depression Scale. DS14 = Type D personality questionnaire.

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[95] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

AVOIDANT coping at 6-months: Behavioural type avoidance measured using the Medical Coping Modes Questionnaire

Bivariate correlations were carried out to explore the associations of MCM-avoidant coping (measured at 6-months) with appraisals and emotions (measured at 6-months). The Pearson's *r* correlations are displayed in Table 9.50.

There were no demographic or clinical variables that significantly correlated with MCM-avoidant coping (see Table 9.51). Accordingly, a hierarchical regression could not be carried out, as there were no predictor variables for Block 2.

Table 9.50: Pearson's correlations showing concurrent associations between appraisals and emotions at 6-months with MCM-AVOIDANT coping at 6-months

Appraisal and Emotion Predictor Variables at 6-months	Avoidant Coping (MCM) 6-months
Cardiac illness-related Appraisals	
B-IPQ – Consequences	**.275***
B-IPQ – Timeline	.045
B-IPQ – Personal Control	.020
B-IPQ – Treatment Control	**.282***
B-IPQ – Identity	.366**
B-IPQ – Comprehension	**.266***
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**.314***
ICD-concerns Questionnaire – total	.234
FPAS – Positive Appraisals	-.045
FPAS – Body Image Concerns	-.202
Emotions	
Anxiety (HADS)	**.452****
Depression (HADS)	.322*
Depression TOTAL (POMS-SF)	.286*
Depression subscale (POMS-SF)	.354**
Tension (POMS-SF)	.353*
Anger (POMS-SF)	.201
Confusion (POMS-SF)	.200
Vigour (POMS-SF)	-.144
Fatigue (POMS-SF)	.112
Negative Affect (DS14)	.339**
B-IPQ – Emotional Response	.446**
B-IPQ – Concern	**.356****

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. MCM = Modes of Coping Measure. **In Bold: predictor variables entered into the regression**

Table 9.51: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with MCM-AVOIDANT coping at 6-months

Demographic & Clinical Predictor Variables at Baseline	Avoidant Coping (MCM) 6-months
Demographic Characteristics	
Age	-.182
Type-D	-.097
Gender	.215
Clinical Characteristics	
Heart failure	-.007
Cardiomyopathy	.074
Angina	.182
Myocardial Infarction	-.041

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). **In Bold: predictor variables entered into the regression

A multiple regression analysis was carried out (see Table 9.52). The regression analysis suggested that appraisals and depression together explained 21.4% of the variance of the model of avoidant coping (p<.05). However, no individual predictor variable was significant.

Table 9.52: Multiple regression analysis: MCM-AVOIDANT coping at 6-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Avoidant coping at 6-months (MCM)	
Predictors	ΔR^2	β
	.123*	
Positive ICD Beliefs Questionnaire		-.075
B-IPQ - Consequences		.038
B-IPQ - Treatment control		.122
B-IPQ - Concerns		.228
B-IPQ - Comprehension		.189
HADS anxiety		.044

N = 60

*p<.05. ** p<.01. MCM = Medical Coping Modes Questionnaire. B-IPQ = Brief Illness Perception Questionnaire. HADS = Hospital Anxiety and Depression Scale.

AVOIDANT coping at 6-months: Cognitive type avoidance measured using the Impact of Events Scale

Bivariate correlations were carried out to explore the associations of IES-avoidant coping (measured at 6-months) with appraisals and emotions (measured at 6-months). The Pearson's *r* correlations are displayed in Table 9.53. The B-IPQ emotional response item had a correlation of .763 (P<.01) with HADS-anxiety. This was considered so highly correlated that they would achieve co-linearity so it was omitted. The B-IPQ identity item was also omitted as it was considered to represent physical symptoms (number of arrhythmias) rather than an appraisal.

Correlations revealed that the Positive ICD Beliefs questionnaire and the ICD-Concerns Questionnaire were highly correlated (-.718). They were considered to achieve co-linearity. A decision to use the Positive ICD Beliefs questionnaire was made because it was based on the ICD-Concerns Questionnaire but created to target *beliefs* rather than *worries* or *concerns.*

Table 9.53: Pearson's correlations showing concurrent associations between appraisals and emotions at 6-months with IES-AVOIDANT coping at 6-months

Appraisal and Emotion Predictor Variables at 6-months	Avoidant Coping (IES) 6-months
Cardiac illness-related Appraisals	
B-IPQ item 1 – consequences	**.397****
B-IPQ item 2 – Timeline	.127
B-IPQ item 3 – Personal Control	-.070
B-IPQ item 4 – Treatment Control	**.382****
B-IPQ item 5 – Identity	.395**
B-IPQ item 7 – Comprehension	.217
ICD-related Appraisals	
Positive ICD Beliefs questionnaire – total	**-.665****
ICD-concerns Questionnaire – total	.616**
FPAS – Positive Appraisals	-.003
FPAS – Body Image Concerns	**-.375****
Emotions	
Anxiety (HADS)	**.635****
Depression (HADS)	.551**
Depression TOTAL (POMS-SF)	.522**
Depression subscale (POMS-SF)	.605**
Tension (POMS-SF)	.446**
Anger (POMS-SF)	**.379****
Confusion (POMS-SF)	**.514****
Vigour (POMS-SF)	-.286*
Fatigue (POMS-SF)	.309*
Negative Affect (DS14)	.614**
B-IPQ item 8 – Emotional Response	.681**
B-IPQ item 6 – Concern	.322**

** Correlation is significant at the .01 level (2-tailed). * Correlation is significant at the .05 level (2-tailed). B-IPQ = Brief Illness Perception Questionnaire. FPAS = Florida Patient Acceptance Survey. HADS = Hospital Anxiety and Depression Scale. POMS-SF = Profile of Moods- short form. IES = Impact of Events Scale. **In Bold: predictor variables entered into the regression**

The age of the patient was significantly negatively related to avoidant coping. This suggested that the younger patients were associated with avoidant behaviour (see Table 9.54).

Table 9.54: Pearson's correlations showing longitudinal associations between age, heart failure, cardiomyopathy, angina and myocardial infarction with AVOIDANT coping at 6-months

Demographic & Clinical Predictor Variables at Baseline	Avoidant Coping (IES) 6-months
Demographic Characteristics	
Age	**-.402****
Type-D	.142
Gender	.183
Clinical Characteristics	
Heart failure	-.065
Cardiomyopathy	-.068
Angina	.086
Myocardial Infarction	-.090

. Correlation is significant at the .01 level (2-tailed). *. Correlation is significant at the .05 level (2-tailed). MCM = Medical Coping Modes. **In Bold: predictor variables entered into the regression

Table 9.55 displays the results of the hierarchical regression analysis for finding the predictors of avoidant coping that was predominantly cognitive in nature. The B-IPQ items that measured consequences and treatment control, the Positive ICD Beliefs questionnaire, the body image concerns subscale of the FPAS, HADS anxiety, and POMS-SF anger and confusion subscales were entered into Block 1. The demographic variable age was entered into Block 2.

The variance explained by the psychological predictors was 49%, F= 9.094, p<.01. An additional .2% was explained by the age of the patient (F=.893, p>.05). The total variance explained after adjustment = 49.1%[96].

The findings partially supported this part of hypothesis $_5$ as positive beliefs about the ICD (an appraisal) explained a significant percentage of variance in IES-avoidant coping at 6-months. The age of the patient was not found to be a significant risk factor.

Table 9.55: Hierarchical regression analysis: IES-AVOIDANT coping at 6-months with appraisals, emotions and demographic characteristics as predictor variables

	Predictors of Avoidant coping at 6-months (IES)	
Predictors	ΔR^2	β
Block 1	**.490****	
POM-SF (anger)		-.129
POM-SF (confusion)		.263
FPAS (Body image concerns)		-.072
B-IPQ item 1 (consequences)		-.046
B-IPQ item 4 (treatment control)		-.098
Positive ICD Beliefs questionnaire		-.468**
HADS – anxiety		.263
Block 2	**-.002**	
Age		-.123

Total variance after adjustment = 49.1%

N = 60

*p<.05. ** p<.01. IES=Impact of Events Scale. B-IPQ = Brief Illness Perception Questionnaire. POM-SF = Profile of Moods Questionnaire (short form). HADS = Hospital Anxiety and Depression Scale. FPAS = Florida Patient Acceptance Survey

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[96] NOTE: The R^2 (total variance of Blocks 1 and 2) required proportional adjustment in order to calculate the total variance explained by the full model.

Summary of Key Findings for Aim 2

Anxiety at 3-months

1. There was a significant (negative) association between age and levels of anxiety. Younger patients experienced higher levels of anxiety.
2. There was a significant (positive) association between having a cardiomyopathy and anxiety.
3. The variation in negative beliefs about the consequences of the cardiac illness, positive beliefs in the ICD and illness comprehension, explained significant percentages of variance in anxiety.
4. The demographic and clinical variables cardiomyopathy and age also explained significant percentages of variance in anxiety.

Anxiety at 6-months

1. There was a significant (negative) association between age and levels of anxiety. Younger patients experienced higher levels of anxiety.
2. The variation in beliefs about the consequences of the cardiac illness and positive beliefs about the ICD explained significant percentages of variance in anxiety.

Depression at 3-months

1. There was a significant (positive) association between angina and depression.
2. The variation in negative beliefs about the consequences of the cardiac illness and positive ICD-beliefs explained a significant percentage of variance in depression scores.
3. The clinical variable Angina explained a significant percentage of variance in depression.

Depression at 6-months

1. There was a significant (positive) association between heart failure and levels of depression.

2. There was a significant (positive) association between having had a myocardial infarction and levels of depression.
3. There was a significant (negative) association between age and depression. Younger patients experienced higher levels of depression.
4. The variation in beliefs about the consequences of the illness and positive ICD-beliefs explained significant percentages of variance in depression.
5. The clinical variable heart failure also explained a significant percentage of variance in depression.

Confrontational Coping at 3-months and 6-months

1. There was a significant (negative) association between age and confrontational-type coping at 3- and 6-months. Younger patients were more likely to use this type of coping.

Acceptant-Resignation Coping at 3-months

1. There was a significant (negative) association between age and acceptance-resignation type coping. Younger patients were more likely to use this type of coping.
2. The variation in beliefs about the consequences to the illness and positive ICD-beliefs explained a significant percentage of variance in acceptant-resignation type coping.

Acceptance-Resignation Coping at 6-months

1. There was a significant (negative) association between age and acceptance-resignation type coping. Younger patients were more likely to use this type of coping.
2. The variation in beliefs about the consequences of the cardiac illness explained a significant percentage of variance in acceptance-resignation type coping.

Behavioural-type Avoidant Coping at 3-months

1. Gender was significantly associated with behavioural type-avoidant coping at 3-months. Female participants were more associated with behavioural-type avoidant behaviour compared to males.
2. The demographic variable 'gender' explained a significant percentage of variance in behavioural-type avoidance.

Cognitive-type Avoidant Coping at 3-months

1. There was a significant (negative) association between age and cognitive-type avoidant coping. Younger patients were more likely to use type of coping.
2. Gender was significantly associated with cognitive-type avoidant coping at 3-months. Female participants were more associated with cognitive-type avoidant coping compared to males.
3. There was a significant (negative) association between heart failure and cognitive-avoidant coping.
4. The variation in positive ICD-beliefs and participants' emotional response to their illness explained a significant percentage of the variance in cognitive-type avoidant coping.
5. The clinical variable heart failure explained a significant percentage of variance in cognitive-type avoidant coping.

Cognitive-type Avoidant Coping at 6-months

1. There was a significant (negative) association between age and cognitive-type avoidant coping at 6-months. Younger patients were more likely to engage in this type of coping.
2. The variation in positive ICD-beliefs explained a significant percentage of variance in cognitive-avoidant coping.

DISCUSSION – Aim 2

Aim 2.1 was to find out whether the theoretical variables from the theoretical framework of Lazarus and Folkman (1984) were able to explain a significant percentage of variance in the key emotional outcomes, and the key coping outcomes. **Aim 2.2** was to determine the demographic and clinical risk factors for these key outcomes.

Predictors[97] of Emotion

The nature of the data in this study was cross-sectional. As such, ***any causality assumed is based on theory*** rather than that derived from data. Appraisals, which included patients' beliefs about their cardiac illness and ICD-related beliefs, were found to explain significant percentages of variance in anxiety and depression at 3- and 6-months. This finding fitted Lazarus' framework (Lazarus & Folkman, 1984; Smith & Lazarus, 1991), which suggested that appraisals predicted emotions. The percentages of variance in anxiety and depression explained by ICD-beliefs and patient's cardiac illness-appraisals remained stable from 3- and 6-months (approximately 50% for depression and 48% for anxiety). However, although the total variances remained stable over time, there appeared to be some 'shifting' between the strength of beta values of specific appraisals. This might have been due to the different number of variables used in each regression, or this might suggest that some beliefs changed over time.

The appraisal variables that explained significant percentages of variance in anxiety at 3-months were beliefs that related to (i) participant's cardiac illness and (ii) ICD-related beliefs. The illness-related beliefs were measured by items in the Brief-Illness Perception Questionnaire (B-IPQ). These B-IPQ items measured participant's level of comprehension (B-IPQ Comprehension) and the belief concerning the impact of the illness (B-IPQ item Consequences). The ICD-related belief was measured by the total Positive ICD Beliefs Questionnaire. By 6-months, only the B-IPQ Consequences item and the Positive ICD Questionnaire explained significant

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[97] In this study, 'predictor' does not infer causality but is a description of a variable that explains some variance.

percentages of variance in anxiety. However, the strength of the beta value for having positive beliefs in the ICD appeared to have increased, which suggests that positive beliefs over time might have become more influential in determining anxiety.

The appraisal variables that explained significant percentages of variance in depression were similar to those which explained anxiety. The B-IPQ item that measured participant's belief about the impact of the illness and positive ICD-related beliefs (measured by the Positive ICD Beliefs Questionnaire) were found to be significant predictors. Therefore, the finding that the hierarchical regressions found that the variation in the level of positive ICD-beliefs explained a significant percentage of variance in anxiety at 3- and 6-months and in depression at 3-months suggests that having greater positive beliefs might be a protective factor against anxiety and depression.

The association between increased knowledge of an illness and higher levels of depression and anxiety might have possible implications for when patients are educated about their illness. There are several possible explanations for this finding. It might be that a participant with a low level of anxiety felt less need to find out about their illness. Therefore, those patients who did seek information about their illness might have been those who had higher levels of depression or anxiety. Another explanation for why a better understanding of illness was correlated with negative emotions is that diseases are usually explained in negative terms. For example, the BHF booklet, Implantable Cardioverter Defibrillators (2010) suggested that ventricular arrhythmias are sometimes fatal and are caused by heart disease (see pages 8-9). This could be interpreted as 'heart disease leads to fatal arrhythmias'. Therefore, the more a patient reads about their illness, the more 'negative' knowledge they have about their cardiac disease. This build up of 'negative' knowledge might have resulted in increased negative emotion.

A patient's low mood might also have been influenced by the way the participant received their diagnosis. For instance, if the doctor had explained their diagnosis and cardiac illness in a way that offered hope, the patient might have had more positive expectations and more positive beliefs, which led to a more positive mood. However, if the illness had been explained in a negative way that resulted in negative expectations and negative beliefs about the illness, then these negative expectations and beliefs might have resulted in a low mood.

In other words, how patients received their diagnosis or were informed about their cardiac condition might have influenced whether patients were more positive or more negative about their illness and about the ICD. The qualitative phase of this study found two participants (an unrelated patient and partner) who keenly remembered how upset they had been at way the doctor gave them the diagnosis and the choice of words used. For instance, N17 remarked on the doctor's coldness (see Appendix V, N17: 478-492). In addition N04.1 clearly remembered the doctor's bluntness when he explained the diagnosis: *"he didn't pull any punches at all you know ... short of him saying 'he's going to die' like... you know that's the only thing he didn't quite say and it was like 'well, it's very bad ... it's chronic .. his heart is into .. 'failure' you know. As I said, he didn't pull any punches and ... frightened us to death like"* (see Appendix Vi, N04.1: 24-28). This study did not collect data on how patients were first told about their illness; however, the relationship between a patient's psychological wellbeing and how a diagnosis is given could be explored in a future study. The finding that increased knowledge was associated with negative mood was comparable to a finding by Marke and Bennett (2012). They found that levels of anxiety in patients with acute coronary syndrome were associated with increased understanding about their cardiac illness.

The finding that ICD-related beliefs cardiac illness-related appraisals explained significant percentages of variance in anxiety and depression thereby supported the theoretical framework of Lazarus and Folkman (1984). The framework suggested that appraisals influenced emotions. Lazarus' theoretical framework further suggested that appraisals, emotions and coping are bi-directional. As such, appraisals and emotions do not cease to be influential after coping strategies are used. Rather, well-being after coping is re-appraised, and this appraisal re-informs emotion and coping. Folkman and Lazarus (1988) suggested coping was a mediator of emotion. Therefore it might have been the way in which patients *coped* with the ICD and illness that explained the changes in beta values found in the regressions. The 'shifting' amounts of variance explained over time by predictors might be because of the cyclical nature of re-appraising.

According to Lazarus, the individual primary and secondary appraisal components are combined into gestalts of relational meaning called ‘core relational themes’ (Smith & Lazarus, 1993). However, this study merely defined appraisals as beliefs about the ICD or the cardiac illness and did not differentiate between primary appraisals and core relational themes. Accordingly, this study’s findings can only be compared with the total variances of primary and core relational themes found in other studies. The current study found that a similar amount of variance in anxiety was explained by appraisals as was found in the study by Bennett, Lowe and Honey (2003), which examined anxiety in relation to a previous real life stressful event. Bennett et al.’s (2003) study and the current study both found appraisals explained about 48% of the variance in anxiety.

The study by Smith, Haynes, Lazarus, & Pope (1993) found less variance in anxiety was explained by appraisals than in the current study. Smith et al. (1993) found primary appraisal components on their own (motivational relevance, motivational congruence, accountability and problem/emotion focussed coping potential) only accounted for 14% of the variance in anxiety. The core relational theme of danger or threat on its own explained 39% of the variance in anxiety. Primary and core relational themes together explained 40%, which was less than in the current study. Their finding also suggested that the core relational theme of anxiety, which is said to be ‘threat’ or ‘danger’, appeared to be more important in explaining anxiety (in terms of variance explained) than primary appraisals. The ‘threat’ and ‘danger’ core relational themes for the current study’s participants related to a potential life-threatening situation, and this might account for why this study found a larger significant percentage of variance was explained by appraisals.

The study by Hulbert-Williams, Morrison, Wilkinson, and Neal (2013) also found appraisals explained a smaller percent of variance in anxiety than in the current study. Hulbert-Williams et al. (2013) used cancer patients who had recently been diagnosed. Therefore, their study used a similar cohort to the cohort in the current study as both studies used participants who had a physical illness. However, more importantly, the predictors of emotion found in Hulbert-Willams et al.’s (2013) study were comparable to the predictors found in this study.

The study by Smith et al. (1993) found appraisals explained a larger significant percentage of variance in sadness (akin to depression) than in the current study, the studies by Bennett et al. (2003) or Hulbert-Williams et al. (2013). Smith et al. (1993) found a combination of primary and core relational themes accounted for 59% of variance in depression. The current study had found approximately 50%, whereas Hulbert-Williams et al. (2013) found only 36.5% and Bennett et al. (2003) only 19%. However, from the findings of Smith et al. (1993), which suggested that the core-relational theme accounted for a larger percentage of variance in anxiety than did primary appraisals, it appears that the percentages of variance will always differ depending on how much the measures used allude to danger or threat.

Predictors[98] of Coping

According to Lazarus' framework, appraisals and emotions should explain significant percentages of variance in the key coping outcomes. As the theoretical variables appeared to explain significant percentages of variance in the key emotional outcomes, this offered support for Lazarus' theoretical framework. Appraisals (beliefs about the ICD) and emotions (B-IPQ – emotional response) explained a significant percentage of variance in *cognitive avoidant* coping at 3-months, which again offered some support for Lazarus' framework. However, in other types of coping, Lazarus' theoretical framework was only partially supported.

In acceptant-resignation coping, the theoretical variables only partially supported their framework in that appraisals explained a significant percentage of variance in this type of coping. However, emotion was not a significant predictor. Acceptant-resignation coping can be seen as a type of emotion-focussed coping. Lazarus and Folkman (1984) suggested that emotion-focussed coping is used when an appraisal is made that suggests nothing can modify the harmful or threatening stressor. As such the variable relating to personal control (B-IPQ – Personal Control) was expected to be a predictor. However, only beliefs about the consequences of participant's cardiac illness and positively held ICD-beliefs were found to be predictors of this type of coping. Emotions were not significant predictors of acceptance-resignation coping

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[98] In this study. 'predictor' does not infer causality but is a description of a variable that explains some variance.

at 3-months. However, by 6-months, positive ICD-beliefs was no longer a significant predictor and only the belief about the consequences of participant's cardiac illness explained a significant percentage of variance in acceptant-resignation coping.

Confrontation-type coping can be seen as a problem-focussed coping strategy. Lazarus and Folkman (1984) suggested that this type of coping is more likely to be used when an individual believes a situation is amenable to change. Problem-focussed coping can be directed at the environment or directed inwards such as changing cognitive appraisals by gathering information. It would be expected that the variable measuring the appraisal relating to the ICD's ability to control the cardiac illness (B-IPQ Treatment Control) might have been a significant predictor for confrontation-type coping. The variable relating to comprehension (B-IPQ Comprehension) would also have been expected to have been a significant predictor for confrontational coping. However, there were no appraisal- or emotion variables which were found to be significant predictors for confrontational-type coping at 3- or 6-months. This finding did not support Lazarus' framework.

The lack of support for Lazarus' framework to explain confrontation-type coping might have been due to the types of emotions that were measured in this study. For instance, the key emotional outcomes in this study were negative (anxiety and depression), but had this study measured positive emotional constructs such as optimism or hope, emotions might have been able to explain a significant percentage of variance in confrontational-type coping. In support of this notion, Moskowitz, Folkman, Collette and Vittinghoff (1996) found problem focussed coping (which in this study was defined as confrontational type coping) was found to *increase positive* emotion rather than *decrease negative* emotion.

Moskowitz et al.'s (1996) finding that confrontation was found to increase positive emotion rather than decrease negative emotion might have transpired because confrontational-type coping involves a coping potential that is challenge-like. Therefore confrontational-type coping might be associated with feelings of hope rather than a damage-limitation coping potential characterised by feelings of despair. Lazarus (1999) suggested that hope is a vital coping resource against despair. Lazarus (1999) explained hope requires the belief in the possibility of a favourable outcome when the present circumstance is unsatisfactory. Therefore, in order to engage in confrontational-type coping, this suggests that hope and a sense of challenge might also be involved.

The Pearson correlations revealed that having greater positive beliefs in the ICD was associated with lower levels of anxiety and depression, cognitive-avoidant coping and acceptant-resignation coping at 3- and 6-months. Having greater positive beliefs in the ICD also appeared to be a significant predictor of cognitive-avoidant coping at 3- and 6-months and acceptant-resignation coping at 3-months. According to Lazarus' theoretical framework, it would be a *reduction in negative emotion* that would result in a *reduction in cognitive avoidance and acceptant-resignation coping.* However, the bi-directionality between the variables within Lazarus' framework means that although low mood can lead to avoidant behaviours, so too can avoidant behaviours lead to low mood.

Aim 2.2[99]

Aim 2.2 aimed to find out if any of the demographic and clinical variables measured in this study, might be risk factors for the key emotional and coping outcomes examined in this study. Hierarchical regressions were conducted so that potential risk factors could be identified from Block 2. Potential risk factors would appear as significant predictors by explaining a significant percentage of the variance that was left after the psychological theoretical variables had been entered into Block 1. However, psychological variables had been prioritised and therefore the demographic and clinical variables predicted outcomes after variance attributable to psychological variables had been explained. As such, there might have been an underestimation of the predictive power of individual demographic and clinical variables. The regressions revealed that some demographic and clinical variables appeared to risk factors at 3-months or at 6-months, but never at both times. For instance, at 3-months, angina was a risk factor for high levels of depression but ceased to be a risk factor at 6-months. At 6-months, the risk factor for high levels of depression was living with heart failure.

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[99] In this study, 'predictor' does not infer causality but is a description of a variable that explains some variance.

The finding that heart failure was a significant clinical predictor of depression was consistent with other research, (e.g., Suzuki, Shiga, Kuwahara, & Kobayashi , 2010; Pedersen, Hoogwegt, Jordaens & Theuns, 2011). This finding also resonated with the experience of a heart failure patient, who was a participant in the qualitative phase of this study. The patient had explained that after his diagnosis, his desired plans for an active lifestyle after retirement became uncertain. He explained that over time, the reality of facing an inactive-empty future was becoming more and more concrete, which had left him feeling despondent. (See Appendix V, S15:384-396).

This study found being 'younger' was a significant risk factor for higher levels of anxiety at 3- and 6-months. This finding might be because cardiac problems tend to be associated with older people and accordingly their cardiac illness was not an age appropriate illness (Sears, Matchett, & Conti, 2009). The finding that younger patients were associated with higher levels of anxiety might also have been because younger participants might still have had dependent children and competing demands such as jobs and financial worries. For instance, the qualitative phase of this study found that some participants who were still working worried about the impact the ICD was having on their finances and their jobs. (For example, see Appendix V, N10: 220-211).

The finding that being younger was a risk factor for raised levels of anxiety was consistent with findings from Vazquez, Kuhl, Bishop Shea, Kirkness et al. (2008). Vazquez et al. (2008) who only used female participants found younger women (≤50 years) were at greater risk of developing psychosocial distress. However, the finding that younger people were more at risk of increased anxiety was inconsistent with the findings from Hamilton and Carroll (2004). Hamilton and Carroll (2004) found older recipients (≥67 years) had higher rates of anxiety compared to their younger counterparts (≤62). Accordingly, it might be that a cardiac illness might be more intrusive at certain developmental points in the lifespan. For instance, in the above example, being retired might influence levels of psychological distress. For example, as mentioned above, the ICD heart failure patient in the qualitative phase of this study, had described how his plans to be active in his retirement had become unrealistic and he now faced a future of being inactive and passive. (See also Chapter 3, Risk Factors: Age and Gender).

This study found that gender was a significant predictor for behavioural avoidance at 3-months. In this study, females appeared more likely to have engaged in behavioural avoidance compared to their male counterparts. However, this finding might have been influenced by the measure used. The questions measuring avoidance in Medical Coping Modes Questionnaire tended to focus around conversations with others. As male patients appeared to have a stoical manner about them when filling out the measures this might suggest that male patients did not engage in avoidance but rather engaged in the concealment of feelings (see Limitations to the Pilot RCT, limitation item 11). The qualitative phase had explored all types of avoidant behaviours rather than those that only related to talking to others. Evidence from the qualitative phase found that both males and females engaged in avoidant behaviours; however interestingly, mainly female patients explained that they avoided visiting places and going on holiday because of the fear of being too far away from the emergency services when in need. (See Appendix V, N08: 117-132 and N17:381-389).

Unlike Bilge, Ozben, Demircan, Cinar et al. (2006), this study did not find that gender was a risk factor for increased anxiety or depression. The findings in the current study with regard to Type-D personality were also inconsistent with other studies. This study found that having a Type-D personality was not a signficant predictor for any particular type of coping. However, Pedersen, Middel and Larsen (2002) had posited that Type-D personalities experienced increased distress because of the way they coped and not because they were *distressed* people. This would suggest that Type-D would have been a significant predictor of acceptant-resignation coping and avoidant coping. However, having a Type-D personality was not found to explain any significant percentage of variance in acceptant-resignation coping or avoidant-type coping at 3- or 6-months.

In conclusion, this study found some evidence for the link between appraisals and emotion. This evidence supports Lazarus' theoretical framework and is consistent with other research, which showed that appraisals were important constitutes of emotion (e.g. Bennett, Lowe & Honey, 2003; Smith and Lazarus, 1993). This study also found evidence for the link between appraisals and coping. However, evidence to support the notion that appraisals and emotions could explain significant percentages of variance in types of coping was not found in this study.

SECTION 2

GENERAL DISCUSSION (Aims 1 and 2)

In Aim 1, the efficacy of the study intervention was tested using a pilot randomised control trial. Results from the ANCOVA analyses suggested that in comparison to the control group at 6-months, the intervention group reported scores that indicated they had a higher level of positive beliefs about their illness[100] at 3-months and a higher level of positive ICD-related beliefs at 6-months. At 6-months the intervention also reported lower levels of depression[101], less device-related distress[102] and a greater acceptance to their ICD[103]. Furthermore, analysis of covariance for corresponding baseline scores (adjusted mean ANCOVA scores) suggested that in comparison to the control group, the intervention group at 6-months were engaging in more mild exercise from baseline measures (see Appendix XXII, table 12).

In this general discussion, using Lazarus' theoretical framework, an attempt is made to use the findings from Aim 2.1 to explain the findings from Aim 1. However, due to the cross-sectional design of this study, ***any causality that is assumed is based on theory*** rather than derived from the data. In this study, appraisals (ICD and cardiac illness beliefs) were found to be significant predictors[104] of anxiety and depression. However, in view of the cyclical nature of Lazarus' theoretical framework, it might well be that mood influenced coping, which in turn influenced beliefs and mood. Nonetheless, the findings reported in Aims 1 and 2.1 do appear to offer some support for Lazarus' theoretical framework.

Aim 2.1 found that appraisals, (positive ICD-related beliefs in the ICD and beliefs about the consequences of participant's cardiac illness) explained significant percentages of variance in anxiety and depression at 3- and 6-months (see Table 9.21, Table 9.24, Table 9.27 and Table 9.30). Mean scores also suggested that the intervention group had a higher level of positive ICD-related beliefs and a higher level of positive beliefs about the consequences of their illness. It should follow therefore, that if the intervention group had higher levels of positive ICD and illness

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[100] B-IPQ – consequences

[101] POMS-SF – depression subscale; DS14- NA subscale

[102] FPAS – device-related distress subscale

[103] FPAS – total acceptance score

[104] In this study, 'predictor' does not infer causality but is a description of a variable that explains some variance.

beliefs, and the variation in levels of these positive beliefs were significant predictors of anxiety and depression, the intervention group should report lower levels of anxiety and depression compared to the control group.

In spite of this, the mean scores showed no meaningful[105] difference in mean scores between groups in levels of anxiety at 3-months or at 6-months. However, means depression scores at 6-months did show that there was a meaningful difference between the scores in both groups with the intervention group reporting scores that indicated they had a lower level of depression. The score on the POMS depression-subscale had a between-groups effect size that was meaningful at 6-months (i.e. there was an effect size that was more than small size) in favour of the intervention group.

The finding that the intervention group tended to have mean scores that demonstrated they had a higher level of positive ICD and illness beliefs, and a lower level of depression compared to the control group, suggests that the intervention group found that the brief psychological intervention booklet was helpful. It is probable that the intervention booklet helped participants to have positive beliefs about their ICD and helped them be less concerned about their cardiac illness (although this concern had not been specifically targeted - see Chapter 8 for details of the intervention), which resulted in their lower levels of depression compared to the control group.

The regressions found that the variation in positive ICD-beliefs was a significant predictor of cognitive-type avoidant coping at 3-months and 6-months (see Table 9.49 and Table 9.55). Since, it has been established that the intervention group reported scores, which indicated they had a higher level of positive ICD-beliefs (see Table 9.7) it should also follow that there would be a meaningful difference between groups for the mean scores in cognitive-avoidant coping. However, no meaningful difference was detected (see Table 9.15).

The demographic and clinical data at baseline suggested that there was little difference between groups in terms of marital status. The intervention group had 10 participants who did not have the support from an intimate partner compared to 11 participants in the control group. It must be noted that the experience of shocks were

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[105] A small-medium or larger effect size (Cohen, 1992)

not accounted for in the ANCOVA or hierarchical regressions. The incidence of shocks was found to be higher in the control group (four participants compared to one participant) and this disproportion might have had an influence on the results. This finding might also have been indicative of the effect of the intervention.

The discovery that this study's cohort reported a low number of shocks might be seen by some to be a weakness and not representative of a typical ICD population. However, in contrary, a low number of shocks actually appear to be more representative of a typical ICD patient population these days (John & Stevenson, 2012; Irvine, Fireston, Ong, Cribbie et al., 2011). For instance, the small number of shocks reported in this study is representative of a primary prevention cohort of ICD patients, who generally report fewer shocks than those by secondary prevention patients (John & Stevenson, 2012). As the indications for primary prevention are widening and more and more ICDs are being implanted in primary prevention patients (Irvine, et al., 2011), the low number of shocks reported was not a drawback.

In conclusion, the intervention group tended to report scores that demonstrated that they had improved more after their ICD implant compared to the control group. The analyses in Aim 2.1 found that positive ICD beliefs significantly explained some of the variance in anxiety, depression and avoidant coping, which offered some support for Lazarus' theoretical model of stress and coping. As the ANCOVAs in Aim 1 suggested that the intervention group reported having greater positive beliefs about the ICD, the efficacy of the intervention might have been because the booklet helped participants to think about the ICD in a more positive way.

CRITIQUE OF METHOD AND LAZARUS' FRAMEWORK

The findings from this pilot RCT offered some support for Lazarus' broad theoretical approach. To recap, Lazarus and colleagues (Smith et al., 1993; Smith and Lazarus, 1993) suggested that two types of appraisal (primary and secondary) elicit emotions. Furthermore, that all negative emotions (e.g. anxiety and depression) are characterised by a primary appraisal of high motivational relevance and low motivational congruence. They suggested that secondary appraisals include a combination of beliefs about: blame/credit attribution, whether the stressor is avoidable, coping potential and perceived future expectations. The core relational theme captures the essences of the emotion. Anxiety would be characterised by uncertainty about a perceived threat, which for ICD patients would most likely be the cardiac illness or the ICD. On the other hand, depression would be characterised by low problem-focussed coping as well as having negative future expectations.

The primary appraisal relating to whether participants in the study would appraise the ICD as important to their well-being was assumed to be met. It was taken for granted that participants would have a high degree of motivational relevance regarding their ICD. However, this study did not measure motivational congruence. For instance, patients might primarily appraise the ICD as being highly motivational congruent (positive) because the patient believed the device was their best treatment option, but it might not have been what the patient desired (negative).

This study generally measured secondary appraisal components. The measures of appraisals that were most frequently entered into the regression analyses were the scores from the Positive ICD-Beliefs Questionnaire, which measured ICD-related beliefs and the Brief Illness Perception Questionnaire, which measured illness-related beliefs. The Positive Beliefs Questionnaire included items that measured perceived future expectations, e.g. “The ICD will give me a new lease of life”. It also included questions that measured problem-focussed and emotion-focussed coping potential, e.g., “I am confident I will cope with any limitations that living with an ICD may bring”. However, the individual secondary appraisal components were usually added together to form a total score. This meant that individual secondary appraisal components of the theory could not be corroborated.

The types of analyses carried out in this study can also be criticised. The analyses conducted did not examine that directionality between appraisal, emotional response and ways of coping. Smith and Lazarus’ (1993) appraisal theory of emotion and coping suggested that the relationship between the two variables were cyclical. Although they posited that initially coping was influenced by emotion, this was not examined in this study.

Lazarus’ broad theoretical approach was partially supported as appraisals were found to predict emotions. The findings from the regressions found that about half of the variance in emotion was explained by appraisals. However, the variance in explaining the different types of coping was not supportive of Lazarus' theoretical approach. To have offered full support for this approach, the study would have had to have found that both appraisals and emotions explained a significant percentage of variance in coping. However, this study found that appraisals only explained a significant percentage of variance in acceptant-resignation coping at 6-months and cognitive-avoidant coping at 3- and 6- months. There were many limitations found in this pilot RCT, which are discussed in more detail in Limitations to the Pilot RCT below (see page 412).

FEEDBACK ON THE INTERVENTION BOOKLET

At 3-months, when sending participants in the intervention group their 3-month Psychological Measure Questionnaire, a Process Measures Questionnaire was also sent (see Appendix XVII). The main aim of the Process Measures Questionnaire was to find out if participants had read the intervention booklet. The other aim was to find what participants thought about the intervention, and its accompanying booklets (healthy eating and stopping smoking).

Although all the participants in the intervention group sent back the Process Measures Questionnaire, many had not provided detailed feedback. This might have been because participants did not have the energy or the inclination to fill in another questionnaire (especially as it had become apparent that the questionnaire consisted of too many measures – see Limitations of the Pilot RCT below).

The majority of participants had not listened to the "Getting on with life: learning to relax CD" or had listened to it once. Of the eight participants who had listened to the CD 'sometimes', only four reported that they found it helpful. Three participants found the CD very helpful but one of them who explained it made him/her relaxed also added that he/she found the CD 'boring'. However, one participant had commented that the CD had been especially useful. Therefore, it appeared that the CD might have been helpful for some participants.

Unlike the CD, the majority of participants reported that they had read the intervention booklet entitled 'Getting on with life: learning to live with your ICD'. Three participants reported they had not read it and one of these explained that he/she had not read the booklet because of problems with attention span. Most participants reported that they found the booklet either very helpful or quite helpful. Only two had reported they were unsure whether it was helpful overall.

To examine the perceived helpfulness of each individual chapter, participants were asked to rate the usefulness of each chapter using an adjective-type scale. For example, the following scale was used: 'very helpful' 'quite helpful' 'Unsure' 'Not helpful'. This revealed that most participants believed each chapter was either very helpful or quite helpful (see Table 9.56). The most helpful chapter in the booklet appeared to be the chapter 'Common Concerns', in which there was a table outlining typical worries or concerns that patients with an ICD have experienced. The second most highly rated chapter was the chapter 'Keeping Active'. Despite the helpfulness of the chapter 'Keeping Active', only seven participants reported that they had used the exercise diary. However, this might have been because of the way the questionnaire was worded; it did not differentiate between using the exercise diary for a couple of days and not using it at all. Therefore, some might have used it for a couple of days.

Nonetheless, two participants reported they had used all four weeks of the 4-week exercise diary, whilst others reported using just two weeks. This suggested that the exercise diary was probably a useful contribution for some participants and should be included in future booklets. One comment from a participant who made use of the four-week exercise diary was that it helped him monitor his progress, and he claimed that after the four-weeks ended, he bought his own diary to continue to record his progress.

Some of the participants had added comments to explain what they had found particularly helpful about the intervention. Twelve comments suggested that the booklet provided general information that was helpful. Some found specific information about worries and concerns particularly useful; one participant explained that the table of concerns had helped him/her overcome worries about the ICD wires becoming dislodged. Another participant reported that the table of worries had answered many of her concerns. Interestingly, although nine participants were unsure about the helpfulness of the chapter on planning a shock strategy (see Table 9.56), three participants reported that they had found this chapter especially useful.

Interestingly, two of these participants had received shocks, and therefore it might be that the value of this chapter might only be truly appreciated after a shock is received.

The process measure questionnaire also asked for participant's feedback about the two additional booklets, which had been sent to the intervention group along with the intervention booklet for more general information about eating healthily and how to stop smoking. From the feedback, it appears that the "Getting on with life: Eating healthily" was helpful for some participants. One participant explained the booklet helped him realise what he should not be eating and consequently it had helped him improve his diet. All participants reported that the "Getting on with life: Stopping smoking" was not useful. The reason given by most participants was that although they used to smoke heavily, they no longer smoked.

The intervention booklet "Getting on with life: Learning to live with your ICD" appeared to have been well received by participants and most had found it was helpful in allaying common fears about the device. It also appeared to be useful in helping participants return to exercise. However, an important minority believed that the booklet did not help with learning to relax, coping with worries or getting to sleep. This might have been because participants did not have difficulties in these areas to begin with and therefore did not require help. This situation had already been addressed by the intervention, which acknowledged to patients that some of them might not feel they need any help whatsoever. However, another possible reason that participants reported some chapters were not helpful was that participants might have found the techniques difficult to learn merely from reading instructions. Participants might have benefitted from an additional teaching aid such as a visual and auditory aid to help them learn how to master the techniques, which could be demonstrated on a DVD (see below 'Recommend Changes to the Written Intervention'). An alternative reason why some participants may not have found these chapters helpful was that they might be having very high levels of distress and need more individualised intensive psychological support. This booklet might be helpful as an adjunct to routine literature for patients with who are not very distressed.

Table 9.56.

Feedback from Participants about the helpfulness of each Chapter in the Intervention Booklet "Getting on with life: learning to live with your ICD". The usefulness of each Chapter displayed in number of participants (%)

Chapter	Total Number	Very Helpful (%)	Quite Helpful (%)	Unsure (%)	Not Helpful (%)
Common Concerns	33	10 (30.30)	16 (48.48)	3 (9.09)	1 (3.03)
Keeping Active	28	6 (21.43)	18 (64.29)	2 (7.14)	2 (7.14)
Getting to Sleep	28	6 (21.43)	12 (42.86)	5 (17.86)	5 (17.86)
Learning to Relax	28	6 (21.43)	15 (53.57)	2 (7.14)	5 (17.86)
Coping with Worries	27	8 (29.63)	9 (33.33)	5 (18.52)	5 (18.52)
Planning a Shock Strategy	31	8 (25.81)	10 (32.26)	9 (29.03)	4 (12.90)

LIMITATIONS TO THE PILOT RCT STUDY

There were several limitations with this study.

1. One major limitation was the low number of participants recruited. This was due to two reasons. There was a lower than expected number of ICD patients admitted to the recruitment sites (hospitals) used in this study and there was a very small window of opportunity in which to recruit participants.

    a. One reason for this small window was that potential participants could only be recruited *after* their pre-counselling session. This pre-counselling session sometimes took place on the evening before the implant. Accordingly, after the counselling session, potential participants were often too tired to take part in a study. This also meant that some participants were recruited a few days before their implant (if they had their counselling session a few days before their implant), whilst others were recruited the night before the procedure. It is possible that those recruited the night before the procedure, might have had different levels of distress compared to those patients who were further away from their implant.

   b. Another reason for this very small window was bed shortages in the main implant hospital. Many patients came from surrounding smaller hospitals and were transferred to the main implant hospital on the day before their ICD procedure. However, because of bed shortages, patients were often transferred to the implant hospital on the morning of their procedure. As Ethical and Research and Development committees had requested that participants were not recruited on the day of their implant, these potential participants could not be recruited. There was also a shortage of post-arrest participants recruited, which had not been anticipated. Many survivors of sudden cardiac arrest were often too poorly to be interviewed, too confused to give informed consent or were implanted with an ICD before leaving intensive care. Therefore, the sample of participants who had had a cardiac arrest might have been limited to those sudden cardiac arrest patients who were less poorly. Accordingly, the sample was not representative of a typical normally distributed sample.

2. The data at baseline was likely to be skewed from a typical ICD population because arrhythmia nurses identified the patients who could be approached for recruitment. Although the study was aware that very distressed patients would not be selected for the study, it was unclear the exact criteria used by nurses to identify ‘suitable’ patients. These should have been determined beforehand, as nurses might have taken other factors (unknown to the researcher) into consideration. Therefore, the scores reported by participants were not reflective of and cannot be generalised to an ICD population.

3. As the arrhythmia nurses did not select patients with high levels of anxiety or depression, as a consequence patients with these high levels of distress were not recruited. Baseline scores showed that the participants in both groups had relatively low levels of anxiety and depression (see Table 9.5). Since Magyar-Russell et al.'s (2001) systematic review suggested that 20% of ICD patients had clinical anxiety and clinical depression, this study's sample was probably not generalisable to all ICD patients. The finding that patients in this study had relatively low levels of distress might have influenced results.

   For instance, patients who with lower levels of distress might be more inclined to engage with a written intervention and all the participants in the intervention group reported they had read the intervention. Findings from the qualitative phase suggested that participants who were very distressed avoided reading any literature related to the ICD (e.g. see Appendix V, N04: 336-340). The relatively low level of depression and anxiety might partly explain why the effect sizes found between the two groups were small-medium (for depression[106]) and negligible for anxiety[107] (see Tables 9.13 and 9.14). In other words, because scores were initially relatively low, there was less possibility for improvement.

4. A more 'typical' sample might not read the booklet. Furthermore, because the sample of patients recruited did not include patients with high levels of distress, it remains unknown whether a very distressed patient might find the intervention beneficial or detrimental, so any further study needs to be cautious.

5. The researcher, the participant and the Arrhythmia nurses were blind to which group the patient was allocated. Therefore, when the patient met the researcher at recruitment, he/she was treated in the same way as others. Participants were allocated in line with the output from a computer algorithm, which was accessed *after* the patient was recruited. However, although the

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[106] POMS-SF - depression subscale
[107] HADS – anxiety subscale

participants were supposedly blind to their allocated group, those in the intervention group might have realised the study was aiming to test the booklet that had been given to them. The intervention booklet was cheaply produced and probably had an 'amateur' finish in comparison to the polished finish of the routine literature given to the control group. This might have distorted results because of the placebo effect. Jackson, Shepherd, Brookes, and Abrams (1999) recommended double-blind allocation to groups. They suggested that even objective tests could be open to bias if the participant (or researcher) is aware of their treatment group.

6. The psychological questionnaire used to collect data used 13 separate measures. Participants were often very tired by the time they got to the end of the questionnaire and some had asked if they could complete it later. Therefore, this might have influenced the filling in of measures; towards the end of the questionnaires, participants might not have been concentrating or just wanted to finish it quickly so did not give as much thought to the later questions and mistakes might have been made. On reflection, there were too many measures and verbal comments about its length from participants often confirmed this.

   The length of the questionnaire might also have influenced response levels, as when participants received an identical questionnaire at 3-months post-implant, some of them may have been reluctant to fill out such a lengthy questionnaire. The issues over the length of the questionnaire could be determined more accurately from user/patient feedback after piloting the questionnaire in a future study.

7. The process measures that collected feedback from participants about the intervention lacked detail. The excessive length of the psychological measures questionnaire initially filled in by participants might have meant participants were reluctant to fill in yet another questionnaire.

8. The study had used the Godin Leisure-time Exercise Questionnaire (Godin & Shephard, 1985), which measured physical activity. This measure was not

suited to this patient cohort because it was too complex for many participants to understand. In particular, they had difficulty with the instruction to change a number of minutes of a total activity into blocks of 15-minutes. Although before the study, the measure had been pilot-tested on an elderly population, the test population had been physically healthy. The study subsequently replaced Godin's measure with a simple exercise diary. However, by the time the new measure was in operation[108], a number of scores from participants relating to exercise were lost.

9. The Positive ICD Beliefs Questionnaire that had frequently been used in the regression analyses was not a validated measure.

10. To some extent, the mean scores in the ANCOVAs in Aim 1 might have been compromised as information about whether participants had received additional psychological support was not collected. It was not known if participants had received counselling, or emotional support from an outside agency or had received help from a specialist nurse to help them cope with their ICD. These findings might be important; for instance, if participants in the control received psychological support, their scores that indicated they had not improved as much as the intervention group might mean the intervention booklet was even more effective than scores suggested. However, if participants in the intervention group received additional psychological support, then this would negate from the effectiveness of the intervention. The costs of health service usage such as unplanned admissions, telephone calls and appointments with the Arrhythmia Specialist Nurse were also not collected by this study, and which might have been additional useful information in testing the efficacy of the booklet. In fact, when testing the efficacy of a behavioural intervention, NICE (2014) highlighted the importance of collecting this added information.

11. A further limitation was the design of the study. The data was gathered through self-reports and therefore the measures might have been answered

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[108] The new measure had to receive ethical and R&D approval before being used.

subjectively, although adjustment by analysis of covariance for corresponding baseline scores had been made to minimise subjectivity. Furthermore, although the majority of participants filled out their own baseline questionnaires, some participants required help, which might have influenced their answers due to normative pressures. For instance, it became apparent whilst collecting demographic information and talking to patients, that some patients had a very stoical attitude, which might have been for the benefit of their families (see the First Order Theme 'Concealment', Chapter 6). In these instances, patients might have been reluctant to admit their true feelings to the researcher. Moreover, some of research questions were of a delicate nature, such as asking questions in relation to their sex life, which visibly appeared to make some participants uncomfortable.

12. The attrition rate in this study appeared to be high compared to other ICD studies. In this study, the attrition rate in the intervention group was 41.7%. The attrition rate in the control group was 39.2%, which was higher than in the UK studies by Frizelle et al. (2004) and Lewin et al. (2009). The higher attrition rate might have been because there was no direct contact with the research team after the initial recruitment phase. Interestingly, the attrition rate in the intervention group was similar to that found by Bundy et al. (2013), whose intervention was also based on no direct therapist contact.

13. The last limitation of this study and one which was quite a major limitation, was that due to lack of time, participants were not followed up to a year. Although the qualitative phase and supporting literature (e.g. Burke, 1996) identified the first year as being critical, participants were only followed up for 6-months. NICE (2014) guidelines suggested that when testing the efficacy of an intervention, participants should be followed up to one-year.

RECOMMENDED CHANGES TO THE DESIGN OF THE STUDY

1. Due to the difficulties experienced in recruiting participants, consideration needs to be made to how participants are recruited and how baseline data is collected. One suggested method is to meet the patient on the ward after their implant and before their discharge from hospital. At this meeting, the researcher could inform the patient about the study and recruit them (if appropriate). During the week post-discharge, the researcher could send the participants questionnaires to assess their baseline psychological, exercise and demographic measures. This way ensures the baseline measures are taken during the first week home after the implant. As the intervention is delivered after the ICD implant, it seems more logical to take baseline measures after the procedure so that participants are not reporting anticipated emotions/appraisals. Collecting measures during the first week post-implant would also ensure that baseline measures are taken at approximately the same time[109]. Another issue found in this study was the poor mental health of some patients before their implant. The pilot RCT found that many post-arrest patients were too poorly to be interviewed or too confused to give informed consent and therefore could not recruited. The study was given access to some patients because they were too poorly before their implant. These issues might be overcome if participants were sent baseline measures during their first week home.

2. The participant should receive the booklet (routine or intervention), along with an explanation of how the participant is to use the booklet, before leaving hospital. This will ensure the delivery method for the intervention is identical to the delivery of routine literature. (See Recommended Changes to the Delivery of the Intervention below on page 428).

3. Ideally, it should be the researcher and not the Arrhythmia Nurse who should identify patients in a future study. In this study, it was likely that patients who were very anxious were not identified as a potential participant. This

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[109] In the current study, it was not always possible to ensure that participants who were elective patient filled in their questionnaire a few days before their implant.

new method would require the researcher not only to have access to the patient's medical records but to be able to understand and make sense of medical jargon and the Doctor's notes. The exact criteria used to identify patients needs to be made clear.

4. This study found the Godin's Leisure-time Exercise Questionnaire (Godin & Shephard, 1985), which measured physical activity, was too complicated for participants to complete. This study established that participants had no difficulty in filling in the exercise diary, which was used in place of Godin and Shephard's questionnaire. This exercise diary could be used in a further study as patients not only found it easy to complete but it was a simple inexpensive measure of physical exercise. Dishman, Washburn and Schoeller (2001) suggested that self-report measures usually offer the most practical and cost-effective method to measure physical activity.

5. This study wanted to measure participants' positive ICD-beliefs; however there did not appear to be a questionnaire that captured this variable. The ICD Concerns Questionnaire was closest in measuring beliefs about the ICD but tended to focus more on worries than beliefs. The Positive ICD Beliefs Questionnaire, which was created for this study had a strong negative correlation with the ICD Concerns Questionnaire. It had a good internal consistency with a strong Cronbach alpha score of .86. If this study was repeated, the Positive ICD Beliefs Questionnaire is recommended as it was a useful measure, however future studies should test its reliability.

6. If this study was to be repeated, it is recommended that any item measure that refers to sex should be omitted. Questions on measures that referred to sex appeared to be trying to determine if participants were avoiding sex through a fear of triggering a shock or to measure levels of intimacy with a partner. However, participants often reported that they abstained from sexual activity due to age or their medication, which made having sex difficult. Although this was not measured, some participants might have refrained from sex due to physical issues such as pain surrounding the wound rather than because they were afraid of triggering a shock. Some of the questionnaires that

included questions relating to sexual activity included the ICD Concerns Questionnaire, Positive ICD Beliefs Questionnaire, and Florida Patient Acceptance Survey. It is recommended that future studies might consider omitting these questions. Of note, although the Florida Patient Acceptance Survey includes a question referring to sex “I will continue with my normal sex life”, this was reported by its authors to be a ‘filler’ question and is therefore unnecessary.

7. Future studies might consider including a measure of emotional intimacy. Findings from the qualitative phase of the study suggested that after their implant some patients felt emotionally distant to their partner. Measuring participant’s level of emotional closeness to a significant other might be a more appropriate to assess intimacy than sex. Emotional intimacy involves a perception of closeness to another that allows sharing of personal feelings, accompanied by expectations of understanding, affirmation, and demonstrations of caring (Sinclair & Dowdy, 2005). One measure that could be used to measure is the 5-point Emotional Intimacy Scale (Sinclair & Dowdy, 2005), which was tested for its reliability and validity on a chronically ill population, which is comparable to the ICD population.

8. This study might have found that symptoms of post-traumatic stress disorder (PTSD) improved in the intervention group had it been measured. During the process of choosing suitable measures, the PTSD construct was deemed irrelevant to this cohort of new ICD patients. Reasons for this belief, rested on the belief that PTSD would only be diagnosable in patients who received a shock from their ICD. However, these patients receive individual counselling for the ICD shock, and accordingly PTSD was not measured as change reported in this construct might be due to the counselling rather than to the intervention. However, in hindsight, findings from the qualitative study suggested that the patient’s experience of sudden cardiac arrest might influence PTSD symptoms (see for example, Appendix V, N14). Therefore, it is recommended that this disorder be measured in any subsequent study.

9. This study deduced that 13 separate measures were too many for patients to complete. In order to prevent participants becoming tired when filling out the questionnaire, the number of separate measures used needs to be reduced. This could be achieved by reducing the number of questionnaires that measured the same variable. For example, the Hospital Anxiety and Depression Scale's depression subscale and the Profile of Moods' (SF) depression subscale both measured depression. It is recommended that a further study use only one measure for each variable.

   The following nine measures are recommended (note: although a total of nine measures is only four less than the original measures questionnaire, which was too lengthy, not all the subscales within some measures have been recommended.

   1. Positive ICD Beliefs Questionnaire (not validated): This was found to be strongly negatively correlated to the ICD-Concerns Questionnaire but targeted beliefs rather than worries or concerns. It was also found to have good internal consistency.
   2. Impact of Events Scale-Revised (Weiss & Marmar, 1997): As well as measuring levels of cognitive avoidance, which would be a relevant construct to measure when testing the efficacy of an intervention based on CBT, this measure could also be used to measure PTSD. There was no meaningful difference between groups on the intrusion subscale so this subscale could be omitted.
   3. Brief-Illness-Perception Questionnaire Revised (Omit item-5, as this relates to a symptom) (Moss-Morris, Weinman, Petrie, Cameron et al., 2010). This was found to be a useful measure to use to assess illness-related appraisals.
   4. Hospital Anxiety and Depression Scale (Anxiety subscale) (Zigmond & Snaith, 1983): This measure did not find meaningful differences between groups in anxiety and depression although another measure did find a meaningful difference between groups in levels of depression (see POMS-SF – depression subscale below). However, the HADS anxiety subscale has been used with cardiac patients and

has been endorsed by a scientific review (Dunbar et al., 2012) which stated that in comparison to other measures it was sensitive to detecting changes in anxiety. This intervention has acknowledged that changes need to be made in a revised version which will place a greater emphasis on reducing anxiety (See Recommended Change to the Written, Intervention below).

5. POMS-SF (depression subscale) (Shacham, 1983): the depression subscale found a meaningful between-group difference at 6-months and is suited to measuring levels of low mood.
6. Exercise Diary: This study found participants could easily complete this measure.
7. 5-point Emotional Intimacy Scale (Sinclair & Dowdy, 2005): This measure could be used to assess the level of intimacy and concealment issues between the patient and partner (or family member) (see Recommended Changes to the Written Intervention below).
8. The Positive and Negative Affect Schedule (PANAS) (Watson, Clark & Tellegen, 1988) (Positive affect subscale only). There was no meaningful difference between-group mean scores for confrontational-type coping. This might have been because measures to collect scores for positive emotions such as hope or optimism were not used. The positive affect subscale of the PANAS would provide this data.
9. Medical Coping Modes Questionnaire (Feifel, Strack & Nagy, 1987a): This measure was simple to use and measured a more behavioural-type avoidant coping, which complements the IES-R (see above).
10. Florida Patient Acceptance Survey (Burns, Serber, Keim & Sears, 2004). This was a useful measure to assess the total level of acceptance towards the ICD.

It is also recommended that the revised questionnaire is piloted using ICD patients to determine whether the suitability of its length and its ease to complete.

10. A future study should also take into account of what happens to the control group as well as the intervention group. For example, what techniques did control participants use, did participants receive additional psychological support, what type of support did they receive, how many sessions, and for how long and why. This was not reported in this study and it is important to know what happens to the control group as well as the intervention group as there could be implications to the results. For instance, participants in the control group might have become so distressed that they were given some form of psychological support to help reduce their distress. This support would influence the results of the control group, which would in turn influence the effect sizes found between the groups. This information should also be collected for the intervention group. The NICE guidelines on behaviour change (NICE, 2014) highlighted the importance of determining the practical detail of techniques used by both the intervention and control groups.

11. The process measures that were used to gather feedback from participants lacked sufficient detail. Therefore, it is recommended that focus groups are used to gather this information instead of relying on feedback measures. However, if the questionnaire uses fewer psychological measures in future, participants might be more inclined to provide detailed feedback. Nonetheless, the feedback provided on the feedback measure could still be explored in more detail during a focus group meeting. The NICE guidelines for behaviour change (NICE, 2014) suggested that as well as qualitative and quantitative measures, it is important to understand why something works or does not work and under what circumstances it works/does not work. As the written feedback was sparse, the use of focus groups would be an ideal tool to identify improvements or changes to the intervention.

12. Future studies investigating coping with an ICD should carry out prospective studies following participants up to 12-months. The findings from the qualitative phase of this study found that the 1-year post implant anniversary was an important milestone for many ICD patients. Quantitative findings

from a systematic review by Magyar-Russell et al. (2011), also suggested rates of anxiety and depression tended to remain stable over the first year, after which, the gap between the lowest and highest scores widened. As the intervention aimed to change behaviour as well as reduce distress, suggestions from NICE guidelines on behaviour change (NICE, 2014) are relevant. The guidelines suggest that it is important to evaluate long-term behaviour change (and not just up to 6-12 weeks following an intervention).

13. Future studies should use an intervention and control booklet that is similar in design and quality. For instance, the information in the routine booklet could be presented in a booklet similar to the intervention. Participants in the intervention group of this study might have guessed that the study was testing the efficacy of the intervention booklet, as it clearly looked less professional compared to routine literature. Consequently, the intervention group might have believed they had a 'special' booklet and their results might have been distorted by a placebo effect. Potential participants could be briefly shown both the books and told they will receive one of them. Jackson et al. (1999) suggested that trials should be double-blind so that the researcher as well as the participant is blind to the participant's allocated group as even objective tests can be open to bias (see Limitations to the Pilot RCT, page 412)

14. The pilot RCT did not take in account use of health care resources, such as emergency admissions, or defibrillator-related and non-defibrillator resource use, and did not measure for quality-adjusted life year's gains or losses. These all need to be measured in a subsequent study.

RECOMMENDED CHANGES TO THE WRITTEN INTERVENTION

Although the intervention appeared beneficial to patients, some findings from the qualitative and quantitative phases of the study and feedback about the intervention suggested that some changes to the intervention could be made. These changes might increase the efficacy of the intervention.

1. Photos of Implant Scars

Participants in the qualitative study reported being surprised by the size of the lump under the skin, made by the ICD after the implant. Despite having seen a 'dummy' ICD device and having been shown whereabouts on the body it would be implanted, some participants were still unprepared for the size of its protrusion. Also, they were often puzzled at where it had been implanted as many participants believed that the ICD was going to be inserted near the heart.

It is recommended therefore that the intervention booklet includes photos of implant sites on several body shapes (i.e., male, female, excess body fat, little body fat) and over time (e.g. first week, 1-month, 6-months, and 1-year). These photos could also include incision wounds so patients know what to expect. These could include photos of incision wounds that need medical attention, such as an infected scar. Photos of implants could not be included in the current study due to the time constraints of the study.

2. A CD-ROM or DVD with Mindfulness Exercises and Relaxation Exercises

Results from the pilot RCT suggested that the intervention helped reduce levels of depression. However, the results also suggested that there was no meaningful change in mean scores between groups in levels of anxiety. Therefore, the intervention needs to include activities that emphasise managing anxiety, especially as raised levels of anxiety has been found to lead to an increased risk of an arrhythmia through increased sympathetic arousal (see Lampert et al., 2002; Burg et al., 2004; Kop et al., 204).

A mindfulness activity based on Kabat-Zinn (2003) might be incorporated into the intervention, which theoretically should help reduce anxiety. This could be delivered via a DVD with comprehensive instructions on how to do a 'mindful' activity. The DVD could also deliver and demonstrate the relaxation exercises. Only a few participants reported they had listened to the CD that accompanied the study intervention, which had recordings of three relaxation exercises differing in lengths. Criticisms of the CD included a suggestion that listening to it was boring. Although arguably, a 'live' therapist might benefit more patients, ICD patients cannot drive for 6-months. For some, this causes problems with travel. For instance, Frizelle, et al. (2004) found many patients opted out of their study because they could not travel. Therefore, a home-based intervention would be more accessible for an ICD population.

3. Dedicated Sections for specific Cardiac Illnesses and Sudden Cardiac Arrest to be included

Findings from the qualitative study suggested that participants might have a specific worry relating to the underlying cardiac condition. For instance, parents with a heritable condition were worried about passing on the condition to their children. Therefore, it is recommended that after the generic section with psychological coping skills, the study intervention booklet might include dedicated sections relating to specific cardiac illnesses, e.g. a cardiomyopathy. These sections could include typical worries of patients with each type of cardiac illness. A dedicated section on surviving a cardiac arrest might also be included. Findings from the current qualitative study revealed that 'loss of confidence' was a unique theme to survivors of sudden cardiac arrest (see Chapter 7: Vulnerability and Uncertainty after Cardiac Arrest). A nursing intervention by Dougherty, Lewis, Thompson, Baer, and Kim (2004) based on social cognitive theory has been introduced for survivors of cardiac arrest in the USA, thereby suggesting that this cohort might have specific needs.

The idea to have sections dedicated to certain cardiac illnesses is supported by the findings of the regressions outlined in Chapter 9. For instance, the regressions found that a risk factor for anxiety at 3-months was having a cardiomyopathy. Further, a risk factor for depression was having angina at 3-months and heart failure at 6-months. These findings suggested that there might be psychological worries/concerns that are pertinent to these specific conditions. These sections could be based on social cognitive theory, using verbatim experiences of patients and partners to demonstrate how varied an individual response to a SCA or an ICD[110] might be. The sections could include 'tips' from patients and partners who could describe coping strategies they have used. For example, the qualitative phase of this study found that one partner's light hearted attempt at keeping her husband 'safe' was to buy him a dog-tag: *"For Christmas I bought him a dog-tag (laughs). A heart-shaped dog tag, he'll kill me for it I know ... his name, ICD, and a telephone number ...* "(251-25, N03.1 – see Chapter 6: page 217).

4. A Section dedicated to the Carer

Findings from the qualitative study suggested that partners of survivors of SCA were often left feeling traumatised by the events that had unfolded. This finding corroborated with Doolittle and Sauve's (1995) suggestion that after the SCA, partners tend to focus on the cardiac event. Therefore, a section could be included specifically for intimate partners or the patient's main carer. This section again, could include verbatim experiences of various partners based on social cognitive theory.

5. Concealment Issues

Tagney et al. (2003) first reported concealment between couples was an issue, with both the patient concealing feelings from the partner and vice versa. Findings from the qualitative phase suggested that one consequence of concealment appeared to be a reduced level of intimacy experienced between couples. In this study, this reduced intimacy appeared to make patients feel depressed and partners frustrated. Therefore, it is recommended that this issue is highlighted so that patients and partners are made aware that this is a *common issue*, experienced by many ICD couples and which can be remedied by talking more openly with each other.

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[110] Social Cognitive theory was used to underpin ICD interventions by Dougherty et al. (2004) and Lewin, Coulton, Frizelle, Kaye & Cox (2009).

RECOMMENDED CHANGES TO THE DELIVERY OF THE INTERVENTION

The findings from qualitative phase suggested patients found the length of time from their discharge to their follow up was too long. However, if the intervention included an appointment with a health professional during this time, it would increase the cost of this intervention exponentially. It would also detract from it being a simple brief written intervention.

Due to time constraints, Arrhythmia Nurses do not usually meet with patients before they are discharged from the hospital. However, if possible a Ward Nurse or the day-case Staff Nurse tries to meet with the patient to deliver discharge information and a shock management sheet (Wendy Churchouse, Specialist Arrhythmia Nurse, Personal Communication, 02/04/2014; Mandie Welch, Specialist Arrhythmia Nurse, Personal Communication, 04/04/2014).

A future study would have to ensure that this meeting took place. This meeting would be an ideal setting for the Nurse to explain the booklet (intervention or control booklet) to patients. This is an important element of the intervention; NICE guidelines on behaviour change (NICE, 2014), suggested that the setting where the intervention is delivered and the person delivering it, may be the two main factors that make an intervention effective. Although the intervention is a booklet, and the nurse is merely explaining the booklet to the patient, it appears how this is carried out might be important to outcomes.

The method of delivery needs to be the same for both the control and the intervention group. Patients in the control group should receive the same contact time with the nurse and be briefed about the 'routine' booklet.

Albarran et al. (2004) had suggested that ICD patients might benefit from an electronic intervention. However as the typical ICD patient is often elderly (for instance, the mean age of participants in this pilot RCT was 62 years) and may not be computer literate, they may prefer a booklet rather than a web-based intervention. Although an electronic version might have some advantages over a booklet, (i.e., it might be more cost effective), the focus of a future study to test the efficacy of this intervention should be to determine if the psychological mechanisms underpinning the intervention are beneficial to the ICD population. Once this has been established, patients' preferred method of delivery and costs could be later explored.

Next:

Chapter 10: Summary, What should Happen Next and Gap in Research Identified from this Study

Part 4

Chapter 10

QUALITATIVE PHASE AND PILOT RCT SUMMARY, WHAT SHOULD HAPPEN NEXT AND GAP IN RESEARCH IDENTIFIED FROM THIS STUDY

QUALITATIVE PHASE AND PILOT RCT SUMMARY

This thesis has focussed on a research project that was carried out with the aim to develop a brief psychological coping intervention for patients living with an ICD. The intervention was developed using the guidelines set out in document entitled 'Developing and Evaluating a Complex Intervention' (2008) put forward by the Medical Research Council [MRC]. The need for this intervention was identified from literature reviews and findings from previous ICD interventions. Literature reviews reported that ICD patients tended to have increased levels of anxiety and depression. For instance, clinical rates of anxiety reported in ICD patients range from 13 to 38 % (e.g. Matchett, Sears, Hazleton, Kirian et al. 2009; Sears & Conti, 2002; Sears, Conti, Curtis, Saia, et al., 1999; Burke, Hallas, Clark-Carer, White et al., 2003). Furthermore, previous interventions identified over the past 10-years (e.g. Dougherty, Lewis, Thompson, Baer et al., 2004 and Lewin, Coulton, Frizzelle, Kaye et al., 2009), have all required a considerable amount of specialist nursing support.

There were no recently published qualitative studies, which used a UK population, and therefore the first stage in developing the intervention was to conduct a qualitative study using ICD patients and their intimate partners. One limitation with this study was that the experience of ICD patients who live alone was not explored. Since previous qualitative findings found that some patients were so afraid of a shock that they would not take a shower unless someone was there to help them (Mert et al., 2012; Bolse et al., 2005) the lived experience of living alone with an ICD might have been qualitatively different, and possibly more difficult.

This qualitative study explored how participants lived and coped with their ICD. From these findings, common worries and concerns of patients and partners were identified. Some findings were used to structure the intervention. For instance, the qualitative study discovered that participants found that the time from hospital discharge post-implant to the first follow-up appointment at 6-weeks, was *especially* difficult. One reason for this was that on discharge participants had been told to '*live life as normal*' and many participants found that this advice was too difficult to follow. They explained that after their cardiac event and hospitalisation, they *simply did not know how* to regain 'normality'. Therefore, one purpose of this study intervention was to be a structured guide, underpinned by cognitive behavioural theory (CBT), which could bridge the gap between hospital discharge and patient's 6-week follow up appointment.

The intervention consisted of a written booklet divided into short chapters and also included a CD. The second chapter included a question and answer table, which outlined the common worries voiced by participants in the qualitative phase about their first few weeks home. For instance, many participants worried about whether the ICD had been inserted in the correct place as many experienced disconcerting physical symptoms. To address general worries, the intervention informed patients of strategies, which could be used to cope with worries. Participants, especially those who had previously been physically fit, complained of feeling weak and unfit after the implant, which they had found distressing (see Chapter 6, First Order Theme: Vulnerability and Uncertainty after an ICD). To address these concerns about fitness, the intervention advised participants how to increase their physical fitness and how to slowly build up their stamina. The qualitative study also informed *how* the intervention should be written. Some participants from the qualitative phase described how they were afraid of educational medical literature. Sometimes their anxieties were so great, that some participants reported that they had been too frightened to read the information. Consequently, the intervention was framed positively, with a strong emphasis that the booklet would help patients return to *normal everyday living.* (See Chapter 8 for detailed information about each chapter of the booklet).

In order to test the efficacy of this intervention, a pilot RCT was conducted using three recruitment sites. The pilot RCT had two aims. The first aim was to test the efficacy of the intervention using a series of analyses of covariance (ANCOVAs). The key outcomes measures chosen were typical cognitive and behavioural outcomes identified from Lazarus' theoretical framework (i.e. appraisals, emotions and coping) (Lazarus & Folkman, 1984; Smith & Lazarus, 1991). In short, Lazarus' framework suggested that appraisals influence emotions, and together appraisals and emotions influence coping. Therefore, it was hypothesised that the intervention would change appraisals, i.e., increasing positive beliefs in the ICD, and this improvement would theoretically lead to improved emotional outcomes, and better coping (increased confrontational coping and less avoidant coping), which would be evidenced by increased patient acceptance to the ICD.

In general, more improvement was found in the intervention group compared to the control group. The intervention group reported scores that indicated they had lower levels of depression than the control group, and were using less behavioural-type avoidant strategies. In some measures, a statistical significant between group effect size was reached. For instance, some of these were positive appraisals about the ICD, e.g., ICD positive beliefs and B-IPQ – treatment control.

At baseline, there were no meaningful between group differences in types of exercise between the two groups (mild, moderate and strenuous exercises). At 3-months, the control group reported doing more mild exercise than the control group. However, by 6-months, the intervention group were engaging in more mild exercise from baseline compared to the control group (see adjusted mean scores, Appendix XXII Table 12). These exercise outcomes might have reflected the overactive-rest-cycle coping response in which the control group exercised too much initially and then ceased, whereas the intervention group slowly increased their level of exercise. As well as in improvement in the amount of exercise participants in the intervention group were engaging in, the intervention group also demonstrated a greater patient acceptance[111] to the ICD that was statistically significant. At 6-months, scores from the intervention group improved, whilst concurrent scores from the control group worsened.

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[111] Patient acceptance was defined by Burns et al. (2004) as the psychological accommodation and understanding of the advantages and disadvantages of the device, the recommendation of the device to others, and the derivation of benefit in terms of biomedical, psychological and social functioning. Patient acceptance was theorised to be a device-specific component of the construct of quality of life (Burns et al., 2004).

Feedback from process measures, suggested that the study intervention had been well received and the majority of participants reported they had found the intervention booklet helpful. From the feedback given, the table of common worries and concerns (created from the qualitative phase of the study) and the chapter on how to keep active were the reported to be the most helpful, followed by the chapter on learning to relax. Unfortunately, although participants were asked for general thoughts and opinions about the intervention booklet, not many contributed additional comments to this section. Those who added comments tended to fall into two categories; those who were complimentary about the booklet in general and those who reported that they were not using the coping techniques because they were 'getting on with life' and not experiencing problems. An underlying theme from the comments appeared to that the booklet helped them 'get back to normal living', which was the overall aim of the booklet. The feedback suggested that addressing appropriate concerns of patients and the behavioural element of the intervention was most helpful and was evidenced by the fact that intervention group had a less device-related distress were doing more exercise at 6-months compared to the control group.

The second aim of the pilot RCT was to find the significant predictors of the key emotional outcomes (anxiety and depression) and the key coping outcomes (confrontational, acceptance-resignation, and avoidant coping) using bivariate correlations and hierarchical regressions. Theory-led psychological predictors from Lazarus' theoretical framework were used as variables to explore the percentage of variance in key emotional and coping outcomes. Findings from the ANCOVAs and the hierarchical regressions were used to explain how the intervention might have been helpful to participants. As the nature of the data in this study was cross-sectional, *any causality was assumed on the basis of theory* rather than derived from the data.

One notable appraisal ('positive belief in the ICD') was found to be a significant predictor of anxiety at 3- and 6-months and of depression at 3-months. ANCOVAs revealed the intervention group reported greater positive ICD beliefs compared to the control group (with a medium between-group effect size at 3-months that was statistically significant). Therefore, the efficacy of the intervention might be due its positive reframing of the ICD that helped increase positive ICD-beliefs. However, the Positive ICD-Beliefs Questionnaire had been created for the purposes of this study, and the reliability of this measure had not been established.

A secondary objective of the hierarchical regressions was to find out if any of demographic and clinical variables used in the study were risk factors for the key outcomes. Although, ICD patients can be considered 'a cohort' of patients, they comprised a multitude of different underlying cardiac conditions, which necessitated their need for an ICD. Having a cardiomyopathy was found to be a risk factor for increased levels of anxiety at 3-months. Risk factors for increased levels of depression included having angina at 3-months, and heart failure (NYHA stages I-III) at 6-months. Gender was also found to be a risk factor for behavioural avoidance; females were more likely to engage in behavioural avoidance compared to their male counterparts.

Whether this intervention is cost effective or not depends on how 'cost efficacy' is defined. It could be suggested that there is a 'trade-off' when devising an intervention; trying to find the maximum efficacy for the least cost. Outcomes from previous studies (e.g Dougherty et al., 2004, 2005; Frizelle et al. 2004 – see table 8.1) suggested that their interventions appeared to be more effective in reducing distress compared to this study's intervention. For instance, the intervention group in Frizelle et al.'s (2004) study demonstrated significant reduced levels of anxiety and depression and ICD concerns. Nevertheless, these studies used expensive resources, i.e., Frizelleet al.'s (2004) group CBT programme included 12 hours contact group time. Their intervention group had opportunities to discuss issues with a cardiac nurse, an opportunity to ask practical or heart disease related issues with electrocardiogram technicians and received a personalised training session from a physiotherapist. Similar to Frizelle et al. (2004), Dougherty et al.'s (2004) intervention also relied heavily on health professionals.

Therefore, although the results from this current study did not demonstrate comparable reductions in depression and anxiety such as those found in Frizzelle et al.'s (2004) study, the intervention group's scores reported a lower level of depression, a higher level of positive ICD-beliefs, a higher level of personal control, engaging in more exercise from baseline and had a greater ICD acceptance compared to the control group. Furthermore, this was achieved by a giving patients a cheaply produced booklet and CD. Accordingly, there is a 'trade-off' between efficacy of the intervention and its cost.

This study intervention booklet is very inexpensive compared to other studies' interventions. Each study intervention booklet and CD cost approximately £1.50 to produce[112]. Apart from the low cost of this booklet, the delivery of this intervention is also straightforward. The intervention (booklet and CD) can be simply given to patients when they are discharged from hospital as opposed to the complexity of planning and running a CBT group (e.g. Frizelle et al., 2004) or arranging 20-minute telephone calls (e.g. Dougherty et al., 2004). In addition, as Nurses do not need to be trained to deliver the intervention, and patients to do not have to make travel arrangements, this intervention is accessible to every ICD patient. Due to the low cost to produce the booklet and its ability to be delivered without using any NHS resources, this intervention should be sustainable long-term.

WHAT SHOULD HAPPEN NEXT?

This thesis has described the creation and testing of a brief psychological coping intervention. Despite the simplicity of this study intervention, the modest results found in the pilot RCT suggest that the intervention group did appear to derive some benefit from the booklet. The intervention appeared to be effective in helping lower levels of depression, increase patient acceptance and to gradually build up levels of exercise undertaken by participants. This written intervention was only tested on patients who did not have high levels of distress. As such this intervention is likely useful as an important *adjunct* to routine care but it is probably not suited to patients with high levels of psychological distress, who need intensive psychological support.

In line with MRC guidelines (2008), the next stage is to carry out a randomised control trial (RCT) using patients from several health boards across the country. However, it is suggested that a RCT be carried out to test the efficacy of this

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[112] Written booklet = approximately £0.81 to print (with colour front and back cover). The CD = approximately £0.20 and case cover and label £0.50

intervention booklet only after some changes have been made to the study design, the written intervention and its delivery. The RCT needs to take into account:

1. The recommended changes to the study design (see section 'Recommended Changes to the Design of the Study' in Chapter 9)
2. The recommended changes to the written intervention (see section 'Recommended Changes to the Written Intervention' in Chapter 9)
3. The recommended changes to the delivery of the intervention (see section 'Recommended Changes to the Delivery of the Intervention' in Chapter 9)

The RCT should ideally have two groups: 1) a control group (routine care) and 2) an intervention group (written booklet). It might be that a web-based intervention like the eTIPS intervention (Bundy et al., 2013), would be more economical than a booklet long-term, and the ability to access it online might appeal to some patients. Albarran et al. (2004) suggested ICD patients might benefit from a web-based interactive intervention but the ICD population generally tend to be older adults an e-intervention might not be as well received as a booklet. A systematic review by Crabb, Cavanagh, Proudfoot, Learmouth et al. (2012) found that older adults (65+) were under-represented in trials to test computerised CBT interventions. Therefore, it is unclear how older adults might cope with an electronic version of the booklet. As a three-armed RCT would require more participants, it is recommended that the RCT focus on the written intervention. If the intervention is shown to be effective in reducing psychological distress, reducing avoidant behaviours, and increasing exercise with meaningful differences found in scores between-groups, then other delivery methods could be explored.

With advancing technology, one day it might be possible to create an app especially for ICD patients. The app could display an avatar (who might be an 'arrhythmia nurse' or a 'paramedic'). A couple of participants in the qualitative phase of the study had already personified the ICD as a 24-hour paramedic named CID. The patient might be able to speak to the avatar to receive reassurance. For instance, the patient might say 'I'm worried that I might ever feel fit again' to which the avatar could pose questions to challenge their thoughts. Because of the increase in genetic testing (see the section 'Gap in Research Identified from this Study' below) over the coming years, there might be younger ICD patients, who might prefer an app-based intervention compared to a written booklet.

GAP IN RESEARCH IDENTIFIED FROM THIS STUDY

To the researcher's knowledge, apart from one US study (Subasic, 2013), there appears to be a dearth of qualitative studies that explore living with a cardiomyopathy or a channelopathy. There do not appear to be any UK qualitative studies exploring how patients with a cardiomyopathy or a channelopathy cope with their condition. Furthermore, despite the advances in genetic testing, there appears to be a gap in research into how individuals cope with knowing that they or a family member might be at risk of inheriting a genetic cardiac condition.

Research into coping with a cardiomyopathy or channelopathy is also recommended for the following reasons:

The qualitative phase of this research study found 'anger and frustration towards the NHS' was a unique qualitative theme expressed by partners, which to the researcher's knowledge has not been published before. Partners were angry for two main reasons:

1) Partners believed the NHS had been slow in diagnosing the patient's cardiac condition
2) Partners were worried that their **children might have inherited** their partner's cardiac condition and were angry and frustrated with the NHS.

Partners were frustrated and angry with the NHS for not always being able to diagnose if their children had inherited the 'faulty' gene. One partner was extremely distraught that the NHS would not fund a DNA test, but would not allow him to pay for the test. Therefore, if genetic testing is not available, partners might benefit from an intervention to help them cope with living with the uncertainty that their children might have an inherent faulty gene.

Results from the quantitative phase suggested that having a cardiomyopathy was a risk factor for increased anxiety at 3-months in patients (see table 9.20). In light of the fact that anxiety has been shown to increase the risk of an arrhythmia (see Burg et al., 2004 and Kop et al., 2004), it is important that anxieties in patients are reduced. Accordingly, it is important that health professionals explore how living with a cardiomyopathy can increase anxiety.

Furthermore, it is likely that in the future more individuals might receive testing for genetic cardiac conditions. Since the discovery of the first cardiomyopathy-causative gene in 1990 and the first channelopathy causative gene in 1995, testing for heritable cardiomyopathies and channelopathies has advanced from being basic scientific discovery to clinical application (HRS/EHRA, 2011). The Heart Rhythm Society (HRS) and the European Heart Rhythm Association (EHRA) suggested that with the increased knowledge in genetic testing, genetic counselling is recommended for all patients and relatives living with an inheritable disease. They suggested that counselling should include a thorough discussion of the risks, benefits and options available for clinical genetic testing. To the researcher's knowledge, there are no qualitative studies, which explore how families cope with the decision-making process for having genetic testing, coping with waiting for results, or living with the diagnosis.

GLOSSARY

Autosomal Dominant	Autosomal dominant means that each child of an individual has a 1 in 2 chance of inheriting the mutated gene
Autosomal Recessive	Autosomal recessive means a person will only develop a condition if both their parents are carriers and two copies of the genetic mutation are inherited.
Elective Patient	An elective patient in this study was a patient who was a primary prevention patient. Elective patients were placed on a waiting list for an ICD and came into hospital overnight to have the device implanted.
Episode	The term 'episode' appears to be a common word for any therapy from an ICD from pacing to shock therapy.
Interrogate	The term 'interrogating' refers to downloading the stored data from the ICD device. Interrogation of the cardioverter-defibrillator is performed by communicating via electromagnetic coupling with a donut-shaped electrode that is placed over the device and attached to a programmer, which is specific to the device of each manufacturer. Interrogation allows the physician to determine which electrical therapy has been given and when they were received.
Primary Prevention	Primary prevention patient are those patients who have not had a cardiac arrest. These patients are fitted with an ICD as they have an increased risk of sudden cardiac death.
Remote Monitoring System	A remote monitoring system is transtelephonic interrogation system that allows heart rate, heart rhythm, and battery status data to be automatically transmitted to a physician by wireless communication without the patient being present at the consultation (Burri, Heidbüchel, Jung & Brugada, 2011).
Secondary Prevention	Secondary prevention patients are those patients who have been resuscitated from a cardiac arrest.
Sudden Cardiac Arrest	Sudden cardiac arrest refers to when the electrical system within the heart malfunctions causing the heart to beat in such a way that no blood is pumped around the body.
Sudden Cardiac Death	A sudden unexpected death caused by loss of heart function eg sudden cardiac arrest.
QRS Complex	The QRS complex represents ventricular depolarisation (ventricles contracting). The QT interval is the time between onset on ventricular depolarisation and the end of ventricular repolarisation (the QT interval is corrected by the Electrophysiologist to take into account the individual's heart rate). The QT reading can diagnose Long and Short QT Syndrome

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Living with an ICD: Developing a Brief Psychological Intervention for Patients Living with an Implantable Cardioverter Defibrillator

Two Volumes

Two of Two Volumes

NINA KUMARI HUMPHREYS

Submitted to the University of Wales in fulfilment of the requirements for the Degree of Doctor of Philosophy

Swansea University

2014

APPENDICES

Appendices for the Qualitative Study

Appendix I	Sample introductory letter sent separately to a patient and their partner who have not experienced an ICD shock
Appendix Ia	Sample Introductory letter sent separately to a patient and their partner who have experienced an ICD shock.
Appendix II	Participant Information Sheet (Qualitative Study)
Appendix III	Participant Consent Form (Qualitative Study)
Appendix IV	Sample letter sent to participants to confirm the date and time of their interviews
Appendix V	Transcripts of **Patients** (S=shock patient; N=non-shock patient) • S01 • N03 • N04 • S05 • N06 • N07 • N08 • N10 • N11 • N12 • S13 • N14 • S15 • N16 • N17 • N18 • N19 • S23
Appendix Vi	Transcripts of **Partners (**S=shock partner; N= non-shock partner) • S01.1 • N03.1 • N04.1 • S05.1 • N06.1 • N07.1 • N08.1 • N10.1 • N11.1 • N12.1

- S13.1
- N14.1
- S15.1
- N16.1
- N17.1
- N18.1
- N19.1
- S23.1

Appendix VI	Table of themes for patients
Appendix VII	Table of themes for partners

Appendices for the Pilot Randomised Control Trial

Appendix VIII	Participant Information Sheet
Appendix IX	Sample Participant Consent Form
Appendix X	Baseline Psychological Measures Questionnaire for Participants. (The 3- and 6-months used the same format but the wording on the front cover was changed to Time 2 [3-months] or Time 3 [6-months).
Appendix XI	Sample form used to collect demographic and contact details
Appendix XII	Letter of Introduction to Ward Sisters
Appendix XIII	Sample Bristol Participant Information Sheet
Appendix XIV	Computer Algorithm
Appendix XV	Covering Letter at 3-months
Appendix XVI	Reminder letter sent to participants after 2-weeks
Appendix XVII	Process measures sent to participants in the intervention group at 3-months
Appendix XVIII	Letter sent to Professor Bisson, which reported the favourable outcomes of the independent assessor, who examined the data of the first 30 participants.
Appendix XIX	Brief Psychological Coping Intervention
Appendix XX	Getting on with life: Stopping Smoking
Appendix XXI	Getting on with life: Eating Healthily
Appendix XXII	Table of ANCOVAs with Adjusted Means

Appendix I: Sample introductory letter sent separately to a patient and their partner who have not received an ICD Shock

REGIONALCARDIAC CENTRE
MORRISTON HOSPITAL
SA6 6NL

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

Tel: +44 (0) 1792 702222

Date:

Dear

I am writing to introduce you to Nina Humphreys who is a researcher at Swansea University. As part of her PhD, she is looking at how patients and their partners cope with living with an implantable cardioverter defibrillator (ICD).

Nina would like to interview you and your partner to find out how you are coping with your ICD. The interviews will provide information to help develop a self-help programme for people with ICDs. The enclosed Patient Information Sheet gives you more information about the study. Because we would like to interview you and your partner, I am also sending them a letter about the study.

If you would like to take part in the study or would like more information about it, please complete the attached form and send it to Nina in the enclosed envelope. The form will give Nina permission to contact you individually so you can ask her any questions you may have, or arrange to meet you.

If you do not wish to take part in this study, do not complete and return the form. You will not be contacted again. Please be assured that your partner's NHS care will not be affected by your decision whether or not to take part in this study.

Yours sincerely

Wendy Churchouse
Arrhythmia Specialist Nurse

Name (please print):
Address:
Postcode:

Telephone: **STD code (_______) __________________**

Appendix la : Sample introductory letter sent separately to a patient and their partner who have received an ICD Shock

REGIONALCARDIAC CENTRE
MORRISTON HOSPITAL
SA6 6NL

Tel: +44 (0) 1792 702222

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

Date:

Dear

I am writing to introduce you to Nina Humphreys who is a researcher at Swansea University. As part of her PhD, she is looking at how patients and their partners cope with living with an implantable cardioverter defibrillator (ICD).

Nina would like to interview you and your partner to find out how you are coping with your ICD, especially since you have experienced a shock. The interviews will provide information to help develop a self-help programme for people with ICDs. The enclosed Patient Information Sheet gives you more information about the study. Because we would like to interview you and your partner, I am also sending them a letter about the study.

If you would like to take part in the study or would like more information about it, please complete the attached form and send it to Nina in the enclosed envelope. The form will give Nina permission to contact you individually so you can ask her any questions you may have, or arrange to meet you.

If you do not wish to take part in this study, do not complete and return the form. You will not be contacted again. Please be assured that your NHS care will not be affected by your decision whether or not to take part in this study.

Yours sincerely

Wendy Churchouse
Arrhythmia Specialist Nurse

Name (please print):
Address:
Postcode:

Telephone: **STD code (________) ____________________**

Appendix II: Participant Information Sheet (patient information sheets were similar but the wording was adjusted to be relevant to the patient)

A study about the Psychosocial Concerns of Patients with an Implantable Cardioverter Defibrillator

Participant Information Sheet For Partners

Please take time to read the following information carefully. Please feel free to contact us if anything is unclear or you would like more information.

What is the purpose of this study?
We are interested in how patients cope with living with an ICD. The results of this research will help us to develop a self-help guide for new patients with an ICD.

Who is carrying out this research?
Nina Humphreys who is a researcher from Swansea University is helping to carry out this research. The senior research team are Professor Paul Bennett, Dr Rob Lowe, and Dr Jaynie Rance.

Why have I been chosen?
We have chosen you to take part in this study because your partner has had an ICD implanted recently. Your experience of living with an ICD may provide important information that will help us develop the self-help guide for patients. Nina hopes to interview about another seven partners of patients who have had an ICD fitted recently.

Do I have to take part?
No, you do not have to take part. Participation in this study is voluntary and you are free to withdraw at any time even after you have been interviewed. Please be assured that your partner's NHS care will not be affected by whether or not you take part in or withdraw later from this study.

Do I have to decide now?
No, you do not have to decide now. If you want more information or are thinking about taking part, fill in the attached form that gives Nina permission to contact you. Return the form to her in the envelope provided. Nina will then contact you to answer any queries that you may have about the study. If you decide you would like to take part, she will arrange to meet you. If you decide you do not want to take part, you will not be contacted again.

What are the advantages in taking part in this study?
Participants in similar studies have found the interview to be a positive experience. Another advantage is that your views and experience of living with an ICD will make a valuable contribution to this area of research.

What are the disadvantages in taking part in this study?
There are no foreseen disadvantages in taking part in this study. The interview will take about an hour of your time. During the interview, you will be asked to think about issues concerning the ICD, which may make you feel worried. Please note that in the unlikely event that the interview causes you distress, you will be asked if you would like to stop the

interview. However, participants from similar studies found the interview helpful and they enjoyed taking part in the study.

What is involved in taking part in this research?
You will be interviewed by Nina, which will take approximately one hour. At the interview, you will be asked if you have any questions still about this study. You will be asked to sign a form, to confirm you are happy to take part in this study. During the interview, you will be asked general questions, such as 'how did you feel when you were told you that your partner needed an ICD?' When the issues of living with an ICD have been explored in full, the interview will draw to a close and you will not be contacted again.

Will my taking part be kept confidential?
All your identifying information collected will be kept confidential and anonymised. All your responses will be kept confidential. With your permission, the interview will be taped and the tape will be destroyed after 10 years.

What will happen to the results of the study?
The results from this research study will help inform a team of psychologists (see above 'Who is carrying out this research?') how to develop a self-help guide to help new patients cope with their ICD. The results will be summarised for patients and this will be sent to you as an information sheet on the completion of this study.

Complaints Procedure:
If you would like to make a complaint about any aspect of this study, please contact:

Professor Paul Bennett (Chief Investigator)
Psychology Department
School of Human and Health Sciences
Swansea University
Singleton Park
Swansea
SA2 8PP

Tel: 01792 606830
Email: P.D.Bennett@swan.ac.uk

Details of Insurance
Insurance and indemnity is provided by the Department of Research and Innovation, Swansea University.

Who has reviewed this Study?
The Welsh Office for Research and Development, (Welsh Assembly Government Health Studentship Award) has funded this study through an award made to Professor Paul Bennett, School of Human and Health Sciences, Swansea University. The South West Wales Research Ethics Committee has reviewed the study.

Appendix III: Sample of a participant consent form. A similar one was used for patients.

Patient Identification Number for this Study:

A Study about the Psychosocial concerns of patients with an Implantable Cardioverter Defibrillator

Consent Form for Partner of ICD-Patient

Please initial
Each Box

1. I confirm that I have read Participant Information Sheet and I have had all my questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and without my Partner's medical care being affected. ☐
3. I know that I may ask for the interview to be stopped at any time without giving a reason. ☐
4. I understand that a digital recorder will record the interview. I am happy for the use of my data, which will be anonymised, to be used in the write up of this study, including quotes used verbatim. ☐
5. I understand that all data relating to me obtained for the purpose of this study will be treated with sensitivity and confidentiality. ☐
6. I understand that my partner's Arrhythmia Nurse Specialist will be informed of my participation in this study. ☐
7. I confirm that my partner is happy for me to take part in this study. ☐
8. I agree to take part in the above-named study ☐

_______________________ ___/___/ 2012 _______________________
Name of Participant Date Signature

_______________________ ___/___/ 2012 _______________________
Name of Person Taking Consent Date Signature

Appendix IV: Sample letter sent to participants to confirm the date and time of their interviews

24th January 2012

Dear Mr and Mrs

A study about the Psychosocial Concerns of Patients with an Implantable Cardioverter Defibrillator

Thank you so much for taking part in this study. Your experience will make a valuable contribution to this research area.

Interview Time: **4pm**

Interview Date: **Wednesday 8th February 2012**

I look forward to meeting with you and if you have any questions in the meantime, or you would like to change the interview time and date, please do not hesitate to contact me on **07512 822142.**

If you change your mind and do not wish to be interviewed, please contact me on the above number to cancel the interview and I will not contact you again.

Nina Humphreys
Researcher
Swansea University

Transcript for S01
Patient with ICD for Primary prevention
Male aged 66 years.
In line with ethics, the participant's name has been changed to 'Tony'. 'I' stands for the interviewer.

I: So, how are ... you have an ICD, where about is it?

Tony: there, (pointing to left hand side of chest).

I: Are you conscious of it?

Tony: I'm conscious of it if I sort of, physically turn over in bed. One of the reasons it's that side, is that I always sleep on my right and I know if I turn over now onto the left, if ever I do it, then it sort of squashes it. And the other consideration was golf so erm .. we did discuss it, the surgeon was very good and we decided on that side...

I: For the golf?

Tony: mainly yes, yes. Erm the sleeping too ...

I: So, is it just uncomfortable?

Tony: yes, yes, it's not even uncomfortable ... I can feel it, I'm conscious of it ..

I: Are you conscious of it all the time?

Tony: no, no ... it's just when you do that (crosses one arm in front of other) ... it's quite easy to move about (wiggles the ICD box through his shirt).. So, initially I asked where it was going to be fitted ... 'well we put it in a little depression in the chest' and I was criticised for not having enough fat so it isn't set, it's quite raised.

I: were you given the option of having it fitted anywhere else?

Tony: No, no, I just took advice, that's all I wanted to do and get on with it

I: So, how did you feel when you realised that you had to have the ICD?

Tony: I don't think I realised initially that it would be more than a pacemaker. And pacemakers were being talked about and the ICD bit only came in when the ventricular tachycardia was indentified. Because I was falling over all over the place so that meant that there had to be a sort of back up, which I really wasn't aware of 'till fairly close to the day, when it all went wrong (laughs)

I: When you say it all went wrong ....

Tony: Well I was ... I don't know whether Liz has covered this but on the day it was due to happen, I went down to .. it's not really a theatre, it's a ....

I: Pacing lab?

Tony: Yes, there do treat it fairly light heartedly there and a piece of plastic came off the device and went intravenously, if that's the right word, and ended up in one of the lungs and I had to be rushed off to other areas of the hospital ... people got kicked out of lifts to get me there. So, it took about an hour and a quarter to track this thing down and to remove it by which time something like four hours had gone by. And erm ... Dr Lee (named changed) who was supervising, although he wasn't actually the man who was trying to put it in ... took over and he was very good in the sense that he followed me down to .. the theatre .. It wasn't where I'd been since but it was a theatre where there had a lot more x-ray bits and all the rest of it. So, the tracking down of this piece of plastic bit and the removal of it, I was fairly shattered at the end of all that, cos I was awake during the whole thing anyway.

But Dr Lee actually came with me so I had a talk with him upstairs, he said what had gone on and 'this is what we're going to do and I'll stay with you' and he did. And that gave me a lot of ... you could have panicked ... but I didn't and the fact that he was there during this fiasco, one knew that if something went more wrong .. bad English, then erm .. the boss man was there as far as the heart was concerned. So, they decided I'd had enough, sewed me up, sent me upstairs.

I think the worst part of it, as far as Liz was concerned was that while I was still being .... 'searched' ... erm ... downstairs .. they asked if there was a relation of Tony X there.

I: Right ...

Tony: and the guys on the ward went (moved his eyes to the side). Erm, I don't know how it could have been done any better but the inference is that if somebody says 'is there any relations here' that you know ... there's been something really nasty. These guys came up with masks on and you know that went down like a led zeppelin, so that ... that is an observation not a criticism. That er ... added to the memories .. certainly. So, if somebody had said er 'he's ok, but he's stuck downstairs ... is there anybody here' then that would have been a more .. but they were a fantastic team of people, the nurses ... anytime day or night I mean I wasn't a happy man, I mean I was wired up all the time till it was actually done and I mean just having a shower, going to the toilet .. you know I tried to con them into letting me go .. erm ... 'No'. No, too wise for all that, so erm ... fantastic team of people.

I: do you and Liz talk about what happened?

Tony: Erm ... I think we did for a while ... erm I'm not sure ... er one the lasting legacies of course is this driving business. So I haven't ... er... I've got about a fortnight to go ... so ... er it isn't possible on a daily basis with me not driving, being chauffeured everywhere to forget why ... yes so that in itself jogs .. you know ... there's no way round that but for Liz, she's had a lot on her plate, a hell of a lot on her plate, so erm you know ... the pressures in work and the rest of it. We've had our own business for about 30 odd years .. so all in all, I've had it easier than she has in my humble opinion. At least I know how I feel and how I felt in comparison to before and after ..

I: How do you think your wife feels?

Tony: Erm ... certainly been better the last couple of months. I still .. even if I adopt a certain pose or I'd be bending over doing my shoes up or ... she used to say it about 20 times a day and it's probably down to 2-a day. Er ... but it will have had a lasting effect. Well, it wasn't much fun before and I was passing out and I was battering myself out at David Lloyd ... somebody saw me go down ... I just went apparently, you know if you fall over (put his arms out in front of him to demonstrate how you catch yourself if you fall) it's automatic. Don't remember a thing, don't remember a thing. So, erm ... I was too blasé about it for too long. Much too long. I was being the brave Englishman or Welshman in this case and it's fine. I used to tell the blokes on the golf course, 'look if I do pass out, count to 20 and I'll be alright', which historically had been the case.

But generally I did not have a problem exercising ... that was one of the things I held on to .. it was more of a potential risk, it was more when I was doing nothing that it was likely to happen. And if I understand from the figures that I'd been quoted. I mean when I was in the hospital and wired up I saw my heartbeat going down to 27 and when I passed out, it was going up to anything approaching 300 ...

I: ok ..

Tony: So, it was this sudden swing ... just sitting here having a cup of coffee, it would go pow! and I'd be out ... cos of course the heart doesn't pump it just shakes. So, erm ... that was the worse bit as far as I was concerned. I came up those stairs one day (pointing to garden steps that led up to the room where we were sitting) ... walked up three or four steps, got to where you are now and just passed out. Ridiculous.

I: So, for you the benefits of having this ICD on a day to day basis ...

Tony: Erm I think the benefits on a day to day basis is the heart ... er ... what's it called ... is the pacemaker element. I don't think, apart from one occasion we got anywhere near needing it. But I do feel, I've thought for years, er ... I saw a couple of specialists Dr Davies, er .. Dr O'Hanlon (names changed) and I used to talk about the palpitations ... which I sort of still get ... erm ... I can feel it ... but it doesn't go anywhere ... whereas before, it did. It could actually raise a heart rate quite quickly and erm ... that really got me down.

I: So, you were very conscious of it?

Tony: Oh yes, yes.

I: Are you conscious of it now?

Tony: conscious of it but it doesn't worry me now, I still have palpitations, more in the morning than any other time, erm ...

I: do you find yourself checking them?

Tony: no, no, I mean this has been going on since 2004 .. the first time I passed out. And I was just sitting at a desk. And suddenly I was conscious of somebody saying 'are you alright?' ... And as the years went on, it happened more frequently but not, as I kept saying, it had never happened when I was driving otherwise I would have stopped. And it never happened when I was exercising. It was more when I was sitting.

The day after, the people were fantastic, the people at David Lloyd. And the day after I went back with friends and was having a cup of coffee, and it happened again, just sitting down. But it could .. it could come from anywhere so erm .... I packed up driving erm .. at the beginning of June and the ICD was fitted on the 13th. So, we've only got a couple of weeks to go and hopefully I'll be driving again.

I still get tired, but then you know, we are getting older and Liz certainly gets tired, and I think she worries about it far more than even I pick up. I do know when she concerned erm .. We were walking through Regents Park earlier and we were going to walk up Primrose Hill and er .. I ... we were just walking along in the park and I felt ... strange. I sat down and sort of effectively got my breath back. Not that I was out of breath ... that's more of a ...

I: This was after your ICD?

Tony: No, no, this was before .... all these things were bringing home the fact that something had to happen and we couldn't go on like that. I said 'oh I'm alright now', because normally after an event, that was it, it might not happen for another week, fortnight, three weeks. And of course the bottom of Primrose Hill, I don't know whether you know it, I was 'come on then off we go!' We went about 10 yards and I couldn't go any further, and that was the first time it had ever happened, after I would say, exercising. It hadn't happened before, and I just couldn't make it. So, erm .. we went and found a cafe and sat and had some water and all the rest of it.

I put it down for some while to caffeine .. I used to drink a lot of caffeine, double espressos and things like that, ... it was the first time I'd felt funny, after a double espresso. And I'd been drinking decaf .. therefore, more recently. I'd cut out the caffeine in case it was just that. You look for simple answers don't you, it's human nature ... it's tiredness .... and stress *undoubtedly* had affected me ... and my son is having to shoulder it all now, which is still a stress. I was worried this morning as I'd worried yesterday. If the phone rings I think 'oh, what's happened' I haven't been in for 6-months now, and I don't want to, which is a worry in itself because I've always been a Type-A person, get up and go for it, you know that sort of ... you know ...

I: So, the ICD has changed your ..

Tony: I think the ICD comes under the heading 'everybody should have one' because as I've sort of said, as it was explained to me .. I have to take things in and convert them as I want to .. what we've got here is an insurance policy and if the pacemaker itself fails then something else is there .. which in itself of course doesn't, doesn't have to work does it? In a sense if it goes off, it might not sort out the problem ... might have extremely high heart rate and therefore that's it. But realistically it's an insurance policy.

I: do you fear the ICD may not work? Because you've experienced a shock haven't you? So, you know it works?

Tony: oh yes, yes, absolute wallop!

I: Did you pass out?

Tony: no, no, well I don't think I did, don't think I did. But I'm pretty sure I didn't cos I commented at the time ... I don't know how to describe it, it was more like being hit by a bus. Somebody said it would be like hitting in the back with a golf club but it was more than that, oh yeah, it was a wallop. And we knew it worked cos I went back for the cardioversion.

I: So how do you feel now you've had a shock?

Tony: (long pause) No different really, in the sense that even when things were going very wrong during the operation, whatever happened next was going to be better than this sort of continual worry that something was going to happen.

(interruption as wife walks in to get her mobile phone and exits again)

Tony: So, I think the knowledge that the pacemaker is there is probably more influential in terms of mental thought .. psychologically, than the ICD.

I: So, the activity you were engaged in when you had the shock .. would that stop you from doing that again?

Tony: (long pause) Yes, probably. But ... because we're both 66 now and erm, I don' think .... things are as important as they used to be ... and erm ... obviously since the operation etc ...

I: I'm just trying to understand why you wouldn't ... is it fear of shock, the pain?

Tony: I think those days are generally more distant anyway erm .... and ... I don't think .. I don't think .... but you know, there are lots of other ways of showing affection than .. perhaps not necessarily having to er .. complete the event. Which is fine, you know ... if ... if it happened, then fine, I don't think it would .... (long pause). I mean it was definitely that, there's absolutely no doubt, it was definitely that that caused it ..

I: the increased heart rate?

Tony: yes

I: right

Tony: definite, ... would it put me off? I think it would have to be a subject for conversation, discussion about it. I'm sure Liz would be ... actually more concerned about .. me ... erm .. and we're happy holding hands ...

I: Did you talk about it afterward?

Tony: (laughs)

I: Is it something you can kind of talk about?

Tony: oh yes, I'm not ... we do .. we do ... I mean we do talk things but I think the only way I can cope with it ... was, I mean there's the classic old joke 'what a way to go!' so the expression is ... which again is how I've managed to cope with a lot of these things ... you know .. I just tell everybody I'm going to live to 130 ... I mean even warfarin I've coped with in the same way. I wasn't happy at all when I first started taking warfarin, but I think that upset me more than anything ... but, it thins the blood 'good'! It reduces the risk of thromboses so, 'good' ... erm ... it's it's that ... I do prefer to joke things ... I mean it would not stop me going anywhere .. insurance and travel is an issue, but I've declared everything as it's gone along. The travel insurance people were quite good. We were going to France, cancelled that .. it was fine, got our money back .. you know ferries and things, carried forward to next year. We were going to a hotel in Devon for a week .. they carried that forward and eventually we went back for a week, not quite in the same apartment .. but fine. So all that sort of thing

I: So, you are trying to continue as normal?

Tony: Oh yes! Again, I mean physically erm ... I don't think I've changed at all, but I mean I love my golf, go down the driving range.. I've ... I'm aware sometimes, I've been digging the garden and all the rest of it 'I think I'll stop now'. You know, I went swimming this morning ... I've never learned to 'breathe' as in breathe properly when you're swimming so, I do a length .. 25 meters, whatever it is without breathing. And erm .. some days that's easy and I'll do eight or ten .. space out .. not at the same time ... other days 'no, don't *like it this morning'*.

I mean one of the things, before we got to the detail of wearing the tape that identified that it was more than just atrial fibrillation ... erm .. I'd had a series of beta-blockers but one of them, I can't remember its name ... I'm on bisoprolol now ... it's something ... I only had to look at it .. I could not, I just stopped taking them .. I rang up (name of doctor) said 'sorry lad, I'm not taking these'. So, erm... then I was fine again

The bisoprolol which has been increased and not convinced, really not convinced, I'll try it for a couple more weeks but I think it's had ... a detrimental affect ... you know I'm on a whole series of you know, ramipril, sorry are you a medical person?

I: No, I'm not .. psychology ...

Tony: so, I'm on things to reduce blood pressure, well blood pressure was never desperately high but these are all good things, I wasn't ... (name of drug) has been changed to fleconide

I: So, you are finding your regime of medicine is perhaps more .....

Tony: I still have a problem with taking the tablets, I don't mean in actually swallowing them but I ... it's the old Type-A person again see ... I don't like being reliant on .. *anything* really .. er .. er .. so

I: So, how do you feel relying on the ICD then?

Tony: It's .. it's sort of like having a good friend I suppose, .. it's nice to know it's there, .. but as I said just now, I don't ... having a pacemaker is what is stopping the heart rate from going too low, or going to high .. so *that's* where I was having a problem. The fact there is a bully in the cupboard just in case and he's on my side ... that's nice to know.... But I don't honestly think about it, I really don't, it's the pacemaker bit I'm pleased about .

I: Do you know the limit your heart can go up to before it delivers a shock?

Tony: I think it's about 200 ... or if it goes through 200. So, the fact it has not been limited by the pacemaker, sort of trips a switch effectively, but I don't know whether there's a margin for error .. if it goes through 200 but doesn't go through 220 that's all right, or whether just going through 200 fires the cannon, I'm honestly not too sure, but it's something like that. But I don't really ...

I: You don't restrict your activity to ensure ... you don't go above 200.

Tony: No, no .. I didn't ... I didn't think anything would knock it up to that ... but ... it did. Other than .. no doubt ... you know I'm not sitting here trying to make light of it, there is no doubt it was that activity which did it ...

I: so, why would you not risk doing it again? Is it because of the shock, because you may not next time ..

Tony: No, but .. erm .. as I said I think it would be very difficult to put that out of one's mind ... honestly, it's er .. trying to think of an analogy really ... I mean if you knew one more drink would put you over the limit, you wouldn't have that drink, whatever the reason was

I: It 'taints it?

Tony: Yes, yes, yes yes so .. er ... er ... I think ... I can't see that Liz would want to run that risk anyway because it sort of .. certainly wasn't very pleasant ... and I mean it says in the book 'would your partner feel a tingle?' Blinking heck, it was more than a tingle. It's a funny ... but it's certainly not affected our relationship. Liz has had trouble, sleep-wise for a long time, which I'm sure is connected with me. And all this driving grandchildren around, take them from one school to ... my daughter's at teacher ... and um ... all that sort of thing also ... you know several times in the past few months, I've wanted to say 'I'll do it!' But I can't ... another two weeks hopefully. I mean I know these things ... somebody down in the DVLA will say I've filled it in the wrong colour ink or ticked the wrong box or

It's certainly not uppermost in everybody's mind ... I am healthy and it works and the rest of it and certainly at our age it's secondary ... it will take a little while to get over ....

(Break, chat about study and who else I'd be interviewing – information that would have been found in PIS)

The trouble is when you're in hospital there is so much info flying around ... and the guy in the next bed has a heart attack and dies overnight .... it's difficult to take everything in.... I mean it's always a good idea to take someone to the doctor with you for something serious 'did he say that? you're sure?'

I: So, how much time did you have to think about ..

Tony: I was in hospital for a fortnight .. as soon as this tape showed the serious problem, I was in the hospital within about an hour and a half.... and from that time I was there for a fortnight,, 15 days specifically ... I've been back a couple of times since, said hallo to the nurses ... as I say, their ability to answer questions day or night 'what's this mean?' 'Oh that means ....' or 'when I've done this, I'll come back; they had a lot of time ...

There was only one doctor who I .. er... shall remain nameless ... who I was very grateful was not treating me ... I thought he was absolutely appalling and it was really really interesting, of our ward, and it was a four-bed ward, there was a professor of medicine ... he'd been down here ... he'd talk apparently a lot of people in (name of hospital) but he did not make his presence known to different people. Er, the nurses only after a while got to hear that he was there ... I mean some of the things he was asked to do by a fairly junior nurse .. um .. were laughable, but he didn't once ... 'oh, sorry you want me to ...'. He was a gentleman, very, very nice. He kept himself to himself, he certainly didn't want any sort of special treatment. But we had a phlebotomist in one day ... it was shear joke, absolutely joke, and he failed to get any blood out of our professor ... had he come to me, I'd have said no. I have no trouble with needles at all ... he was incompetent, seriously incompetent. And he turned round, tripped, hit the tea-trolley, which had a tea-pot on, sent that spinning on the floor ... it ... it was Eric Sykes stuff .... oh but that one doctor. Oh I'd give them a ten out of ten (presumably talking about the other healthcare staff), fantastic really were, superb ...

You hear some horrible stories of ...

I: How about the literature you were sent home with?

Tony: We had the book, sort of leaflet, read that, I've joked about the bit I've just referred to ... although I have made light of ... I mean people at the swimming pool say 'what's that sticking out of your chest?' .... but we ... to answer your question, went through the leaflet .. found it informative all the rest of ... but it's not till it happens you .. you know what its about. As I say it was .. definitely a thump (pretends to thump chest) ... no it was fine

I: You were given a couple of British Heart Foundation books?

Tony: yes, so we looked at the AF, there's some news bit about that ... knew I had AF but it was obviously more than that ...

I: it's the tachycardia that the life-threatening bit?

Tony: yes, Dr Linton was fantastic, Dr Lee and Dr Peters (names all changed) was the one that went on the fishing trip ... er .... as I said I went down originally about 12 o'clock and I think it was gone five when I came back ... I was absolutely ... so they just sewed me up and said 'right we'll see you tomorrow'. And Dr Lee said '*I'm* doing tomorrow'. So, back down the next day and erm .. quite simply he said 'I think you've had enough' and I don't remember anything else ... whereas I was awake the previous day.

I: So, he knocked you out did he?

Tony: Yes, yes, but strangely I wasn't ... I'm not a panicky person ... I do get angry about things ... I don't get to point of phy-physical action ... erm ... but I had a lot of time to contemplate 'what if ..' and you're looking at all the monitors .. the X-rays, and this thing going round .. and he wanted a longer one and that didn't work ... and I was too tall, it was a pity, if I'd been shorter, they could have done this, and could have done that ... and you're looking at the clock and an hour and a half's gone so, erm ... it's.. it's sort ... it's that I'll remember for a long time ... and I'm sought to tell Liz some of the thoughts but I was, I was extremely calm. I know, I couldn't go anywhere, couldn't do anything and I had a lot of faith in the people. Obviously more so, after a successful conclusion but also at time.

(break – chats about the make of his ICD)

I: Some ICDs that are fitted now are remotely monitored ... how often do you go back ...

Tony: yeah, I go back and they put a donut over you .. I think it was initially ..., one might have been a couple of weeks and after another one three months on. I went back after the firing last week .. er .. a couple of weeks ago now. Yes, I'd heard about the ... it's just amazing isn't it ... 'do this, do that .. you can feel this ..heart increase? Yes good'

I: How do you feel if you didn't have to go into the hospital? Do you enjoy going?

Tony: no, no I don't have a white coat syndrome or anything like that

I: Do you feel reassured by the nurses and technician when you go in or would you prefer to do it from home?

Tony: it doesn't bother me ..honestly .. either way .. I don't have any hang-ups about going in there, I'm not concerned when I go in there. The nurse is a nice girl .. I don't feel worried when I go in ..

I: Do you gain anything from the nurse by going in

Tony: Well, this is six-months on now you see ... definitely to start with I did and then, child-birth is an obvious ... eventually it fades to a point when you are daft enough to do it again ... and so, it really doesn't bother me. I was obviously more concerned after the event but I think the euphoria of feeling better ... I er ... wasn't then suddenly concerned as I said before, I have nothing but confidence in the people who looked after me, so I've never been in a concerned state. Not even a couple of weeks ago when I went in because ... I knew what had caused it. So, you know ... I have no concerns at all .. to date um .. um .. since it was sorted .. and the euphoria of that probably hasn't um .. hasn't gone away ... it's still fantastic.

I: That's great. You're looking well, not that I knew you before but you look well

Tony: Yes, it's a bit warm in here and I'm a bit flushed ... I certainly ... erm .. I enjoy a kip in the afternoon but on the other hand .. I can live without it .. in the sense that if there's something to do I don't suddenly feel too tired. I'm better now than I've been for years you see .. it was a constant worry, worry, worry and now it isn't and won't be unless something goes wrong and it goes off for no apparent reason or the pacemaker bit doesn't do its job ... but if I had once concern it is when I go back in and have it replaced, which is probably about three years. So I've got that, certainly not in the front but in the back of my mind as an event ... and I was a bit concerned with the .. what's it ... the cardioversion? Which I had no reason to be concerned about .. you sleep through it anyway, but I suppose I wasn't ... I thought that was going to be far worse ...

I: Could you feel it?

Tony: No, no, cos you get knocked out ..

I: Oh, I see, sorry

Tony: But before that I was concerned ... I don't know why, I was far more concerned about that ... I think I was trying to explain to somebody else .. I think it was more a question of 'I feel fine, don't want to go to hospital, don't want an anaesthetic, don't want you touching my box of tricks cos its working very nicely thank you very much ... erm ... so I don't want you messing about with it.'

I: When did you get the cardioversion? Don't they do that after the implant?

Tony: No, it was done about ... say about 2-months .... I thought it was going to be done the following day or something but no ... I think they wanted recent data and ....

(looks for date of cardioversion in his diary)

Tony: operation June 9th so sort of two days 9th and 10th ... lots of INRs of course because of the warfarin ...

I: What's an INR sorry?

Tony: INR is checking the erm ...

I: Clotting level?

Tony: the clotting level yes, the international ... something something .... (looking in diary) .. went back in July

I: Did you have any literature on that? Did you know what was going to happen?

Tony: Well, I got this St Jude follow-up type of ... erm ... I got this description in my erm ... mind, of the heart being stopped and restarted ... now I think that helped my concern ... erm ...... there we go! (points to diary entry) 26th August ... so two

I: two and a half months?

Tony: at 8 o'clock in the morning. So, I think that's a description of the heart being stopped and sort of restart ... I wasn't ... over fussed with that sort of description, but then again I felt so good anyway I wasn't too keen on being messed about with in case something went wrong that wouldn't have gone wrong if they didn't mess about with me ... but again ... boss man did it

I: has it changed how you view life?

Tony: ... hum .... how I view life? ... I've been more aware re- ..... I've been working ... I have always worked for the future, so in terms of money that we take out the business for pensions and things like that ... there was a time the business would be our pension but that's not how it worked out. So with things as difficult as they have been in the past couple of years, I think I have become more aware of my age ... not because of anything medical ... er but 'lucky to get over that one .. probably going to have a new hip next year, come on, you're 66, let's do something positive over the next 10 years' erm ... but I'm not thinking of that (touches where his ICD is placed) but what it did when I had the er .. good look around (name of consultant) said ....

when the phone rang and I was coming in, I was sitting there eating a Chinese take-away and I said to Dr (name of doctor) 'I'll just finish my Chinese' 'no, I want you in now' ...er ... that was a bit of a shock in itself ... But having had all the tests ... they'd obviously talked about it (two names of doctors) and one of the last things he said to me was 'you can go home now and finish your Chinese' and that was a fortnight after the event so .... It was very good to know that although I had *a* problem, if I'd also needed quadruple heart by-pass as well cos I was all furred and clogged up .. the fact that I wasn't ... I've got .. you know .. in very good nick .. that was good, you know 'yey!' I'm pleased about that, but I don't .. don't think about it (ICD) .. I really don't ... it's not something I'm aware of apart from physically moving or once or twice on the golf course but it was standing in a peculiar position .... it certainly doesn't restrict me in any way.

Notes:

Description of cardioversion – light anaesthetic is used. Wording could be changed to appear less traumatic.

After interview as I was leaving, he said that if the ICD shocked him and he could not attribute the shock to an increased heart rate, he would be very worried indeed.

Transcript for N03
Male aged 49 years.
Primary prevention patient ARVC
In line with ethics, participant's name has been changed to 'Tom'
'I' stands for interviewer

I: So, can you tell me a bit about why you had your ICD fitted?

Tom: Yeah, it was ... I do quite a lot of running ... run for 25, 30 years and I'd just done a race down in P.. Penarth ... it was only a small, short, short race, three miles, three and half miles and er .. maybe half an hour, three-quarter of an hour afterwards after finishing the race we walked back to the car and I said 'Karen, my heart rate doesn't seem to have come back down to normal', which is unusual for me and er, I was in the car, in the back of the car changing etcetera, etcetera and literally I said to Karen 'I feel like the car ..' we got a hatchback, I was in back of the car changing, ... 'I feel as if the car's shaking' you know, 'vibrating, the car'. Karen said 'don't be silly' She said, we'd better get going, get back home like, you know. So, I changed etcetera, etcetera ... luckily enough then, Karen was driving ... so I'm in the passenger seat now and we'd only gone two miles and .. you know where Comeston Lakes is?

I: Yes, yes I do ...

Tom: All down Redlands Road, hadn't quite reached the hospital, Llandough Hospital ... just coming to the lights there ... I remember coming to the lights and thinking 'oh God, I can feel myself starting to go here' and I just (clicked his fingers) flaked out. I don't remember going around the bend at the lights or anything like that .. I just (clicked fingers again) flaked out. Karen and (son) was in the back as well .. I think they thought I was messing about you know, but er ... Karen pulled over then past the hospital, obviously shook me to get me round and that you know, and I came round quite quickly really ... but sweat ... sweating and shaking, just literally shaking you know .. sweat, never know anything like it really but it was pouring out of me like you know. And Karen was like 'I'm going to take you to the hospital' .. that was where we were close by like you know. I said 'you can't go to Llandough anyway .. there's no A&E there .. there is an emergency admissions, but there's no A&E ...

I: So, you realised there was something wrong?

Tom: I .. well, I didn't think it was that major .. because I have, have fainted in the past .. I have fainted in the past and literally (clicked fingers) come round .. didn't think more of it you know. I've been to see my doctor on a number of occasions but he just put it down to something ... er ... a faint .. vasovagal faint .. something like that, um, that's all history, put it down to, over a number of years this is,

.. so thought it was something like that but when we went into the Llandough Hospital, Karen pulled up in the hospital .. so anyway, said 'go into the car park, lean back a bit, I'll be ok now'. So, I was leaning .. put the front seats down but no matter what I tried to do .. just sweat and shaking .. literally shaking, sweating and if I tried to get up, I'd just go giddy. So, then I think I knew there was something different .. this time you know. Obviously I could still feel my heart racing like that you know ... Karen was like 'right, now I'm going to take you into the Heath' 'No, no, I'll be ok, don't worry' and she starts driving home and that and Karen heads towards the Heath anyway and er ..'pull over' ... you know the Tesco, by the University of UWIC?

I: yes, yes,

Tom: I said 'pull over by here and I'll see if I can sit up, and if I can we'll go home'. As soon as I started getting up again, I started going all giddy. So, 'come on then, we'll go to hospital then' ... the rest is history really ... as soon as I went in ... I didn't have to wait long, ... they took me straight in .. put me onto the monitor ... well, within minutes, seconds, there was half a dozen people around me ... when they put me on the monitor, shoved me on this, shoved me on that and as I said, there was half a dozen people around me .. I think my heart rate at the time was 218 beats a minute .. and that's where it stayed for what seemed like ages to me, but it was probably an hour, an hour and a half I think something like that, obviously tried to transfer me to another part of the .. accident place and that like, and then they were about to ... give me the old paddles like, you know. They called for the anaesthetist to give me an anaesthetic or whatever to give me a belt ...

I: So, you weren't in AF yet?

Tom: No, no I never went into AF at all, just into tachycardia ... they were just about to give me the paddles and that .. I don't know, it was strange, I just said to one of the nurses 'I feel ill, I feel I want to be sick' you know. And as she turned over, turned my head I retched ... and as I did .. little cough or whatever .. (clicks fingers) I come out of it like that. My heart came back to normal. So, they didn't have to give me the paddles ... and then after that then, they transferred me onto .. onto the .. the ward ... coronary care, I think it was first off, for the one night really, to keep me monitored ... and then from there on I was in ... can't remember which ward it was, but I was on it for nigh on three weeks. Constantly on the monitor, they wouldn't let me go anywhere .. wouldn't let me go anywhere, even had a shower with the flaming monitor on and all that, which was a bit of a nuisance, but I know it's got to be done like, you know. All sorts of scans, I had no end of echo scans, ECGs, and a MRI scan in the end ... obviously as a result of all the tests then .. they said I was to have an ICD ... which obviously was a bit of a .. bit of a ... I wouldn't say 'shock' .. I didn't feel a shock, strange to say, but what

I felt really was 'oh well, they know best, they know best .. obviously if this is what I need, then I'm going to have it' That seems very accepting. Did you feel anything else? What you said was describing how you thought, so what about how you were feeling?

I: Have you a medical background, because you work in a hospital?

Tom: No, no, I'm in maintenance, I'm a plumber, plumber by trade.

I: Had you heard of ICDs? Did you know what they were?

Tom: No, no, nothing. Nothing at all .. nothing at all. But actually it was .. it was one of the cardiac nurses came and told me that I was going to be having this ICD, you know. You know, obviously, it was totally new to me. And they did hand me the booklets, the British Heart Foundation Booklets, which were brilliant. Was there anything you'd like to have read about in the BHF booklet? Was anything you read particularly good or bad for you? You know, obviously, we found as much information as we could from those then. One of the nurses then, in the hospital then brought me an actual .. device .. you know, to show me what it was going to be like etcetera, you know. And that was really it like, you know. Just wait really until it was actually going to be done then ... because I knew, probably a week, week and a half before I had it fitted ... it was going to be .. fitted then really. And they just wanted to confirm what the actual problem was .. with the heart you know, so had to wait for .. an MRI scan .. Obviously before I had the ICD fitted because I wouldn't be able to get in to get a scan otherwise you know. And I had the MRI scan on .. the Thursday and I had the ICD fitted on the Friday, you know so ... And home on Saturday.

I: What was the actual problem?

Tom: It's um ARVC. Arrhythmic Right Ventricle Cardiomyopathy. It's ... it's like a disease of the .. heart muscle really. I think it upsets the .. na-natural rhythm of the heart sometimes so, so ..

I: So, how did that make you feel knowing that?

Tom: er ...

I: Especially as you are an athlete?

Tom: yeah ... yeah ... again I don't know what I thought really. It's something I got to put up .. something I got to put up with and knowing ..... and what made it easier for me to accept perhaps was .. 'cos I'd been incapacitated really, 'cos it'd taken me out there really you know, and what one of the nurses had said .. what she'd said was 'if it wasn't .. if he wasn't as fit as he was .. you know if his heart wasn't as strong as it was ..' You know, believe it or not, I had to have the ICD fitted and yet they say my heart was pretty strong you know. If I hadn't trained my heart so well .. I probably wouldn't be here ... What about how you were feeling? Again, what you described were thoughts, so how were you actually feeling? Can you describe the feelings you experienced? So, I think *that* .. so I think *that* then really the underlying thing in my head you know, that running has kept you alive .. you got the fitness to get you back up again and you got to accept it and that's it ... and I must admit I've never .. never found it difficult to accept really .. at all.

I: You've never found it difficult?

Tom: No, no not at all. I would have thought you would have found it difficult as racing was such a big part of your life, and yet you say that you didn't find it difficult. So, why don't you think you found it difficult? Did you do anything to replace running competitively?

I: And has your lifestyle changed? Do you still run?

Tom: Yes, yes .. not to the extent I was, you know I used to do the peaks, I used to run marathons you know ... They have said I can run a marathon if I wanted ... they have said I could run if I wanted so .. th-they could see I was pretty keen into getting back into doing some exercise ... they arranged the treadmill test for me to see what sort of level .. what sort of level I could go up to ... And also, probably .. it helped me probably to know what ... they took my heart rate up to .. they took it up to 170 on the treadmill .. and it was still ok, you know. You know, that's what they said to me .. as long as you don't push yourself to the .. to the anaerobic level ..

I: The what sorry?

Tom: The anaerobic ... you're in oxygen debt then .. you see you're really, really pushing yourself to oxygen debt .. which I used to .. I used to race sort of thing .. you know, I wouldn't class myself as a fun runner, I was a racer and er .. so you were always flat out when I was running .. I was always flat out, especially when I was in races and that like you know,

I: Are you talking about short distance now are you?

Tom: Yes, yeah, well no, I used to run 4, kind of 10 K, 10 miles, half marathons, marathons, but I was all out, I was out ... you still do get into ... you know ..... Oxygen debt really I suppose .. you know, especially at the end of a marathon like, you're trying to get as much oxygen in as you can just to get all your flaming muscles moving you know ... but it's more .. like with training ... you know when I .. when I was doing interval training or 'forklike' (?) training as you call it .. you would really push yourself to the anaerobic state then you'd relax a bit for a set period and then you'd go back again to the anaerobic state so it's just those really, it's the training aspect more than anything ..

I: You must be very in tune with your body .. and your heart rate ...

Tom: Oh yeah, yeah, yeah .. I used to wear a heart rate monitor as well .. even then .. before ...

I: Before the ICD?

Tom; Yes, before .. So, I knew what my muscle heart rate was .. I knew what my resting pulse was .. my resting pulse was always .. God .. 40, 41, 42 .. less than that sometimes .. um .. which is very low .. actually when I was in hospital, I think in the nights my heart rate was going down to 28 I think they said ... very low you know ... when I was on the monitors in the hospital like, you know. So, I was .. I knew, you know what sort of shape my heart was in ... what the levels that my heart could go to really .. you know.

I: So, the ICD hasn't stopped you from doing anything .. apart from running a marathon?

Tom: yeah, I could run a marathon, I just couldn't run it to the levels I was ... to the speeds I was ..

I: So, why wouldn't you do a marathon now then?

Tom: I would .. I would do it yeah ... I would still run a marathon .. like every marathon I run before .. I'd want to run it faster than I did the other one you know, but I can't do that anymore ... you know I've got to accept that .. you know but I'd rather do that ... you know .. than do nothing at all. You know. I can't see that I would be running a marathon again but certainly ... I can see me running 10 miles and half-marathons .. you know, I can't see that being a problem. But where I used to run a half-marathon in .. I don't know .. 70 odd minutes, I used to do it, one day 72 minutes .. it'd probably take me 90 minutes now ... but doing it in 90 minutes is better than doing nothing at all isn't it?

You've been told that you can run a marathon, so why have you decided that you probably won't run one again?

I: so, have you done any competing since?

Tom: No, no, no .. 'cos I know ... I would .... to be able to compete I would have to push my body too much I think ... so I think, I think I've resigned myself to the fact now it's more of .. er .. just run to keep fit more than anything .. I've always said years and years and years ago, I won't run unless I can race, whereas it's the complete opposite now really, I'll run now just to keep fit. I know, you wouldn't to look at me like, but I have put on a stone, stone and a half like, you know... But it's one of those things like, you know. Probably look a lot better for it, you know in the face and that you know, it's just mentally I'm here and I'm happy to get on and do a little bit of exercise like you know ...

I: So, how do you feel that you can't compete anymore? When you raced was it to win the race or to beat your personal best. It sounds to me as if you needed a challenge, so if you are not going to race anymore, how are you going to cope with not being challenged?

Tom: ... um .... It doesn't ... I don't think it bothers me that much now .. doesn't bother me that much ... I'm 49 next week in January .. I did one race that I needed to and I got what times I needed to really, for the certain distances you know. And erm .. I'm happy with my lot really .. you know .. just run really now to keep fit. You know, if I did enter into races, say 10 miles, half-marathons, it would be more for the ... not to actually race it but just to run it .... maybe I'd enjoy it more you know ... maybe I'd enjoy it more ... I'd be looking at the scenery more rather than the guy in front now, you know .. yeah ... so, when was ICD fitted – maybe ask: why haven't you entered any yet?

I: so, for you what are the advantages of having your ICD?

Tom: Um .. knowing ... I think the value of it is .. knowing that i'm probably now in a better position than normal people are really should the same thing happen to me again like you know.

I: When you say 'normal people' you mean the average population?

Tom: Yeah, yes, you know, if the same thing happened to Joe Bloggs .. say we were walking along some remote path whatever, .. the same thing happen to both of us .. I'd probably be the better off because I .. got literally carrying around with me a paramedic you know. That's er .. that's how I feel about it really ... and I think that what .. initially Karen wasn't so happy for me to go out .. you know running etcetera, etcetera you know, by myself you know afterwards, and someone said to her 'Tom is in a better position now than he was prior to having the ICD .. you know, at least you got the ICD there that will keep him alive' .. should something happen, it will keep him alive'. How did Karen's worries affect you? Did you talk about them with each other?

I: Have you ever had a shock from if?

Tom: no, nothing at all .. touch wood .. hope I never do you know (laughs) .. no, nothing at all .. I think they've said there's been a few .. it's worked at the bottom end of the .. of the scale but they also said that it can ... it can .. excuse me (sniffs – has a cold) .. they said should my heart rate go above .. I think they said 220 beats per minute , it'll give me the shock. But also on the bottom end of the scale .. it's like a pacemaker as well and they said should my heart rate go below 40 beats a minute ... you know they set it down that low .. not very happy with it at the moment .. if it goes below 40 .. it'll ... it'll just pulse it back to up to at least 40 beats a minute and I think it's that bottom end, it 's done that on a number of occasions as well you know ... when they do the read-out etcetera , etcetera .. I go for the check-ups ..

I: otherwise you wouldn't have known?

Tom: no, no .. nothing at all. In the beginning it as very awkward ... I used to find it quite awkward actually cos when they first said I was going to have it put in .. you know they said it would be below the collar bone, you know I expected it to be maybe here (shows me on his chest) you know between the shoulder and the neck .. Literally by here ... but it's literally over .. by my arm .. so as soon as I start to move my arm (moves his arm) .. you start hitting it straight away, which I used to find very awkward .. used to find it very awkward .. but now, it doesn't bother me at all, you know I can move my arm anywhere (moves his arm around in circles) ... you know I think it's found its own pocket like you know ...

(shows me his scar)

I: It's quite neat isn't it?

Tom: yeah, yeah .. and as I say, there's not a lot of meat on me like .. you can literally see the shape ... I 've got used to it, I must admit .. you know, it was awkward at the time .. just got used to it really. I couldn't lie on one side .. we've actually swapped sides of the bed you know ... excuse me (coughing fit) ... but even that, that doesn't bother me really .. You mentioned you've changed sides of the marital bed, can you tell me if the physical side of your relationship changed?

I: So, if I was to ask you about the disadvantages, does it stop you doing anything, is there anything that you're not supposed to do?

Tom: It's hard like in work, I can't do certain things in work like .. cos I work in maintenance in a hospital ... I can't go anyway near, like the MRI Scanner .. can't go in the room with MRI scanner and stuff like that ... obviously there are generators, we maintain generators in work .. you can't go .. you can go close to the generators but you can't like lean over them etcetera, etcetera when they're running or it could .. alter ... switch it off ... but apart from that .. it's nothing really .. it hasn't affected my work at all really ... and work as well has accepted that as well you know .. 'if you can't go anywhere near ...' you know, at the end of the day, if you're the boss you've got the boys to mess around with the generator ...

I: you said earlier 'thank God you hadn't had a shock' .. for what reason would you ...

Tom: erm .. I don't know ... whether .. they say it can be quite severe the shock that you get .. you know it can be literally like (claps hands together) a horse kicking you in the chest ... whether it's that or .. Whether it's 'oh hang about maybe it's something more serious' .. you know, if I do have to have the shock you know, 'oh hang about something's getting worse' maybe ... but you know, I said, I never think of it as any worse, as far as I'm concerned I'm better than I was before .. you know ... just get on with it really, you know ... some days you don't think of it at all .. the only times you think of it is like when you .. it obviously has implications .. cos when you go to the shops .. you can't linger in shop door ways .. the anti-theft devices and stuff like that ... and these .. in the big supermarkets you know .. you got the escalators, you know with the trolleys .. the ones with the trolleys? Well that's a magnet isn't it? So, you can't go on those .. you know, you go 'we've got to find a lift or go up the stairs' .. and stuff like that .. but that's the only time you seem to think of it you know ..... other than that I don't think of it really ... and like a mobile phone, I can't use a mobile phone ... you put it in this hand, now it's natural ... it hasn't been hard to accept I don't think really ....

Additional Interview

I: Something you said to me, you said when they said you had to have an ICD, you said 'well, they know best' but how were you actually feeling, cos even though you thought that ...

Tom: I thought first that how can someone who is so fit then .. 'all of a sudden why should I need this' you know, that initially probably went through my mind, you know, two days ago or five days ago, i was running home from work you know. You know, 10 miles, no problem at all .. and yet 5-6 days later, they tell me I need this thing to keep my heart going etcetera, etcetera you know. Initially it was that I suppose and then .... how all of a sudden my heart .. not failed but .. not been like it's always been .. But thinking of the previous couple of years where I've been for the angiogram etcetera, etcetera and this is probably the culmination of it, you know.. I think that was on my mind at last they have found out what it is .. and I think that's what it was. You got to accept it, you had all the tests possible and I think that was it really ....

I: I know racing was a big part of your life ...

Tom: yes, yes .. I say it was .. but maybe tailored off a little bit, in the last year or two .. But it was always still on my mind .. I'm always looking for a race to do. As I said in the previous interview, I won't run unless I can race.. and that's what always kept me going really ... But now, it's completely different you know, it's just one of those things ... I can still run to a certain level, I just need to set myself another set of goals really .. oh yes, definitely..

I: Another thing you said, was the doctors have said you can run another marathon and yet you said you probably won't ..

Tom: yes, I think that's probably because I know the work that is involved ... not to actually run the race itself or to run a marathon itself but it's all the training beforehand .. the time and the effort you need to put in before that .. for the actual race, I think that's what put me off .. the training, not the actual 26 miles you know ... cos you know, it's not just turning up on the day and running the 26 miles, it's the 4-5 months beforehand you know. Because it was once Christmas was over, it was 'bang' straight into training .. the marathon in April, so it was always 3 or 4 months of training, hard work, that what I didn't look forward to .. not the race itself .. I've always said, you do the training, you do the race .. the training is the hard bit .. if you've done the training, you'll do the race, no problem at all. That's always been my thinking, so it's that really that would probably hold me back a bit .. knowing the effort that i would need to put in beforehand .. over a long period ..

I: ok, ok, Karen said initially when you said you wanted to go out running, she was very worried .. did that affect you?

Tom: It did to an extent, because I've always been used to going out by myself ... I went with clubs etcetera, etcetera ... I felt I'd lost a bit of independence really, I couldn't just go running when i wanted to .. you know I'd have to 'oh, what you got on Karen .. any chance you could come out with me now'. You know, one of the kids would escort me on their bike you know and rather before, I could say 'right I'm off' and I can go.

I: so, you didn't go off on your own then?

Tom: not initially .. first couple of months I can say really, Karen would go on her bike .. she'd go on her cycle and I'd run you know.

I: Was that a joint decision?

Tom: yeah, yeah, it wouldn't have bothered me if I'd gone out by myself .. it was more cos Karen felt a lot happier doing it .. so quite willing to go along with that, you know... Knowing she was there anyway, just in case anything happened .. yes it was reassurance, this will do the job anyway, the ICD, but at least Karen was there as well or somebody ... if Karen was out (son) would jump on his bike and go ...

I: When did you start running again after your ICD?

Tom: I had the ICD in July ..... it wasn't the initial couple of months, it was ... probably March before I went out again, March/April you know. ..

I: that was after your six-months

Tom: yeah, after 6-months ... they had already put me on the treadmill anyway .. on .. after having the ICD fitted anyway ... They wouldn't do that .. don't know what it was actually, ... initially when they said I was going to have the ICD, they knew how keen I was to keep on running, they said 'oh, no problem, we'll arrange for you to have a treadmill test just to see how far you can go'... I envisaged I'd have the ICD and they test me out a couple of days later but obviously that wasn't the case you know... It wasn't for a month, two months maybe ... I think it would have been two uncomfortable to have run before that really .... when I did that (treadmill), I felt that I could go out and do a bit you know.

I: your wife said that when you came back from hospital, you didn't leave the house for 5 days ..

Tom: yeah I think it probably was ... I think that was more for comfort more than anything I think ... you didn't want to be all wrapped up etcetera, etcetera, cos you're still feeling a little bit tender and I think it was more for that really ... it was quite difficult to go round as a passenger in the car cause the seat-belt comes across that side ... didn't feel like being a passenger in the car initially .. you know, doesn't bother me now, don't think of it anyway .. doesn't bother me like but initially that was one reason why I didn't want to jump in the car to go elsewhere to go for a walk, you know what I mean ... I think it was more for comfort than what this might do (touches ICD) ...

I: This is a bit sensitive, don't have to answer if you don't want to ... you said you've changed sides of your bed because of the discomfort ... has the physical side of your relationship been affected?

Tom: no, no, ... I don't think so anyway ... I hope Karen gave the same answer! (laughs)

Transcript for N04
Male aged 68 years.
Primary prevention patient (Chronic Heart Failure)
In line with ethics, participant's name has been changed to 'Derek'
'I' stands for interviewer

I: Can you tell me a little bit about why you've got your ICD? A bit of background?

Derek: er yeah, originally I had two heart attacks .. I had the first when I was 4 ....7 ... I had the second one when I was 49, so obviously that caused damage.... But the doctor wasn't very good is about the size of it ..

I: ok ...

Derek: And he told me to leave my tablets off which I did do and had the second heart attack and that's the one that done the damage. So, there's been a history from then. I'm now 68 so obviously there's been an arterial deterioration .... Then .... two years ago, just after, erm .... they said I was in heart failure ... I can never say that I've felt ill with this, which is a funny thing, some people perhaps might, I don't. It's a matter really of them telling me .. what state my heart was in. And to be honest, just before the .. the .. er a year last June'ish time, from then on is when I was seeing the doctors (names) in (city name) .... They painted such a picture of woe really .... With hindsight now I probably would never have done it ..

I: never had done?

Derek: I would never had had it fitted ..

I: the ICD?

Derek: yeah.

I: right ... why would you say that?

Derek: why? Cos it hit me so bad. Like I said this time last year I was ill and I thought I was on my way to be honest with you. I never had an ounce of energy ..from being someone before the operation still feeling great ..

I: So, before your ICD you were feeling ..

Derek: fine .. you know, obviously I wasn't .. and I accept that .. but I felt fine ...... But after the operation I had no strength .. . You see it was a funny situation, I went in and had the thing adjusted and struggled to walk in and come out like a two-year old .. but that never lasted ... perhaps it's just me, I don't know. So, I experienced

... it was funny really .. so I felt that ... adjust it so I can act .. so I can be like that .. it would have given me the kind of life I'd had before. You know what I'm trying to say?

I: So, when they adjusted it ... what did they actually adjust?

Derek: I presume they adjusted the right ... I mean obviously it's all about circulation ... the worse thing I have felt again .. to say that I felt ill, yeah I did feel ill last year, that's probably the first time really .. but I really felt ill after having it done ... But it's the weakness, I'd never had any strength whatsoever, it was all I could do to get up the stairs at the end of the day ...

I: and that was since you had your ICD fitted?

Derek: yes. It was fitted December last year, not last year, year before .. just over 12-month now .... Just over 12-months now .... I went in and had it checked and they said, the last time they said 'yes, it's gone off twice' but apparently, it's this one, I don't even know it's gone off either ... cos so far I haven't felt anything .. which seems strange to me, I doubt whether it did go off .. although the time it did go off, it was shortly after having it done and I was feeling pretty poorly to be honest ... But I never felt anything from it ... and yet other people have been knocked down with it, kind of thing .. you know?

So, that' s just generally the picture, I've never been .. I'm not a worrier .. probably my faith ... and that's why I said, I probably wouldn't have had it done.... I had it done (coughs) cos of the family really .. more than me ... it's alright I don't even think about it to be honest with you .. very, very rare do I give it a thought ... Really, when I have a twinge, I ... I make it a little more comfortable, where it seems to be, is pretty protruding really ... sometimes when I'm lying in bed, it's a bit uncomfortable ... but apart from that I don't even know I've got to be honest

I: So, can you see any advantage in having it?

Derek: only what they tell me really. If they say, well your heart has stopped three times and it's started it then I've got to take their word for it ... but I haven't felt anything ... And I still suffer a little bit with lack of energy but that doesn't stop me .. been up to London to see a show just before Christmas and I'm about with my grandchildren ..

I: So, you haven't let it stop you?

Derek: Oh gosh, no. No, I ain't going to either. And that isn't sheer stupidity I got to .. I've just bought myself a little mobile .. scooter. I've got that in the car so I can .. when we go shopping, I use it.

I: so, there's no activity you've stopped since you had it?

Derek: no, no.

I: did you do any form of exercise before your ICD?

Derek: yes, we go for walks ..... I'm prone to put on weight. To be honest I was a stone lighter than I am now ... but if you saw what i eat, you wouldn't say that I would put on weight.

I: Were you active before your ICD?

Derek: yes, yes up until about 6-months before I would say, in all fairness to them .. up till then I was still pretty active .. I could do most things .. but since the run up to it when they said 'oh well the trouble is your heart's in an awful state ... it's in a state of heart failure' ... I did lose that little bit then before, you know ... But I've lost an awful lot since (energy).. since the operation, I've certainly not felt this ... (couldn't catch word)

I: and why do you think that is?

Derek: I don't know ... just fatigue .. that's the biggest thing really ...

I: Do you think that's your heart condition or your ICD?

Derek: I mean I don't know ... Put it like this, when I went to see the doctor's ... I can't remember her name, she said to me my heart was 15% .. sorry, 10% .. 10% functioning this time last year. When I went in August, she told me that'd gone up to 25% ... so again, it's going by what they say rather than how I feel. But obviously there's a big difference. They gave me an old fashioned drug then .. helps the heart beat apparently, it seems ... they got it pretty well under control to be honest.

I suppose I've been pretty active so yes I would say there's been a big difference in the last 2-years, last 18-months .. but I still do, I do probably more than most, you know. I mean before Christmas I finished tiling my bathroom upstairs .... but I don't have the 'wooof' that I used to have, do you know what I mean? I used to have a second wind but I haven't got that now. Once I've had enough, I've got to stop .... But no, we don't let it stop .. we go to Weston, we like Weston ... it hasn't stopped up going on holiday this year, you know. I haven't gone abroad, won't fly ...

I: Won't fly since your ICD or ...

Derek: well, they advised me not to ... I had a few funny turns to be honest .. self-induced I suppose and not ... once we were standing in the queue waiting for the flight in Spain, and they put it forward an hour without us knowing, so standing in the queue and suddenly they changed the destination .. we were in the queue, right almost there and so I had to run through the airport .. run out to the plane, cos they stopped the plane for us .. by the time I got on board, sat down, give myself a few minutes .. so we start eating and suddenly I went out like a light .. and I spent all the journey on the floor of the plane then ... there was doctor on board and a nurse so I was lucky, they said to me 'do you think you've had a heart attack?' I said 'no, no I've not had a heart attack ... I think what I've done is rush through the airport, have food .. the blood has rushed to my stomach to digest the food and it starved the brain, and I fainted'. And that's what it proved to be. So I've had a few funny ...

I: And that was before your ICD?

Derek: yes ... I went on a go-cart and I went blind .. I don't know, for a half an hour. That was the worst I'd ever felt. But fortunately I don't panic so I was able to just sit there .. and relax .. and came round you know, so obviously .. there's damage and there's weakness there and what those spasms was, I don't know but what I'm saying is it's all about the same thing isn't it ... But I was only thinking .. probably last week .. that I don't have any more months of feeling bad .... I don't feel bad except for the first month, six-weeks or so after having it done .. What they done is he admitted he (doctor) had made a bit of a mistake .. Mr (doctor)

I: right .. so this was the person who implanted the ICD?

Derek: yes, what he said was he saw my shoulder and he said 'because of the kind of man you've been and the exercise you done ..' he said 'your veins are so big' he said 'I thought to put two in the one vein' the probes .. 'that was a mistake when we got you back to recovery' he said ' with the instruments we had to take you back down' so I had double the shock ... whether it was that that knocked me so low .. erm, I don't know. But that was a pretty low ebb to be honest .. with hindsight I wonder whether it was worth it ... There's worse things than dying .. you know, I ain't worried about that .. um so like I said, because of my family really, they don't want to see me go that quick .. So, er .. I had it done ... I can't say it has caused me any problems whatsoever, whether I accept the low ebb, whether that was part of it, whether it was because i had to have the prolonged surgery .. in that sense, I know it's not cutting you open ... oh, what I didn't mention, I've also had a by-pass .. They wanted to do a treble, but they could only do a double ..

I: how long ago was this?

Derek: that was .... hmm, I'm bound to get this wrong ... ask my wife this one I think ...

I: So, it wasn't about the same time as the ICD?

Derek: oh gosh no, no ..... erm ..... 6-years? I might be wrong .. but I seen him on the telly ..

I: seen who on the telly?

Derek: this surgeon .. (name) in (city) (name of hospital) and he'd invented a pump, so this person's heart was really bad, you know, he actually used an apple core and he went like that (demonstrated using an apple corer), took a chunk right out of the hear t and shoved him pump in ... I was so impressed .. thought pretty good ... saw the bloke 3-months later walking down the beach, you know so I'd been waiting for Cardiff for gosh 2-3 years .. they kept telling me I was on top of the list but never got there ... cost me £18,000 ... went to .. had it done in (city) was in within the week and I had the operation on the Thursday and was coming back down the motorway on the Tuesday. And so quite honest, that was quite good, I've lasted for quite a few years, I felt quite good.

I: So, can you see any major disadvantage with ..

Derek: .. with having this thing? No, no, I don't even think about it to be honest with you. When i say I wouldn't have it done, it was because how low I went ...

I: But you did pick back up, but you haven't got your ...

Derek: yeah ... it got better .. and I am better .. like I said, I do all the things I want to do within, within .. you know .. obviously I'm 68 but at 60 I could still jump a fence, I was pretty active ..

I: you still go for walks?

Derek: well, there again, there's lots of things they don't want me to do now, so I don't do it ..

I: do you have faith in your doctors?

Derek: to a degree ... obviously I want to judge for myself ... yes I mean, gosh, as long as they tell me what the bad things are as long as the good things ... with the tablets, some people have terrible effects with ... but I never, it hasn't seemed to have bothered me. I don't seem to have any reaction ... the worse thing really has been the appetite ..

I: right .. right .. has it picked up or ...?

Derek: From being very, very good, you know I'd eat anything. I mean we had dinner .. Sunday I find awfully difficult ... even being in the house cos of the smell ... I try cos it was a beautiful bit of beef ... I couldn't eat it, one mouthful and I had to go out and spit it out .. you know, it would only make me vomit.

I: Why do you think that is?

Derek: Well, I don't know .... I really don't know, from liking my food to some things having no taste and feeling when I'm chewing, it's laborious ...

I: how long's this gone on for?

Derek: oh, that's been since ... but I wouldn't say that's the ICD, it's probably the drugs ... I talked to another man .. accidently really, we were having dinner .. it was the wives talking it was and they said - she said 'oh, my husband has had that done' and he had it done 12-month before me ... and he was having exactly the same thing with the food ... but again, it could be the drugs rather than the ... rather than the machine, you know.

I: the doctors seem to have limited you exercise-wise, is there anything they advise you to do?

Derek: well no, I wanted to swim because I swim you know, but he said no, cos in a swimming pool you don't know how much you're doing and you might just over stretch yourself and make yourself too tired. So, I just haven't. You know, I still walk, although I'm saying I got this .. the mobile thing .. sometimes if we're only going into the one shop, I'll go in and walk around. I'll go in and walk around Asda's or Tesco's in (town), no problem at all like but it's prolonged .. and that ain't just because of my heart ... having played the .. silly game (rugby) you know, one cartilage, one cartilage really gives me a lot of stick, so when I'm walking, I'm not comfortable anyway ... So, it's not all because of my heart, it's because of my knee ... I would love to be able to swim to be honest with you ... My wife still goes ... but er .... they said don't do it, so I haven't done it.

I: is there anything you could do instead, that they would be happy with?

Derek: I don't know .. I'm the kind of guy that'd do it anyway (laughs)

I: but you haven't been swimming against their advice?

Derek: no, ... the way it is, the way I feel now, whereas before I could have said to you,' I would probably build up my stamina', they give me the impression I can't do that now ... I ain't never going to be able to do that ... for whatever reason,

I: the nurses said that?

Derek: yes, and the surgeon, the doctor, when I say surgeon, I think he's a surgeon .... I mean (name) is the one that done it, he's the one that's got the facilities, but he's obviously high-up ranking anyway ... And he painted ... he's a character mind ... (laughs) .. my boy said 'dad, don't go and see him' cos every time I'd went and seen him I'd come out feeling like (laughing) .. you'd go in (put hand up high to show a high height) and come out like this (puts hand lower) ... you know, if I was somebody who did ... you wouldn't feel very happy if you know what I mean. But then he tries to be honest, you know what I am trying to say, and I appreciate that .. you know I would rather be told rather than not know but again, there's a lot of complications in that, in what i believe and my faith and that makes a big, big difference of course.

I: in what way?

I: Well, I know where I'm going ..

I: right ..

Derek: the only sadness for me would be to leave my family, you know I-I ... obviously nobody wants to do that .. but I'm quite happy when the time comes , and that really has been my attitude I suppose, I don't care what they put in .. whether it's a machine or whatever it is .. I'm going to go as long as the Lord kind of wants me to go and that's the end of it, and I'm content with that .. so it does make a big difference .. I do appreciate that.

I: When you were discharged from hospital, were you given British Heart Foundation booklets?

Derek: yes, did I read it? No. I'm terrible sometimes ..... yes of course, I've read bits .. I've read bits as we've gone along. I read before about the machine, I wanted to know what it did and I did all that, but I don't retain things ... because I'm not interested. You know I read at the time, and I probably know as much as anybody at the time ... But like I've got a brother-in-law, he knows what his tablets are, he knows when he's got to have them .. he's ... you know what I'm trying to say? .. Everything has got to be ... well, he's still walking round like an old man and I've had far more than him and I'm still far more active than he is. Because obviously, you get in a routine and you start to worry about yourself .... So, really I can't say I have found any great benefit from it (ICD). Is it doing its job, well probably it is.

One girl said 'it's gone off twice'. 'Well, I can assure you I haven't felt a twinge, never mind gone off twice like' and I wonder whether it was real or just the time when we were adjusting the machine and doing all the things to it and whether there was some kind of a glitch anyway, you know what I mean? .... You mean I've spoken to people, the dentist and his father had it done and he's walking out after having it done and it hits him on the floor ... you know, he had to go straight back in. He's alright, but what I'm saying is, he had one enough to ...

I: does that worry you? That you could have one like that?

Derek: no, no. Never think about that. The only ever negative thought I had , I asked her once 'this thing won't revive me once I'm in my coffin?' you know what I mean, cos that wouldn't be very nice. But that's the only thing that I asked really .. and it took me a few weeks to think about that to be honest. Suddenly dawned on me, hey yeah

I: so you said that you would do your own thing anyway, but you haven't gone against their advice, what stopped you?

Derek: because I tried .... in all fairness ... If I was doing it (swimming) because it was a love or something like that rather than being an exercise, I would have probably been still be doing it ... but because they said to me 'don't do it' or 'we'd rather you didn't do it' ... you know that might have been then .. just after and before to be fair ...... you know if I'd listened to (doctor) I was lucky that I was walking around .. you know what I'm trying to say? .. that was .. because that's the first thing I thought 'gosh, this must be serious then'. Because up till then, I didn't give it a lot of thought.

I try to be sensible, that's what I'm trying to say, I do try to be sensible .. I realise I'm an older man now ... whereas before I had all the energy in the world .. I could wrestle with my kids .. you know they are men now, have a bit of fun .. obviously I can't do that I don't try .. cos of the strain, but what I'm saying is, you do check yourself in certain ways ... and I still get pulled about by my grandchildren a bit .. .. but I don't let it .. I don't let it interfere ... I never really think, 'oh can I do this' or 'can I do it' ... if it's something I know is heavy I just say to one of the boys 'I want you to do ...' now, whereas before I'd do it myself, now i ask them. So, I just try to be sensible within .. within the limits.

Am I never going to swim again? I ain't going to say that I am .. no .. I've never been a great swimmer but I swim and we were in the right circumstances ... you know I'm not supposed to go in the sauna, 'don't go in the sauna', you know but I did .. you know, blow it. So, I sat in .. up to here (hand at waist) .. I wasn't silly about it ... and after I thought I'd had enough I got out ...

I: do you find you're listening to your body more?

Derek: no, I'm terrible, I really am, no I don't . I'm not conscious of it at all ... I can honestly say that I don't. I got a blood pressure machine down there ... my family use it, that 's why is down there ... I don't think I put that on for ... oh gosh .. 3-4 months ....

Sometimes before I had this, before when i was quite well, I used it far more often ...

I: Why don't you now?

Derek: because .... really it's just the tablet regime and I used to check it then to make sure the dosage and everything was alright .. that was the mental .. the thinking behind it. But since August I've felt really bad anyway .. I'm not bothered .. I don't bother ... If i felt ill, or if suddenly I felt it wasn't going right I would .. I would probably check it.

I: so, you've been put off flying?

Derek: well only cos they said 'don't fly', I mean I got a place in Spain. Had it over 20 years. We just haven't gone. We're having letters from our neighbours now before Christmas .. he 's a lecturer in a university in Madrid .. and they're great like, we've made great friends out there .. but .. we just haven't gone .... Well, I was nervous flyer anyway ..... at one time you would never have got me in a plane I got to say ... but no, I could take a flight now ..

I: But they've advised you not to?

Derek: well, what it is, you can't trust them can you? Because of the .. because of the air-conditioning and everything .. the pressure ... you know what I'm saying, you can do it but it might not affect the others but it would affect me .. you know what I'm trying to say? I'm a bit nervous about that .. bit nervous about that .. cos it's the wrong place to have something go wrong isn't it .. I mean I've already experienced that and it's not very nice ... you don't feel well, you know? I mean that time I told you about they were actually ... it was only because I said 'no, I haven't had a heart attack, and the doctor agreed with me .. that they didn't pull off and land in France .. cos that's what they were going to do. So, that wasn't a very nice experience and I was ill for a few days after that one, I got to say.

I: your wife must be worried?

Derek: yeah, yeah, I mean she puts on a brave face .. she's like most women, she can do without me, you know what I mean .. she don't need me, but you know, she'll probably break her heart if anything ever did happen to me ... I mean, we've got a good relationship, we've always ... oh gosh, it's been a long time you know, I met her when .. she's 65 this year, I'm 68 .. I met her .. oh dear .. she was so we've been going out together since that kind of time ...

I: so, you talk quite openly with your wife about ...

Derek: oh yes, we're like that in the family anyway ... my son, he's like the Mother Superior, watching over me .. he's the fuss-pot you know.

I: so how does that make you feel?

Derek: Well, it makes me happy ... he cares ... that's er ... he is a character .. he is .. she .. his wife found it very hard in the start ... her father's got a farm in (town) .. they so different to us .. you know, whereas we'll talk openly but tend to ... you know, funny bloke, I mean I know him well .. cos he's another one that goes to chapel so I do know him .. and his wife, I grew up with .. in church ... so we .. I know them anyway .. they are more 'close' ....

I: so since your ICD, have you talked openly to your family?

Derek: In what sense?

I: well you said you're not afraid of dying. Having the ICD has it brought that to the fore?

Derek: no, no. I mean my son, this last year when I was poorly, he must have asked me once every day, 'now you are trying dad, aren't you ? .. because I know you!'

I: trying?

Derek: to survive, you know. 'You are trying to survive dad?'

I: because at the end of the day, that's what the ICD's there for isn't it

Derek: yes, but you know what I'm saying like, there are times when I give the wrong impression .. I said 'son, there's worse things than dying, I'm not afraid of dying butt'

I: that's quite an open thing to say to your child

Derek: probably but then we got that relationship you know ... I mean pride and all those other things don't come into it ... if I need a scooter, I need a scooter, I use the scooter, I don't even think about it .. you know what I'm trying to say? People are governed by feelings which are absolutely stupid ... you know ... I ain't like that and so my family aren't like that, cos at the end of the day I'm the one that brought them up ... my father was a Royal Marine, he lived by rules, I lived by rules ... I showered him every day .. he had cancer .. we shared till the very end .. my dad and me ... he said to me 'I preach this now son, now I got to live it' ... 'it's easy to preach it, now I got to live it' and I said 'course dad, that's what it's about' ....

We are a close family and we don't have secrets, well not really ... I mean nobody reveals everything of course but what I'm saying is we don't have secrets ... it don't really matter what it is ... you know about 3-4 years ago I become impotent .. finally .. because of all the tablets really ....

Transcript for S05
Male aged 50
Patient with Idiopathic Dilated Cardiomyopathy (secondary prevention)
In line with ethics, participant has been named 'Joe' and 'I' stands for interviewer.

I: Your wife was telling me about how you came to be fitted with the ICD ..

Joe: traumatic events .. well funny enough ... she probably explained I just felt a little dizzy and next thing .. I had an awareness of the impact funnily enough .. when we hit this curb and this lamppost .. did she explain that to you?

I: no .. well I know you hit a lamppost

Joe: oh, yeah ... brought me back apparently .. I got out the car feeling as right as rain and actually went to assist other people, not realising there was something wrong with me really .. I just felt absolutely normal ... I had felt a bit dizzy and a bit clammy and we were only going to go another couple of hundred yards to Charlotte's office .. I was going to stop and have a cup of tea or something .. didn't make it so

I: how did you feel when the doctors told you that you had a cardiomyopathy?

Joe: I didn't realise the full implications of it .. the seriousness of it, because I felt so well, I just felt fine, it was as though I just fainted and come back so I didn't at the time, appreciate the seriousness.

I: (inaudible)

Joe: well, I was, I was on a trolley for 36 hours and being monitored and had some X-rays and as I said at that time I didn't realise the seriousness of the problem, cos I felt I'd just fainted. Obviously, the implications were serious, crashing the car and everything, but for myself I just felt that I'd fainted and recovered. And I was fine.

I: How did you feel when the doctors told you that ...

Joe: erm ... shock and surprise really cos I had always been very fit, played rugby only a couple of weeks before, I was a regular runner so I couldn't understand why my heart should be giving problems when I had been constantly fit and active, all my life really so that was .. even now, they're not sure of the cause of it and I find that er .. If someone could say 'well, you did this or you did that, hence you got this' I could .. it would be more acceptable

I: so it's the uncertainty ..

Joe: well we're having several tests, had the profusion test last week .. trying to isolate the reasons for it .. but so far, no luck so ... I had a shock before Christmas, did Charlotte explain to you?

I: I believed you had two?

Joe: well two shocks, two in the same time sort of thing .. and again it was er ... that came as a shock .. I er .... If i stand up quickly I can feel a bit dizzy, just be bending over, I can recover very quickly and just for a very brief instance, I felt this dizziness whilst I was walking and then whack! .. I was hit with this thing ... and ... it only took a second to realise what had happened. I was in the train station and of course the traffic of people was quite considerable at the time, so I couldn't sit down or be killed in the rush, so I had to get out of the place and the car was parked at the back and I had to walk through ...

I: you felt like you wanted to sit down?

Joe: but that was the instruction if it happened .. to relax .. so I was trying to find somewhere to sit down and relax and of course the car was the obvious place so I got there and on the way to the car it hit me again and ..... and er .. but having sat there fifteen minutes I was fine. But I think for the week or two after that I was very apprehensive of it happening again .. but I'm over that now ..

I: what was going through your mind whilst you were sitting in your car?

Joe: I didn't know what had caused it .. because although I was rushing around and a bit stressed but I'd been in that sort of circumstance before .. I didn't understand why it had gone off, I thought maybe it was fault with the machine ... I had a friend with one who had had a similar experience .. when his had gone off, but it was the machine's fault and not his so I assumed that was the case with me but it wasn't .. it was a very serious genuine shock.

I: how does that make you feel knowing that?

Joe: well ... er .. it's a good job I got it fitted or I'd be dead .. so I'm pleased in that respect ... concerned that it should go off. We went to an afternoon meeting, seminar, with the arrhythmia nurses and other people who have had these fitted .. I don't know about a year ago .. and in the room of about 30, 40 people, only one person had it go off you know in whatever the period of time was. So, for it to go off is obviously unusual and a bit concerning really.

I: so you felt concerned ...

Joe: yes, yes ... and having since met the consultant and having .. confirming the fact that it was necessary for this thing to go off, was a bit disconcerting really ..

I: so how do you cope with these feelings?

Joe: oh I'm not one to worry about things .. even when it all happened I .. er ... I ... I just get on with these things, it's happened, it's happened, that's the way I treat it really

I: your wife was saying 'you just got this thing fitted and you just got to get on with it'. Are you saying that to make your wife feel assured?

Joe: no, i don't think so. That's the way I am. I find it frustrating cos there I was in April playing rugby, full 40 minutes each way .. full contact .. running about and then bang, in June this happened and ever since .. I struggle to run. I can run but not very far and not very fast, whereas before I used to enjoy running, I used to enjoy extending myself. I find it very frustrating now. I can't experience that cos it's a struggle to run ... so for whatever reason I can't do it.

And as regards about having it fitted. I was fine about that ... initially ... until i was shown what was going to be put inside me .. the size of it I found disconcerting .. it is big .. I've seen pacemakers which are considerably smaller .. but this thing was big, I thought 'cor oh dear' .. And even the doctor putting it in said it was going to be very pronounced on me .. cos er .. my physique meant that it was not going to sink in. It was going to be prominent. It's an amazing operation really, when they put this thing in you under local anaesthetic you know ... I remember speaking to the doctor when he was putting it in .. saying 'is this going to affect my transfer value?' and he said 'yeah, you're not worth anything anymore' (laughs) .... so that was a comical incident on the operating table. But immediately afterwards, it was uncomfortable, very prominent, very obvious and unpleasant really. I'm used to it now ..

I: how long did it take you to get used to it?

Joe: I don't know. I know we went on holiday not long afterwards to Spain and I can remember walking alongside the swimming pool and being very conscious of this .. it seemed to be much bigger .. I can remember that .. I mean I'm over that now, it's there, it's there, that's it. But it is prominent. The boys think I got my wallet in there so I can't buy them a drink anymore ...

I: tell me about the disadvantages with the ICD .... you can't run anymore

Joe: well I can, but it's not enjoyable cos it's a struggle .. it's hard to describe what the problem is .. it's not a muscular physical thing ..

it's not as though I'm out of breath, it's as though I'm very very unfit, that's how I feel. I never felt it before .. it's horrible .. it's not nice .. Charlotte started running when I started running and I should be able to comfortably beat her but she's leaving me behind .. and that was worse in many ways ... even recently I asked the doctors if it was ok to exercise and he said yes . I used to go on the rowing machine and there was a competition and people had put their results in .. and I was pushing myself as hard as I could and I went to look at the results and they were probably half my age mind, but even so .. I was way out of it. And I thought 18-months ago, I would have done that easily .. so that's the only frustrating thing really

I: so, how does that make you feel about yourself?

Joe: well ... well again I accept it. I can't do anything about it at the moment.

I: have you stopped exercising? Or will you persevere

Joe: I am going to persevere .. I mean i haven't run for a long time .. I mean the weather's been atrocious and what have you, and I desperately want to start again. I mean, I work physically hard .. like I landscaped the whole of the back garden since this has been done, which has been quite a feat. I mean I've even made a patio wall .. but that was doing my own garden, finishing the house. So, I'm much improved in that way, cos when I first came out of hospital, I only popped out for 10 minutes and ended up in their for 2 and a half weeks you know, well I left a truck full of stones round the back which had to be unloaded .. chippings .. well, i remember coming out of hospital and thinking 'well I'll do that now, I'll make a start' . Well, I couldn't do it. I just felt er .. very faint, so I had to stop but I can do that comfortably ... so I've improved a lot since the operation

I: do you see yourself regaining your former strength?

Joe: nowhere near no, nowhere near. I don't know if Charlotte mentioned this stem cell trial. Cos it seems to me the .. this device and the medication is looking after me and stop things getting worse but the stem cell trail seems to be able to improve matters .. so, I'm quite excited by that .. it's effectively re-growing the muscle in the heart ... they talk about a 5 to 8% improvement if it's successful and I'm assuming that's the initial improvement so you could probably have it done again, couldn't you, and again and again. Hopefully, I will be playing for Wales next season.

Speaking to the Consultant in the Hospital (ICD), he's a bit sceptical about it .. he said it's very difficult for the stem cells to actually be implanted where they need to be and to be retained there. They won't stay in the right place and they won't necessarily function. I don't know if you know, but charlotte's work is research staying the area of cardiomyopathy and stem cells. She has a technique to implant stem cells and she's hoping to liaise with the doctors in London .. so I'll be the guinea-pig for both of them.

So, of course it's been put back, this stem cell trial. It was supposed to be last week, but because of this thing going off ... they've put it back a couple of months.

(talks more about stem cell trial)

I: When you stand up and feel dizzy do you think at the back of your mind it might be another shock coming?

Joe: I did initially and I was apprehensive but not anymore cos I'm only where I'm back where I was before now ... if I stand up and am dizzy, it's because I stood up too quickly ... but if I stand up slowly I'm fine. I find if I do stand up too quickly and feel dizzy I just bend over for a few seconds and I'm fine ... I'm as right as rain now.

I: Why do you think you are coping so well?

Joe: don't know really. I think it's perhaps the way I am. I had quite a serious rugby injury many years ago and I haven't been able to straighten my arm since, can't get it near my shoulder .. but that's it .. my nose has been altered a few times, so there you are. I think it's probably just my make-up.

I: what did you think of the literature you were sent home with?

Joe: from the hospital? Interesting, learned a lot. Learned a lot more from the internet because there's vast information on there isn't there? And I have to say Charlotte's (wife) support has been absolutely fantastic, because she's very knowledgeable anyway, about these things and drugs and goodness knows what. It's just been a huge help to me but .. I don't actually have to read anything, she does it all and tells me (laughs).. I mean it was her that discovered this stem cell trial

(talks more about trial and how his wife met contacts etc)

Joe: that morning I was on a double extension ladder .. fully extended, right to the top and I was doing some work on a fascia board and if I'd had known the shock was as severe as it was .. I wouldn't have been up there, it would have thrown me off easily ..

I: have you been up since?

Joe: I have, but not so high and with a safety thing on and all sorts of other precautions ... you're not supposed to ... I was thinking afterwards, I mean the station was very busy ... there were people around me .. I must have straightened up like this you know (straightens himself) .. they must have thought 'god, what's happened to him?'. It's quite dramatic but over in a second.

I: Was it worse than you thought or better than you thought?

Joe: it was a much stronger impact than I expected ... I thought it would have been far more concentrated here (points to heart), but in fact it went through me .. I remember a friend .. he helped me build a house here and he had one fitted .. I guess about five years ago and he was telling the story of immediately after having it done, he couldn't drive and he used to go out on his bike just to get some exercise ... and he'd gone somewhere and this thing went off .. He got off his bike and stood there and it went off again and he thought he'd better phone the hospital. And he put his hand in his bag to get his mobile phone out and the thing went off again and threw his phone over the hedge! It was that violent a shock. He thought 'that's three times, and I'm supposed to call the ambulance now but the phone's over the hedge (laughs) ... but of course this was the chap that it was the machine at fault.

I: Is it nice to have someone to chat to about it?

Joe: yes it is, well amazingly, another friend of mine and one of these put in about 20 years ago. He was only in his 30s. Again, a very, very fit rugby player and although I knew he had this done ... cos not long after we went on trip somewhere and I shared a room with him and it was on top of this hotel three storeys up .. and to get up there, he had to stop on each floor and get his breath. And I remember being quite amazed and concerned that this chap that I knew as a very fit, very fit man was suddenly reduced to this man who could hardly get up the stairs. But it had happened to him, it hadn't happened to me, and you don't really .. I mean you know about it, but it doesn't really concern .. a horrible thing to say, but it's not you is it? And you don't really appreciate what's happened. So, it was only years later, when I had it done and I looked back and I think 'oh dear' and he was at that age .. I don't know, early 30s I suppose. And yet he's a lovely chap, always smiling, never complains. And amazingly we were at the hospital talking to the consultant a week ago and his phone went while we were talking to him and he answered the phone and was obviously speaking to another doctor and he said 'ok, well if it doesn't resolve itself by this afternoon, we'll stop it and shock him'. So, we were thinking 'ah right, someone's got a problem'. And he put the phone down and said 'that's another friend of yours' ... we've got a couple of common friends, the consultant and I ... anyway I went down to A&E to see him and there he was, his heart beating twice as fast as it should, but full of the joys of spring. I've put both these friends onto the stem cell trial and they're absolutely delighted with the prospect, so they've both signed up for it.

(speaks about stem cell trial again)

Joe: They are still trying to find out what it is (causing sustained VT). It might be hereditary. My daughter fainted recently up in Sheffield so I've her go and see her doctor and she's seeing a cardiologist .. just to check

I: do you think it's hereditary?

Joe: no, no I don't. There's been no history of heart problems in the family ... ever .. so I don't think it is. But with my daughter fainting, I mean, that's what I did, faint. I got a son in university and he plays hockey, very fit and I haven't had him checked yet, we'll see what happens with my daughter first. Because with this chap (friend) it is hereditary with him .. that's not good is it .... If that was a scenario that I had to experience it would be quite demoralising .. that I had passed something like this on to your children you know. Fortunately at the moment, I don't think I have. Quite confident I haven't but .... so, I'm not doing too badly I suppose.

I: no, you're doing well. So, there's nothing you've stopped doing?

Joe: no, not really, but not to the same extent with the exercise that's all .... immediately after the car accident, I felt absolutely fine, you know as though I'd literally fainted and recovered .. I couldn't understand when the police man said 'get in the ambulance'. I said 'what for?'.... the car, there's a picture here somewhere, quite a dramatic picture ... we were dead lucky, cos it was a soft top car and .. it was a very powerful car ... and when I went down on the wheel, my foot ... this thing can do 0 t 60 in about four seconds .. just woof it went! And it was midday, there was a crossing with lots of people there .. Across the road, in front of other cars, there was curb about this size (shows with hand above floor) about that deep, hit the lamppost and stopped the car ... wife got out, not seriously hurt .. I did too, but we could have killed people .. the other thing was, the curb was so high that if we'd been straighter and the front wheel had gone on it .. we would have turned over and been killed definitely ... so, you know, lucky.

I: mmm lucky

Joe: I mean the lamppost came down on the van just facing the other way and there was nobody seriously hurt there either, so. When I thought back, I remember the policeman saying to me 'you need to go to hospital because if you think of what's just happened, you're lucky to be alive ...

I: how's that affected your driving?

Joe: it hasn't .. initially perhaps but of course I couldn't drive for six-months and that takes away the impact of it .. then I remember the first time I drove after that, I was absolutely fine .. because I'd had a warning, I felt dizzy, I felt clammy, but didn't realise the extent of the seriousness of this .. and it this happened again, I'm quite confident I would immediately stop, pull in .. I don't think it's something that's going to happen and I've this fitted as well. I was thinking about this the other day, when this thing went off .. if it went off and I was driving .. I'm quite certain I can still control the car, and you know, make a successful halt

I: so fair to say, you feel very positive about your ICD, the actual device itself?

Joe: yeah ... I suppose I'm lucky to have it fitted really aren't I because I would be dead otherwise ... still very protrusive, very pronounced and I remember when it was being fitted, the doctor actually putting his palms of his hands, you know, trying to push it in ... it just won't sink, so it's on the surface ... Course the other problem then was they thought it might break the skin there .. so although I don't take any great precautions to look after it .. it's not actually damaging the skin, I'm fine. I hope this has been some use to you ..

I: were you happy with the arrhythmia literature that you were given in the hospital?

Joe: well as I say, Charlotte is very knowledgeable and has filled me in ... myself, I'm not sure I would sit down and read a lot of literature .. I might look on the internet and find out .. what I wanted to find out but I wouldn't read endlessly

I: so you were search for something?

Joe: yes I would but even more likely I would ask the doctor .. if I wanted a specific answer then they are obviously able to answer the question .. then you can go back and fore and expand the question, whereas very often if you looking at a piece of literature, the question there is answered but there might be something on going from that which might be beneficial .. the doctor is far more beneficial I think ...

I: how often do you go for check-ups?

Joe: Every six months but with these couple of tests I've had recently it's more .. been going more often ...

I: Do you find it helpful to go in?

Joe: well it is (sounds doubtful) but the technology .. the technology fascinates me .. it's incredible, you lie there and they put this thing on you, and clip it and they rest it on top of the device and they can read off the last six-months ... quite amazing ... and they tell me three months ago, it kicked in just to control .. they said 'did you feel it?' 'no, didn't feel it'. That's another thing, I've never, never felt any palpitations or my heart racing .. I've never experienced that ... Although before it happened, Charlotte would say she'd often see a pulse in my neck which was quite pronounced and i've never noticed that and never experienced it ... so perhaps that was a sign ... I know that in how many years, the battery will have to be changed ...

I: does that bother you?

Joe: no, no, no .. just something else that's got to be done isn't it? It's quite amazing how they do these angiograms, where they go into your groin and go up into your heart, it is amazing ... even this, the way they put this into you .. fantastic technology isn't it .... I'm very confident in the surgeon's ability and it's amazing what they're doing ... so I've got no worries about having the battery changed or any further treatment .. so there we are.

Transcript for N06
Male patient aged mid fifties
Has ICD for secondary prevention, survived a massive MI and cardiac arrest.
In line with ethics, participant's name has been changed to Sam. 'I' stands for the interviewer.

I: just to start us off, can you tell me a little bit about why you had an ICD implanted?

Sam: I had a heart attack back in January 2010 .. on 16th January 2010 ... er no warning, I was out for the night ... er came home and it just came on me straight. And my wife phoned the ambulance and they rushed me to hospital ... I don't know nothing else about it .. from about that day, till about two weeks after. I was unconscious, they kept me unconscious er .. two weeks .. I can't remember nothing about it whatsoever.

I: so when was the first time you realised you were going to have an ICD?

Sam: Er .. that was quite a while after that .. they did talk about it first off that I might have to have one but they didn't say definitely that I would have one ... but when I seen Dr X [consultant] that was a few months after that when I was back home when he did state that in his mind that it would be beneficial for me to have an ICD put in.... And you can't go against the doctor so ...

I: did you understand why they wanted to put one in?

Sam: yes. He did .. far do to the doctor, he did explain everything to me and he was very good about it like, but ....

I: how did you feel when you realised?

Sam: a little bit apprehensive at the time .. because i didn't understand a lot about it and when he explained that I'd have a metal box inserted into my chest .. slightly apprehensive but erm .. it's in now, so there's not a lot I can do about it.

I: you seem to have faith in the doctors ..

Sam: oh definitely! I'm afraid I've had a lot to do with doctors all through my life .. I was born [chronic condition] so I've had quite a few operations ... so I've always had faith in doctors. But since I've had the ICD fitted I'm getting a lot of trouble with my arm ..

I: your arm?

Sam: my arm, the top end of the arm ... Now erm .. I'm saying it's the ICD that's causing this cos I've never had trouble with it before .. only since it's been inserted ... I've informed the hospital and I've got an appointment to go back down and see the doctor now on the 17th of this month .. so hopefully, i can ask somebody to sort it out .. what, I don't know but I can't really go on like this ... cos it's affecting the movement in the arm ... I can't use it to its full potential .. so something's got to be done about it . What it's going to be I don't know ...

I: so for you what are the benefits of having the ICD?

Sam: ... well at the moment, I can't see any benefit in having it to tell you the truth because i haven't had any reoccurrence of a heart attack since last January ... I've been pretty good really ... getting about alright, back in work er ...

I: how what that going back to work?

Sam: It was alright, bit strange first off because I was off quite a while. But work has been very good with me .. the manager in work and the team leaders .. they been very good .. At the moment they won't let me do nothing .. I think they're afraid – concerned I might have another heart attack or something or rather, I don't know. But as I say, they've been very good with me. But as I said, I've got an appointment with the doctor now .. the 17th and I would like to get to doing the job I was doing before I had this heart attack ...

I: and what was that?

Sam: I work for XX, which is a disabled company that employs disabled people down in [name of town]. Erm .. we make furniture , assembled furniture, kitchen units , wardrobes, stuff like that. And that's what I was doing before I had the heart attack. Now I suppose they don't want me doing that because it involves a lot of lifting, although as long as the lifting is not what I would call really heavy lifting ... no it's not, it's parts of what you're doing

I: so how does that make you feel .. they don't want you doing that?

Sam: well I've always been active. You know, I'd rather be doing something in work rather than sitting down and doing nothing.

I: how long is it since you had your ICD?

Sam: That was fitted on 17th September last year .... so it was a while after I had the heart attack ...

I: so it's only been 4 months since you had it in?

Sam: yes, in September yes. Well, ... I don't know what's going on ... to me , it feels as though it's moved. It seems to have gone over [touches chest and shoulder area] to left shoulder more than when it was first put in. I don't know whether it might be me thinking that because it's affecting my arm, but it seems to me that it's moved over and .. I'm not a doctor, but whether it's resting on a nerve or something? Which is causing the muscle in the arm to ... I don't know. As they say, it's something I'm going to have to find out when I go down.

I: so you say you want to return to your former activities at work.

Sam: I don't think they're gonna leave me do the exact job that I did before, but there are plenty of other jobs that I can be doing there.

I: but you still feel you could do those jobs?

Sam: oh yes. I feel alright now like, except for my arm. You know the job that I was doing involved a lot of stretching .. at the moment I haven't got the full mobility in my arm.

I: are you hopeful you will get that back?

Sam: I think i would if the ICD wasn't in. As I said, I never had any trouble before the ICD was put in. But lost the full mobility of the arm that's only since it's been put in.

I: do you feel anything else about the ICD? Do you feel protected?

Sam: I don't know. Cos what the doctor told me was .. it's there in case I do have another heart attack or ... but as I said, I haven't felt as if I'm going to have another heart attack .. I've felt pretty good. But saying that, I didn't have any warning I was having a heart attack in the first place .. I didn't feel bad ... nothing, it just came on, which was rather strange. But as the doctor said, it's there to prevent so ...

I: why do you think you had your heart attack?

Sam: I haven't got a clue.... I was a smoker .. don't suppose that helped much ...

I: you say 'were' a smoker?

Sam: I was a smoker ... I haven't had a fag since the 16th January 2010 ... once I had my heart attack, I give up. I haven't had a fag since the

I: Why did you give up?

Sam: well the fact that I had a heart attack ... I've felt a lot better about it since I have given up as well ... I got to admit that. And obviously, once I give up, the wife give up as well. So we were .. so well, I had more incentive to give up than she did, having a heart attack but fair do to her, she give up as well. So, since that day, we haven't smoked at all ... marvellous, and as I say, I do feel a lot better for it.

I: So, apart from at work, what else did you used to do?

Sam: I did a lot of fishing. I do like my fishing.

I: that's quite solitary isn't it ... have you been since?

Sam: I haven't no, not been since no. Most of last year, I couldn't go .. I just wasn't in the health to do any last year ... I'm going as start back this year now .. the season starts now on April 1st , so I am definitely going to start back .. with my fishing now this year ... I feel as if I can do it now .. feel alright, feel good ..so .... it's something really, I've always enjoyed ..

I: how do you feel about going on your own?

Sam: I'm not nervous no ... as I said I haven't had any occurrence .. felt alright, felt fine .... Walking is a little bit, erm how can i say .. not difficult but slower than I was before ..

I: before your heart attack or before your ICD?

Sam: before my heart attack I would say. So, that's a little concern, not a great deal but that is a little concern. I do use a stick now .. most of the time when I go out with the wife and when I go to work, which I never used to before

I: are you doing as much exercise as you did before?

Sam: no, I don't think I am. No, I got to be honest about that, no I don't think I am.

I: do you think that could have something to do with your speed of walking?

Sam: could be .. could be. But erm as I said, I'm going to start my fishing back up now so that'll give me a lot more exercise than what I'm doing now ... which I really enjoy in any case so ..

I: can you walk to the lakes?

Sam: no, you got to drive

I: so you're back driving?

Sam: oh yes, yes. You got to drive, there's nothing-there is a pond up here in which I can walk to but there's no fish in, so there's no point in going up ... But I do go a walk, walk around the pond like ... so I do walk around ...

I: so, have you had any concerns about your ICD?

Sam: yes. It hurts.

I: it does hurt

Sam: yes. It wakes me up in the night if I'm sleeping .. if I turn over on that side [points to left side] .. I can't, it does wake me up and as I say movement in my arm, if I move my arm in certain directions, it is really painful on the muscle. They give no warning of this whatsoever ..

I : have you read any of the books they have gave you?

Sam: I have but to tell you the truth no, I haven't

I: for what reason?

Sam: ay .. I don't really know ... I've taken it in what the doctors have told me about the ICD like and as I say .. he wouldn't have told me I need an ICD if it wasn't necessary., so I was quite happy to have it implanted but .. since it's been in, it is ... funny. Well, with the movement of the arm and as I said earlier on, I don't know if its moved a bit. But it seems to have gone over to the left shoulder more now .. but whether it's just me thinking that ... I don't know. But it seems to have moved over to the left shoulder a bit ...

I: have you had a check since it's been implanted?

Sam: no, no. They have sent me out a box now .. that I put on to the telephone and it sends it straight down the hospital

I: how do you feel about that?

Sam: no problem

I: would you prefer to go to the hospital?

Sam: Erm ... Yes, I think i would. I think I would rather talk to a doctor ... if I've got concerns like I have now then .. you know, .. I can talk to someone. But I got to say the specialist Nurse in hospital has been very good. She's been excellent she has. If I have got any concerns, I phone the Nurse up and it's sorted straight, fair dos to her.

I: have you told her about your arm?

Sam: I have yes, actually she made the appointment for me now but she won't be there, she's off that day but I'm not concerned about her being there. I will be able to talk to a doctor about what's happening by here, which will be a blessing in a way .... I need something done with it ... I don't think it can be normal cos my wife's nephew, he's got one implanted as well .. he had one a few months before me. And he's had no trouble with his whatsoever. But he's a lot bigger boy than I am .. so whether .. that's got ... I suppose it had. It does stick out .. a lot .. but as I said he's had no problem with his whatsoever .. he said its marvellous but he is a bigger boy, bigger boned than me so there's more room on the implanted chest for the- more than mine like ..

I: I suppose that could have something to do with it. Do you think it will affect your fishing?

Sam: no, I'm right-handed so it shouldn't do .. I will try though .. I determined to try .. I got to ...

I: how does your wife feel about you going?

Sam: she hasn't said anything to me ... but I don't think she' got any concerns about it.

I: do you talk to each other about the ICD>?

Sam: oh yes, yes, yes. Oh we don't hide anything from each other you know. She knows it's giving me some gip ... because she's told me when I'm turning over in the bed at night .. she can hear me moaning ... so she knows there's something wrong- something like. I told her about my arm.. so she knows everything about that like ... you know, she understands why it's got to be there and she's been very good with it, I've got to say that like ... But I need to go and see someone to reassure myself. Because at the moment I can't talk to the box ... I've got a letter saying I've got an appointment .. I think its the 18th September to go down and have the ICD checked. But to me, that's too far away .. I'm not going to put up with this for another 6-months .. before I find something out about it. Something needs to be sorted out about it. Yes, it does, because it does hurt.

It's alright like this now, it's great [waves his arm around] ... but I can't do [does a movement] .. mind you, I couldn't do that with this arm 4-months ago ... you know, that's come 100% now. I can't stretch it .. full extension .. cos if I do, the muscle on the top half up there [points to arm] it really hurts.

I: did you have to have a by-pass?

Sam: I had a stent put in ..

I: do you look up about your condition? Do you do any research?

Sam: no, i don't want to know anything about it, to tell you the truth ... it's not that I'm frightened of it .. there's nothing I can do- well I can help it in certain ways, like I've stopped smoking .. you know that in itself is ... well, it's made me feel a lot better .. my chest, no problem with my chest anymore, coughing .. no, it's been great ... I did have problems with my tablets first off ... One of the tablets, I can't remember which one, well the side effects of that was coughing and all I was doing was coughing and I didn't understand why .... Until I went down .. can't remember

I: let's go back to your work, how do you get to work?

Sam: I travel with the boys , we all travel in cars

I: have you always done that?

Sam: yes, yes always done it

I: and how do they treat you now since your heart attack?

Sam: great, no problem ... oh everybody's been marvellous like you know. I think they are a little bit concerned about what I can and what I can't do ... I have found that out since I been back to work .. well they seem to be keeping an eye on me ...

I: do you think that's because you've had a heart attack or because you've got an ICD?

Sam: I think it's because I've had the heart attack .. well that's what I think in any case. I don't' think it's because I got the ICD. They do er .. take the mick a little bit (laughs) but I don't worry about that but no, boys in work have been great.

As I said, if it wasn't for what was happening with my arm .. everything would be great .. it doesn't bother me, I know it's there ..

I: how would you feel if you didn't have an ICD? Apart from your arm?

Sam: I don't know .... as I said, I haven't had any occurrence of ... any chest problems since I've had the heart attack so ... I have got to be truthful, I have thought of asking the doctor about removing it .. because of what's happening with my arm ... that's the only reason why .. because I haven't had any reoccurrence .. at the moment, touch wood, but the doctor said that's there to prevent .. if you do have another one .. it'll give you a little boost until the paramedics come.

I: is that a comfort?

Sam: sort of .. it's the arm, that's the only thing really .. it's the discomfort in the arm

I: if you had to choose between the arm and protection from a heart attack, which would you choose?

Sam: oh well, it's got to be if I had another heart attack I'd be saved, it's got to be that .. you know, it's got to be that, but I need to have something done with my arm because it is really annoying me, to tell you the truth .. the scar, no problem whatsoever ... it's the fact that it is causing this pain in my arm ... I can feel the ICD there .. but that's what I'm saying, I think that's moved over .. and maybe that's what causing whatever is- I don't know. It seemed to be more over here first off [shows with hand on chest] .. seems to have gone over more to the left shoulder now.

II: some people have told me they've had to change the side of the bed they sleep on ...

Sam: I've had to. Yes, I cannot sleep on that side now. But you know obviously when you're sleeping you do turn. And if I do turn and I turn on that side, it wakes me up ..

I: is it painful or are you worried you're moving it?

Sam: oh it's painful .. it's painful

I: so would you be prepared to put up with the pain if there was nothing they could do?

Sam: No, no

I: you'd have it taken out, but earlier you said ..

Sam: as i said, I wouldn't go against the doctor if he says it's got to stay in ... I wouldn't go against his words but I would if possible like something done about it to get this pain ... gone away, cos it is affecting me to doing work as well. And I've got to be fair to the manager in work .. I've been with the firm quite a while and I need to get back to doing something for my own sake. But I need to get back to doing my work for my own sake as well as-the boys at work as well .. as I say, work has been great .. they've been marvellous with me, but I'm just fed up just sitting around doing nothing .. it is boring and I need to get back to doing what I used to do before. With this pain in my arm I can't do it ... which is bloody annoying me to tell you the truth .. sorry to say that, but it is ..

I: what do you do for leisure time apart from fishing?

Sam: play pool

I: what about that stretching?

Sam: not too bad, not too bad playing pool now .. but of course I haven't got to stretch fully out .. my arm is still bent.

I: anything else you do?

Sam: Darts I can't play now ... I've given them up.

I: why's that?

Sam: I couldn't even reach the board ... my arm like that now is great [puts arm in a position] but when I picked darts up and threw a dart at the board, forget it I couldn't even reach the board and my arm was too painful .. so I've given up darts.

I: Given up? You going to go back?

Sam: no, no.

I: but you said you've got your strength back now?

Sam: My right arm was good before .. I threw a dart and it went straight .. god, it was terrible pain ..

I: in that arm [pointing to right arm]

Sam: but as I said, I got full movement back in my right arm now. It's no problem whatsoever, but I haven't played

I: so why won't you go back to darts now?

Sam: I don't know ... well I think I'd rather-out of the two, I'd rather play pool than go back to the darts ..

I: couldn't do both?

Sam: well I suppose I could but it costs a lot of money, so one had to go so I'd rather give up the darts. And I couldn't throw darts in any case. Well I just couldn't .. it was too painful. So, I let them go, I didn't bother ... and I haven't thrown a dart since. But I do enjoy my pool. But I'm still playing pool in any case ..

I: you're not missing out playing darts?

Sam: oh, no, no, no, no, no I wouldn't think so, no.

I: do you do anything to increase your heart rate? Do you know about the ICD and about the thresholds?

Sam: No, no, this is what I need to find out. This is what I need to ask the doctor .. what in his opinion am I capable of lifting weights.

I: right, so you don't know any of this information?

Sam: no, not at the moment. This is why I said, I'd rather talk to someone, face to face, which I haven't been able to at the moment and until i go down on the 17th now ... but I will be having a good chat with the doctor then, cos I need to know for myself

I: have you written a list of questions?

Sam: the only question I need to ask him, is in his opinion how much weight am I allowed to lift then and I'll do the rest ... but I'm er .. nothing but determined. If the doctor tells me 'don't go lifting stupid weights' ... I know that myself .. but 'am I allowed to lift 25 pounds, 30 pounds?' And would it affect me. If he turns around and says to me 'look, you seem alright, yes in my opinion you can lift those weights up no problem' great, I'll go back to work, I'll start doing that next week.

I: you seem very anxious to get back to fully working

Sam: well I shouldn't have done it but I did start doing a bit of work yesterday

I: how did you feel afterwards?

Sam: well i was on a machine, with one of my mates at work, which involved a little bit of lifting .. which was nothing heavy ... just a piece of wood about so long [shows with hands] and so wide [shows with hand what must have been a fairly hefty piece of wood] and it was just lifting that off and placing it onto the machine, and taking it off, which I haven't done for 13 months ..

I: How did it feel to go back and work?

Sam: good. Good, yes so that's why I need to go to the doctor and have a good word with him, so I can go back and tell my manager 'look, the doctor's told me I can do this, so I'm going to do it .. and don't have any concerns about me doing it cos I've had the ok off the doctor'. And hopefully when I see someone on the 17th that is going to happen on the following Monday, I go back to work and I start work.

I: How has your wife helped you?

Sam: oh, she's been great ... oh good God yes. ..... First fortnight after I had the heart attack, I was out of it completely and the second fortnight I was back on the ward , she was down every morning, she was down every evening. When I came home, she had a bed downstairs by here [points to area by stairs] cos I couldn't walk upstairs ... I had a bed down here and she was doing everything for me, fair dos to her ... her and the daughter, they have been absolutely brilliant. Couldn't have asked for any more cos they have done everything for me .. sometimes they tell me 'get up off that settee and get it yourself' ... Which i do, I do that in any case now ...

I: are they helping you become independent?

Sam: oh good God yes. Oh yes, definitely .. oh they've been great fair dos. First four months they done everything for me, fair dos. Well I'm talking ..

I: are you talking about after your heart attack or the ICD?

Sam: the heart attack, when I came home, I couldn't even walk tidy. It was like training to walk all over again. I'm not like that .. I'm not someone who can cope with that very easily see, cos I like to do things for myself

I: so how did you cope?

Sam: I found it difficult to tell you the truth at first. I don't like having other people do things for me. I like to do things for myself .. I always have ... like I said I was born [medical condition] so I er .. wouldn't say I've struggled all my life, cos I haven't .. I coped with everything, I got on with everything .. I've done things that doctors thought I wouldn't do or shouldn't do, I don't know. But I've done them, I've just got on with it.

I: how did you feel when you came back from hospital after your ICD?

Sam: oh very awkward .. oh good God yeah. As they told me, I wasn't to use the arm for 6 weeks to give the ICD time to bed in and of course everything else and .. and it was very awkward to tell you the truth. Not being able to have the movement in the arm .. no stretching, no lifting, no nothing. And it was awkward, very awkward .. you don't know how much you miss your arm, until you can't use it.

I: what about the other side to your marriage, like showing your wife affection ... was that difficult?

Sam: Yes. I think so, yes.

I: Are you ok now?

Sam: yes, we're fine, yes. Yeah, yeah we're great ... as I said the wife has been absolutely tremendous ... been marvellous, and my daughter and her little one and all .. so you know, it's great .. no problem whatsoever. It's just this box, that's the only thing I got a problem with at the moment.

I: you haven't looked at the literature at all, to see if there are any answers to your questions?

Sam: No, i'd rather talk to a doctor, face to face like. I can tell him exactly what's happening and ...

I: what about a support group, would you be interested in joining one of those?

Sam: I don't think so. No.

I: for what reason?

Sam: I don't know like. I'm very open really with the family but in a group I don't think I'd be so open ..

I: you don't think you'd gain anything?

Sam: I don't know. I couldn't say I wouldn't gain anything from it ... not having been to one .. I wouldn't know if I've gained or not, tell you the truth.

I: you don't appear worried about the ICD?

Sam: Oh, I'm not worried about it no. No, no, I know it's there for a reason ... the only thing I'm worried about is the pain I'm having in my arm ... if I could get shot of that pain in the arm I wouldn't worry about it. But I'm not worried about it. The ICD's there, but it doesn't concern me ... if they can sort the pain out, the ICD doesn't worry me at all. I know it's there for a reason, so be it, no problem.

I: why do you think they gave you a remote monitoring one?

Sam: I don't know. I've done a reading ..

I: was it ok to use?

Sam: yes, simple. But I'd rather see a doctor than use a box but if they want me to use that, I don't care. The box is not going to tell me why I've got a pain in the arm .... I've seen my local GP but no 'it's something you got to put up with', that's the answer I got off them. But I'm not putting up with it, 'Sorry, it's a pain'. 'Oh, take some pain-killers' ... 'no thank you'. I don't like taking tablets, never have been, I take my heart tablets now cos i know I have to, but as for pain killers or anything like that, I don't take them. The wife is a bit annoyed about that 'you got a pain take one'

Transcript for N07
Female ICD patient aged 60
ICD fitted for prophylactic reasons
In line with ethics, participant's name has been changed to Jane.
'I' stands for interviewer. EP stands for Electro physiologist or Consultant.

I: so, can you tell me a bit more about your ..

Jane: condition? My background is nursing, I was a midwife for many years, I retired about 4 years ago and about ... oh I think it was about 15 years ago I went to a well woman clinic in hospital in work, and they did various things and one of the stages was an ECG and they picked up from the ECG that it was abnormal. They thought it looked as if I'd had a heart attack. So, I called my GP who said 'look we need to refer you, cos this doesn't look right'. I went to see a consultant at the hospital and had an echo done and the echo was perfectly normal so the ECG was abnormal but I was asymptomatic ... so that was it, I was fine, I wasn't worried.

So, that probably went .... about 5 years later I started having palpitations which I thought was due to the menopause ... so probably this is about, say 10 years ago. Yeah, I started having these palpitations, they were intermittent .. they weren't there all the time, so I didn't take much notice ... so they went on for about a few years. So, then about ... so that went on about 3 years I think.

I started to have ... the first one I had was when I was running .. I'm not a runner but I had this fitness thing ... I was walking a bit, running a bit, walking a bit ... and I had a long bout of atrial fibrillation ... my heart was really going and it lasted for about 7 hours .. and the first time I didn't do anything about it .. just thought 'oh it'll go now, it'll go' and it eventually did go .... my heart rate normally is quite slow .. 48, 50 my heart rate is normally ... so when I go with this it's about 170 .. you really feel it beating in your chest, you know ... you don't feel ill, you just feel a bit .... strange you know. So, the second time it happened and I thought 'oh, I'd better go and see the GP'. So, I went to see him and in view of what had gone on before, he said 'I think we'd better refer you'.

So, I went to see Mr X who's a cardiologist in X Hospital ... did some 24 hour rhythm things .. you know the monitor, went back to see him and he said 'yeah, I think there are abnormalities I think we need to send you to see the electro physiologist ' ... but because I was a midwife he said 'in the meantime, if you do get a bout and you're near an ECG machine, get them to do an ECG on you.

So, I was in work one day, I started to do Ante-natal clinic ... I work mostly in the community ... and I started to have a bout so I finished the clinic, as you do, and I said to the nurse, 'do me a favour, do an ECG on me .. don't be alarmed now, cos it is going to be abnormal' and I told her the story. Well, she did it and she said 'look I can't let you go home like this' and the next thing I was in an ambulance going into hospital which actually was very good because what it did was it expedited everything ... I was there under the consultant and he was absolutely fantastic. I mean, I had everything done you could think of. I was in for about 2 and a half weeks which was a long time, but I had every test under the sun.

And they came up with nothing, it was like everything was normal except for one blood test ... which was always a bit of a mystery .. but nothing, everything was normal .. which was reassuring but for him, I was a puzzle ... I was an enigma. The other thing that complicates this is I lost a brother at 24, 34 years ago with a sudden heart attack. But at the time they said it was a heart attack, you know he was perfectly well, he'd had ... he was actually applying for a new job and he'd gone and had a medical just a few months before ... so it was very sudden. So, that was the other thing that was the bit of the jigsaw puzzle then.

So, from 6 years on now I've seen this .... they tried to give me beta blockers in hospital but because my pulse was so low, I didn't react to them very well to them at all ... so I came home with nothing. So, that's gone on for 5 years, 6 years really, he's been seeing me. Every 6-months, then once a year and then there was one year that I missed a year ... and he's always been ... not been settled by me. He's always thought, what will he do.

So, I continued to work, I continued to have bouts about once a year of AF where I'd have to go in and they'd have to sort of give me some drugs to get it ... so I've been there about 3 or 4 times over the past 5 years . Anyway, I went to see him in September last year ... and I found I was having bouts of ... quite light-headed? And I felt I was going to faint. I wouldn't faint and it would last only a very short time ... but I knew they were significant and I knew they were there ... so I just told him about that and he said 'it's been six years since I've done a cardiac MRI and an echo , I think we need to repeat them' . So, when he repeated them there were changes. So, the left side of my heart is not pumping as it should be and my cardiac MRI was abnormal as well ... so I went really not thinking anything would happen .. he never mentioned what he might do but he talked about a defibrillator then .. and it was a bit of a 'whoa ' a shock, you know . He said 'in view of this I think this is going to be my line of action, I think this is what we should really do'.

And then he said 'I think we'll do an angiogram .. just do everything first, cos it's quite a big decision .. so I had the angiogram, which thank God, was absolutely normal ... so I haven't got any problems with my arteries at all. And then, when I was having the angiogram he had a colleague in with him and he said 'we've been talking and there's a professor up in London ... and I'd like him to see your notes .. he might be able to throw some light on the subject ... I keep your notes on my desk and I'm aware of them in case I do spot things as I go round'.

So, they were very good in London, they rang me up and asked me to come up cos they'd like to do a few things ... so they did a cardiac biopsy cos in the meantime now when I was well he sent me to see the .... genetic consultant ... cos again in my family, I got two male cousins on my mother's side who died late 40s, early 50s sudden death ... so it seemed to be a strand you know.

So, when I went up to London he thought a cardiac biopsy might be useful ... he'd be surprised if anything did come up ... and I'd have another MRI. So, we went up in June last year and they did that . So, came back, sort of waited and then I had a phone call from the registrar of this professor saying they were having a case review the following day ... and I was one of those they were reviewing .. she wanted just a little bit more information and she would ring me straight after to tell me what and it was excellent. At 12 o'clock the next day, she rang and they said that they agreed with what Mr [electro physiologist] said .. that they thought it would be useful to have a defibrillator fitted.

So, the y sent Mr [electro physiologist] a letter, they sent me a letter ... that this was the way forward, so that was a strange time, from September when he first told me about and I eventually had it done in the November .... Well it was a bit ... not my life on hold but couldn't make any plans cos I'd wonder when it would be ... so eventually went in in November .. 29th .. and had it fitted.

The cardiac biopsy, nothing came up with that ... so don't know

I: so you haven't really got a diagnosis

Jane: And do you know what, perhaps we never will, what he said I have a form of cardiomyopathy ... but of course, there are implications for my family ... for my children .. and that for me ... I'm actually fine with it, and it's not changed my life at all [ICD] ... no not really. It's funny, I have a faith, a really strong faith and I really believe that has kept me in good stead because I believe there is a time to be born and a time to die. So, I've not felt like 'oh, my word!' ... never ever felt like that, never felt scared ... so it's been amazing really, I don't know how it would have been if I hadn't. Cos you know, losing a brother so young might have spooked me a bit, but I've not worried at all really about it and I can honestly say that .... that I have not lost any sleep over it.

I: before you had your defib, for that year, you weren't concerned at all for your own health?

Jane: No, no I wasn't concerned about my health, I was concerned- although I'm retired ... I retired as a midwife about 4 years ago and it was really this that pushed me into it. Cos I was having these bouts and they wouldn't happen all the time and I have intermittent palpitations very often , which I'm used to, but the long bouts are actually- if I'm under any sort of stress , telling you what work was like and particularly as a midwife, it was getting busier and once you hit your 55s .. there's definitely a change in the way you work .. oh definitely, I think whatever sort of profession you're in things become different ... 50s on you become different and coming up to 55 work was- I loved it, loved my job but I couldn't do it as I used to do it .. so I found right I'd have to take things a bit slower ... so I thought right 'I'm not rushing over this' but this meant I was nearly twice as long .... I tried changing the times of my clinic to the morning instead of the afternoon, so I wouldn't get so tired and I'd be going slower and I'd be coming in here at 7 o'clock in the night .... And I didn't think of retiring at all but the last time I was off for about 3 months .... I think in about two years, I was off for about 3 months when I'd had about of AF and I'd gone in and I thought 'you know what, I can't go back yet'. And the second time it was very stressful, cos i had extra responsibilities in work .. as supervisor .. and I really felt dreadful, I didn't feel well at all ... had a lot of palpitations, so I had 3 months off, went back to work and didn't want to go back ....

So, I retired .... I do a lot of crisis work, girls that get pregnant and i go round all the GP surgeries doing presentations to promote this work and I couldn't do many. I didn't know when I was having it fitted and I couldn't ring up and say I couldn't come so it held me back a bit ... and I couldn't' take any long term clients ... you know I didn't want to start something I couldn't finish .. so that was the thing ... as for being worried, I wasn't worried ..

I: how do you think you'd feel if you ever had a shock?

Jane: Now that was the thing that ... the only thing I was a little bit concerned about .. I was ok about the procedure ... and I actually relax very well but the only thing, speaking to the Arrhythmia Nurse Specialist was the fact they test out the machine .. once they put it in .. they test it out before [patient leaves the Pacing Lab] ... and the Nurse said 'you know what, I've seen lots of patients, nobody ever says they remember it' ... But that was the only little thing ... it just made me feel a bit 'oooooh' you know.

I: who told you about that part?

Jane: She [Arrhythmia Nurse Specialist] told me about it .. and they didn't do it once, they tested it twice ... so they would test it cos they had to make sure it worked .. but by this time and she went through the procedure .. 'they give you diamorphine first and they give you this dose of "medalozine" .. you know it's the forgetful drug and you won't remember anything about it' she said 'I can guarantee it, cos i've never had anybody but remembered'. But it's still a little bit ... and I've never liked anaesthetic .. one minute you're awake and the next you're completely out of control ... no I don't like that .. I'd rather be awake, no matter what they're doing to me. But actually it was great. It was incredible One minute .. he'd put the device in .. he put the local anaesthetic, I felt the pushing of the device going in ... and after that I don't remember anything until I was back in the bed. So, she was quite right.

And when I came home, I was a bit nervous ... first few times I started to have some palpitations ... although he told me it's set at 40 and 200 and I've never ... no, 250 it's set .. so I've never had a pulse rate of over 200 ... it's always been about 180, 190 and she said 'to be honest if you had a pulse rate of 250, you'd be out ... that's the likelihood' .. you wouldn't know anything about it anyway. And likewise, if your pulse went under 40, you'd be fainting off .... But I was a bit nervous the first few times I had these intermittent palpitations that you can really feel in your chest

I: And what did you do?

Jane: I just sat quietly and thought 'it'll go now' and it-they did go and nothing happened and this was the more, you know after about 2 or 3 times when I had them ... it's fine now. It's ok now. I know that nothing is going to happen. So, I suppose that's the only thing that makes you feel a little bit – if I think about it. I mean most of the time, I forget it's there now ... it just becomes part of you ... when one of the grandkids cwtches into you and presses it, you can feel it you know.

That's the only thing that would make me .. if I dwelled ... 'ooooh the thought of having a shock' that would make you a little bit nervous if you wanted to dwell on that, but I don't

I: has your lifestyle changed at all since the ICD?

Jane: No. Last year I took up ... took up, well I can swim a bit ... but I started swimming three times a week ... I was quite overweight last year ... I lost my mother three years ago this month, she was my best friend ... oh my very best friend .. .. and she was around the beginning of when I went in to have the tests six years ago ... and i didn't want her to worry about me. We'd lost my brother and my father 30 years ago, we lost them in 10 months you know .. so I'd lost my dad and brother, and she'd lost her husband and son in 10 months. I was quite devastated.. 24 and his wife expecting his first baby ... it was a tough time ... and of course there was she and I left and we were very, very close .. I always played things down, 'mum I'm fine' .... so one of the things now is I'm 'so glad you're not here now mum' cos she'd be worried to death about me you know ... but in that three years I comfort eat and I put on about 3 stones .. my knees were bad, my back was bad and this year, I'd come to the end of that terrible grieving ... you know, intense grief ... you know, I could cry as I talking, I've got a lump in my throat here [touches neck] .... so, I thought I'd start losing weight which I did ... and I started going swimming .. so by the November by the time I went in [for ICD] I'd lost 2 half stones .. so I'm now much fitter .. my knee has been much better ... I'm in these clothes because I'm going to go to the gym after [she was wearing a tracksuit]

So, the reason I'm telling you this, cos I've not been able to swim now since November cos they told me, you can't sort of raise your arm up ... they said be careful for 3-months until the leads embed within the muscle of the heart ... so it's not a good idea to swim ... so March now [in 2 months time], I can go back to swimming .. I did nothing for December, nothing for January, but February .. where are we now .. February ... since January .. my daughter in law's parents have got a gym down the road .. which is very useful, so I've been going three times a week ... Well I'm thinking 'if anyone knew I had one of these [ICD] in here ... cos I'm a bit full-on when I'm there ... I do 40 minutes on the treadmill ... fast walking, little bit of running ... but I'm not a runner, I'm just fed up, I just fancied a little run you know .. so off I go .. so you can feel a bit of a rub as you're running .. it's not a pain, you just know it's there ...

I: are you conscious of your heartbeat?

Jane: no, not really, no, no. My pulse is fine so I do an hour ... yes, it's good so in March I'll go back and swim and I'll do the gym about once or twice a week ..

I: And you're feeling better for it?

Jane: oh yes, much better, much better. So life is good. The thing for me now is the kids. Cos I got two sons .. so one's 36, one's 34 ... both live locally. The 34 year old is married and he's got 5 children .... so I'm very busy with my grandchildren... the older two one's 15 and 9 they are from his first marriage and they come and stay with the family once every two weeks and then they come down for tea, once in the week ... so you know, we get a lot of contact with them. So, he's got two by his first marriage and three little ones, a 5-year old, a 4-year old and a 3-year old. My older son, he lives near here just down the road and he lives with his partner and they haven't got any children.

So, when I was in hospital 6-years ago, Mr [electro physiologist] said it would be quite useful for your sons just to come and have an ECG .. which they did .. they just came in whilst I was on the ward. X [older son] looked ok, but Y [younger son] looked quite similar to mine .... So, he's reacted .. well, not strangely but in an understandable way really .. he has some palpitations, he does have some palpitations so I think he thinks he's got a condition like mine .

So, when I saw the genetic nurse and the consultant, going back 2 years ago did a family tree and they said my two sons and my brother's son ... cos my brother had a son, if he ... he's 33, so the three of those should definitely be seen .. ECGs and Echoes .... Unfortunately, I don't have a lot of contact with my brother's son and I've tried to contact him, but I've not got very far with him ... I spoke to two sons about it, now the younger one is ... didn't really want to know ... didn't really want to know .. because the implications for him are far reaching ... because at the time he was driving a lorry, an HGV so there were lots of implications for him ... you know, it was his livelihood at that time and as Mr [electro physiologist] said, if they did find out, he wouldn't be able to drive .... So, younger one was a little bit 'I'm not going any further with this at all' and then when I had this [ICD] put in in November .. he came with husband to come and pick me up ... and he couldn't look at me, he could not look at me ... I could see he was really scared. I didn't say anything or do anything that day ... but he came within a week and his wife had said he'd said 'oh imagine if something happened to me, and I'd left you with all the children' ... so it's obviously something he's thought about.

So, he came back to me and said 'I've been thinking about it mum and if I need to have tests, I just need to have tests' ...... [Long story of son's wayward ways at school and all his subsequent jobs on leaving school]. Anyway in the meantime, I had a letter from London who told me that it would be good for my two sons to have further investigations ... so there's two letters, one each for them .. But you know I've held back, held back, cos I'm seeing Mr [electro physiologist] in April and I just thought, 'you know what ... nothing can be done for a minute now .. let me see Mr X first, give younger son a bit more time to settle into new job' and then .... I'll give them the letters. But I feel nervous for the boys, not for eldest I think he will be ok, but for the youngest. But you know I was talking to the Arrhythmia Nurse Specialist and it just means he will have another ECG ... another echo, his echo is probably going to be normal like mine was for years and years ... so they're not going to do anything ... but he just needs to be checked upon ... So, although it's ok for me, it has got implications for ... the family. So, that's my story ....

I: Thanks, the ICD doesn't appear to have affected you at all ...

Jane: when I was thinking about you coming ... I don't know whether ... maybe if I was a person who was more worried and anxious ... there's not ... and I'm saying this now, but it's not a criticism because I know the Arrhythmia Nurse has said 'anytime' and she's fab .. she's just the right person for that job, cos she's fabulous ... wonderful, oh I mean she's really been good ... but you have it done [ICD implant] ... if you have it done in the morning, you're out in the evening .. I had it done in the afternoon, so I was there overnight .... I went in the morning. And Mr [EP] came to see me and said 'oh I won't see you for 3 or 4 months' or something like that. The Arrhythmia Nurse, I'd missed because I'd come home ... but I rang her within a couple of days because I had a feeling in my chest that I was a bit concerned about so I just rung her to just check on what she thought ..... But ..... there's no .... it's like from November ... I don't know if it would be different if I'd had it done for a different reason, a cardiac-heart disease, whether ... but it *could* be quite a big life change and there's nothing in between, there's no sort of ....

I been invited ... I got to be careful what I say now, cos it's not a criticism ... I had a letter inviting me to a patient support group, but to be honest I don't want to go ... I mean, I couldn't actually go to that one, but maybe if I could help somebody else that would perhaps be a reason for me to go but I didn't feel as if I needed that support at that time ... so that was something that was supportive, but there's nothing from November till seeing him March .. December, January, [mouths months under breath]... that's like four months ...

I: What do you think would have helped?

Jane: I don't know

I: how were you feeling when you got home from hospital? Were you on edge when you got home, were you kind of ....?

Jane: no, no, after a couple of days I had this sort of ... it wasn't where my heart is ... it was in my sturnam ... and when I breathed deeply I could feel a pressure there ... and I think .. my friend's husband is a consultant anaesthetist and he said 'actually there's a lot of pushing and prodding when you're having this done ... and I thought it was muscular, bruising ... but I thought I'd just ring her and check ... so I must have been a bit concerned because I rung her ... and she said 'ooh, that's strange, cos I've not heard of that before' . And I said 'I don't think I'm imagining it ... but I think its bruising, that's what it feels like ... it's not there all the time but when I [takes deep breath] take a deep breath, I can feel something there .. pressure. And she said 'well keep an eye on it now, and if there's anything just come back or ring me back anytime'.

But I don't know whether .. you know what people are like, you don't like to bother ... you don't like to sort of ring and sort of .. I don't know whether any- just something, rather than you being the one to say .. pick up the phone and ask .. whether there just needs to be just something in-between that time.

I: just in the first few months?

Jane: yes, yes ... cos there isn't anything really.

I: what did you think about the literature that you were given?

Jane: yeah, yeah it was ok .....

I: but?

Jane: um

I: anything missing?

Jane: no, I don't think there's anything missing cos they do talk about psychological things, relationships and sexual activities and such .. it's all there so you don't have to ask those questions ... but I just think it's that physical contact with somebody ... you are not having to ring up because you're worried but they're saying 'just come ... just come in a fortnight and have a chat'

I: ok

Jane: yeah, that link with somebody in between .. that 3 or 4 months .. that's them saying 'you come' not you having to pick up the phone if you're worried. Cos it's like ... not that nobody cares but it's like you've a tooth out ... and it isn't really like you've had a tooth out .. it's something a bit bigger than that .. do you know what I mean?

I: yes

Jane: I tell you what it's like ... in midwifery you've had to tailor the care you give them and it's changed so much over the years ... you know years ago, you used to see them far too much .. far too much, you know you'd see them as soon as they were pregnant, you'd see them a month later and da da da da ... And so we were guilty of .. actually you were spending too much time with women .. they become too reliant on you .. you're seeing well women, for what? .. so there's a money implication here but we came to a stage where we seeing them too little and so we'd see them when they were first pregnant but we wouldn't see them until 16 weeks ... and women felt I think, 'I'm pregnant, and nobody seems to care ... It's a big change in my life' ... so the gap was too big ... they've tailored it now and we've come back a bit. And that's the sort of feeling I have ... it's just a bit ...

I: a bit kind of 'left to get on with it'?

Jane: yes.

I: inaudible

Jane: Yes, for me that was ok ... well it's funny, because Doug's [husband: name changed] not communicative .. he's not a communicative person at all ... typical man, you know he doesn't talk about emotions so .. or feelings .. and has not sort of said that he's been worried at all .. hasn't shown any-but deep down I think he has been .... And then when I went in to have it done and I woke up in the ward .. it was the sense for an hour or two that he was there ... it was non-verbal but there was a lot of touching ... I was just of sort of glad it was over ... I was relieved, it was done, it was over and there was an unspoken word ... unspoken ... I think he was there for about an hour and a bit .. and I said 'I'm fine, just go home' ... So off he went.

So came to fetch me the next day ... I think he spent a day home with me and I said 'oh just go to work, I'll be fine' ... And I think it was a while later, I don't think it was very long ago I actually said to him, I said to him 'I think you were really relieved when it was all over, weren't you ... you were quite worried'. Again, he didn't say anything, which said everything. You know, I think he has been worried ... because although there's not a .. Mr [EP] has not given a diagnosis, they've obviously agreed that i have some form of cardiac myopathy ... so ... that possibility is always there .. you know i've got this now [ICD] which is fantastic ... but yeah ... I think he has been concerned ... You know when the letters came[study invitation letters], I said yes I would do it cos it might be useful for other people and actually I was quite looking forward to you coming and me being able to talk about it ... Because when you first have it done, people are interested to know 'well, what have you got?' you know, but then ... I suppose you just carry on .. so I was quite looking forward to just talking about it. Just acknowledging I'd had it done and da da da .... so I thought what about X [husband] .... I thought I'm not going to say anything so when I said you'd rung and you were coming I said ' it would be quite useful if she could talk to you afterwards' and that's the way I put it. And he didn't say no. So, that was a yes.

I: has it changed your relationship at all do you think?

Jane: I don't know .... I think ... maybe a bit closer ... I think to start and then things get back to ... he's very much a typical .. not old fashioned but Doug is the man ... the typical Welsh man .. and we know our .. roles .. you know although Doug cooks and he's a brilliant cook and he'll cook a meal for me now and again you know, I do the housework .. this is my domain ... He likes his meal .. he doesn't get it on the table as he walks through the door, but he'd love it to be .. so he's a typical ... we're happy with that, you know I think there's something to be said about knowing your roles .. there's something to be said about it, it's ok .. it's suits us. But we're not-we don't communicate well .. never have done, so things haven't changed in that way ... we don't talk more .. you know I think perhaps at the time there was a sense of-more of a sort of closeness. You know, particularly I remember on that day, just like a relief you know. So, I don't think it has changed and you know, we're certainly back to normal ..

I: and it hasn't affected your sex life?

Jane: no, our sex life has never been very good for the last few years anyway ... but that's actually, I don't know now ... the physical side of our relationship has suffered .. oh for years and years and you know, probably the last time we had intercourse was about 4 years ago ... which is an awful thing to say, but that's the way we are... It's something that he-we don't address ... but I wonder will this make it even .. thinking 4 years ago, say 3 years ago ... it's at least *3*, and maybe before that it was at least *3 years* ... so I think it's something I wanted to address years ago but he won't address, and so .. the years go by ... Doug's 66 this year and I'm 61, and I think 'bit sad .. I'm only 60', the desire's still there but it becomes the walls, the barriers and it's very hard then to bring the barriers down. So, I wonder if *this* [ICD] ... will it make it worse?

I: and you can't ask him?

Jane: maybe a day will come when I will but um ....

I: so, what would stop you asking?

Jane: .... he's never ever been a talker you see, never ever .... it's been one of the things in our relationship that ... you know just talking with you, he probably has no other problems talking with other people , friends ..... but lots of stuff you know through the family, growing up ... you know our families are so different ... you know I had really good relationships with my parents ... I was totally unconditionally loved, my mother was never- ... but not so with his family .. so you bring it in [to relationship] and unfortunately unless you' re prepared to talk about it .. it ..... I know that he really cares about me, really cares about me ... but he can't express it really .... and so I just get on with my life, I think well I can't dwell now .... the grandchildren bring a lot out of him .. he can express himself with them .... but I find it quite sad and I don't know whether this [ICD] has made it even worse really .. so it's sad .. you can't have a one-way conversation, so if I start talking there's no response or he'll walk away .. change the subject or .. just will not communicate ..

Jill – Well .... you know he said to me that I was breathing when he phoned for the paramedics, he came downstairs to open the door, by the time they came in, and he said they must have been camped you know on our road, because they were here so quick, it was unbelievable, you know, he said by the time they went upstairs, you'd stopped. And they had to shock me and .. I mean, I'm quite an emotional person anyway, right so if I start crying, don't worry about it ... but everybody tells me I shouldn't be here ... (tearful) .....really shouldn't.

I – Who says this to you? Your family?

Jill – Um .... Jo said to me, you know, you're very, very lucky, because you know, someone's watching over you, really, uh .....oh dear ....

I – Ok?

Jill – Oh yeah, I'm like this always, so it's not just, you know, I'm one of these that cries at Lassie, very emotional. And I mean, everybody sort of says to me, you know, you are extremely lucky. I was talking to an ambulance driver on Sunday, 'cos my mum was taken into hospital, and you now, she said to me, it is so good, she said to see somebody who's actually had a cardiac arrest that's here to tell the tale ... you know its ...... but I don't, like I said, for me, I have no panic or trauma because I don't remember anything

I – Mmm

Jill – For other people it's probably awful, 'cos you can't ....My voice is like this (a little croaky) since I came out of hospital, um, for a fortnight after being in hospital, two weeks then of no voice at all. I think there was tubes, or whatever that went down .....so it's very sort of croaky, you know, for me, I feel fine.

I – Do you find you think about it on a day to day basis?

Jill – No. I'm quite, um, a positive sort of person. No, I mean, obviously if, I mean when you got this stuck in where it is, I mean you can feel it so you know it's there, but I don't ... no ....because everybody seems to think ...and I've got it in my head, that I'm probably safer than everybody else now, because I've got it there.

I – So, you find it reassuring...

Jill – Yes. Because when they said I had to have it my first thought was, well, hurry up and put it in.

I – Right

Jill – Because, I was afraid to go to sleep in case I didn't wake up. So when they said, you know, it'll be in there, and if your heart stops again it'll shock you, I just thought well, put it in as soon as you can. You know that's ... I suppose, different people react differently.

I – Yes...

Jill – (laughs) you know, but I just, you know, I really couldn't wait. I had a heart monitor on, but you always sort of think, is this really connected? 'cos I mean you could.....you know they go around and think it's going off, but no one comes to see you to check if you've stopped breathing...or...(tearful)....

I – Mmmm

Jill – But um, well I just thought, you know, if I've got to have one of these in, just put it in as soon as you can.

I – You feel reassured, as you've said, and you trust it (the ICD)?

Jill – Yes. Well no point having it if you're not going to is there? It's like going to the doctor, if you don't believe what he's going to tell you or tell you to do, don't waste his time and go then. Yes, so I ... yes. But you know, I mean, they told me the mechanics of it..... that 180 beats, if my heart gets up to 180 beats it'll pace it, and if it goes to 240 it'll shock it.

I – Mmm

Jill – So you know, they don't even know why it happened.

I – No...completely a one off....

Jill – Yes, they can't find any ... I mean my arteries aren't furred, I've got no heart disease, well I've got dilated cardiomyopathy, um, but the consultant said, because he couldn't find anything else I don't think, I could have had a virus up to five years ago, that affected it. But, you know, I had no symptoms, before, and I had no symptoms after.

I – So, now that you've got it, do you feel your day to day life is any different than before?

Jill – Um, I wouldn't say it's any different, um, you ... you know, if I go out I will make sure that I change... you know, you have a card saying what the device is that you're supposed to carry with you, I do make sure that I take it from one bag to another, in case it should happen and if I go somewhere, like I take my grandson to a playgroup, well I mean, I've told the people there, 'cos I mean family will know, but I've told the people there if anything should happen to me, in my bag will be a card, to tell, you know whoever, ambulance people, whatever, what is there. So you know, you do obviously...but I'm a methodical sort of person, anyway you know, uh, I would....if they say to me, you have to carry this, I mean I carry it, I change bags. And I suppose the first time we went away for a night was in December after Christmas, and I must admit it was um, it wasn't the hotel as such because it was like uh, a place where people have a retreat...

I – ...right....

Jill - .....and my first thought when I went in to the door was, there's no phone... so if I need someone, there's no phone. I mean we all carry phones..... and you also think, you know, small place, so I wonder where the nearest ambulance station is (laughs). Because, I mean the ambulance station is close here, but when I came out of hospital, Terry said, we'll go for a ride in the car, and we went down Gower, and my first thought going down there was, they'd never have got to me in time....because there just didn't seem anywhere where there was an ambulance station. So I suppose you do sort of think to yourself, where's the nearest hospital? You know, where I am, is it accessible for somebody to get to you? But um, I suppose that would be the same with any sort of illness wouldn't it?

I – Mmmm....

Jill – You know, if you're an asthmatic, you hope, will someone get to me, whatever it'll be. But you do sort of make yourself a bit more aware of certain things like medical help I suppose, if anything should happen, they do say to me it might never happen again, it might never go off, so you know...but it's there (touches chest)

I – Yes, and you can feel it, so you can't forget it.....

Jill – Oh no. Cause it's like a brick, it's really hard.

I – Is it painful?

Jill – Um, not so much now, because obviously, you know, it's healed a bit, but, it is hard if you know, you got children, who for some reason like to put their elbow to help themselves up.

I – Yes...

Jill – Well, if anything digs into it, 'cos I mean, have you felt one?

I – No...

really know, she said. Unless they ultrasound it, you know, scan it that way. But I mean it just physically doesn't give does it?

I – No that's right...

Jill – If it won't give, you know the rest is flesh, I just don't know...

I –Mmm...

Jill – Because I think I'm due this year you see...

I – We can try and find that out for you... Referring back to your whole experience of hospital, did you leave hospital and then go back to have the device fitted? Can you tell me about the procedure you went through and how you felt?

Jill – As far as I can remember, because that's still a little bit they can, um, I think it was Jo who actually came to see me and said you know, you have a problem with the electrics in your heart, you know, because they reckon it might have been a rogue heartbeat that went really, really high and caused the cardiac arrest. So she said you need to have a device implanted. Well, I mean my dad has a pacemaker so it wasn't sort of alien, I suppose, and I said is it a pacemaker, and they said well it's not a pacemaker, but it will shock you from the inside. It's like the paramedics did on the outside but this will be inside. I must admit, she went through everything, she was marvellous, so a number of people would come and say well do you know what it is and I would say yes. Even when I went to have it done... Well I had the cardiac arrest on (gives date) and it was implanted, I think on (gives another date, two weeks later).

I – So quite a short time space then?

Jill – Yes, so you know, it was done then before I left the hospital. And it was explained quite a few times, and in, I don't know what you would call it, because it wasn't a theatre... It wasn't actually that glamorous you know to be honest it looked more like a little cupboard (laughs). You know, I mean they went through everything there, so... But I was.... I knew what they were doing because it had been explained fully and it went exactly as Jo had said, that is how it was done so I've had no problems with that.

I – So you felt secure are with the staff?

Jill – Oh yes, oh yes marvellous.

I – So when you were leaving, were you given any information or given advice about life at home?

Jill – Um, the main thing that was stressed was that gets back to normal as soon as you know possible, just carry on. I mean obviously as far as, you know, the operations side was concerned, sort of six weeks you have to be careful. But then try and get back to doing what you did before, which is what I have done, what I do.

I – You do feel that you have done that then?

Jill – Oh yes, I mean I got a back problem so I often say, when I went to rehab for the first time, now listen my back causes me more problems than the device or the condition that I'm supposed to have, well not supposed to have, got, because I have. You know apparently some people are in denial as to.... You can't, whatever's happened has happened, but you know you just get on with it. So my back causes me more problems than my cardiac arrest has.

I – I can see you're quite emotional now.....

Jill – Oh yes, that's me always, so it hasn't changed, from being say a hard person to being you know.... This is just how I always am. Like I say, I could be bawling at the television, if my sons were there, they'd say you're not crying again, I'm always an emotional person so it hasn't changed my personality, you know, it's changed my.... I don't think this actual device has.... But it's changed my, my tastes (laughs)...

I – In what way?

Jill – You're going to find this really strange, I'm the type of person who loves or loved chocolate, I could..... If I eat chocolate, I could have eaten chocolate for breakfast.... But I can honestly tell you, hand on heart that since the time I went into hospital I haven't touched chocolate and I cannot stand it.

I – Really?

Jill – You know to me that's really, really strange because I can't even you know, I'm giving chocolate to the children, and even if there is some on my fingers I can't lick it off.

I – How does that make you feel?

Jill – I can't stand the smell of it, the.... It turns me, it's really.... Yes. Terry was here one afternoon and he was eating some chocolate and I said to him can you turn away please because I can't stand the smell of it. If somebody had said to me, you know, you won't eat chocolate, I would've said you're stupid, because everybody knows I love chocolate. But now, I don't think I've ever eaten so many oranges, fruit, all the time. Grapes, you know I go through grapes like I don't know what. But totally different way of.... And not because people say, you know, you shouldn't be eating chocolate try and cut it down, there are boxes of chocolate upstairs from Christmas full, and before they would not have been any left, I keep chocolate for the children in the fridge and it doesn't enter my head to touch them. It's totally different.

I – So you genuinely crave fruit? Is this a positive thing?

Jill – Oh yes, but you know it's strange, because I don't know if it's a normal thing that other people... Because I mean..... I go to the cardiac rehab class.... Because everybody finds it so strange that I'm there, and they all had, say heart attacks, bypasses, that sort of thing. And then you know I'm sitting there, and I'm thinking, well that doesn't apply to me and that doesn't apply to me. They think it's amazing that this thing is inside me, because the first time the cardiac nurse said, do you mind telling people what you've got, this chap said to me where is it then? They expect you to have a box or something with wires coming with a battery up to here (points to chest), I'm not sure if they thought I had to be plugged in all what (laughs), but you know, they found it quite strange. It's amazing technology, absolutely unbelievable you know.... They, I think, were more in awe.... you know that the wires were going into the heart and there was nothing visible, you know. I said the only thing is you know.... They said at clinic, if it's not used the battery will last for 7.4 years, now how precise is that, you know, it's amazing. I mean, there wasn't a matter of, or as far as I'm aware, well this device costs £10,000, and there wasn't a matter of where is the funding for it you know, it was straight in. Really amazing. But it has left me with a croaky voice..... I don't know if it's from the tubes, but like I say the two weeks I had no voice at all, but you know what it's like, I think I should have asked at the time if it's a normal thing, because, to be honest with you I didn't even ask whether I had tubes down.... Whether the paramedics put tubes down, or whether they just shocked me, I know that I got to intensive care and my sister-in-law tells me, you know, you had tubes and there was machinery everywhere. But I don't know whether... If I had tubes going....

I – Would your husband know?

Jill – You know I haven't had.... You know sometimes.... I say, you know.... Something will come into my head and I will say to him...... what happened at, you know then..... He says well, you had tubes and.... It's str....... I have no thoughts at all, you know, no recollection I should say, of anything. Bearing in mind I like to watch hospital programmes, I find them educational. My husband doesn't, he can't stand it

I – Is that now, or has he never liked them?

Jill – Oh no, never has, he says why would you want to see somebody suffering? I say I don't, it's just you learn so much from these programmes, it just makes you think well, how clever was that? I find it amazing, but……. I, I haven't asked him… I just presumed the tubes were from the hospital.

I –Do you talk about it much?

Jill – Um, I think he can see that I'm pretty well and I suppose if I had a question that perhaps, he perhaps could only answer…. But you know… Yes… But you know…. As to putting the thing in, then no, that was all…… in fairness that was explained to both of us you know by Jo, and that was all processed and dealt with, you know, and I was quite happy with that. It's not that….. I'm not afraid to ask him anything, it's just sometimes….. It hasn't come up perhaps. So, you know……

I – Do you talk to anyone else about the ICD and how you feel?

Jill – If there's a need to, yes, but I mean I think that I've got it straight (laughs). But , in fairness, you know, I go to cardiac rehab, and there is always someone there, a nurse, and they always say if there's anything worrying you, if you're depressed, you can speak to them one to one. So I know that that is there but at the moment I've got nothing that is bothering me.

I – So you attend rehab alone…..

Jill – Yes, because it's really exercises and that sort of thing, then relaxation and a talk, whether it be about heart disease or the pharmacist might come and explain your tablets, or what happened when you had your, you know, by-pass and that sort of thing. For some of the people, they had pains in their chest and arms, and perhaps crushing and they might have felt terrified, whether I did, I don't know, but I can't remember so for me that's fine…not that I'm sweeping it under the carpet, I just don't know. So I don't know whether anybody else could say to me, you know, you did have pain, because I just didn't feel it. So I suppose in a good way it's fine for me (laughs). I've got no frightening memories of fighting for breath or clutching, or I don't know, how you see heart attacks portrayed. But it wasn't a heart attack, you know, they say to me "you haven't had a heart attack, you've had a cardiac arrest" (laughs), so I just don't know…..

I - You're being wonderful, thank you, telling us an awful lot......so do you find other areas of your life have been affected....social life, exercise....

Jill – Well, because of my back, I couldn't do any exercise anyway really, um, no I just don't .... I don't know whether sometimes people just think I'm in denial but like I say I had no symptoms before and I don't feel any different now, so I just do whatever I did before. I don't think to myself, oh I can't do that. I do find that now, whereas before for my back I might use a lift I do say to my husband now, we'll take the stairs because it's better for your heart (laughs), you know, they obviously stress that you should be having exercise and you know, get the blood pumping around, so although it's a struggle walking up the stairs, I suppose psychologically I think to myself, well I'm doing my heart some good going up the stairs. So you do tend to .... but only for your heart condition, you do sort of think well you shouldn't be eating that or, you know .... because they tell you in the hospital and if you don't take it on board there's no point, you know. I mean luckily I've never smoked and I've never drunk, so that baffled them for a start (laughs), 'cos that's normally one of the first things they ask .... "Do you smoke? Do you drink? Ohhhh..." I said well I don't smoke, I don't drink, I don't drink tea or coffee so I've got no caffeine as such, you know, I don't like milk, so (laughs) ....

I – A healthy person ....

Jill – Well I don't know about healthy, but you know, some of the boxes ......

I – You have a healthy lifestyle, so you don't feel you've had to change an awful lot ......

Jill – No, that right, no, like I say, I suppose if I was getting out of breath then you'd obviously have to adjust wouldn't you, but I can honestly say, I don't get any symptoms to sort of say "Oh, you shouldn't be doing that", but I just haven't got any symptoms, which I don't know sometimes whether they think, you know that's a bit of denial, because you're bound to have some, but I haven't. Because, you know, I'm not stupid, and if I thought I was doing something that I shouldn't be doing, if I was jeopardising, then I wouldn't do it. But I haven't got any .... I haven't had to adjust or alter my lifestyle at all, I don't think so. I still see to the children, I will say that I do get more tired, um, but I mean, if I sit down, if I've got time to sit down, you know I will drop off to sleep, but I'm pushing on, (gives age) (laughs). So other than that I haven't got anything that has caused me to alter .... I wasn't five days in the gym before, you know, I've had a problem with my back since 1990, I've had several operations on it, so that has restricted exercise, even when I go to rehab now I can't do the exercises because of, you know, I can't go on a treadmill, I can't do step-up's because my back will go into spasm. So, they have to do the exercises to my pace and whatever I can do, but it's meeting other people and you know........

I – Have you attended the support meetings at the hospital at all?

Jill – Not yet, because the first one was in (gives date) and that was on my Grandson's 2nd birthday, so we had a birthday party, but you know, Jo sent it out, and actually my two sons .... because they didn't know if this was genetic, they suggested that my two boys, they're 30 and 32, had echo's done of the heart just to make sure it wasn't a genetic thing. They've both had it done, they've taken blood from me and my two boys, but apparently there's no funding to test it as yet, it's gone to (gives name of a different hospital), it's frozen somewhere (laughs) .....

I – So you're waiting?

Jill – Whenever there's funding they will test it, but their echo's were ok, so like I say it was the day of the birthday party so I sent a message saying their doing my son, because they were there the Thursday before the Saturday, and I asked him to let Jo know that we can't come, so I haven't actually been yet ...... how often do they run?

I – Three or four times a year, you'll receive a letter for the next one .....

Jill – Cos I did sort of say ..... I think I sent it back saying sorry, I can't make it this time, but I think there was a place to tick if you wanted them to let you know when there was another one, which I did you know.

I – So you can attend these with your husband as well ....

Jill – Yes, well I said to him, and he said well yes, no problem ....

I – He would be interested in coming?

Jill – Yes, as long as it doesn't clash with (gives name of local football team) (laughs) .....

I – So, as a general feeling you have, is your husband supportive?

Jill – Oh yes, very.

I – And do you feel you can talk to him?

Jill – Yes, oh yes, he's as good as gold.

I – Do you feel he worries about you more now?

Jill – Oh yes, probably, (tearful) I would have thought so ...... I think he knows though ..... cos he tells everybody, "She's safer than all of us now" ...... well he would do wouldn't he whatever it was? We've been together 34 years so yes, I would imagine that ..... I think you can tell, well I can tell if there's something bothering him, so, yes we're good .... we're good. Yeah, I did say to him, I said, I've got something to tell you now, and it's going to upset me more than perhaps you (very tearful), stupid thing to say, but I said, if anything happens to me, I don't want my good wedding ring on, I said, buy a cheap one and will you please ..... cos i don't want to go to the crem with my good one (cries) .... but .... you know I don't know why, I was just thinking .... I wouldn't want my, you know what I call my good rings ..... I said get a cheap one and put it on my finger ...... (cries) ,,, I said I want to go with a ring on ... and I said listen to what I'm saying now right, you know, it was so quick before, you just don't know when you'd have time to say anything do you? ...... So, alright he says, yeah that's fine. But you know, I could tell him anything .... I don't know what he's going to say about me mind (laughs), but .... yeah. All you'll have is me crying on that thing (laughs).

I – That's fine, are you ok to continue?

Jill – I'm fine, yeah.

I – Do you feel that there are any obvious disadvantages to having the device in particular?

Jill – Well I suppose the first thing that comes into your head, is if you needed an MRI scan, you know, I would imagine they could do some other sort of scan, but I mean that's basically one of the one's that sticks out, you know, they say you can't have that scan, um, I suppose. Nothing lasts forever, so it'll have to be replaced, you know the battery has to be replaced, so, uh, I can certainly put up with it being a bit hard, which it is, but you know, you can't have it all ways can you? If it's there doing its job that's all you need, you know, that's all you can ask.

I – Do you ever think about the fact that it may go off one day?

Jill – Well I think you've got to, got to have ..... it's like an insurance policy, you've got it hoping that you'll never have to use it but if it does then you've got it haven't you, so you've got to have it in your head that it may go off, I mean they've told me that it could go off, you know, randomly, you know and sort of a few at a time, cos they give you a magnet to put over it just case (a little tearful)..

I – So what do you understand that does?

Jill – Stops it. Anything magnetic will interfere with it, so if for some reason there was a fault and the device kept going off there's a magnet, it's in my bedside cabinet about that big (gestures) that I'm presuming you put over it and it neutralises it or .... sort of stops it giving shocks, giving multiple shocks ....

I – So that's not something you feel you have to carry around with you?

Jill – Gosh no, cos I think provided that you have, you know, you've got your information on you, I'm not sure whether... I mean I suppose they wouldn't want to shock you again if you're already having shocks. I'm not sure whether ambulance drivers carry magnets around just in case, I don't know? But, Jo's words were, you know, here's the information and here's the magnet, don't let it worry you, put it in the draw out the way. So it's there in case, but I mean, I got the impression that, if it did shock, by that time I might very well be unconscious so I wouldn't even be aware of it shocking. But it's there and if it needs to (shock) then it will do it.

I – Do you have a remote connecter for your ICD, some patients keep a remote device by their bed to transmit the information remotely to the hospital?

Jill- No, they did say that some people do, um, and I don't know whether it's something I'll have in the future, or if it's something you have if you live a long way from the hospital, cos I mean the hospital isn't far from here. I just find it really amazing that when I went for the first check up at the arrhythmia clinic, that they, for all the world .... well extension I called it, they put the extension round with a hole that sits on top of there (gestures to chest) with all these reams of paper come flying out of the computer, and you know, she said, I can see from this you've had no abnormal heart rate, everything looks really fine and we won't see you until (gives date six months from current appointment). Which is, you know ...... the information is ... she said I will now be able to check that the leads are still in the right place, she said that you might be able to feel a little fluttering, but you might not. And I had to say to her then, it's not going to shock me is it? No, no she said, just a little fluttering, then she said, there we are that's all done, and it was as quick as that, and I felt nothing whatsoever. I just find it totally amazing, I do, it is unbelievable, everything is computerised and the information ..... like I said, half a rainforest came out. And I thought, there's reams of it, I just thought .... all the information that's on there is unbelievable. It really is astounding.

I – Was it comforting afterwards to know that everything was fine?

Jill – Oh yes

I – Because it can tell you .....

Jill – Oh yes, it can tell ..... well I suppose she would be able to tell that on such and such day, I don't know whether it tells you a date, but you know, that if there was a slight raise of your heart rate or, cos she said, there's no abnormal readings at all .... yeah, just by putting this thing over it, you can access all the information that you need.

I – It is amazing .....

Jill – Flippin' eck, you know, they told me in the hospital they do about a hundred of these a year at the cost of £10,000 a time. And I mean there was no, you know for me, I don't know why other people have them fitted, but for me there was never a question of, you know, we'll send you out now and we'll get you back, or we haven't got funding, or whatever, it was right you will have this before you leave the hospital, and that for me was marvellous. Because you know, if perhaps hadn't had it fitted I may have gone to bed every night thinking well, you know, am I going to wake up in the morning? But there wasn't because it was done straight away, there was no hesitation at all. It was straight in.

I – So, it was reassuring ....

Jill – Oh yeah, gosh yes.

I – Did you feel worried or anxious after it was fitted?

Jill – No. I don't know whether I'm abnormal but ...

I – Not at all, I'm just very interested .....

Jill – Cos you know, we had .... when I went to cardiac rehab there was a form there that said, within the last seven days, have you felt anxious or whatever, and I just didn't, you know, I just take it it's there if it's needed and other than that it's not, I'm presuming the heart is working normally, well as normal as what it is and therefore, it'll only be called upon when it's needed and as far as I'm concerned that's good, and if it's not needed you know, but I know that if there is a problem, as opposed to people who have had a heart attack, they have got no idea when that is going to happen, but they have to then rely on external factors don't they?

I – Mmmm

Jill – For me if the heart rate goes up past what it should, it kicks in and that's fine by me.

I – That's very positive ....

Jill – (Laughs). Have you seen many other people?

I – Not yet, no ....

Jill – Cos I was wondering what the ages would be?

I – Yeah, you're relatively young in the UK ICD population.

Jill – There seems to be more men ... they say it's ..... when we were talking in the classes about heart attacks and things, it's gender, up to a certain age it's mostly men, then I think they mentioned, sort of past the menopause then, it can affect it, the numbers sort of even out after. Up 'til then anything heart wise tends to be men.

I – Yes, statistically, we were expecting to see more men, but we're interested in everyone's experiences....

Jill – Well I mean I had no prior .... well I really just wanted to make sure my boys were ok. So (tearful) ..... (long pause) ..... I hated the thought that it was something genetic that I had unknowingly passed to them, cos, you know, you hear of like a healthy young lad playing football, not knowing they've got a condition, perhaps like cardiomyopathy, and just like .... dying. You know ... so, another little weep there (laughs).

I – Do you worry about that now?

Jill – Um, well not .... Jo said, you know, that all we can do is suggest people get scanned, you can take a horse to water but you can't make them drink. So if people decided they didn't want it done, you know, we can't force them, but there was no problem with the boys, cos I think they thought if there was something wrong, then do something about it now and not try and do something after the event, isn't it? For me, you know, I've had ECGs before but apparently that wouldn't necessarily show it up because it's the, you know, the muscle or whatever, so it would have to be an echo. My youngest had a few echos done anyway cos he had um, um, cancer when he was five and a half .... He had Hodgkinson's disease .... So he was 5 1/2 when he got that and he's 31 now (laughs) ...

I – That's wonderful ....

Jill – We are a house full of miracles! But that was awful, but he's champion, he lives in (gives name of a city) and he's a (gives name of occupation). So he's good and he's home on the weekend.

I – So you've been through a lot ...

Jill – Well, yes I suppose (tearful), it's all right now though.

I – Yes, and you seem very positive

Jill – (laughs) ...

I – Just to finish, what about driving? Did you drive before the ICD?

Jill – Um, I haven't driven for years because of my back. They told me that ... I mean they asked me if I was a driver because I don't think I could just six months could I?

I – No that's right

Jill – But only because I can't sit for long or move suddenly because of my back or whatever, so I haven't driven for years anyway. I suppose that would have been a problem if, if you, everybody likes their independence don't they, so if you are stopped driving that would be a major blow wouldn't it? Because you'd have to rely on others or make alternative arrangements. So I can imagine that for a driver that would be a big problem.

I – And what about adjustment to your medication ....

Jill – Well I've never ever taken tablets, well I say never but that's a lie, obviously you have to take tablets sometimes like .... But I have never taken them long-term. I don't tend to have a very good tolerance with tablets I can't take strong painkillers with my back, because they upset me. They make me sick and give me a headache, so I avoided all sorts of tablets. So that's something I've had to get used to is taking tablets on a regular basis now. Not that they upset me or anything it's just you know when you've never had to take them .... I do become a bit paranoid, you know, I got to take my tablets now, six o'clock, eight o'clock ... I can normally remember the breakfast ones and going to bed ones, it's the six o'clock one I think all I need to take my tablets and my husband will say it doesn't matter if it's half an hour, you know, after. So if I think I might be doing something and forget I might take one half an hour before, but that's you know I mean because I never had to take them on a regular basis before. One tablet I take apparently is to remould the heart, put it back into better shape, now that I think is very clever isn't it? You know Jo said to me one of the tablets is to remould your heart, to put it back into a better shape because it dilated and a bit enlarged and out of shape, so one of the tablets is for that. That's clever.

I – And any side effects?

Jill – No, no, I don't. One chap told me that one of the tablets he takes give him the most horrendous nightmares, he said, I have woken up screaming and crying. He said I had a terrible nightmare last night and I was screaming. So you know I've got none of that so that's something to be thankful for. He'd had a heart attack and one of the tablets he takes, he said, can cause these nightmares and he was in a terrible state. So that would put you off wouldn't it, taking the tablet, wouldn't it? I wonder if there's something different he could have had because imagine if you were having a nightmare, surely there is a strain on your heart? (Laughs) .. That, psychologically thinking, a terrible state would increase your heart rate....

I – That's right ...

Jill – But yes I'm fine ...

I – Is there anything you think would be useful to tell someone who's just about to have an implant like yours?

Jill –(long pause) I don't think so because it was also explained so fully to me at the hospital that I wasn't that worried about having it done because it seemed quite straightforward. They told me they do them so often ... The only thing when they're putting it in is that they have to test it, and I don't think then that you know, will they test the shock and will I be aware of it. But apparently they either sedate you or give you oxygen or some gas so that you go off, and I didn't remember anything. You know, because I suppose when you see it on the television when they shock you externally, you know it seems to be quite a hefty jolt, and you see them sort of jump off the bed and I suppose you just think well, how much of a shock is it going to be if it goes off you know ...

I – Television can be dramatic, do you have any ideas what it would be like if it were to go off?

Jill – Well would you want someone to say stick your hands here and we'll shock you just so you know? Or think, well if it happens it happens, and it's obviously happening for a reason because you need it and don't give it a post-mortem, take it as it comes.

I – And that's the way you look at it is it?

Jill – Yes, you know I mean, like I say it's insurance, you've got it in case. Hopefully it doesn't have to be used but if it does it's there and it's got a job to do. Like I say it's an amazing piece of technology...

I – Thank you very much. I'll stop recording there. (57 mins 38 secs)

Transcript for N10
Male aged 47
Patient has ICD for hypertrophic cardiomyopathy. No shocks.
In line with ethics, participant's name has been changed to Steve.
'I' stands for interviewer. EP stands for Consultant Electrophysiologist

I: Can you tell me why you've had your ICD implanted ...

Steve: I've had this cos the checklist criteria I think ... four or five check point thing, and when I came to review my HGV, I'm 45 now ... for driving lorries and all that ... I had to go through a stringent test like. Because of my brother died of 'hocum'

I: Hocum?

Steve: 'Hocum' hydro .. I don't know what it is, it's something to do with heart disease, it's called hydro ... 'hocum' is the abbreviation, I'm not sure of the proper name for it. It is something to do with the valves in the heart it is. My father was the carrier of that and they [doctors] seen something in my- I'm not sure what it is .. when they put that squidgy thing round you, what's it called?

I: angiogram

Steve: angiogram, yeah. They seen something they were unhappy with so they wanted information and effectively it cost me-well to cut a long story short, it was three of the five then [criteria], because my father was the carrier, I had another thing and cos my brother died of it .. it was three out of five, or something like that .. and although I never had-I've been quite fit and all that like, I asked Dr [EP] ... I'm not questioning Dr [EP], I think he's a great doctor .. I think this is a bit of a peanut ... a sledgehammer to crack a peanut, if you know what I mean.

I: so you don't think your condition is that serious?

Steve: no, I don't like. I dunno, I just think this thing is just bothering me a lot like ... I've never had any attacks yet ... I just struggle with this daily.

I: even though your brother died?

Steve: yeah, I .. well, I don't see how this would have helped him even, cos he would have had to alter his lifestyle, you know what I mean. I think ..... maybe you're better off not knowing like, yeah I really do like. Cos my father, he was the carrier like ... I think he would have been better off not knowing he was the carrier of the gene that killed my brother, if you know what I mean .... he struggles with that he do, but .. this thing, every time I turn over in the night it's there like, you know what I mean ... sticking out of my shoulder .. it's tough like

I: you don't feel you're getting used to it?

Steve: no I haven't .. look, it's sticking out there like [shows me where the ICD is implanted] ... a neat scar and all that but as I say, constantly- my missus, my wife puts her head on my shoulder .. she's even conscious of it, I'm conscious of it. I've been to a couple of these .. what do you call them .. workshops and they're quite good they are ... I can't think of any of the Nurses now .... [says their names] ... there were three of them ... they're all good nurses, but the difference I found with them cos I thought I needed a bit of counselling ..

I: you thought what sorry?

Steve: a bit of counselling like .. so you could talk about .. and in fact one of the blokes [with ICD] he did actually phone me up and I found it helpful ... I'm really, really struggling with this .. continually ... and he was helpful ... All of them had attacks or something like that like, so it was like a preventative measure like ... so I really thought, that brings me back to a sledgehammer to crack a peanut .. I just struggle with it.

I: did you have a choice when you had it?

Steve: well to tell you the truth, I don't think I was given enough- cos my father ... I didn't put him off the idea but I said to him 'Dad, you're 71' or whatever, and I'm struggling with this like, and I said to my wife I hope he don't have it because .. you know, I can't see the point of 70 odd years of age going through the same sort of stuff I'm going through like.

I: so, what's the hardest thing about it?

Steve: it's just there, I don't see the purpose of it really .. like every time I move, I used to be quite fit like, I used to go to boxercise, you know what I mean, and all that. I used to do a bit of boxing and all that ... Gaelic football .. you know what I mean ... now I'm conscious of it, you know what I mean

I: Can you still do those activities?

Steve: I don't think I can like. I've asked the nurse if I can do boxercise and she said 'not really' .. it's not really contact, well I suppose it would be ... anything which involves, I mean, striking with .. you know it's striking, stretching .. but I'm continually doing that at work, I'm stretching .... I can't give up work like, but it's the depression thing as well ... depression .. it's tough like, it's tough ... tough on her as well, putting up with this ..

My sister in law is erm ... don't know what she is, she works in a hospital ... she's a cardiac-I said this to her, I said it's a sledgehammer to crack a peanut ... and she said ... from a medical point of view I can see like, but from a personal point of view .. an emotional point of view, and a physical point of view .. I'm really struggling with it.

I: so if you had the choice ..

Steve: I wouldn't have had it, I would take it out tomorrow ... but they said they can't do that ... if I could take it out, knowing that I'd get my HGV back and all that like, I'd take it out no problem ... but they said, all they could do is turn it off like ... so I think may as well keep it in there like, know what I mean.

I don't think it's right ... I don't think I was given the right [information]... like with my father like, he was given the option, ok we'll do it on increased medication. Now I'm on Atenol 50, and he's on Atenol, half that strength ... 20 or 25 ... or whatever, and they said they can do it on medication ... but I wasn't given that choice, or I might .. I don't think I was. Cos what happened was .. Dr [EP], he tried to convince me really .. and fair play like to him, you know what I mean ...

I: they don't usually put them in unless it was necessary ..

Steve: I know, I realise that .. and I realise it's expensive, it's 10 or 15 thousand pounds worth of gear like, isn't it. I know they really are expensive,

I: but you still don't feel it's really necessary?

Steve: Well, you know what I mean .. if that's the case, if that's how expensive it was ... to be quite honest, I would rather some little kid get this rather than me like, who probably needs it more than me like ... cos I don't feel, at the moment .. I know there were tests done on me like, I'm just struggling with it constantly like ...

I: What's the worst thing about it?

Steve: knowing it's there ... put your hand on my chest, there .. it's there, you can feel a lump you know what I mean ...

I: you don't get any comfort from know it's there?

Steve: nah, nah I don't think ....

I: you don't feel it may save your life one day.

Steve: well, maybe possibly it will, but ... I mean we don't know until the time comes ... do we like, I mean, it may never be used, that's what I've been told like. I haven't had a previous attack like, so I don't know. And another thing, it's a defibrillator and every sports ground has got them now ... I mean a lot of places have got the full on defibrillator ... I think that's part of every sports club criteria ... so if you're in a football club or whatever like, ... they're handy like. All paramedics carry them, don't they like, you know what I mean

I: how did you feel when Dr [EP] said he wanted you to have one? Did you know the implications of it then

Steve: yeah, he explained all that to me ... I can't remember the way the conversation went ... but I think Dr [EP] is very, very good at his job like and all that but I-I ... see, this is what my sister in law said,' it might save your life' .. 'it will save your life' but I said, well what happens if you get run over by a bus or something, you know, fair enough, I know what they're trying to say like, a dysfunctional heart will ...... I just don't feel, I know there's no way of telling like but I just feel it probably won't be used like [ICD will not be used]. Maybe I just got it in my head .. maybe I'd feel different if I had an attack and it was used or something like that ...

I: so at the moment, you don't feel it's necessary?

Steve: I'd take it out tomorrow, definitely I would, honest to God ... I really don't think it's for me .. I go back to the sledgehammer to crack a peanut like, and you know what I mean, I think it's a bit of an over reaction ..

I: you've struggled from the very beginning

Steve: yeah, yeah

I: and it hasn't got any better?

Steve: no, no ... it's a depressive kind of thing more than anything ... just knowing it's constantly there. Like, I used to love contact sports like er .. Gaelic football and boxing and all that ... And I mean I tried going on the bike a few weeks ago .. it lasted a couple of weeks, but you know, I can't motivate myself ... you know what I mean ... like even walking the dog sometimes like .. I mean it's a struggle like. I'm not blaming that on all ... all the depression's not down to this like .. probably a couple of things like a bit of a lack of work sometimes, but it all builds up like ... But I've struggled since I had this and I said this to [nurse] .. I actually asked her .. and fair play to [nurse].. I phoned her up one time and said 'I'm struggling with this' and she got a man to ring me .. he's a runner and all that like, brilliant he was like, he said to me 'you can lead a normal life .. you can go road running' and all that .. And I've always loved running but I just erm ...

I: have you tried running?

Steve: I can't get motivated ... I just feel .. I dunno, I just feel lethargic ... it's not the drugs, I'm only on Atenenol

I: what do you think causing this depression?

Steve: what I really struggled with was when I went to review my HGV .. this is going on two years now .. like I was 45 when I had to do the medical .. passed all the stuff great stuff but when they done .. what is it, the angiogram .. when they done that, they seen something that they .. or Dr [EP] seen something, which he wasn't particularly happy with ... and the DVLA got hold of it. I was always going to use that HGV license as a back up .. you know what I mean .. you know if I do a bit of groundworks and all that and if I wanted to get out of work and work 2 or 3 days a week that was it .. So, my *whole lifestyle* had to alter ..

I: so all your plans for the future ...

Steve: well it just messed them up, not messed them up, but you know what I mean, I got to re-evaluate everything like ... so I'm still working as I am like, but you know but that's not very good neither like at the moment like .. I just dunno ... I was always going to fall back on driving .. cos I love driving and all that ... bu-but having said that, they haven't taken my car license off me so it's not the end of the world like, you know what I mean like ... it takes a bit of getting used to like, that's all ..

So how do you feel about that and how do you cope with those feelings?

I: is there anything you could do instead that you could enjoy as much as HGV driving?

Steve: well there probably is, but I just haven't .. got round to that yet really like, cos it was always going to be driving, I've always been around wagons, and machines and plant [?] and all that and suddenly it's like somebody pulling the carpet from under your feet ..

I: how do you feel; do you feel angry?

Steve: ah no, I just feel a bit upset .. I didn't feel angry like, I just felt a bit disappointed .. upset. There's no point in being angry if that's what it is like ... but I just felt a bit let down, disappointed, upset ..

I: let down by?

Steve: just let down ..

I: let down by your heart, the NHS ...

Steve: I dunno .. no not the NHS, just let down by ... I mean I'm 45, I had ideas of retiring at 50 and all that like, you know what I mean .. me scaling down or something like ... I'm 47, I mean I'm not far away from it now like ... it's the whole lifestyle change isn't it? And I don't like change, I like being in my comfort zone like ..

I: you recognise that ..

Steve: and this thing ... it's just constantly .. *there* if you know what I mean ... wake up in the night and I feel it .. turnover and I [feel it], you know what I mean ..

I: has it affected your relationship with your wife?

Steve: well, not really .. well, it hasn't made it any worse, if that's what you're saying like you know what I mean ... She may have to sleep the other side of me now like, you know what I mean and all things like that, just little things like that ...

I: what about when your heart rate increases? How do you feel about that?

Steve: I don't know about that, I don't know, I don't feel it beating faster or something ... I don't know whether it does or not like .. I can't see ... it must be fairly stable, my blood pressure, they've always said it's been normal so it must be alright like.

I: do you know the thresholds your device is set to?

Steve: ooh, I ... they set them not long ago, I don't know what they are, no.

I: does it bother you not knowing?

Steve: It .. does .. not.. bother .. me, they can take the bloody thing off for all I care. But I mean they won't like, you know what I mean. How many people you interviewed .. say in the last week?

I: oh I don't know off hand, maybe one a week

Steve: and what's the general consensus, they think it's a good thing, are they all like me or are they all ...

I: most are fairly positive..

Steve: so, I'm the most negative one you've come across am I? (loud laugh). But they've all had attacks, I bet ..

I: not all of them, but maybe the difference is for you concern the HGV license. It was obviously a big thing for you .. your lifestyle and the two hobbies you like you can't do

Steve: It was like ... see I'm not ...... See, I could put up with that [hobbies].. oh, I dunno.

I: were you depressed before the ICD?

Steve: well, maybe I was a little bit like ... maybe I was a little bit like, cos work wasn't going too well. As I was saying I was looking at possible going on continental truck driving or something like that. And then ... you know what I mean ...

I: tough

Steve: but as I say, it's not the end of the world, the positive is I still got my car license, if they took that off me I-I ... you know what I mean. In fact, I was feeling of appealing for my HGV. Because Dr [EP] said, if he mentions to some ... he knows a doctor who's on the board of DVLA or something like that, and he said 'look there's not a chance' like he said. If I get an attack .. even with this in like, it could do a lot of damage like. I think I've accepted I won't get my HGV back ... the upsetting thing for me is knowing it's constantly there like.

I: so it's just knowing it's there

Steve: I feel it's there ... very, very heavy at first it was .. don't seem so heavy now so ..

I: some people have referred to it like a 'friend'

Steve: a 'friend'? oh, I don't think he's my friend. He maybe will be one day like, but I mean .. there .. I can't get to grips with it all .... It's just gone a year last November, so it will be two years this November, the 11th I think it was.

I: did you have any concerns when you first had it implanted?

Steve: I think the only concern was that would it go off unexpectedly or false alarm ... I still don't even know .. if I am able to set it off ... as you know I do a bit of travelling, back and fore like [Ireland].. I know I'm not allowed to walk through them [detector], but I have done that, done that by mistake there one time .. but it didn't matter like .. you know I wouldn't do it all the time like, you know what I mean ... I've never had to show it, the card, I've never had to show it .. they've always taken my word for it like, you know .... Flying is not fun anymore, with all this security, I loved flying at one time .. but no more.

I: how's your wife helped you to cope?

Steve: Oh, she's been great, she has like. But I don't think ... I know she's upset, the fact I lost my HGV, the fact I just said to you now, about my father .. she's in total agreement with me over my father, we don't think he should ever have known he was the carrier ..

I: how old was your brother when he died?

Steve: 30. And his son now, he's just got the all-clear. His son's about 18 now .. yeah, coming up to 18 in November .. and he's just got the all-clear I think. I had this thing since my brother died, in 97 I think it was

I: was it a shock?

Steve: oh definitely. When he died in 97, I got screened then and I got the all-clear .. and you're meant to done every 5 years, something like that ... so I must have had another 5-year one and then got the all-clear again and then this come up then .... I don't think it was a big major deal .. Dr [EP] said it was half a millimetre or something .. I forget what term-phrase he used, but it was enough to show concern like. He said it's not critical but it is enough to ... but it is a bit of a struggle like.

I: What do you think of the literature you were sent home with?

Steve: I can't remember that .. I can't remember, I probably did flick through it .. I tell you, I been on the web-sites and all like

I: so you have read up about it

Steve: yeah, I have read up about it ... But i really ... I don't know if I want to know about it .. truth like, does that sound strange like? To be quite honest, I still struggle with the idea ... of knowing you've got something which alters your lifestyle which there really is not a cure for, you know what I mean ... and I just think maybe I'd be better off not knowing. But then having said that .. sorry, having said that when I think of my son and that ..he's been given the all-clear like.

I: so if Dr [EP] said tomorrow, ok I'll take it out ...

Steve: without a doubt. I would take it out tomorrow

I: despite the risk?

Steve: I don't think there's any risk .. how can I say, my case was borderline ... but what I said then now about defibrillators, there's a big push on them to be everywhere now ... I'm not saying they're everywhere like but they are in a lot more places, more so than ever been ..

I: so you'd take the risk?

I: yeah, I think I would. But if it come to the crunch, I got it like ... I think if I was going to do that ... I wouldn't' have had it done in the first place. I don't know if I'd have it .. I say I'd have it pulled out, but don't know really ... I would like it pulled out but I'm thinking of .. it's there now, it might as well stay there, you know what I mean like .... If I was given the choice at the beginning 'would I want it', I would have said no, spend that 10, 12, 15 grand or whatever it is on somebody who needs it more than me .. you know what I mean, a kid or somebody ... I-I wasn't top of the priority list anyway .. I was borderline he said

I: what about if you could have it out, but you couldn't' have your license back?

Steve: well, there'd be no point in having it out then ... I probably won't get my license back now anyway ...

I: so you wouldn't?

Steve: well I think from a comfort point of view [I would] ... I'd have to talk to my wife, but I'd say 90% of me says 'take it out'. It's an uncomfortable-ness, an awkwardness. I said I'd have it out, but I'd have to talk to my wife ... but I think this should have been done at the beginning like .. like I said, if I'd been given the choice at the beginning, I'd have chosen no.

Transcript for N11
Male aged 67
Has ICD for primary prevention. Has sustained ventricular arrhythmia.
In line with ethics, participant's name has been changed to Sam. 'I' stands for Interviewer and EP stands for Electrophysiologist or Consultant

I: Could you tell me a little bit about why you've got the ICD.

Sam: Well, it started um .. last year, actually it was in January, I was walking-nearly two years ago now I was working- ... um that's right, I play badminton and I felt faint and-I was in the middle of a game and I felt 'ugh'... went down on my knees and felt a bit strange .. a bit dizzy.. and got up again and carried on playing but I could see- there was a fellow there who was a dentist and looked a bit concerned .. so I went to see the doctor and they fixed up an appointment .. a heart person, but then I got a job for seven months in Germany, Berlin and so it was fixed up for something like April ... nearly two years ago now, but as I was fine working, I stayed in Germany, I didn't go to the appointment and then I finished my job and came back ... And then I noticed I'd been put at the bottom of the list again, which happens but in the meantime I had a couple of these episodes starting and suddenly I'd feel 'ooh, strange'.. kind of dizzy but it would only be 5 seconds, 10 seconds and on one occasion, when I was walking, I had gone with the ramblers- ... And in Berlin I did loads of activities, I did cycling, I walked miles and miles, I was up on the top floor of this block of flats ... I was stuck at work, it was quite stressful .. with children .. and I wasn't aware of anything going wrong at all ... came back, and then I started going with the ramblers again, played badminton .. that was fine. One of the walks I did .. a hard walk which was walking up an ascent ... it was one of their hardest walks ... I almost felt they were walking too slow .. I felt so fit after Berlin. And even then, not once I was walking but I would feel strange ... I just didn't know what it was.

And once we went out for a meal, I felt it several times on that occasion .. made me worried that something strange was happening .. my pulse .. but by the time I felt my pulse everything was normal ... So I went back to the doctor .. I asked if there was any way they could speed it up a bit, I felt it was getting serious, it was happening more often .. I was in a pub Friday night in Cardiff, and I felt it a bit there, this strange sensation again. I got so worried and it was so slow this process that I actually paid to see someone in (private) hospital ... the GP recommended some person, so went to see him. He put me on an ECG, put me on for half an hour, I think it was, ... he said something in the ECG was a slight up and a slight down he suggested, on these patterns, these waves and he said my pulse rate and heart rate should go up but mine had gone down slightly ....

Anyway, in the meantime I had a 24 hour ECG and these things happened again ... sometimes it doesn't happen for say 5 days but then it will be two days in succession .... I handed the ECG back in on Saturday and on Monday they said 'come in now', they said. ... And I was admitted there and then and I didn't realise it, it was because of tachy-tachy

I: tachycardia

Sam: Tachycardia on the ventricles which is rather more serious than the atria ... and they did tests and took an echo of my heart and said my heart wasn't functioning properly and all these kind of things and then they gave me an MRI ... and that actually said everything was normal ...

I: so conflicting ..

Sam: yes, conflicting .. it said my heart was not enlarged ... so by the end it was a mixed report, and they put me on some medication and fitted with this thing ... they actually checked my heart again afterwards and they said it was functioning reasonable well .... they had another person check it , a technician rather than a ...... anyway, they wanted to know which was right the MRI or the other thing, ... but when they did it... a scan of the heart ... it was alright really, my heart wasn't particularly enlarged .. it was functioning on the lower end of normal ...

I: how did that sound to you?

Sam: well, I felt a bit better after that my initial diagnosis which really worried me, I thought 'oh god, all these things I've be en doing, all sport' ... you know, I've never been a great athlete or something .... They were keen to find out the cause of it, kept asking about the family history and if there was a problem. I did remember though while I was in my 20s .. I was the third child, I had these really nasty chest pains and we went to the doctor and the doctor gave me something for indigestion ... but I hadn't really taken these chest pains on board really ... although I remember at the time changing my life insurance ....

I: really?

Sam: yeah .. before I went to the doctor with chest pains .. because I was concerned about it, it was a frightening pain ...

Anyway, they never found out the actual cause of it [arrhythmia] other than I've got this problem ... this arrhythmia ...

I: how does it feel not knowing why it's happened?

Sam: well it's nice to know, but it's also nice to know it's nothing in the family proven .. I wouldn't want it for my kids either .. it's not a genetic condition ...

I: so, how did you feel when he said you had to have an ICD?

Sam: I was a bit alarmed first of all really ... I don't like the idea of having anything stuck in my body .. it was an unpleasant idea and when I saw how big it was ... at first he said a matchbox, but there are matchboxes and matchboxes ...

I: it's a big matchbox

Sam: It was quite a big matchbox ... more like a Swan, even bigger than a Swan Vesta box ..... and also they said you wouldn't be able to see it, and I could clearly see it ... you can see how big it is, quite prominent really [shows me where his ICD is implanted]. I wasn't hugely affected by that but [taps the ICD], it does remind you that it's there all the time. I think a pacemaker is smaller, I think it's because of the battery for the shock [that it is big]...

I: Did you have a choice? [whether to have it]

Sam: no, no, no, no, no, this was it, I wasn't asked whether I wanted it or not, I just .. I also didn't like the idea when I asked them .. the ca-wires go into the heart.. how do they get to the ventricles, well they fit through the valves, well valves open and close so I know a bit about the heart .. a bit of science, I'm a science teacher so I found this a bit alarming this wire going through the heart, from the top part to the lower part through the valves ... but most of my concerns have .. well, I've got used to it really I suppose ...

I: so, you think you've simply got used to it?

Sam: yes, I've accepted it I suppose really ... and once they got my symptoms sorted out, I think it was one of the medications they increased ... I was still having these-when they analysed the um .. this ICD with this mouse thing over it .. you could tell exactly when it had gone ... I tried to relate it to activities and I could never relate it to-to what I was doing, it never seemed to be worse when I was doing anything stressful or heavy than other times. So, they increased the medication and I was glad when I went up there was no more .. er .. incidences of this thing [ICD]... I was also concerned that the EP I was put with was actually leaving the place ... and when I went-he was going somewhere else .. I was bit concerned that he-well, I don't know .. I mean the nurses were great, the doctors were fine apart from the occasional one-when they got this measurement wrong .. I think that might have been lack of experience you know, maybe someone else should have been doing it .. um .. I went there once, to check after swimming once, I can't remember how many months, about six months, four months, five months that the thing was firing off properly ... so I went, and they gave me an anaesthetic and they tried it out and the shock was working, and I remember being there for this occasion and this EP who had never introduced himself to me .. never spoken to me, never been aware that he had treated me, he was with a salesman from the firm that made these devices ... and they were just talking about me, waiting for this thing as if I was an object there, being tested and I wasn't fussed on that part of it ... it was like, give a shock, ignore the patient ... I like the idea that a doctor, patient should have a little bit of a relationship really ... and it turns out this gentleman was actually leaving .. so actually it was like .. being demobbed ... I shouldn't say that really, but he didn't seem to be particularly interested in me.

The nurses, they have been more supportive since I got back from these checks ... they always ask me how I am, how are things .. I'm very grateful to the nurses, they seem very concerned and if you ask them a question and they wasn't able to answer them, they went to see this other EP who was available .. and when I spoke to this EP .. he was most um, well clear in explanation ... that's what I wanted really and he said things should be alright and that um .. that reassured me a lot really ..

I: Ok, so the literature you were given in the hospital, how helpful did you find it? Did it answer questions?

Sam: up to a point, I had a booklet and I did look in the booklet and it did answer questions ... but at the time, 'I just want to get through this' ... I didn't really want to know too much really ... I didn't want to read about it a lot, I wanted to know the basic idea but I didn't want to label myself as something awful ... I tried to shake it off in a way I suppose. That's what I tried to do.

I: right, so did you find it hard to accept that there was something wrong?

Sam: yes I didn't like that idea at all really ... who would ... and I was concerned about my lifestyle as well .. that I wouldn't be able to do things that I normally did ... all I heard .. well on my thing, it says 'heart failure' and I'm not actually sure if heart failure has actually been diagnosed ... I suppose heart failure would occur if something went wrong again ... I read about heart failure, and people feel too weak to do dishes and things like that, let alone go for walks, swim and so on ..

I: so, have you managed to regain most of your activities?

Sam: yes ... I think I haven't been walking as much, I think I've lost a bit of interest in that ... you have to drive to a certain place and then you'd go from there .. and a few things happened, and I think I got out the habit of it ... I haven't really got back into it as yet ... I am planning to go walking again, the harsh stressful walks, I might think twice about those …

I: for what reason?

Sam: well, … in case I do something harmful to myself really I suppose .. I'm a little bit concerned that it might-I might um .. I might precipitate this shock thing, which I don't want really to happen .. that's what would worry me, if I had this shock thing, other than when it was induced as a test.

I: ok, so what do you think the shock means for you?

Sam: well no driving for a start, also I- what would it mean? Um … it's a bit … dicey really … things are getting a bit dicey really, if it's got to that level really …. The medicines are not doing their work .. and things are getting worse ..

I: so you would interpret a shock as something getting worse.

Sam: something was getting worse .. the medicines are no longer coping with my level of problem … cos they increased the medication, and it now works and if it didn't work anymore, I'd say 'this medicine isn't working anymore or something's got worse'.

I: what about if you pushed your heart rate towards threshold and you had a shock … would that concern you?

Sam: yes, that would definitely

I: that would concern you?

Sam: yes, yes

I: even though it's supposed to do that?

Sam: well ….. not sure the question, sorry can you say the question again

I: say .. you know your ICDs been set to a upper and lower threshold … so if it dropped too low it would pace it back up, and if it beat too fast, it would shock slightly to lower it, so if you pushed your heart, I don't know, running or something that pushed your heart rate up and that induced a shock simply because you had pushed your heart rate to go fast, would you worry about that shock?

Sam: I would worry about that yes, yes, at the moment I don't know where that level is and I'd think 'oh this could happen again' and I'd be afraid of it happening again really. I don't know .. I haven't felt the shock yet, I'm a little bit afraid of having it the shock really ..

I: what do you think it would be like?

Sam: unpleasant really, I've been told ... I shouldn't really say this, but I go up ladders, clean windows , things like that .. I do swimming, I measure my pulse now, which I never used to do ..
After say 20 lengths

I: and if it was fast would you stop?

Sam: it usually goes to 90 and I think that's acceptable ... my heart rate was quite low and with these medicines, it makes it lower again. My blood pressure was quite low before and now it's low again ... I hadn't thought about it going low and shocking ..

I: it paces it not shocks.

Sam: ok, but if it did shock, I would be alarmed yes

I: do you think you would avoid certain activities?

Sam: well badminton is what I've stopped, partly because it's an explosive sport, I've never been sporty but I play badminton .. quite pleasant, and a few women have started going, and these blokes are very competitive and if you let them down you always feel guilty ... they crash into the women, and two women have given up, cos they got smacked in the face by overenthusiastic men you know. Because they are ex-sportsmen and they don't know when to stop ... so it's not worth me getting bashed .. it's says no contact sport, and badminton should be non-contact but it could be a contact sport in that sort of environment

I: so you'd be afraid of getting hurt?

Sam: yes, it's not worth it really, is it?

I: could you take it up somewhere else?

Sam: yes, in a church hall, with nice old gents and ladies perhaps yes .. but I'm fussed on doing that, I quite liked the buzz of it .... so I thought oh it's not worth it, exposing myself to that ... so I make up the exercise in swimming and though swimming's boring .. it's good to have no weight on the legs and you can stop when you've had enough .. pack it in and do it again another time. I will walk but I won't do badminton, I really liked the buzz of these keen blokes .. and some keen women, it was more fun.

I: so now you haven't got that buzz in your life, have you been able to replace it with anything?

Sam: no, not really, I haven't found anything- I mean I walk fast and sometimes if I'm late for something I'll run a bit ... sometimes I'll go by train and sometimes if I leave the house a bit late I'll run .. and sometimes I think 'I shouldn't be doing this' so I'm definitely watching my excesses whereas in badminton it was strenuous bursts because they [the men] demanded it of you .. so I haven't found anything to replace that ... dynamic cardiovascular exercise I suppose really.

I: sorry, can you just tell me how long you've had your ICD in for?

Sam: ICD, it ... last year, so it's actually a year and a half now ... it was August, not last year, the year before ... and I'm also concerned when the battery's going to wear out so when I go back I'll have a check 'is the battery still alright?' I don't fancy having this thing opened up and they got to cut it right open again and pop another battery in ...

And I also think 'do I need it?' I know a doctor friend who I go walking with said a woman has had hers removed but I'm not that bothered by it ... perhaps the woman wanted to wear low clothes and perhaps she was more aware of that ... Also when I go swimming I'm supposed to tell people-life guards that I've got this device, I usually do, but I don't always do ... and I'm also concerned when I go abroad and I go through the um .. the check [security] and I've read somewhere that you're not supposed to go through it ... but then I've asked since then and they said you can go through these things ... so I'm still not quite sure ..

I: oh right,

Sam: When I was searched someone wanted to put this small device over my body to check and I said 'I'm not sure you're supposed to do that' so you get separated from the rest of the crowd .... and I'm also concerned about my mobile phone, I have it in this pocket .. it might affect it ... I wouldn't want to set it off or make it inactive or whatever .... I asked this doctor friend, when this woman had it removed, what did they do with the cable things ... 'oh, they leave them there' and I thought .. thought that's a bit grim, you've got these cables in you ... I appreciate now, this device is very expensive so I must have needed it badly for them to fit it ..because it is a very expensive device ... and my heart was in a very serious condition, because I was told my heart rate could go up so fast it would begin f-f-

I: fibrillating

Sam: yes, so it would be curtains as well, so I didn't realise that either .. I didn't realise I was that near ... of the end possibly

I: mm, so for you what are the benefits of having the ICD?

Sam: well first of all, I don't have those strange sensations anymore ... I know a little bit more about my condition .. the arrhythmia .. the benefits, in most places I carry on my life as usual ... in most places, and I can't complain about not playing badminton really but I can swim ... so the benefits are-I have a slight sensation it's there and the tablets- it definitely is there but not really a huge hassle.

I: do you feel protected when you go out? Do you feel reassured?

Sam: ... well the whole process that made me more aware .. I thought maybe one of my blood vessels here had blocked up ... they did all these tests .. they said my arteries are pristine .. which 'what a waste' I thought (small laugh) ... they explained there was no blockage at all in any artery ... and to have these fine but something else is wrong ... but then you get to accept these things really .. and I feel, most of the time there isn't a problem really

I: so you feel hopeful?

Sam: yes, from what I've been told really ... they said you can carry on with your life normally and people as young as 16 have these things fitted ... I'm just hoping my condition isn't actually getting worse really, that's what ...

I: that's your main concern?

Sam: yes, I don't to be this ... not that I love doing dishes, but I wouldn't be able to do dishes without feeling overtired. And although I feel a bit more tired than I used to be ... it doesn't really bother me to that extent that I can't do anything except badminton really ...

I: do you think it could be the drugs making you more tired?

Sam: yes, it is the drugs, that's why I've got colder hands and feet and I'm also concerned about being dependent on drugs. For example, I've had a sore throat and cough and the cough is one of the side effects of one of the drugs ... and the sore throat, I looked it up on the internet-actually I rang up today to check that it was also possibly a symptom of-side effect of this thing [drug]. I went to the GP about my throat and he gave me an anti biotic and it still hasn't got better so I was relieved to find-it could be a side effect of this medicine. But I suppose I will go back to make sure ..

I: ok, just one last question, can you tell me how you've managed to adjust to your ICD? What thoughts have gone through your mind that have helped you adjust to it?

Sam: well just carry on with everyday life, and you're busy doing other things and forget about it ... I totally forget about it when I'm doing most things I do, even when I'm walking ... when I cycle round [nearby lake], I cycle fast and I feel 'yeah, I'm ok really'. Just that little bit more tired late at night really with my condition. As for the ICD, well I suppose it's the essential friend, that's the way I look at it ... not sure if it's a welcome friend but it's an essential friend.

I: ok, thank you.

Sam: I still feel, I'll never get completely used to the idea that I've got this thing really, because it was quite a shock finding out about it really ... and this [touches ICD] is a permanent reminder of it but then it could well have been life saving though, so therefore, be grateful.

I: thank you .. thank you very much

[we talk about study and his working life ... Tape put back on later as he begins to talk about facing death]

I: .... up until then you think you're going to live forever don't you? I guess you face this kind of mortality issue with your wife but not with yourself, because you've always been fairly fit and active ...

Sam: Except I felt, with the mortality in this situation .. well I imagine you'd have a nasty experience for a short time and curtains, so it's not like a slow .. nasty experience. So, you know, I've no desire to be like my mother, she's 89 .. I suppose she has a life but I wouldn't-I suppose it may change as you grow older .. but that doesn't appeal to me at all really ... stuck at home .. not a life anyway really ... I suppose I can see five years, ten years but when I start to think of being in your 80s and not being able to do this and not being able to do that ... I think if you're no longer there, then you're not missing an awful lot really ... and my mother's quite open about it as well ,,,

I: are you quite an open family? Do you talk a lot openly?

Sam: well, my mother does yes. My wife is quite the opposite .. she's never talked about anything like that .. talk about the cancer .. never like that .. or death .. But my mother's quite the opposite ... when I was a young man- a boy actually and we were in the car off to the seaside ... my mother said 'I think I'll leave my eyes to the hospital' ... (laughs) ... she's always been like that ... so I've been faced with these darker things in life from a young age so I don't fear them ... I would like to think when I come to [dying I'll be ok] .. but I'm not so sure ... but I think it's better to be in the rough and tumble of life rather than be cushioned from them

I: are you able to talk about your ICD worries with your wife?

Sam: yeah, yeah ... but it's funny with women, they talk about everything in detail but when I come it's not mentioned ... [talking about male friends] unless somebody is causing somebody to be ill at that particular time and they don't discuss these things. And it's also done so flippantly as well ... they joke about hips and things but they don't talk about it seriously in the same way ... I guess that's a male thing I think ... sexist I know, but men are more ignoring of health issues or death

I: you don't strike me as someone like that ..

Sam: well you can't talk about it when you're in a centre of a group but I'm quite happy to talk about with you.

Transcript for N12

Male aged 67

Husband has ICD for secondary prevention: survived two cardiac arrests.

In line with ethics, participant's name has been changed to 'Kevin'. 'I' stands for interviewer and EP for Electrophysiologist or consultant.

I: your wife was telling me you had your ICD implanted because you had a heart attack?

Kevin: I had a heart attack about 35 year ago and now and again, I get a few sorts of pains, that sort of thing .. but no real problems up until ... last year. They didn't say it was a heart attack .. what it was was my heart just started racing .. and it got that fast that I arrested ... but luckily when I arrested I was in the A&E ... and then they checked it all out ... they couldn't find anything ... it was behind the heart where the problem was, so there they found a little bit of dead heart, or damaged heart from when I had the heart attack, and that's what had caused it.

I: how did you feel when you knew you were going to have an ICD?

Kevin: oh it didn't worry me as long as it fixed up my problem ... the only thing .. when I had the op-was waiting to be told what they were going to do, cos they did so many bloomin tests, in the fortnight that I was in the hospital ... it was just waiting to find out what they were going to do ..

I: so once you had the diagnosis you felt better?

Kevin: yeah, once they had taken me up to do a test ... what-they just re-created the problem ... I was semi-conscious ... they deadened everything and then they put a thing into my thing [heart], and brought on the attack .. it was the same thing ..

I: you seem very calm about it ...

Kevin: it's happened ... it-it ... I haven't had any trouble since ...

I: did you have any concerns about it?

Kevin: oh just minor, whether-what actually the purpose of it was, why I needed it, but it was all explained to me so ...

I: do you feel you do need it?

Kevin: well, I haven't had any problems since *but* you never know

I: right ok,

Kevin: you know I was out in the garden and I was here alone when it happened, so pretty scary

I: so, for you what are the advantages having it?

Kevin: well, it's just a precaution much as anything else ... just gives you peace of mind I suppose

I: if you were without it, and your wife was at work, how would you be?

Kevin: well, I'd be .. well, put it this way, I wouldn't be doing too much .. so, it's allowing me to get on with my life ... because if I am out in the garden doing some gardening and [wife] is not here, and something happens .. at least if I black-out this thing's going to come in and kick start me, which will give me time to get inside and phone for her.

I: do you do as much as you used to do, say in the garden?

Kevin: well, I have at the moment, because I'm also on dialysis .. so that restricts me quite a bit ... by the time you work out you've got to do about 15 hours a week .. you know by the time you set the machine up .. do your dialysis, come off dialysis, clean the machine .. that's five or six hours of your day gone ...

I: so what do you do the rest of the time?

Kevin: well depends, depends whether I go on in the morning, the afternoon or I go on in the night ... it does restrict us where holidays are concerned, we can't go away on holiday. We can go away for a couple of days, but that's as far as ...

I: are you a keen gardener?

Kevin: oh I don't mind, I'm not a keen, keen gardener but I'll do a bit of gardening, I'll weed

[talks about gardening here compared with gardening abroad]

I: so you said, if you didn't have an ICD you wouldn't do as much

Kevin: probably not.

I: so what do you do now then that you wouldn't without one?

Kevin: I cleaned all my windows yesterday .. I walk the dogs

I: Do you think about the ICD whilst doing these things?

Kevin: I probably do, but I make sure someone was with me ... but I do all things that I used to, hang out washing, sweep ... go up ladders

I: so has your lifestyle changed at all with the ICD? I realise the dialysis plays a huge role in your lives.

Kevin: just be more careful .. if I work, I make sure somebody's around, you know especially if it's manual sort of stuff, if it's only light stuff, I'm alright ..

I: so, when you're doing work, you'd prefer to have someone there? Even with the ICD?

Kevin: even with the ICD I think

I: why's that?

Kevin: I don't know, don't know. I probably feel more comfortable

I: can you think of any disadvantages?

Kevin: I know it's there. And yet it does restrict your movement ... you know, stretching wise and that sort of thing ... I feel a pulling and I feel it moves around a little bit.

I: does that concern you?

Kevin: well, I just know it's there and if you knock it .. you know it's there .. you think 'oh that bloody thing is in the way'. The only thing is after I'd had the operation .. I had quite a lot of bruising and swelling and I spoke with the Arrhythmia Nurse about it and she organised me to see EP. But he wasn't overly concerned, he didn't want any follow up or anything. I've see EP once since I had surgery ..

I: did that make you feel assured [that no follow-up was necessary]

Kevin: well no, I'd have preferred to see him afterwards the operation ... it was only because of the swelling I saw him anyway ... I probably wouldn't have seen him at all ... The Arrhythmia Nurse rang me to see how I was .. and I said I was a bit concerned about the swelling. And she had a look, she came out here to look at it and said 'yes it is, I think I'd better get you in to see EP'. Which she did a couple of days later ... And since then I've been to the hospital, to the cardiac out-patients once, and that was only to see the technician to check this .. [touches ICD] ... I haven't had it a year yet, just over six months ... cos I've just applied to have my license back .. well actually they were slow, I put in all the paperwork when I went in hospital but they didn't cancel my license till [month later] .. so that's a restriction too, cos I can't go anywhere ... If [wife] at work, I'm stuck here ... I can't take her to work, and have the car or anything ...

I: is that what you used to do?

Kevin: oh yeah, quite a few times ... sometimes she'd take the car herself and sometimes I'd drive her and go and pick her up ... And it gives me something to do, you know if I want to go somewhere during the day .. you know, get down to B&Q, pick up a few things ... there's a couple of little jobs I want to do but still haven't had the chance to go and get the equipment I need to do it ... so it's that sort of thing, you can potter .. do the house cleaning .. I prepare tea for when [wife] gets home .. but you know, there's only a certain amount of things you can do.

I: so once you've got your license back ...

Kevin: well you know, I can take her to work ... that'll give me the chance to go and do a bit of shopping ... go and do something ... but I wouldn't say it's really affected me ... just a little bit tentative about some jobs.

I: so what did you think of the literature you were given?

Kevin: when I first-they gave me a lot in the unit and she explained, she went through the ICD and that sort of thing and it was pretty straightforward, it was pretty straight explanatory ... I can't remember which books they gave me .. I had a couple of things off the Arrhythmia Nurse, just a couple of things, it was just a book on the ICD .. that was about it ..

I: did it answer your questions?

Kevin: yeah, it was pretty self-explanatory ... what it does .. what happens when it goes above what they've set it at [ICD thresholds]

I: do you know what your threshold is?

Kevin: 66 I think it is, something like that I think it was ...

I: is that the lower one?

Kevin: yeah, I'm not sure what the higher one is ...

I: so you don't consciously try to monitor your heart rate.

Kevin: well now and again, I get very, very light headed ... but that could be to do with the dialysis as well see ... I always had high blood pressure .. now it's the opposite, because of the dialysis and that ... when I'm on dialysis my blood pressure can drop to 50, 40 and I know, I can feel it coming on, so it's just a matter of adjusting the machine

I: what about the upper threshold?

Kevin: well it's never-since that last episode had any problems ... all I was doing was putting a rockery in .. in the back garden there .. just outside the back door, I was down on my hands and knees .. I had made all the .. thing to stop the weeds and that and I was just putting some rocks on

I: were they heavy rocks?

Kevin: no, they were only little pebbles ... I was just spreading them ...

I: so if you were to repeat that activity out in the garden-

Kevin: nah, it probably wouldn't have any effect, probably just feel a bit lightheaded

I: so it wouldn't bother you

Kevin: no, I would just sit down, sit in the chair out there ... sit there for a few minutes then continue

I: so, how do you feel about going out on your own?

Kevin: oh that doesn't worry me, if [wife] not around, then doing minor little things .. I don't mow the lawns anymore .. mainly cos the mower broke down .. we got somebody in when I first got back home, and we've just continued that .. saves me going out buying a new mower anyway .. but I still get out there with a strimmer and that ...

I: so if you weren't to get your license back, would you be happy using public transport?

Kevin: yeah, I've got my free pass .. I used the bus last Saturday cos [wife] was at work .. walked down to the bus, on the bus, walked down to my mate's place then onto the match ... I still get around.

I: has the ICD changed your life at all?

Kevin: no ... no I wouldn't say it's changed my life... just made me probably a little more aware of my ticker ... just got to watch what I do, and try and keep my weight down.

I: when you say 'watch what you do'

Kevin: oh don't over exercise .... overdo anything ... If I went out there to dig up a bit of the garden or something .. I would find I'd have to have a rest during it .. I can't sort of keep going .. I get too much out of breath ..

I: but is that your heart or your kidneys?

Kevin: well I'm not sure ... probably a mixture of both

I: how long have you lived with your kidney condition?

Kevin: I was diagnosed at 21, had it over 40 years, only been on dialysis for two years, had a few problems, nothing major, played cricket till I was 50, played golf ... still got my golf clubs there ...

I: do you think you'd take golf up again?

Kevin: I might ... it's just that I'd have to .. play by myself or meet someone on a course cos I don't know anyone here that plays golf, see. Whereas back in [country used to live] I had friends who used to play .. I used to play with my brother-in-law and all that ... but I will go to the football probably

[talks about the difference in health service between UK and other country]

... I've settled here, but [wife] hasn't. She would go back tomorrow if she could ... but while I'm getting this treatment we've got to stay here

[chatting about health care over in the other country]

I: can you think of anything you'd have liked after your ICD that may have helped you?

Kevin: I probably would have been happier if I'd seen the EP one more time .. but other than that no, I'd like to have seen him in say the first month after surgery ... I saw him once but that was only because I was worried about the size of the swelling and then there was no follow up .. and then I saw the technician to see the ICD was working

I: so you'd like to have seen the EP

Kevin: I think it was just reassurance that there was nothing wrong because of the swelling ... but then you would expect after surgery to have at least one appointment to see the surgeon ... it was about 2 months before I saw the technician ..

I: was the EP there?

Kevin: never saw the EP, just saw the technician ... so I saw the Arrhythmia Nurse and EP a fortnight after because of the swelling and that was only because I mentioned it to the nurse, when she rang to see how I was .. I had bruising everywhere ... the ICD was raised this much [shows with hands], I was black down this arm and all down through here [shoulder, chest]

I: so if you'd seen photos of what to expect would you have been so worried about the bruising?

Kevin: Oh, I wasn't worried about the bruising, I bruise and the warfarin doesn't help ..

I: so what was worrying you?

Kevin: well what worried me more was when they said I was going onto warfarin ... because if I'm sticking needles in me every day, it means I'm going to bleed ... I used to bleed enough and now it's worse

I: so that was more a concern?

Kevin: that was the biggest concern, going on the warfarin

I: more so than the ICD?

Kevin: more so than the ICD.

I: what worried you in particular about the swelling?

Kevin: that it was exorbitant cos they told me it would be flat ... I can still feel the [touches ICD], it's not flat ... and it's annoying as much as anything else

I: annoying?

Kevin: yeah cos of movement ... god knows, when I lie in bed and it twists itself and sometimes it's here [moves ICD in shoulder and pokes it out] and it's on one edge ..

I: have you swapped sides of bed?

Kevin: no, I'm on that side anyway, but I tend to lie on that side see, ... and my sleep pattern's not the best at any time

I: how's your wife helped you adjust to the ICD?

Kevin: well, not much she can do ... she was supportive when the problem happened and when I got home and that, I couldn't do anything for six weeks .. wasn't allowed to, wasn't allowed to lift my arm or anything ... so that sort of restricted me a bit ... other than

that ... not being able to drive, that's the bug-bare ... if I want to go
somewhere I've got to wait for [wife] to be around to take me

Transcript for S13
Male aged 68
Has ICD for secondary prevention. Fast, constant irregular heartbeat. Had it in for 3-4 months
In line with ethics, Participant's name has been changed to Jon. 'I' stands for Interviewer and EP stands for Electrophysiologist or Consultant

Participant has leg which is badly bruised elevated on a chair.

Jon: couple of bleeds, and of course taking warfarin, anti-coagulant .. so that's what laid me up, rather than this [touches where ICD placed]. B-but to be truthful, not overly impressed .. not being able to do anything .. days are long .. naff telly but you get used to it ...

I: right [do ethics]

I: right, first of all can you tell a little bit about why you've got your defib ...

Jon: I've got, apparently an irregular heart beat .. and I'm told from the power that be that .. quite a lot of people go through life without having any problems with it whatsoever .. named a few names, like Tony Blair and a few other people .. fine you got it, fine, ok .... For some reason .. in 19-.. 19 when, I was in the middle 50s, 52. 53 something like that .. I partly-being on warfarin, I partly lost the sight in one eye .. blinding headache, didn't know what was happening ... went into [hospital], I was there about two weeks and whilst I was in there they asked 'when did you have your heart attack?' I said 'what heart attack?' You know, I didn't know I'd had one ... The ECG had shown up that some time in the past-oh fair enough .. didn't know anything about it. Then I was put onto warfarin obviously to- .. my blood had thickened up and I've been on that ever since. .... And the wife and I, with the van out there [points to motor home outside the house] since we've retired, my daughter lives in Germany and that's one place we've done a lot of travelling around ...

And we were in France on the one occasion .. only an overnight stop and the supermarket was supposed to be just 800 meters up the road .. well, I don't know where they got the tape measure .. but it was pitched like that [uses hand to show steep incline], and it must have been a mile and a half, and it was cold and windy ... and we got back to the van, and I thought 'that's me finished, that's the end of the holiday' .... came back, went to my doctors, had various different tests, and they sent me out to see an EP and he referred me to- .. and with him I had an angiogram .. and then he referred me to another clinic .. I think under a Dr X, I'm not sure ... we had a chat and we –he went in through the groin, had a look around and said a defibrillator is needed because of these electrical discharges

... he explained it, the heart muscle .. the meat of your heart if you like, is designed to dissipate electricity .. as in static electricity .. um, but scar tissue isn't and the scar tissue in the heart from the first one ... any maybe subsequent heart attacks .. scar tissue, which stores to a certain degree static electricity and fires it off periodically .. like when you touch the door handle of your car .. 'bloomin' heck', you know and that sets off a pattern, which causes the heart rate to accelerate ...

I mean I'm sitting here now, talking to you knowing that my heart rate is about 105 beats a minute .. which apparently is double what it should be ... but because I can't feel any palpitations .. I can't feel any problems whatsoever .. he sent me home, and I've got to go back in for a blation .. abalation? They tried it at one time but it ... but for some reason, they couldn't-the strobes in the heart which went in through the groin .. sorry artery and vein both sides of the groin .. were designed for a 6'4 American person apparently ... by the time he got to the jigs and the bends in my arteries and veins there was barely enough for .. to finish the job. So, he'll go in through a different angle this time ..

I: ok

Jon: and when I was home, I thought I had a shock ... I'm lying in bed here ... I said to the wife, 'I've had a shock, what do we do?' It's the first time, first and only time, I thought ...

I: why did you think that?

Jon: well I was asleep and I woke up with I thought a tremendous pain in the chest ... but obviously, never having had a defibrillator or an active .. I didn't know what to expect, other than it's going to shock the heart .. to restart it, slow it down or do whatever it's got to do ... And I genuinely believed I had a shock .. told the wife, talked about it. And the Arrhythmia Nurses up at the hospital say a little poem which goes to the effect of 'one's ok, two is fine, three or more ring 999' ... right, ok it gives you an idea ... We didn't ring 999 .. obviously cos I had the one, but later in the day telephoned and went up there .. They put me on an ECG .. on their lunch hour, no signs of anything ... nothing at all .. whether it was psychological, whether something had happened, I don't know .. I felt I'd had a belt ... and they kept me in to do something- the wife might remember, cos she's got a list of the dates of these over there [points to kitchen] .. and they kept me in .. but while I was in CCU ... two staff nurses sitting there and all of a sudden, and all I can remember is screaming out, and just above me was the monitor and it was big red flashing lights with 206 on it and then the god almightiest belt I ever had in my life ... I then realised that what I thought I'd felt in the morning or earlier, certainly wasn't the real thing .. Cos when this thing activated, it was like someone hitting me in the chest with a flogging hammer-that's the way I felt. My heart rate had shot up to this 200 plus, the defib was set for 200 .. kicked in .. bumph .. did its job .. slowed everything down and well, within no time I'd –fair play to the two staff nurses .. they sort of chit, chat calm you down sort of thing .. and everything seemed to be ok, touch wood . But I hope the only time I ever have a belt was that time. I wouldn't wish it on my worst enemy to be honest, but it did the job.

I: so now you've had one, do you feel more assured, know what to expect?

Jon: now I know what to expect, it's like everything else it's –if you're in a situation of .. the unknown side of things, let's be honest, you don't know what to expect, now I know what to expect ... yeah ok, it's not the most pleasant experience I've ever undergone but now I've had it, I know what to expect and I know at the end of it, it's beneficial to me in some respects .. it brings my heart back down to where it should be or puts it back up to where it should be and .. says he hopefully, prolongs life .. at the end of the day ...

I: so when you had your shock, you were lying in bed.

Jon: I was in the hospital bed, yeah, just lying in the hospital bed . I don't know what would have happened if I'd been driving for example ... I really don't know ... I wouldn't like to say, I've no idea

I: so for you what are the advantages of having the defib?

Jon: well I don't know, as I say, having experienced it the once ... yeah ok, I'm a bit limited at the moment because of something akin to it but-through no fault, you know what I mean and I've been laid up for a month pretty much ... At the moment I would say I'm a bit breathless but that is probably an inactive lifestyle cos as I say my right leg was just a complete purple ..

I: so you're usually quite active ?

Jon: generally speaking, generally speaking. I'm not saying I'm running half-marathons or anything of that ilk but I'm not used to just sitting on my butt and .. having the wife to wait on me ..

but that's not the defib, that's the .... [patient had pneumonia] but the defib, realistically because I've been laid up, I haven't really had chance to test it out. Yeah, ok I feel a lot more mentally ... they tried to explain to me, if I didn't have it, it was basically a matter of time. Now I've got it fitted and hopefully everything works tickety boo .. as they said, there's still little things that can go wrong ... this thing will effectively stop my heart accelerating to explosion .. you know what I mean, I mean if there was nothing to control it, it could race into a self-destruct mode almost .... Yeah I've got to go back in again for this ablation, if it's unsuccessful the EP suggested I might have to have some kind of surgery ... That is at the minute pie in the sky- I don't know what's happening there but as I say, from a point of view of peace of mind, it's good I got it.

Every time my granddaughter comes in now and she puts her arms around me and 'it's still there Bamp' ... she can feel the lump

I: so you feel a peace of mind

Jon: oh yeah, I certainly feel a lot better mentally the fact that it's there .. I know it's looking after me, if you like ... what's it going to do if it goes band and I'm sitting there, I don't know ... but the fact, as I say, it happened on this occasion ...

I: do you think about that a lot?

Jon: I think I do actually. Again, possibly the fact that unfortunately I'm sat about these last two three weeks and I haven't been able to do anything really and you're just sitting around reading the paper, put the newspaper down, do the cross word, watch the telly, I'm sat here .. Whereas normally I'd be out. The grass wouldn't be as long and things of that ilk.

I: and do you think you'll get back into it once your leg ...

Jon: oh hopefully ... as I said earlier, I've certainly no intention of doing any half-marathons but ...

I: do you think you'll be conscious of the defib when you're working in the garden?

Jon: um .. I don't know, I think I'll probably take things a little easier than I would have done, whether that's good or bad I don't know ... my youngest son is built like a .. whatever [rugby player] so if there's anything that requires digging for example, it's down to [son] now ... whereas years ago, I would do it for him .. my daughter's away, the others have got the their jobs to do .. you know, I have plenty of back up put it that way, but [son] being the younger one and the nearest to us residentially wise ..

I: but would he have done these things for you regardless of your health?

Jon: oh yes, if I want something done, oh yeah

I: so, it hasn't changed then in that respect?

Jon: oh not to that great extent no .. but I used to enjoy doing it myself .. and getting involved in it ... If [son] had a job on, he's a plasterer, if he had a job on, he's say 'Dad, what you doing on

Tuesday or Wednesday?' 'nothing mate, why' 'do you want to go and get some bags of plaster for me' 'yeah, ok'

And I'd drive across and I'd get the stuff and I'd bring it and I'd enjoy doing it ...

I: do you not see yourself doing that again?

Jon: well I would like to think so ... I really would like to think so but .. just remains to be seen, see what happens ... as I say, it's unfair on the defib at the minute because of what happened with my leg, cos I haven't been able to do too much .. even struggling to get upstairs .. because of my leg ... and shortness of breath but apparently that is, hopefully according to the EP, the ablations hopefully would assist the shortness of breath .. but obviously until that's done we won't know. I just keep my fingers crossed and praying that it's going to work, and if it does then fine, I'll be out there with the ... lawnmower .. whereas before I just didn't know what was going to happen. Having said that, I didn't expect to have one of these fitted ..

I: how did you feel when he said you had to have one?

Jon: um .. I don't know ... I think .. I don't think anybody would want anything fitted ... I mean it was the first intrusion operation-first time I'd ever had a cut ... I mean I've been stitched up from accidents but I've never had an operation in my life ... it was all new territory to me and I'll be honest, I was bit scared. You know, as in 'what the hell's going to happen? What's going to happen to me, what are they going to do?'

Yeah, I was certainly a bit apprehensive. I would say, scared at the time. But when the doctor referred me over to .. I think it was Dr X's clinic I think, where the EP is anyway ... went to see him and obviously the compared notes and my wife being a nosy blighter, she reads them .. and I'd rather not know ..

I: so would you rather not know, seriously, would you rather not know too much about what's happening?

Jon: yeah I think so, yeah. Just get on with it, as long as it works ok, fine. If it don't work, I don't know what to expect ... you know I'm not expecting anything ... I'm not expecting miracles. If something is beneficial, that's fine ... if it doesn't work, I didn't know about it anyway .. so I'm not missing it, you know what I mean?

I: what about the defib though, you said there may be things that go wrong with it

Jon: the defib, not so much goes wrong with it ... sorry I don't get the question

I: I'm sorry, I thought you said earlier that you were aware that something may go wrong with it

Jon: oh no, not so much with the defib no but I didn't know what they were doing when they were putting it in there ... and the ablation side of it ...

I: and you've still got that to come ..

Jon: I still go-as I say, they did try it but .. it was insufficient of whatever the strobe type thing is to do the job properly, so the EP obviously couldn't do any more at the time and sent me back-sent me home and I've got to back up there on the 13th of next month ... if there's a bed ... He said he was going a different route, instead of going up and down over the heart into the chamber , he's going in through the side or something .. it's all double Dutch to me ... which gives him considerably more of this strobe thing to do the job and he's- he was of the opinion he was able to do it, but ... so, I'm just touching wood and keeping fingers crossed that he can do what he's hoping to do.

I: can you think of any disadvantages that you've had with the defib? Has it caused you any concern or have you had any problems?

Jon: um, not really ... no I can't say I've had any major problem with it ... they do say, magnets for example, aeroplane screening .. which obvious I've got the certificate thing to show I've got a defib fitted ...

I: you don't have any worries about it?

Jon: no

I: nothing goring around your mind, thinking about it?

Jon: well as I say, initially going around in my mind was 'what the hell is it going to feel like if it goes off' ... now I've had a belt, I know what's going to happen

I: was it better not knowing?

Jon: I don't know. No, I don't think it was .. truthfully. Now I know what's going to happen, I know what to expect or I'll rephrase that, if I feel that belt, I will know something was not quite right and this thing has kicked in and sorted things out for me, hopefully. But now I've had it .. as I said earlier, I don't particularly want it again if I can avoid it, but now that I had it .. I know what to expect ... As appose to being in a situation of the unknown .. there's nothing worse than not knowing ... your mind generates all sorts of pictures of .. well, whatever ... and 'I wonder what will happen if this goes off, I wonder what's going to happen when that goes off' ... Well now it's' happened I know what it does ; it immobilised me, it knocked me back onto the .. it really did

I: how long did it last?

Jon: I really couldn't tell you. I honestly don't know ... it might have been a split second ... it could have been seconds, it could have been minutes, I honestly could not tell you .. truthfully. The only ones that could tell you that would be the two nurses who were sat there. I honestly don't know. I would suspect being the shock it was .. probably a split second ... I've had many an electric shock over the years, my trade was electrical .. I've had more than enough electric shocks over the years ... and a splat will let you know what's happening, but again it's only a split second and I guess this probably was ... I would guess.

I: so do you think you will try to avoid having one?

Jon: well, I don't know what to do, to actively avoid it, other than sit around doing nothing. And then it wouldn't necessarily work as I was asleep at the time [of shock] ... they are hoping that by doing these ablations, which should hopefully contain the heartbeat, well not contain it, control it to a certain degree or it will go all over the place ... Hopefully if these ablations are done they .. the EPs opinion they will work, then fine, then effectively, I could have this thing taken back out I suppose ... you know, effectively. But for obvious reasons, it wouldn't be done... But I'd like to say, get the ablations over ... I'm not looking forward to going in for that now ... but at the time, when I was in the hospital, when they did the ablations the first time I'd been in because I'd had a bit of pneumonia and I was coughing and I mean coughing ... and my youngest boy and his partner were visiting and they were just about to leave and coughed and 'Jeez, that hurt' and it bleed, so of course the staff nurse was getting ice packs to control the bleed, which is part and parcel of why I'm laid up so much. But I think had I not had that coughing fit, I would have been a different guy now, as appose to having all this-cos I had a bleed when they sent me home after a day or so, I had a bleed at home here ... had to call the ambulance out, *back in* ... the wife put some ice-packs on my leg, which kept it-controlled it to a degree .... but again all of this unrealistically is to do with the defib ... it is a knock on effect .... By having this [leg] I don't feel I've done justice to the defib ...

I: you've got plenty of time, you've only had it fitted 3 months?

Jon: yes ... as I say at the time they couldn't shock test it .. I was up there recently .. you could go yesterday or you could go tomorrow .. to the clinic. You get fitted up to various machines and it's like a little circle which they put on your chest .. whatever that does, I don't know, it must be an aerial for the machine or something ....

I: so I suppose if they didn't shock you initially then actually when you left hospital you didn't actually know if it worked.

Jon: no, no, that's right

I: did you think about that?

Jon: well it went through my mind ... as I say, at the time they were waiting for my INR to come back up, cos they knocked me right down 1point something as appose to 2.5 ... my therapeutic grade is 2.5 to 3.5 and of course they had to bring me down because of the anti-coagulant ... if they're going in, they have to have the blood congealing ... so for some reason, they couldn't do it at the same time. And they were waiting for me to have three-initially they were waiting for me to have three consecutive blood tests that were in my therapeutic range ... It was working up, I was getting there, then I went into hospital for the chest and my range was quite good at the time but not perfect ... The Arrhythmia Nurse came to see me when I was in the dungeon up there ... and arranged for me to go and they had a look at this [ICD].. did the shock test and whatever ... But they put me out a few times but they had to use the manual defib to fire it back up, now what-whether that's normal, I don't know

I: I wouldn't know

Jon: I've no idea .. but they fired it up with that ... so I presume, they stopped this, and used that to start things whatever ... I don't know, but any way they did what they had to do ..... The EP sat and down and went through a lot of stuff, not necessarily the best scenario but at the same token, a possible alternative .. not that we want it-just want these ablations to work ... He gone through what I said earlier, these little peaks ... He described the inner of my heart as like an egg-shell .. what he meant by an egg-shell, whether it's calcified, I've no idea .. and these peaks are on it, and what he's got to do is get rid of these peaks, cos these peaks are firing off little electrical charges, which is causing me to a) have a fast heartbeat and breathlessness and several other things ... I suppose it wouldn't be the blood going around the body that's causing the breathlessness ... I know it takes oxygen round the body .. I know I'm going off the subject but my INR, if my INR is high, say 4point something, I get breathless ... if my INR is low, I get a bit breathless .. because either the blood is going round too fast, in the higher number or too slow ... so having taken warfarin for 15,16 years I've a rough idea of what I'm supposed to feel like when I'm right. I mean going upstairs here, there's only 12 or 13 steps but at the moment I'm struggling, I'm really struggling. Coming down's not so bad but I feel heady and I got to hold myself .. not giddy exactly but heady .. you know, lightheaded. And if I get up from here [chair], say to go to the loo for example, I go 'whoa, blimey' because the blood pressure has really, gone down to rock bottom. That's what I presume is happening any way ....

I: what did you think of the literature that the Arrhythmia Nurse gave you? Did you read it?

Jon: quite a bit of it .. the wife probably read more than I did .. I'll be honest, I didn't really want to know what was going on .. I got to be truthful with you. Yeah, ok, it might have made things easier, I don't know ... but to be fair, I've only seen two regularly but there are three nurses in the Arrhythmic section, and I got to be fair, they've been great, they've been really great, I've got to be honest ..

I: is there anything that you think could help ICD patients? That perhaps you would have liked when you left hospital?

Jon: I don't know .... they said it was unusual ... for some reason, it was unusual to fit a defib when I was on warfarin.. whether this is right, I don't know .. Hence the reason, they had to wean me off it for a couple of days and I've got to do the same now ... before I go in next month, I got to go off it for three days. Whether that is right, I don't know. You'd think a Heart Unit would be used to people taking warfarin .. you know with various types of heart problems. Whether I've got the wrong end of the stick or not, I really don't know ... They went through everything, they didn't glamorise it, don't get me wrong, but by the same token they told me what would be happening, not necessarily when, but what would be happening and hopefully the effect it would have .. which is basically what I want to know.

I: And you feel quite hopeful about the future?

Jon: yeah I do, I do touch wood ... I mean [wife], my wife, they may have spoken more with her about what's going to happen with me, I'm sure they probably did ... I don't know, I don't know how my wife's feeling on it but they went through everything they needed to and as I said, they didn't glamorise it .. they told the truth, what could or may not happen. Touch wood, so far what they suggested has happened, has happened ... the only knock back as I say has been the problem with my leg. That has been the only knock back, that I haven't been able to get out and walk about. The wheel-chair we borrowed to go to the clinic at the hospital and the like .. to get out and about .. you know, in fairness to the porters, they only had a limited number of porters and hundreds and hundreds of patients, but having your own chair [whistles] you're in and out-more convenient. But if i hadn't had the bleed, hopefully I wouldn't have needed the chair to get back and forth to the hospital and clinics ... it's my leg that's held me up nye on a month

I: so you haven't appreciated the benefits of the ICD yet?

Jon: no, I suppose ... it's not been fair on the unit [ICD] the fact I've been laid up .. it's not been really fair on it ..

I: but the first month you'd have to rest the shoulder

Jon: yes, I wasn't to move my arm above shoulder height for six weeks, things of that ilk ... not to drive for a month .. ok fine, we got through all that .. I had to use my shoulder or arm but not .. as I say .. you know, wash your hair with one hand, you know ... Alright, a bit of a fiddle but you get used to it ... and it's not for ever, only for a couple of weeks ...

I: when you came home from hospital, how did you feel then about the defib?

Jon: well apprehension would be involved ... but basically I was saying to myself, I hope to God it works ... the shock was about 2-3 months after it was fitted and as I say, I thought I had one in the night but I must have dreamt it, funny dream (laughs). But having said that, I'm glad I did, cos having had one that night afterwards, and being there anyway ....

I: so each time it happened in the night did it?

Jon: yeah it did, yeah

I: and do you think about it now when you're up in bed?

Jon: I haven't been to bed now, couple of nights, I'll be honest, I'll sleep in here ... I've been sleeping in the chair

I: because of that?

Jon: I don't know. I've got five pillows so I'm sort of half sitting up in the bed and I get the feeling I'm choking ... sitting there and it feels as if there's pressure on the Adams apple if you like .. and I have to sit with my feet at the edge of the bed ... I mean I went up to bed last evening, last night, first time for 2-3 nights and i did give it about an hour and a half I think ... in the end, I said to the wife 'I'm sorry, I've got to get back up' ... I came back down and sat in the chair for the night ..

I: Has this happened since you had a shock?

Jon: um, I wouldn't like to say it's a result of the shock ... possibly it plays on the subconscious mind I don't know .... I haven't really thought it's the shock .. because it's only been the recent couple of days .. that I've been downstairs sleeping ...Prior to that I might wake up, I've been in a cold sweat, you know, 'blimey it's warm in here' but I'm shivering .. now whether that's in fact the psychological fact of lying down there and having had a shock and that part of it, I wouldn't like to say ... I don't honestly think it was as a result of the shock ... there again, I can't say it wasn't

I: what do you do when you're lying there and feel like you're choking?

Jon: sit back up ... put my legs at the edge of the bed ... whether you could qualify it as a panic attack I don't know .. I don't get any palpitations or anything of that ilk .. whether it could be a panic attack with the choking... I'm trying to associate what I feel ... but I certainly find sitting is a lot more comfortable and ok, maybe you don't quite get the same type of sleep but at least I know I'm sitting here ... if I'm up in bed, not that the wife minds, but I'm disturbing the wife, whatever .. she accepts it, it's not the end of the world but from a peace of mind point of view, sitting here I feel happier ... Cos last evening we tried something else .. went to bed ... all my pillows up as norm ... and we have a daughter that stays from Germany and we have a little bed that can stretch ... and the extra pieces of mattress, we put those at the foot of the bed .. so I didn't slide down into a lying position. And it appeared to work initially, but I still got to the stage where I was sliding down and something was pulling on my throat ... like as if I was choking ... as I said, prior I was waking up in cold sweats and it's getting worse ...

Transcript for N14
Male aged 56
ICD fitted due to Brugada Syndrome 5 months previously
In line with ethics, participant's name has been changed to Mick.
'I' stands for Interviewer and EP stands for Electrophysiologist or Consultant

I: Do you mind telling me why you had your ICD fitted

Mick: right, three years prior to 2010, I had pains in my chest in the night .. I go to bed early, I got woken up about 12, 1 o'clock with pains right in the centre thinking 'oh'. So, I popped downstairs for a cup of tea .. so not to get on [partner's] nerves and I had to go to the toilet to do number two ... had a cup of tea, stayed down here ... went back to bed and went to sleep. I woke up on-that was Saturday/Sunday morning ... I woke up Sunday and [partner] was doing dinner and the pain came back and I thought 'oh', I'll go and get checked out cos of my age ...

I: do you mind me asking how old you are

Mick: not at all, I'm 56 .. had to think then ... so I went to the A&E in the hospital and they whipped me in straight away 'pains in the chest' and they kept me in all day ... and they gave me ECG and discovered I had a abnormal heart syndrome , which turned out to be Brugada, if I've pronounced it right. And then I had to wait three years ... So, I was quite shocked to have Brugada. I looked it up on the internet ... it's very new in fact, did you know ... So, I had to wait three years then thinking I could possibly be taken out in three years and then my time was up and they said I had to go in and hence me having to have it inserted in then ...

I: why did you have to wait three years?

Mick: health .. health system, health cuts I presume ... I spoke to a lady in hospital and I'll tell you about that now .. and she was from England and she said I wouldn't have had to wait at all, it was just Wales ... So I'm fortunate to be around. So, I went into the hospital .. shall I get some data of when I went in? Do you want precise dates?

I: no, no, just roughly what happened and how you were feeling

Mick: right then .... I went in for a test ... I got signed off on the sick on [date] and then I went in I believe on [date] thereabouts in October for them to see if I was high risk or low risk ... because if I was low risk, I wasn't going to get this ...

I: and this was after three years?

Mick: yes, in three years time I got a note saying I will be getting called into Hospital ... had my notes, saw my doctor .. my doctor signed me off 'awaiting insertion of defibrillator' ... right, I get the dates right now ... the [date] I was signed off, I went into the hospital then the next day and nil by mouth, because I was going to have my heart stopped .. to see if I was high risk or low risk .. That was on the Thursday, they did that then EP, if I've pronounced it right, he's the top notch in the hospital, he said 'yes, I was lucky, i was high risk' but he said, because of my age, it might never happen ... I said 'but I don't want to take that chance after waiting this long' .. 'Right' he said 'we'll call you in one to two weeks'. They let me go on that Thursday after stopping my heart ... I came home .. so that was Thursday night, then Friday then Saturday [partner] said 'oh lets go for a walk in [town on coast]. So, she drove me to [town on coast] and we were sitting in some gardens, as we normally do, looking at the lovely views ... I got up and I started having an attack ... And I had the same sensation as when EP- when I was in the operating theatre and they put these wires up through my groin and he said 'can you feel a sensation?' and I said 'well I'm starting to feel a bit tired and I think yes I am going' and the bonk, gone ... I think they had a job bringing me back cos I had burn marks where they tried to get me back and I heard the EP say to his colleague 'well done for that'... They left me just outside the theatre, well my heart was racing .. hard to breathe, well I had the same feeling in the Gardens in [town by coast] just before I went out ..

I: so you passed out

Mick: no, no I was hanging on for dear life ... because I'd had it through my groin, I took a walking stick with me .. just to keep..er .. standing ok. And I'm sitting on the bench and holding on .. and by all accounts ..[Partner] can tell you as she was with me .. poor girl ... I was getting hot and cold .. sweating and shivering and ...

I: what was going through your mind at this time?

Mick: going through my mind was the fact I hoped I could keep it together .. to keep, how do I put it, awake .. cos all my body wanted to do was [falls sideways onto sofa from a sitting position] was keel over and call it a day ... And it came in spasms .. It came three or four times .. I'm holding on for dear life ..[partner's] panicking .. trying to phone the emergency services, trying to tell them where we are .. we didn't know the name of the Gardens .. and then I was coming back thinking 'oh thank goodness for that' and then the next thing it would come again .. It came three or four times... Then the paramedic-paramedics came-arrived and then took me to [name] hospital because no-one [other hospital] would have me .. at the Hospital there were no beds, he didn't know what to do ... one hospital said they didn't want me, they didn't have the facilities [for Brugada] so the paramedic said 'I'm just going to dump you in the Emergency Services .. you know, I've got to do something with you' and I said 'good' that's where I met that lady from England and she said I shouldn't be waiting [for ICD] but there you are, that's Wales for you I suppose ....

So then .. I was- most of that day I was in that hospital waiting for a bed in the [Name of big hospital] Hospital ... then there was one available, they took me in there, they wouldn't let me go and they said they could fit me in to have this [ICD] done, which was about 10-days. Kept me on a monitor, if I needed to go to the toilet, I suppose you know this [Interviewer says no] they gave you something to [shows with hands a belt around waist].. they know if anything happens, they can get you. So that's that ...

I: thanks for sharing that ..

Mick: very, very scary so um .. shall I carry on?

I: yeah, yeah go on

Mick: so, that was that .. I went home, was off work rest of November, December and I actually went back to work in January, which was the wrong idea. I went in and spoke to the Directors and said, I'd had this done .. and my roles need to be downgraded ... I'm a lecturer, I teach plumbing and gas .. so I'm an Assessor, an IV

I: IV?

Mick: internal Verifier ... City and Guilds .. and they said my role would be more .. they said 'they were a growing company and they had lots of candidates coming in'. I'm not allowed to lift heavy things, I'm not allowed to go near Solanol-solanoids, magnetic fields which we have. I am not allowed to go up a ladder but being a tutor/assessor/IV, it's not like working for Swansea College, it's a private company so they expect-they get you to do more than you should really do; rather than having four candidates on NVQ levels you have nearly eight, also three on NVQ assessing which as an assessor, you're only supposed to assess one candidate at a time ... It doesn't work like that ...

I was getting home from work, and literally finding it-driving the car, finding it hard to breathe as if .. not to be crude .. as if my nose is blocked [strokes nose]and I want to blow it and there's nothing in there to blow and I'm finding it hard to breathe. And coming home sitting in the kitchen on the settee, like this, for an hour before I'd come round. Can't do anything. Just er ... absolutely exhausted and hard to breathe ... how can I put it .. breathing like this [breathes slowly] to get me back so hence, me seeing the doctor and he said 'it's not recommended I go back to work'. And the conditions in work were .. how can I put it .. were not very pleasant .. not that this has anything to do with my defibrillator .. they turned our rest room into an office, so I didn't have a rest room .. And as you can appreciate in January it was cold and my defibrillator, I don't know if you've had anyone else .. it feels the cold ..

I: the defib?

Mick: yeah it feels cold and it does feel hot in the hot weather ... I've not er .. got a lot of fat on me as you can see .. I've lost a stone ... you can feel it if you like, it's protruding and it feels cold and I was getting pains in the neck and my arm, also I was getting a lot of pains round here [chest area] .. whilst its knitting in or settling in ..

I: so what happened?

Mick: well I'm not in work ... I won't be going back .. I've got close colleagues in Technical colleges when I got my Assessors Award, my IV Award .. so I know other assessors. Like the company I work for .. not a nice company, they've approached other people and said I'm not coming back, would they like my job? I haven't been getting proper statutory sick pay .. I've been involved with the DWP [Department of Works and pensions] but they've not been much help

I: so you've got a lot going on ..

Mick: lots ... I don't need to bore you with that .. you've come to see about this and not my work really .. So I've been at home. So, I *have* been going for walks with my mother's dog, cos my mum's old and go up to the woods here, the [name of woods] but I must admit I can't walk as far as I used to ... I did walk quite far, and I'm a bit sort of paranoid; I take my mobile phone but I was knackered again, breathing .. And I had to sit down for quite a while .. and then I thought 'on my' cos in the woods, not a lot of people walk in the woods ..not a lot round here .. most kids are on computers and that so I was thinking 'oh God' ..

I: you said you feel paranoid?

Mick: um .. sort of. Thinking, I'm out of breath, knackered, sitting down in the woods
and thinking I've got to get back .. I've pushed myself too far .. so I don't tend to go for a long, long walk and I take a walking stick .. I don't use it round the village but I take it to the woods, that helps .. I just sit down when I feel I should sit down ..

I: so how does that make you feel compared to how you used to feel?

Mick: oh my life I would say, has changed dramatically

I: and how has your life changed?

Mick: well ..... sleeping, [partner] sleeps in the front room because um .. I'm wriggling in the night .. I don't just lie on my back, I lie like this [demonstrates lying on side] or the other way .. this hand-sorry this arm up .. I can't cos if I do I get pains, I get uncomfortable ... and I have to lie on two pillows, and I've never liked pillows ... [partner] will tell you, but I have to have two pillows .. but I'm like a mummy then, there's no other way to put it

I: why do you have to have two pillows?

Mick: It's just comfier .. for being up with my defibrillator than being without a pillow or just one pillow, it's just comfier ... And I get pains in the night and if my body's resting .. I get pains that wake me up and I have to go back to lying on my back ..

I: What kind of pains are they? I mean, what goes through your mind?

Mick: Through my mind 'oh, get off this [ICD] it's hurting' ... um ... just uncomfy pains

I: so you've had to change rooms because of ...

Mick: Oh yes, [partner] hasn't come back in bed with me ... I'm on-on my own in the bed .. we bought a bed that slots out into a double bed for up here [points to room above] and [partner] has been there since ... Cos when I came out of hospital, as you can imagine, it was very nerve wracking, for [partner] as well, for me more than [partner] cos I've come out of hospital, I've got this inside me ... yes, yes, it's changed my life dramatically really ...

Driving .. well it's ok ... I can't sort of-if I pull the wheel like that [shows with arms] this is pulling this arm, which makes it very uncomfy here .. that might knit up and be ok, I don't know. I've asked the doctor to go for physiotherapy for my arm cos it's not like it used to be

I: when you say that, is it weaker?

Mick: yes, it's weaker ... I couldn't lift it above my head for ages ..

I: so how has your lifestyle changed since you had it? You're not sleeping ...

Mick: The sleeping is-the doctor has prescribed me Tamazepam, a strong sleeping tablet .. I don't take them every night, cos we all know they're addictive ... I do take one, maybe every four days .. just one, just to get knocked out ... Sleeping is a major one, a major issue ..

I: how has that affected your relationship?

Mick: oh we're fine, we've been together for years .. not married, but been together 26 years .. what do you mean, sexually?

I: yeah .. also I suppose if you sleep in separate rooms ... closeness ...

Mick: well, personally, you can ask [partner] when she comes down, I think we've got a good relationship as a couple ... Don't have sex often ...

I: so that's no different now to before?

Mick: both a bit wary, bit worried, to put my hand up, to tell you the truth

I: worried about ...

Mick: if anything could happen I suppose

I: a shock ... are you thinking about the shock?

Mick: I do, but I don't mention it to [partner] cos I don't want to worry,s yeah but I do think about it .. I think about certain things ... I don't lift heavy things ... before I was a lecturer, I was a heating and plumbing engineer .. you know, years and I went into the teaching cos I got arthritis, in my legs, my arms, I've got it in my spine .. my neck ... this arm for instance, it won't go [tries to bend it straight] .. I can't do that look, so I thought 'what can I do?' and that's why I diversed into teaching ... and then this kicked in ... so my life is dramatically changed .. financially big one, and mentally I would say ..

I: how mentally?

Mick: worry .. thinking about it ..

I: thinking about?

Mick: this .. it feels like a stone in jelly .. and it moves in bed as well ... obviously you're aware of how it's done, they cut the muscles to put it in .. here's the defibrillator [shows me through his jumper], you can feel the muscles cut there and it jams into this shoulder here .. which yeah ...... In a nutshell , you can ask me this question, would I have had it if I'd had the choice of having it or not having it and if I'd gone by myself when I had those pains .. I probably wouldn't have had it in, cos I wouldn't have known about it, would I? But probably being a bit selfish, it could have kicked in, been taken out [arrhythmia] and cos I've not got it ... It's nice to be living isn't it?

I: so it that what you tell yourself?

Mick: yeah

I: so for you the advantage of having it ...

Mick: yes the advantage is I'm on this planet and I am with [partner] and I see my grandson and step-daughter and if I didn't I wouldn't

I: and the disadvantages?

Mick: Disadvantages are, I was going um .. well ahead in my career, especially at my age .. I've achieved numerous certificates ... to no avail now really cos I don't know if I can get another job cos the way I feel and the defibrillator has to be renewed every four years doesn't it?

I: approximately

Mick: the wire, well that 20-years, said to EP at least if I could get on without it being taken out, at least I've got 20-years on this planet ...

I: they will replace it before it wears out

Mick: yeah the EP, whether he was trying to put me off cos of cuts, because this is an expensive piece of kit isn't it, it's about 10 grand ..

I: would he have suggested it if he didn't think you needed one though

Mick: well he did .. he said it's a lot of money, you're high risk but at your age .. you are more likely to have an attack in your teenage to 20s rather than 30s, 40s, he says 40s yes, but not 50s ... but that's Russian Roulette to me .. I don't know about you ..

I: I think I'd feel the same as you ..

Mick: oh good, so I had it done, but I think if he'd-if I'd had said no, he would have been happy .. I'm not being facetious.. it's a fact, with cuts and expenditure, yeah if they got to keep within their budget .. if they say I don't have it, then that keeps their budget ..

I: why did you say you don't feel you'll get another job because of the way you feel?

Mick: well, if I'd be fortunate to have an interview with a college, I'd have to explain to them my condition surely .. that would probably be a disadvantage .. cos I have got this inser-insertion in me whereas if they were interviewing you, you haven't got one ..

I: so you feel you'd be discriminated against?

Mick: ...maybe ... maybe

I: how does that make you feel?

Mick: well ... [says name of interviewer], at 56, I know it's not old .. it is in some ways ... I've been fortunate enough to live to this long .... it's a bolt of the blue and as I say, I'm not the same fit person, though I had arthritis .. I got off the tools, now I had this [ICD] it's changed my life ...

I: so even though EP said the chances of you having a shock are very minimal, you are still afraid of exerting too much in case you have a shock?

Mick: yeah ... yeah ... I mean .. er .. well this house was a wreck [his home] and I used to do up other houses, you know, I wasn't afraid of working .. I'd be very reluctant to lift up a concrete lintel which I probably would have done on my own before .. or a boiler hanging on a wall, I wouldn't do that now ...

I: so that part of your life, you would now get help in ..

Mick: yes, I wouldn't be self-employed now, not at my age .. after doing six years training-teaching, I'd got out of that to diversify

I: ok sorry, just going back to what you said about you and [partner] you are wary of sex because of fear ..

Mick: um ... we have had sex .. twice .. there, I'll be honest, you can ask [partner] this .. since November but I think [partner] was wary as well .. same as if you had a partner, you might be

I: does it come in the way of your closeness ... is it something you talk about? You said you wouldn't tell [partner] about shock because you didn't want to worry her

Mick: oh I wouldn't, things like that .. maybe you should .. but would you want to worry your partner .. don't forget she's been through the mill with me ... especially with the attack-although I didn't black-blank out in [town by coast], that was touch and go ... Although I'm not a doctor, I know in my mind there was a very thin line between me being here now and not being here ... to tell you the truth ... It was exactly the same as going out in that theatre, definitely, without a shadow of a doubt

I: so that was a close call with death

Mick: mm

I: And how's that changed you as a person?

Mick: (big sigh) ... it makes me think before I do things ... yes, I've been taking things very easy, whereas before I used to play rugby for the school, I run for amateur athletics .. I've done the Duke of Edinburgh Award, I've done this and that ... I wasn't afraid of doing things .. that was a long time ago mind ... when I was self-employed I worked sometimes seven days a week ... After I did the [teacher] training, I unwound, ... you still have to go to the classroom and explain how things are done .. down from the classroom, the practical and demonstrate how to do things and go from there ... but with my profession as teaching and assessing and IV'ing, which is just paperwork ... specially training, you are demonstrating so you are ... weather a chimney out of lead .. so I show how to dress lead from sheeting into a square box .. without welding .. before the candidates do it, I have to show them how it's done ... and that.. it's taken it out of me... that, threading iron pipe work ... it's meaty work, well I have to demonstrate before they do it .. all too much .. and the amount of work, they put on me ...

As I say, if it was Barry College or Swansea College it would be totally different ... private company, they push and push, they want ..

I: your blood

Mick: thank you, yes, every drop of blood ... and yes ... too much as I said to my GP when I went to see him at the end of January ... I said, first of all I think I went back to quick-but I wasn't shy of work. I went back voluntary, he didn't say to go back. He said are you sure you want to go back, and I shouldn't have ... went back ... I said to GP if I don't get a note off for sick, I'm either going out [dying] of an attack or in a box .. one or the other

I: so how do you feel emotionally now ... are you depressed?

Mick: yes I can be ... I don't want to sound like a Jonah, some days I can ... thinking 'what do you do?, got this ... out of work' ... yeah [participant starts to cry]

I: are you ok?

Mick: yeah

I: do you want to stop?

Mick: yeah, I will walk a bit ...

[Interviewer chats to Mick about aim of study: to find out these feelings of despair or fear that participants may have while Mick walks around the room]

Mick: sorry about this ... yeah carry on ... you talk

(interviewer carries on talking to Mick – that although ICDs save lives, people have to cope with its limitations sometimes with little help)

Mick: you're very, very true, I'm awfully sorry about that ... (Mick sits down and says study can start again)

I: has anything in particular upset you?

Mick: I think that er ... let's get over this wave .. I haven't been like this [cying].. it's just talking about it to you .. it's all (crying again) .. all my emotions, I keep to myself cos [partner] at work ... I'll be sitting in the garden, you think of things .. life ... do you want a cup of tea?

I: no, I'm fine

Mick: I'm sorry about this [still crying]

I: please don't worry, I really would like to know how you're feeling [passes him a tissue]

Mick: this hasn't happened to me before ..

I: you said you've never spoken about it?

Mick: well, who's there to speak to?

I: your partner, your mother?

Mick: oh my mother's an ex-nurse ... I tend to keep things like this to myself ... I don't want to worry my mother really, I don't want to worry [partner].... maybe I should have gone to er ... it was in the booklet, you can go to a sort of club where other people have had it. I don't know.. like Alcoholics Anonymous, Defibrillators Anonymous then .. whatever's the word for it. I'm awfully sorry about that [crying]...

I: don't be sorry, honestly ... you're not the first ...

Mick: aren't I? Oh good ... Ok, I think I'm ready for more questions

I: so you're feeling very down

Mick: yes, especially with work, because they haven't been ideal company to work for, I mean when I spoke to the Director, he said 'I thought you'd be back in two weeks' and I said 'it's a defibrillator' and he says 'yeah' ...you know. When I went back on the sick, you know I went in after eight weeks after a major operation and after that sort of attack in [town by coast] and then when I went back on the sick-I have a colleague who comes to see me every fortnight, takes me out .. said the Director said 'oh your mates off again, what's he having? Another one in the other side of the chest?' Those are the people that I work for ...

When I went into work, as I said I had eight candidates .... I'm running round teaching lead, and assessing and doing a new portfolio for the NVQ ... it was so cold, I go to work with a shirt and tie, v-neck, trousers, blah, blah .. I had a fleece on as well and we have to wear white coats, as though we're doctors .. but there you are; for show .... But with a fleece on and a white coat, it was so cold, I was getting pains here right up my neck ... we went in the lecture room [names colleagues] to eat our dinner because we have no rest room ... and the Head Director walked past and said 'what you doing in here' and ... he said we should be on the floor eating not in there .. I mean there's no heating in the practical area .. it was minus .. and that's what we got to put up with

I: so how do you see yourself now? Do you see yourself working again? Perhaps for someone else?

Mick: I don't know, I really don't know ... I don't want to go into an interview and then let them down ...

I: how will you let them down?

Mick: I don't know ... What was really worrying me, whether it was just the company I worked for and the pressure ... coming home and really finding it hard to breathe ... going like this [takes deep breaths] to get my breathing in rhythm for it to be normal-for it to come back to normal ..

I: you've been to the doctor? What did he say?

Mick: he said I've going to sign you off .. stress ... I mean it wasn't really, dare I say it, safe driving back from work .. in the car .. when you're finding it hard to breathe ... so there you are ...

I: It has changed your life ..

Mick: it has changed my life dramatically yeah, definitely

I: so you say you sit out in the garden and you think about life, what do you think about?

Mick: well I look at the weeds ... un .. well I think about what I've done in the past and where I am now really and what the future holds

I: do you see it negatively?

Mick: I try not to see it negatively because that will only bring you down even more

I: so what do you tell yourself? You know, we have these voices in our heads ... what do you say to yourself?

Mick: well, I could be dead, but I'm alive .. lucky to be here is the end result .. I could be in Afghanistan, a child bombed for no reason .. like that poor girl getting shot in London at her age and I'm 56 and I've lasted this long .. if that makes sense to you

I: I do, but I'm not sure if I was you, it would make me feel better ..

Mick: it doesn't make me feel better, but it puts things into perspective really, the worrying thing for me and for you probably, is being without a job .. I know money isn't everything but unfortunately in this world it is ... lucky [partner] works, but she only works part-time

I: is this the worst aspect of your ..

Mick: I used to love swimming .. in the good days, when I worked hard, I used to be able to afford to go to [private health club], and swim, I wasn't one for going on the weights but I used to swim at half past six in the morning or an hour or half hour, then I'd have a sauna, then I'd go to work, seven days a week. So fit .. well I was

I: how long ago was that?

Mick: well since I worked for this company I work for .. six years .. but the time even before I had this .. by the time I came home from work, I was knackered any way ... and the spare time I had, I'd be revising books .. Probably like you, I'd be looking at books ready for students. Sounds like a swot but you got to be on top of it so you can give the best you can to the students ... I don't know if this will help really, but before I had the defibrillator .. there were times I had to sit in the car and take deep breaths but maybe it's to do with my condition .. I don't know. I was having it before [breathless] but with this it's a lot, lot, lot worse. You can ask [partner] .. we haven't made a pact, when you said you wanted to interview us, I haven't told her what I will say to you and she hasn't told me what she will say to you. We haven't devised anything up, which you will suss out for yourself hopefully ...

I: thank you, you've been very interesting

Mick: I hope I have managed to give you some of the aspects of it ..

I: yes, because I really wanted to know how you are feeling ..

Mick: yes, cross my heart, I do not feel the same person .. definitely. So, it's taking time to adjust to this implant and the advantages and disadvantages of it .. The advantages hopefully if anything happens to me it will kick in ... Does it modulate me .. palpitations does it keep them on an ebb or..

I: I wouldn't know sorry, you'd have to ask the nurse

Mick: I used to get lots of palpitations .. since this is in I still get them but it might be of interest to you, it's in my records .. dates back to 20-years. I like coffee and I like strong coffee, Alta Rica .... I used to have two cups in the morning, then take a flask of it to work, and have more when I got home. I used to get butterflies, palpitations and I went to see the GP and she diagnosed that I drank too much coffee .. roughly 13 cups a day .. So, she said 'stop it, drink coffee, drink decaf and if you're going to drink decaf, have one or maybe two in the morning, none in the day and maybe one after work. And I did that for years, but what it really was my condition, my Brugada

I: and how does that make you feel?

Mick: I used to get these flutters and think 'oh God, what's happening' and it would get worse, maybe psychologically, panicking ... now I know .. I think 'oh, it's starting up again' and not think 'oh my God'... I know what it is ... if it got worse, the defibrillator would kick in ..

I: so do you have any particular concerns about the defibrillator?

Mick: um .. I don't think so, not really .. I mean it hasn't gone off .. one of the EPs said if it did go off it would be like being thumped really, really hard in the chest ... whether it's gone off when I've gone to sleep, when I eventually go to sleep, I don't know ... I don't think it has, cos I'm a light sleeper ... it's just a pain .. a pain in the butt to have, but I have to put up with it ... that's the best way to describe it ..

I: it is a huge adjustment

Mick: it is ... I don't know whether it would be good for patients to have a good talk with someone like you a colleague in the department, to let them know, but at the end of the day there's only one real way of knowing what it's like .. it's when you have it done, isn't it .. And yes, since I've had it done, since the end of October [5-6 months previous] I'm still in the back bedroom and my sleeping pattern is off the wall .. not like it used to be

I: do you think you feeling like this is due to defibrillator or how you are feeling generally

Mick: No, cos whether it will knit up, or knit .. as I say, I was so used to sleeping this way and then this arm .. pokes up into frame of my body [Mick is demonstrating trying to lie comfortably] ..

I: it's a big box

Mick: it is a big box, and the weight it is and the worse way is if I go this way and the pillow is here .. this is pushing into there ... Sitting down in the evening, I'm always on the move, I can't get comfy cos of my arthritis .. sorry, I'm sounding like a Jonah here .. I can't be normal .. It's constantly there ...

I: are there any times of the day when you forget about it?

Mick: there must be times when I forget about it but no .. no ... Well I know it's with me now for the rest of my life .. yeah, I am aware of it, yeah but on the positive side, I'm not going to be taken out, specially not through my heart stopping ...

I: and if you had a shock, would it concern you?

Mick: .... um .... I don't think I've had a shock .. but if I had one ...

I: what is it you'd be wary about .. shock wise?

Mick: .... (long pause) to have a shock, sitting here now .. would be .. how do I put it, ok if I was sitting down right .. I'd be supporting my body, but you can have one in different circumstances ... it could be worse .. how can I put it? ... Dare I say it, I don't drive that much ..driving, if I had a shock driving .. it could be curtains for someone else ...

I: do you think about things like that? Does that play on your mind?

Mick: not driving, sometimes when I think of it driving, I think 'oh, don't be so silly .. come on, keep it together'. And other times you think about it more, whereas before I 'd think nothing of walking .. especially at the weekend, I love walking, I love nature .. I'd walk miles .. I wouldn't do it now ..

I: because?

Mick: As I explained to you, I did walk sort of back to by normal walking area but I felt absolutely knackered, sat down and thought 'oh God, how am I going to get back', there's no-one in the woods .. now this might seem weird to you, but I'm with my mum's dog .. but if something did happen and that's why I take the phone .. I might not get found for a couple of days to tell you the truth. I am-I am not the same, fit person I was ...

I: if someone has been out of action for a while, I guess their fitness would go down ..

Mick: Oh I don't sit here all day, [partner] off Monday, Tuesday, works Wednesday, Thursday, Friday. I get up at 6.30, bring her tea in bed .. I'm down here, cleaning up .. I'll go for a walk, a walk around the village ... I am not at home, sitting on the settee, being a vegetable ..

I: so you're keeping active ..

Mick: I'm trying to keep active but ..

I: have you been swimming?

Mick: haven't been swimming, would have to be supervised it says in the book, I believe ..

I: lifeguards

Mick: Can't afford to go up to the [private health club] now ... not pleading poverty, but can't afford to go there ... I'd have to go to a- a council one. I've been to them before, I'd have to go there. I think I'd rather have physiotherapy first before I went swimming ... I'd like him to say I was ok .. I wouldn't like to do over arm ... in case something happened

I: when you say 'something happen' ..

Mick: well the wire, I know it's in, I know cos the surgeon knitted it in .. cos I was awake, I was talking to him as he did it .. he was having trouble getting threading it into the vein to get into my heart, there was blood everywhere .. but that didn't bother me. I 'm used to having knocks ..

I: so you weren't worried about the procedure itself ..

Mick: oh no, I was glad to have it done, especially after what happened in [town by coast] if I'm honest ..... I shouldn't really be here, I believe

I: because of the close call

Mick: yes, oh yes, [partner] said, whether she was exaggerating, you can bring it up with her, she said I was ashen white, and all the veins were showing in my face ... I didn't know, but I could see people looking at me ... I wouldn't have cared if they all queued up to look at me .. I was just trying to keep myself awake

I: do you think that perhaps that incident was more upsetting than you realise?

Mick: well yeah .. it's never happened to me before ..

I: do you think about the incident?

Mick: I try to black that out, now I got this in me .. I try and black it out but it's obviously-I've even gone back to the park just to get ... rid of the ghosts about two weeks ago. Two weeks ago, was the first time I went back to that park ...

I: and how was it?

Mick: pretty ... saw the bench where it all was but I thought 'go forward' ..

Transcript for S15
Male aged 64, ICD due to MI and HF
Participant (p)
Interviewer (I)
Arrhythmia Nurse (AN)
Electrophysiologist (EP)
ICD for 9 months

I: I usually ask first of all, why you've had your ICD implanted

P: It's going back 20 years of thereabouts, I had a heart attack, which came at the end of a game of squash. So I'd been on the squash court for about an hour and without going into all the details I had a heart attack then. But there were-although it was a heart attack, it was a severe heart attack, I arrested three times on the way into the hospital. And the defibrillator that was used on the ambulance had only just been put on. I was its first patient. The local community had actually raised enough money to buy one, to go on the ambulance. And to skim a bit of history, I recovered reasonably well, as well as could be expected, no angina or effects or anything like that. Um, I was able to lead a normal life. I was Head teacher at a school, secondary school, but then indications were that things were getting back-back into a bad rhythm

I: you could feel that could you.

P: It was vital signs really and cos I regularly went to the doctor ... On one particular occasion, she asked me when I was going to retire, so I had already worked out about three, four years and she turned round, this was Christmas time-she turned round and said what about this summer. So I said oh no, I couldn't afford to retire this summer, thereupon she turned round and said, 'well either carry on for the next three, four years in your job, which you could do and then enjoy one year of your retirement or finish this summer and enjoy, 15, 20 years retirement, it's your decision.' So put that way, it doesn't leave a lot of choice really.

So then went through the rigmarole of trying to get retirement and all the rest of it. I took early retirement, and in the end I took it on health grounds .... so retired on grounds of ill health, which coincided with me being ordained, which is why we ended up here cos I took a house with duty position. Then, oooh about 12 months ago, something like that I noticed that, particularly coming up hill-um, not too much out of breath, it wasn't that dramatic, a little pain in my arm, just one or two signs. Went to the doctor, he sent me for an ECG and all the rest of it, and fine [ECG] so concluded it must have been a bit of a virus ..... and then it was May 29th I think and I was coming away from a church service, everything had been fine but by the time I'd driven back and dropped somebody off-and in the car, [wife] had said 'are you alright' cos I'd gone very quiet, so I said no, not really (laughs). Got back here, and cold sweat and all the rest of it, not too much pain or anything of that nature but it did feel-my pulse was racing, so quick that you couldn't actually count it. [Wife[called paramedics, the ambulance, they came, took me down to hospital and my heartbeat was about 160 plus and they couldn't actually lower it. So they ended up giving me an electric shock

I: while you were conscious?

P: well they put me out. They put me out

I: so you don't remember

P: that part I don't remember. It was then suggested I went down to [name of regional hospital]. So, I went to the hospital and they did, what d'you call it, an angiogram. While they were doing that, they put a stent in so that would explain for the bit of pain, I don't know, I'm not a medic so I don't know...... And then after a couple of days discussions they decided they were going to put an ICD. So that happened the Thursday following the stent or maybe Wednesday, anyway a couple of days after

I: how was it being told about the ICD? Did you know what an ICD was?

P: I had it explained, I had an idea ... I only had an idea cos people had explained things, what its purpose was, and how it worked and everything like that I didn't know. All I knew, if things went wrong it would kick in type of thing, put it right. I used to play a lot of golf, that was my main interest and I wondered about the effect that would have on playing golf, but I was assured everything would be alright provided I waited until things settled down. He gave me a period of six weeks.

I: so how did you feel about having the ICD .. initially?

P: um .... sort of reluctant acceptance if you like. Reluctance in the sense that you wouldn't have wanted to have it in the first place but an acceptance with an overview of thinking it's there, it's going to be an aid obviously. From what I was told, it wasn't going to be something that deter me from doing things I was interested in. Read a few reports, because at that particular time, there were a few reports coming out in the national papers about people who had had ICDs and how it had changed their lives for the better and they were able to do this, that and the other. So from that point of view it was very positive ... so the actual notion of having it put in, wasn't a bad one. I accepted that with a lot of positive things really

I: So, what was the reluctance part?

P: well, you don't want things to go wrong in the first place, so you certainly don't want to have something inside you that is there because you'd rather it wasn't there ... I'd been living 20 years after the heart attack, a normal life, I wanted that to continue really. But the fact this wasn't going to continue, that's the kind of reluctance really ... It's coming to terms-the actual coming to terms with it didn't take long

I: what helped you come to terms with it?

P: Resignation I think (laughs) ... yeah, just resigned to the fact that it was there and-the most difficult thing in actual fact, was people telling me to take it easy ... including my wife. And everybody, out of the best of interest, the best of concern 'oh take it easy, don't do this and don't do that, and sit down', and I'm not that type of person.

I: so how did that make you feel?

P: that was frustrating. Very frustrating. And just went against the grain, cos if I-I just like being active. So I enjoyed being out in the garden, I enjoyed playing golf, I enjoyed doing things, particularly outside ... that's my nature, DIY you name it. Sitting still and reading a book, I'm slowly getting round to that, and becoming lazy but I do feel that's a lazy thing. And I have great difficulty in actually doing that. So when people are trying to force that on top of me-they're not forcing, but because they're saying things, it seems to me, quite an oppressive thing in the sense they are 'don't do this, don't do that'

I: do you think their advice is right?

P: no.

I: and can you say that to them?

P: I do but it's er ... I tend to do that but in a flippant way, so as not to cause any offence really. There have been several times, when I have turned round and said 'oh you sound just like my wife, I want to be active' sort of thing and just at the end of the day, I want to live a life that is normal and then all these constraints are being thrown at you

I: so it's the constraints from others rather than the ICD

P: yeah, yeah, certainly that was the case. [But] things have changed since I went into shock. But the period between having this implanted and the shock, apart from the frustration of people telling me what not to do, what to do, um yeah I was fine. I did have a few games of golf and my confidence was-was good. But then the shock came.

I: and can you describe what happened?

P: yeah. Very vividly (laughs). Um that week, I hadn't been feeling particularly good

I: in what way?

P: well on the Wednesday, I'd had like a migraine without the headache, and by that I mean, I was seeing stars, flashes of light ……. And so that was on the Wednesday and I'd spent most of the day moping around doing nothing, in fact I went to bed for a large part of it um, … probably conscious of my health and wanting basically to get right again. Mentioned it to the nurse that I saw on the Friday and apparently she got on the phone to the nurse at [name of regional hospital] saying 'this has happened, this has happened, you need to get in touch with him' but we'd gone out for the day. We'd gone out for the day on the Friday so we didn't get any message from then until we got back home which was evening time. Cos they did try and contact me. But on the Saturday, I hadn't been doing anything, sitting around, perhaps it was the frustration I don't know, sitting around, doing a bit of reading, watching TV, reading about sports, I love sports and then in the evening started doing some cooking ready for Sunday, we were cooking curry, what have you.

And it was about 9 o'clock and I was just coming to the end of the cooking and I suddenly had this horrible feeling … As if my whole body was weird. Um I can't describe it, cos I'd never experienced anything like that before and it was just a sudden 'ooer' … put my hand on the units there and I said to [wife] I feel lousy. That's when she got hold of me … because she said, she saw the colour drain from my face, and as she got hold of me, that's when the thing went off. And it was a severe shock and I-that was that instance …. [wife] went dashing out of the kitchen to the bedroom, because there's a big magnet you can have to isolate it, she went dashing to the magnet and I started following her into the hall. And I said 'no we don't need that'. So she just-she got the magnet anyway, I came and sat down here and then I felt as though a mule had kicked me. And they often say this, the ICD is there [pointing to ICD] and all round here [underarm, down side of body], it was aching. And she brought the magnet and I said no, we don't touch the magnet, leave that. She was just in a bit of a panic I think. But then, apart from the shock and the kicking feeling if you like, I felt ok. But nevertheless, we ended up going down to [regional hospital] in the ambulance. My pulse rate was fine, and then everything was ok. That was the Saturday night. Monday, went down to the technician there [hospital] and he was able to analyse what had happened on the Saturday. And apparently, this took place at just after 9 o'clock, Saturday evening and he showed the ECG graph that he had pulled off indicating that my beats here … nothing to do with how I'd been feeling earlier on the week at all. ... The pulse rate, the beat rate was 70, fine, and then he said, 'this is where is begins to increase' and the pacemaker side of the ICD tried to kick in, but the heart didn't respond until it got up to 220 beats and that's when the defibrillator kicked in. Hence the shock, and you could see this big line on the graph and after that, back to normal and all that happened, I think he said, within 30 seconds. He's asked previously how long did I think everything had taken, and I said half a minute, seconds, a minute I don't think, but sure enough it was only half a minute, 30 seconds. But since then that's when my confidence went suddenly down.

I: why, why did it go down?

P: It was the very fact that my heart had gone into this rhythm and I hadn't been doing anything out of the ordinary. If I'd been wielding a pick axe or something like that then I'd had said, right the exertion had-it was my stupid fault, it caused the heart to go like it is. But I'd actually spent the day doing very little, sitting around, moping around, doing a bit of cooking, which I'd hardly call strenuous. So, I couldn't understand why the heart had gone into this rhythm. Certainly to me, there was no outward sign as to why it should happen and that's the thing that's unnerved me a lot. So, it's meant that I've not played golf, which is, you know, my big enjoyment in life. And its, fear's the wrong word, it's the thought of something happening like that ... And it's logically, it should-in my head, the logic behind it says, yes, everything as it was before and the thing is there. And in fact if it hadn't been there then I wouldn't be here now and it's done its job and all those logical things are there. It's the notion or whatever it is, it's certainly something that's affected my confidence, which is slowly coming back but it's taken quite a bit of time

I: what could it be? Is it the pain what do you think?

P: I don't know what it is. The horrible feeling just before the shock, shortly after it had happened, I said to [wife] that is something I would dread more than the actual shock itself... just before the shock, cos it was a grotesque feeling, the whole body just seemed to go [shivers]. As I say, I can't really describe it ...If I try to describe it, it will put a wrong emphasis on .. If I say it was like I was drunk and ready to fall down, but I wasn't ready to fall down ... I needed support, I put my hand out on the unit, but it's just this horrible feeling before the actual shock itself. And it's ok, I didn't like the feeling, but it's only seconds. OK, the shock is not something you'd volunteer to have if you-if you could avoid having it, you would do. And there's certainly no other reason but it certainly did leave me with this complete lack of confidence and I suppose the thought that I hadn't been doing anything and it happened – it just confirmed the idea that this could just actually happen at any time. I could be talking to you now and something will happen. Now, I've been told this, and yes, ok if it happens it's a little kick and people carry on and all the rest of it, cos I've also been told that. People just feel it, and just carry on. And in the hospital I actually said, look within five minutes I seemed ok again. So, if it should happen, I hope it doesn't, but if it should happen, is there any need to go back into hospital. And they said 'no, if you don't want to, just inform us, tell us it's happened. If it continues, if it happens three or four times, ok, yeah, get to the hospital. But if it just happens on that one occasion and you feel alright after five minutes, you know you'll be ok.

I don't know why, psychologically it's affected me cos logically, and I used to be a maths teacher so, there's an element of logic in me (laughs). Logically, it shouldn't but it has done, quite strongly initially.

I: it happened in November [two months previous] .. so how has it effected your day to day living?

P: It's changed a lot ... I go for the odd walk ... and those walks will vary between one mile and seven or eight miles. We used to do a lot of walking but golf took up the place of the walking if you like. And I've wanted to do it with a dog [walk?] , I've been thinking about it for a long time because we've always had dogs but then we got rid of our last two dogs because we thought [wife] was allergic-she has asthma. But then we had a cat and I think it was the cat giving her the asthma-exacerbating the asthma not the dog. But out on these walks I think it would be much nicer to have a dog with you .... I find walking for the sake of walking can be a bit boring. So hence the dog, so obviously that's going to change things quite a bit because we're back to having a dog again. Um, the fact that I can't drive at the moment, means I'm limited although [wife] can turn round to take me whenever, wherever, it's not always, suitable, convenient. And if I suddenly feel like .. I dunno, go to a shop, not that I do, but if I feel like going out to [name of town] and going to a shop or something, I can't do so ... unless [wife] takes me.... That is a big, big thing

I: how has your life changed psychologically having had the shock, you said you've lost your confidence? Like going for a walk?

P: strangely enough, I'm ok going for a walk, I'm building up now. I take a mobile phone with me, which in this area is probably more than useless really cos can't get the signals (laughs), so not really the best of things, but at least I got it there. I walk where I always walk, that's the same. As I say, golf, I haven't played golf since this went off.

I: for what reason?

P: er well, certainly initially it was the confidence thing. There are days when I can feel so-'I don't fancy playing golf today anyway'. I just don't feel up to doing things. But that's a kind of lazy attitude, feel like a lie-in or something

I: and you've not felt like that before?

P: not, not in the same way. I'm normally out there with get up and go. Ok, there might be the odd occasion when you might feel yeah, I'll have a lie-in today, but they are few and far between. But now they're fairly frequent.

I: Do you think you do feel like a lie in or are you avoiding doing something?

P: yeah I can see what you're [trying to ask] .. um trying to answer the question .... um ... the thing is it could well be a kind of avoidance but its bordering on the laziness 'oh I can't be bothered'. It's almost like a sort of depression, you know when you're depressed you just feel like doing nothing and it's that kind of feeling in many ways.

I: and that's only since the shock?

P: yeah. Well since the ICD was put in, the lazy bouts in bed have increased. Er I mean we're up at 8 o'clock , don't get me wrong we're not lying there till midday or anything. Eight o'clock, 9 o'clock. When I was working, I was at work-or I'd get up at half five, quarter to six, that's when I was teaching, I was in school then about quarter to seven, something like that then working through-doing the 70 hour week, kind of thing. So, always busy and I don't think the fact that I've retired that I've suddenly shifted, it's definitely something to do with this [ICD]. It's not easy

I: so how are you coping?

P: sometimes it's very difficult ... especially when it's been a day when-I do a lot of reading and if it's a day when I've been reading and doing puzzles, things like this, you feel ... not quite a waste of space but you're not doing anything constructive. And so then you can start feeling 'oh, where are we going?' You know, what is in the future? If it's like this all the time, that's not my cup of tea.

I: Before you said you were quite active and now you have the odd day you're just reading – is it because you just don't feel like doing anything else?

P: yeah. I seem to be it more, or maybe it just seems that way. I suppose the weather doesn't help, the fact that it's difficult to get out anyway. But in the past it hasn't been a deterrent but it's a good excuse now

I: so has it made you think about the future a bit more?

P: yeah, it definitely does. It makes you think what *is* in the future. Yeah, at one time, talking about being active, I did-I'd want to have things like a house with a big garden, being in a house that needed a lot of renovation so I could stuck into little projects and if I could get involved in projects then well, that's great, that's great to me. The thought of perhaps not being able to do that kind of thing, cos particularly with [wife] now, she doesn't want the idea of me getting involved in anything that might be deterrent to my health as she sees it. It's very, very difficult for her cos she's going through these and she comes down to [city] and visits me when I'm in hospital and she absolutely hates driving. She loathes it.

I: It's quite a trek isn't it

P: It is a trek and of course she has to do all the driving now – I'm back on the driving business aren't I? No, but she hates the driving and I hate being a passenger so it's not a very good combination. But she has gone through it all and in some respects, it's probably harder for her than it is for me cos if the shoe's on the other foot, I think I'd know how I'd feel, if she was the one who'd had the heart attack and ICD fitted and gone through all that. It's- it must be quite stressful for her.

I: do you talk to her about it?

P: oh yeah, yeah, I talk, I don't know what she'd say, probably not as much as she'd like it. In some respects you .. you have an image of what's going to happen in the future, as vague as that might be and with mine it was obviously going to be quite active. And then you have that futuristic view changed, um, and ok, to a certain extent you accept that and I can handle this, but in some respects you don't want the reality to set in either. So, if your active future is changed to sitting around in an arm chair reading all day, it might sound alright but when the reality is there, it does hit you and I think that's what happens to me every so often. Especially if I've done nothing but reading and playing and doing puzzles and things definitely inactive, I suppose that's when the reality hits in. And I think that image is becoming more concrete.

I: do you not see yourself as active in the future?

P: no, I certainly- that's the desire, that's the wish and that is definitely what I'd hope for but er, whether it's achievable, I don't know. It's because of this knock of confidence.... After the heart attack, the least little twinge, in your chest particularly, you focus in, you become more aware of what's happening to your body, and you're focussing onto that. And then it probably took about 12 months, 18 months before those twinges you were aware of, you became less aware of. Because you have twinges all the time but most people will ignore them and not even notice them. But when you've had something like that, you do notice. And that's another phase that I've been going through. You see, when the ICD is put in, you notice it all the time, you've got a constant reminder cos you can feel it all the time and sometimes it gets a bit itchy and rubbing it, so you're aware of that all the time. So, that's a physical thing that's a constant reminder ... a constant reminder of the fact I've got one there, which then reminds you of why you've got one. So, you feel this thing there .. I mean, it's a solid thing as you probably realise and it protrudes a little bit so it's not hidden in your body completely. It's there and initially [wife], she wasn't aware of it being there, in the sense that she would suddenly go bang (hits his chest on ICD site] and now I realise that if you do go like that [bangs chest] nothing's going to happen. But the very fact it is there is a constant reminder and if you get any little twinge, you just wonder what's happening

I: how has that changed since the shock?

P: it's worse since the shock I would say. When that [ICD] was put in, it was terms of acceptance really. the thought that yes I just carry on. And in fact we did some walking on the coast and I remember these cliff walks, quite steep and getting there without panting and yes, I was feeling great and thinking well, that's probably the stent that's done that- opened up the airways and allow the blood to circulate and feeling really good about it. And in fact wondering why you had to wait six months for your licence to be given back because I really did start feeling very, very good. Went over to Ireland, had a few games of golf there and a lot of walking over there but it's since the shock that all this seems to have imploded in some respects and that goes along with feelings in your body. You're looking for everything and you're just wondering what's going to happen

I: how has that affected your relationship with your wife?

P: to be honest i don't think it has

I: some couples have reported that they feel closer and some more distant

P: ...... I don't think it's a barrier because we talk about it. The frustration came out, certainly in the early days when [wife] was turning round saying 'do this, do that, don't do this, don't do that' and then we went to see er, the cardiac nurse down in [hospital]. And she did a lot of good because I was on about playing golf and [wife] was 'no you don't play golf', so we had this loggerheads. And then it must have been less than a week after that [wife] suddenly said 'actually if you feel like doing things then you ought to', it's not up to her to say not do things. If I feel capable of doing something, then it's me that should make that decision and stop doing something when I feel the need, which is what I've been trying to say to her, but it hadn't registered. It was as if the penny had suddenly dropped. She recognised that for what it was. I don't know whether [wife] would agree but I thought it was because of talking with the nurse. Because the nurse was saying try and live a normal life, there's nothing wrong with going out on the golf course and doing gardening. Ok, you might have to take twice as long, the mowing and things like this but yeah, carry on. And I think that had a lot of influence because then she suddenly, a few days later, suddenly it shouldn't be up to her to say what I could do, not do. The last thing I wanted to be was cocooned, wrapped in cotton wool, I'm just not that type of person, or certainly not ready for it yet.

[Visitor arrives, participant goes to answer door]

I: ok then to sum up, what would you say are the benefits of the ICD? For you as a patient having the ICD.

P: Making the assumption that I had to have one. Being positive, the logic behind it all. Now one of those articles that I read said it was like having your own paramedic on your back and actually that is very, very true. Because if for whatever reason, my heart does go into some kind of rhythm and I'm accepting that that could happen anytime, without any logic attached to it the very fact I've got this thing here to bring the rhythm back to normal – they, they are the logics. And the fact it has gone off, cos lots of people said well at least it works, yeah. And I keep saying, logically yeah, I accept that, it does work and if it didn't work, then judging by the rate-it had gone from 70 to 220 in half a minute, nobody would have been able to get to me in time to save me. So, if this wasn't there and hadn't worked, I wouldn't be here now. The very fact it is there-it's knowing-it's a protective measure.

I: knowing that it has saved you and if you didn't have it, you might not be here now, to me, that sounds quite hard to deal with

P: in some respects, you realise you come dependent on a machine, so things aren't of a natural process – I suppose if the machine breaks down, you're in trouble (laughs) but the monitor system and the backup system is there, so everything is in order to actually safeguard your life. And the actual ICD itself and having that implant, I can't think of anything too negative about it, I mean ok I can't go scuba diving and things like this. I did do some snorkelling back in September and then thought I shouldn't do that. Came back and asked the doctor and he said 'oh, I've never been asked that and he looked it up'. And he sent me a little letter saying it's not advisable. But you see, that's me, if I see something I'd like to do and not able to do it, the challenge is then taken away and that itself is a defeatist type thing. But you know, I'm not going to go snorkelling a lot, scuba diving rather, but the recommendation is that you always have somebody with you.

I: that would be sensible for any person wouldn't it

P: yeah, yeah. Of course it would. And in some respects-we have a charity we support in Africa and over the last few years, we've been going out to [Country] to help with this charity, this time round we've had to cancel it. We weren't going to cancel this until this went off and it's because this went off, we thought we'll not go there and the reason we're not going there is because quite frankly where we go is a little island. By the time you get off that island, cross the water, get a vehicle the other side to take you to the nearest hospital- it's not much of a hospital, you wouldn't want to go there, you wouldn't even want to go to the toilet there, let alone be a patient in there. So you wouldn't want to go there but event then you're talking 20 minutes on the water, half hour to other side so talking the quickest is an hour and a quarter to get there. But as I say, you wouldn't want to go there

I: so if you hadn't had the shock, you would have gone?

P: would have gone to [country] yes we were going for six or seven weeks. Even after the ICD was put in, we still had in mind to go there. It was after the shock, that we said 'no, can't go there, run this risk, not this time round.' I think that was one of the confidence things. I mean, now perhaps I'd thought differently I don't know. My confidence is building up, but it's taken a lot longer than I would have thought. It's getting there. And some days I'm fine, some days I get up and I feel 'yeah', I'll do this, that and the other, and I'll feel really good. And now it's a case of those days becoming more frequent, when you feel good. You know, feel as though you can do this, that and the other, climb Mount Everest or whatever. But yeah, we're getting there. But I wouldn't think too negatively about the ICD being put in, certainly if somebody was thinking about having an ICD put into them, I would think 'yeah, great thing, go for it'....

But the fact that it's there and needs to be there, it is a kind of bereavement cos the life you've led beforehand was free and easy, without constraints has suddenly transposed into the life you are leading now, which doesn't have too many constraints but it does have the awareness there. And that's the thing you've got to come to terms with yeah. But as I say, I would be very positive with anybody who is about to have one implanted and tell them straight, the advantages certainly outweigh the disadvantages. Don't know what [wife] thinks (laughs)

I: yes i guess you're better protected than me now if I were to have a rhythm problem

P: yeah, that's the ironic thing. When I was in Africa and I was swimming-what I had noticed with swimming then is how I got out of breath and couldn't swim as long as I used to but put that down to age and lack of practice and all the rest of it. Looking back, actually it was because of the heart problems more than anything else so in many ways, I was in a worse position then swimming and doing this, that and the other, than I am now. There's still this thing though, isn't there, your brain has an element of logic behind it and logically you can accept these things but emotionally, you still got to come to terms with them. And I've been saying that, well ever since it's gone off, I been saying that particularly in the early days when I had this lack of confidence and negativity and if you think logically yeah. If you think logically you think I should be thankful that it's there and it's done this, but it's just that bereavement type of thing that is also evident. And that's something that wrecks your confidence. I can see signs of it building up [confidence] and I'm positive in that respect, cos I'm positive I'll be back on the golf course soon

Transcript for N16
Female aged 48 years.
Multiple Cardiac Arrests during routine hysterectomy
In line with ethics, participant's name has been changed to 'Jean'
'I' stands for interviewer

I: I usually begin by asking ... um ... how long have you had your ICD?

J: 23rd December

I: last year?

J: last winter.

I: So, coming up for a year. And what happened, why did you have to have it?

J: I went in for a routine hysterectomy ... I had multiple cardiac arrests ...

I: right ... while you were in hospital?

J: whilst I was operating

I: So, you're not aware of what happened?

J: No, none at all. I can ... (long pause) remember I had an out of body experience and I was watching them shock me. But apparently during the time, I was resuscitated about 50 times ... they put a balloon in to give my heart a rest ...

I: what was the out of body experience like? Can you describe it?

J: I was just floating up in the air .. looking down ... on the people.

I: Did you feel anything?

J: At the time, no. But it's frightened the life out of me. I keep getting flashbacks, having flashbacks

I: about how often do you have these flashbacks?

J: It varies. It depends if I'm on a 'low'. I don't sleep very good in the nights since I had it ...

I: Is that because of the ICD or the flashbacks?

J: I don't know, I think it's a combination. At the moment it's still psychological ... you know, I can still feel it, I can still feel it in there. You know, it's sometimes like ... my bra strap will sort of catch where the wires are ... well, I think-as far as I know it's the wires. And that makes me feel uncomfortable.

I: So, your out of body experience was frightening?

J: oh yeah. But at the time I thought I was still in (name of hospital), having a hysterectomy. And then going home what my husband has told me there was a few times that - ... I was transferred to the (name of large hospital) ... Cos I went in on the 7th of December for the hysterectomy, the 8th of December I had the hysterectomy. So, when I came around (long pause) I thought I was still here, and I asked for my husband and she said, 'yes, I'll get him now'. And I said 'where you been? Nobody's been to see me. I had my operation yesterday'. 'What?? Jean, it's a week later, you've been seriously ill'

I: And you don't remember any of that? That week?

J: no. Sometimes it's frustrating but then as (husband) says, it's probably for the best, that you don't remember any of it. Because the amount of times I was shocked ... I even sort of had .. my skin peeling off where they kept shocking me ...

I: And do they know why you had a cardiac arrest?

J: I had been having tests for shortness of breath .. even on the flat, walking on the flat. Get out of breath really easily, but I had my lungs tested, my heart tested, all these tests before the gynaecologist agreed to do the hysterectomy. And they said 'no everything's fine, nothing's wrong'. But something must have been not quite right with me having the cardiac arrests.

I: So, how do you feel about the ICD then? What does it mean for you?

J: I don't know. I get sort of moments when I'm frightened ... of it

I: frightened of it, in your body?

J: it's not so much in my body as having the first shock.

I: Have you had a shock?

J: no,

I: so that's what you're frightened of is it? Why are you frightened?

J: Cos I felt a couple of the shocks they give me in the hospital.

I: What did they feel like?

J: just like somebody crushing my ribs.

I: Is that what you think it will feel like do you?

J: people say you got a better chance of survival than any of us, cos
you got something to kick start

I: And do you believe that?

J: it could be something else that ended up killing me. Do you know
what I mean? It's not ...

(long pause)

I: Were you happy to have the ICD or did you have some
reservations about it?

J: I don't know 'reservations', cos my cardiologist, consultant
wanted me to have tests and whatnot done, cos it's turned out it's
on my mother's side of the family ...

I: there's a genetic link is there?

J: they think it's um, something to do-cos my Granpy died in his
early 50s with a heart attack, my uncle was in his 50s with a heart
attack, my mother's sister was younger. One of my cousins died in a
car crash but I am not- I don't know if that was his heart

I: he was driving was he?

J: yeah. So, sort of stemming back from my mother's- but I'd had a
paint and ductus repair when I was 5 ...

I: a what sorry?

J: paint and ductus. One of the valves in heart was leaking, so they
repaired that so I thought it might have been to do with that, but
they said no, everything was fine.

I: And that was with the breathlessness?

J: sorry what?

I: when you said everything was fine, that was with the
breathlessness?

J: yeah. (long pause). I find I forget things

I: since?

J: since I had the cardiac arrest

I: your memory's not the same is it?

J: no, and they go mad 'what you saying, you just ...' and I can't for the life of me think what I was going to say.

I: Do you think that's normal for what you've been through?

J: I dunno, probably ... from what i've heard and that it's normal .... Something, some brain cells, you lose some brain cells when they .. erm .. when they ... I dunno

I: but you feel your memory's been affected?

J: aye

I: So, that's ... that's nothing to do with the ICD, or is it?

J: no, it's all that I've been through ...

I: hmm, quite a traumatic time

J: aye, yeah (participant is trying not to cry)

I: so this is your first Christmas when you've been well I suppose

J: yeah 'cos I didn't come out of hospital till the 23rd ... So it was trying to be happy for our youngest son, and the grandchildren, but it were a strain like 'cos it was sort of I had to remember I'd had a hysterectomy as well and heart surgery, if that's what you can call it. You know, so I was still having my off times

I: Mmm not surprising ... So, how did you feel when you got home? Like the mother, the grandmother?

J: I was more, I was like every night I was praying please let me wake up in the morning .. cos I was petrified.

I: so you were scared to go to sleep were you?

J: Well, after I came round from having the cardiac arrests, I didn't sleep for five days ...

I: through fear was it, or??

J: Um, I think it was a bit of both, through fear and not feeling tired at all

I: just not feeling like you wanted to sleep?

J: no, and like the nurses were starting to worry a bit 'cos I hadn't had any sleep since I had come around and you know, I tried to make a joke of it, you know 'I've just been asleep for 7 days, 8 days, whatever and how much sleep has one person got to have like?' (laughs). But if I did manage it would just be half an hour and that would be sat in the chair ...

I: and how's your sleep now, a year on?

J: very restless, I wake quite a few times through the night ...

I: Why do you think you wake?

J: I dunno .... (long pause) I dunno

I: what do you think about when you wake up?

J: I've had some vivid dreams as well and it's trying to remember what I was dreaming about and it was something a bit frightening and I'm afraid to go back off to sleep in case it comes back into the dream I'm in. 'Cos my husband tells me 'I don't know what the hell you were doing last night but you were fighting with the bed'

I: And this is only since you've had your cardiac arrests and ICD?

J: yeah. I still get moments where I want to be in the house, I don't want to go outside. I don't like being in a crowd of people because I start to feel panicky

I : and this is since you had ...

J: It's got worse since I had the ICD

I: So it's got worse? So , it was there a little bit before?

J: It's just at the beginning I think, it was just when you go shopping you got to watch certain things what to buy, you know, security and things, and shops, and coming out (of shops). You know, if somebody stops you to talk, make sure you're not by the entrance too long. And I still do it now 'can you move out my way so I can just move'. You know people are stopping and chatting and I need to get away from these (shop doorways) 'can I pass you' like. And the flat escalators in Tesco's or Asda, can't go on them at all and it's all looking out to where the lift is and I still tell myself if I go out on my own I say to my husband, 'I'm going out on this bus and I will be coming home on this bus'. And if I haven't finished what I went to town to do, it's left. 'Till another time. Cos I've just got to get back in the house. If he's with me, I'm not so bad, I'll have a couple of moments. Like, last week my sister in law came down from (name of city) and she wanted me to go to Cardiff with her cos she wanted to do some shopping. And I thought 'oh come on, push yourself'. You know, I 'm talking to myself 'push yourself, you've got to do it'. I done it, I went with her. I had a couple of panicky ... but I didn't let it show, that's my sister in law. You know, 'cos she was visiting down from (name of city), I didn't want to show that I was having a panic like. So I just sort of ... looked in a shop-a shop window, just to try and take my mind off it 'it will be fine, you're alright, stop panicking'

I: And what do you think triggers the panic? Does it happen at a certain time?

J: no, it could be anywhere... at this time of year it's going to be worse, cos of people shopping and what have you, but I just can't cope with crowds of people.

I: since your ICD?

J: Hmm.

I: why do you think that is? What's changed?

J: I dunno, dunno. I just panic. I know I shouldn't. I should be grateful that I'm still here because they had to call my husband back in a few days-times, 'can you come back to the hospital, she's not going to make the night'.

I: gosh.

J: and that's what he was doing

I: and how does that make you feel now? Thinking about that?

J: oh very grateful to the hospital for doing all that they did (long pause)

I: it sounds like an extremely traumatic time

J: I know I should be a little bit more 'life is full now' with what I went through ...

I: what's holding you back?

J: I dunno.

I: Do you trust the ICD to kick in if it's needed to?

J: oh yeah probably, but it's .... Like I went to the hospital last week for a check up with my arrhythmia nurse 'cos I've been off the amiodarone for 3-months so they just wanted to check the machine. The third part, when they put the one part over that was fine, and they started to raise my heart and I said 'stop it, I don't like it'

I: so you can feel it beginning to race can you?

J: (nods)

I: so, when you're out and you can feel your heart beginning to get faster, that panics you does it?

J: yes but I tries to calm myself down cos I don't want it to go off

I: right ... so that's what you're fr- ... I mean apart from feeling a crushing pain, which will be very quick, from what I've been told, I don't know, cos I've not had one?

J: I've been told it's like somebody's punched you in the chest

I: are you ok? Do you want some tissues?

J: nah, I'm ok.

I: so you said you should be living your life to the full, so why do you think you should be?

J: it's like I've been given a second chance

I: is that you telling yourself that is that other people?

J: well, a bit of both.

I: you've had a hysterectomy, which is a major operation isn't it?

J: but the thing that's come out of it ... some of my family have been tested ... they were given literature to get tested to see what it was. And in two of my brothers, they've found something with their hearts and they're on tablets ... as far as I know. And I think, well if I didn't have that, it was waiting like a time bomb waiting to go off. And I've put a lot of stress through my husband, the children. My daughter, she phones everyday 'you alright mam? How you feeling today?' And if I say, I'm not feeling too good today, she'll be back on the phone quite a few times 'are you ok?' And I think 'oh just leave me alone'. I know she's only looking out. But I've said to (husband) as well ' I'll just go, live somewhere else', I feel like I'm a burden to him.

I: has he said that, or is that how you feel?

J: feel

I: its' how you feel? Have you told him how you feel and what's he said?

J: (nods) 'Don't be stupid, neither of us are going anywhwere'

I: before your hysterectomy, did you feel depressed?

J: not really

I: no? So, everything's changed since then has it?

J: yeah (long pause). I know I should be shouting from the roof tops 'I'm still alive!' I was reading the paper the other day about a woman, 30, she's had an ICD fitted. She' s very fit, she's doing some marathon now. She was asking the doctors will she still be able to run. Yes they said and six months after she's had it fitted she's training to raise money for the British Heart Foundation. You know, and I think 'my god, she's doing all these running and things ...'

I: she was an athlete before wasn't she? So, I suppose in a sense she is trying to do what she used to do. Is there anything you've stopped doing what you used to do? Anything you've stopped altogether?

J: to be honest, I can't remember

I: right. Do you feel a different person?

J: yes, I'm completely frustrated when I can't remember. Like, yesterday my daughter phoned, 'do you want to go for a cuppa?' So, I said ok but I've got to go into town a minute. I'll be on the one bus, I'll be back on the other and then we'll go out for a cuppa. And she was asking what I'd got for the two grandsons for Christmas, cos she didn't want everyone getting the same . And I said 'oh, pass', I can't remember. I know for her youngest boy I got a computer thing but she was on about pyjamas the mother in law had got. And I said I got a pair of them for (boy). And I said once I know what I got, I'll call you. And she phoned me 5 times yesterday, so I said, I'll have a look when I get home and I'll give you a ring. She rang me 5 times yesterday and I give her the answer at 10 o'clock last night.

I: cos you kept forgetting?

J: Cos I kept forgetting. I said, I'll go up now and have a look and she was asking me other questions and she said it's alright, you haven't got them (presents). But it's just ... I know it's frustrating for my husband, and you know, my children. And it's been a lot of pressure for our youngest one, cos he's only 10 and we've had our youngest grandson, he's been diagnosed with cancer (talks about cancer). But it's frustrating, before the hysterectomy they kept telling me everything was fine and there was nothing wrong. But something must have been wrong for that to happen.

I: so how does that make you feel? Having been told it would be a straightforward operation. I know how that would make me feel.

J: Frustrated, angry

I: you would have thought you would have had a right to be angry wouldn't you?

J: I keep saying He's (God) trying our patience ... He's trying our patience upstairs, really putting us through the mill at the minute. Cos my eldest grandson has got to go for blood tests tomorrow to see if he's got celiac disease. 'Anything else you want to throw at me?'

I: so, you're feeling that He's getting at you?

J: yes. Before I had to have the ICD fitted, I had to have an MRI scan and tests done with the arrhythmia nurse and then have the ICD fitted and so that was like the Monday, Tuesday, Wednesday. I come home Thursday then. But while my arrhythmia nurse was doing the test, she was setting it off 'it's coming, I can feel it, I don't like it'. 'Oh come on Jean' she said, 'I've not had anybody die on me yet and I'm not having you go either. Just look at the ceiling and sing some songs anything take your mind off it'.

I: And when was this? What was she doing? Testing it?

J: she was testing my heart to see .. some stuff had to go into my arm to see and check and they check my blood pressure

I: so this was before your ICD?

J: Monitored with a heart machine and I kept having ectopics and I'm thinking, 'I'm not pregnant' ... I'm thinking ectopic is to do with pregnancy like. I think I was in ICU and they were doing the test, it was either ICU or CCU and they pulled the curtains across so they could do this test and that and the nurse was telling me 'sing'. So as it was coming up for Christmas, I was singing Christmas songs and I heard a little girl behind it saying 'mammy, why is that lady singing in there?' (laughs). I know, bless her, not the best singing voice but I got to do it, got to take my mind off this. But she had to do it-it's supposed to be a 5-minute test but she had to stop it half way through 'cos I kept getting ectopics. So I was really nervous then when they say I had to have the ICD fitted (not audible)

This gentleman was lovely mind, who done it. I said 'now I'm not going to die now am I'. ' No', he said, 'you're not going to die, this is going to keep you alive'. I was wired to portable machines and he said I'll tell you what, I'll put you out slightly, like they do with children, just relax them, but I woke up while he was stitching me up. I could feel him stitching me there (points to chest).

I: you could feel pain?

J: sewing, putting the needle in. 'Oh keep still' he's going. I said 'it hurts'. But I think I came round a bit quicker, 'cos they had to stop my heart to see if ... to work it, so I didn't feel what it felt like (shock) and I think I was glad in a way but then I thought at least I would have known what it felt like. Touch wood, just grateful it hasn't gone off

I: If it did go off, what would you think? What would you think had happened to your heart?

J: um (long pause). I think it would be-I'd be wondering then, why's it gone now, what's happened and I suppose I'd think 'is it my time to go?' You know, cos one of the local GPs in the doctors here, cos I'm on anti-depressants now ...

I: since your ICD?

J: yeah. I'd started to take them before I had the hysterectomy and I think that was more I was worried about having the hysterectomy done. And I was a bit down, so they put me on a low dose. But since I've had the ICD fitted, I've been upped on them. But as the one GP said you know, you're given a date for your birth and they said you're given a date for when you go at the same time. And I thought 'I know that but that's not something I needed to hear like'. And then I'm thinking 'is it my time to go' and then 'no, stop thinking like that'. I tried to reassure 'son' then

I: your youngest?

J: my youngest son cos he was ... if he's got to go somewhere and I'm not there, he'll say 'no, I'll stay with you mam and make sure you're ok'. So I am 'I'm alright, I'll get there and sort of like. People say to me 'oh looking well' ... 'yeah I'm alright'. So, I do put on a brave face if that's the right word, when I'm out, but inside I'm cringing. I know I shouldn't feel like it

I: I guess we all feel things we wish we didn't, that's being human but, ... so what is it that's so frightening about the shock? Because you may never have one.

J: I know, I have been told that. That it may not, not even get used. I know I am I am a worrier. Like at the moment, it lasts about 6-7 years, depending on how many times it's been used and whatnot. But perhaps it will go a bit longer and I won't have the operation again then.

I: so you're already thinking about having it replaced. You're a bit of a worrier. That's your nature is it?

(long pause)

J: I can have days when I'm laughing and joking and then I think 'good, we've had a good day' and then I feel guilty when I have a good day.

I: why do you feel guilty?

J: I don't know.

I: did you used to feel like that before the ICD? Is it since? Do you feel you don't deserve the ICD?

J: I don't know, I ... I don't know, I dunno. We had the letter from the GP about the flu jab and I thought why have they sent one for me. You know, they have never sent one before. And I rung and they said 'it's cos you got chronic heart disease'. 'What you mean chronic heart disease? I've had an ICD fitted' . So they said, yeah that's what they said. Well I said, I didn't know ... you know?

I: so you're getting mixed messages are you? Have you had a diagnosis of chronic heart disease?

J: not to my knowledge. So, whether it's letters they've had from the hospital or what, I dunno.

I: Have you asked your arrhythmia nurse?

J: no, I haven't at the moment.

I: do you want to know?

J: to be honest I don't really know what it means .

I: about the chronic heart disease?

(Long pause)

I: some patients I've spoken with don't really want to know about their heart condition, they just want to know they've got an ICD and it will work when it needs to. And that's all they want to know, they don't want to know the details. And there are some patients who want to know everything. Where do you fit in that?

J: I think I'm a bit in-between. I think I want to know, but then I'll probably think 'do I really want to know that?'

I: you want to know bits that aren't going to worry you?

J: well ... it's ... cos people say to me 'well what does it mean?'

I: what does what mean? The ICD?

J: It's the same with any illness really, it's like with my tablets, 'what are you on these ones for'. 'You got me now' (I don't know)

I: so .... do you trust what the doctors are giving you?

J: yeah

I: and yet you are also a bit angry with them?

J: yes because they didn't find out ... I suppose they can't find everything, it's trial and error but I just feel really frustrated. I thought it was just the hysterectomy that's all and I didn't think I'd be too frightened to end up having any more operations .... in case I went into a cardiac arrest again but I know I've got the ICD there. There are times I think can we just turn the clock back to the last few years, none of this happened, it's like I just want it all to go away.

I: you've been through a lot and come out the other side

J: I know, that's what I should be grateful for but as I said to the arrhythmia nurse last week, it's – when she done the test on me and waiting for the porter to take me back down to the ward. As they turned up, just waiting for the nurse to come and take me back down as well and this person just seemed to appear ... from nowhere like. And I said 'oh sorry' as she was looking at me notes and she went 'yes it's you' she said 'you've been very ill' I said 'yes'. 'Yes, very very ill' and I said 'oh, thank you for anything you done for me here, I'm sorry if my children gave you grief'. And she laughed and she said 'no'. She held my hand and put the other hand on top but her hands didn't feel like hands, they felt feathers. And when I was looking at her ... It was like, she didn't have nurses uniform but a chiffon dress ...

I: this was in the hospital?

J: this was in the hospital.

I: and this was after the ICD?

J: no, this was the day before, after the arrhythmia nurse had done the tests

I: ok, before you had it ...

J: 'Cos I kept saying i'm sorry if my children have been, you know, gobby if you like. I know my daughter, she flew off from what husband was saying, flew off the handle a few times, she thought they weren't doing enough for me ... and she said 'no, it's ok'. But the hands, I can't get over the hands, you know they were so soft.

You know, if you touch our hands (participant touches interviewers hands), the bone, none of that .. it was like ....

I: so who do you think it was? Do you think it was a nurse?

J: to be honest, she looked a bit like my daughter

I: right, and have you asked if it was your daughter?

J: No, it's ... the nurse, I said 'oh who was that then?' 'oh it was ...' So when I went downstairs I went to husband 'was there a nurse called' do you know i can't think what her names was. He went no, you didn't have a nurse by that name. But she was so um, softly spoken...

I: do you think it was a nurse or I don't know

J: I think it was an angel . She was just so very softly spoken. And it was like she had skin like us but it was like touching feathers, really soft feathers and the skin, to be honest it was softer than a baby's skin. It was, I think in a way it was calming, (Karma?) whether she was coming to tell me it'd be ok, you know. I think they were letting me know, I'd gone through the worse and I was going to be alright, it shows how seriously ill I was. I think I should be grateful for that

I: so you should feel grateful? But you don't feel grateful. Why should you feel grateful?

J: (long pause). Because it's given me the chance to see my youngest boy grow up because my other children are a lot older

I: so he's 10

J: yeah and the next is 22. I was 38 when I had him cos it's a second marriage

I: so the ICD has given you a chance to see him grow up? Do you believe that?

J: yes and no. Yes and no. I mean at the time I just kept saying to the arrhythmia nurse 'thank you'. I mean even when I woke up after having the ICD, I looked at the doctor and said 'thank you, you didn't let me die'. Cos he'd come and seen me the morning I'd had it done. And he said 'oh the arrhythmia nurse has had a word with me, I'm going to put you out lightly, I'm not going to put you out completely, you're supposed to be awake for the ICD'. But he said you're very anxious, so when I was in the room, he'd asked the one, who had given me the stuff and she said 'oh but they're supposed to be awake' and all I remember is him saying 'oh I'll tell you later'. So, I thought there was something going to happen, you know, like a misunderstanding on my part, so she (Arrhythmia Nurse) must have been telling him how anxious I was. Like when I had the MRI scan, I was panicking, 'you're not going to let me die in that are you?' And that was all that kept going through my mind. When I came out I was shaking like a leaf.

I: were you frightened of dying before? Before your out of body experience?

J: no, I was never .. oh, once your time's up, your time's up, it's time to go like..... I should be skipping around ....

I: have there been any benefits for you then, having the ICD? What good has come out of it?

J: it's just been able to see my youngest boy and my grandchildren grow up

I: so you feel it's given you that chance?

J: yeah

I: but at the same time, you're limiting your life, cos you don't want to set a shock off?

J: I know I shouldn't but you know, I can be sat there, I get some palpitations, I can feel my heart pumping and I know it's normal

I: what do you do when that happens?

J: I just sort of (deep breath) 'come on, you're ok, you're fine, nothing wrong, you're alright' and I sing in my mind, I've always gone back to what the Arrhythmia nurse said

I: so you've learned to cope

J: I still get my moments when think I can't cope with this anymore, I just want everything back to normal. You know, there's nothing wrong, I don't need this (ICD). I think 'husband' was too scared for me to come back home before ICD, in case it went again (CA) and he'd lose me, because he wouldn't get me back quick enough for me to get shocked.

I: has it affected your relationship with your husband? Thinking about intimacy, sex, increasing heart rate ...

J: I think since I've had the ICD, he's very frightened

I: what about you, are you frightened?

J: No, to be honest, it's sometimes my sex drive has gone higher ... only at certain times in the night, other times, I don't think of anything ... but I think he's frightened that if he gets too intimate, he's going to set it off. You know, I don't know. This time I just feel that he's .. perhaps he's gone off me. Do you know what I mean 'cos he's not ...

I: have you talked about it with him?

J: we have a couple of times. Once we've talked and I said how I feel, it 's ok. It's like, I know you're there, but I can't do the physical ... since the ICD ... and it's 'what's the matter, you don't want me?' And he said 'no, it's not that, I still love you and I do want you but it's just times I'm frightened

I: what's he frightened of?

J: the shock, i think that's what he's frightened of. We have had intercourse since I had it fitted but it's not on a regular basis

I: so, that's a change since your ICD? And for you, has that effected how you feel as a couple?

J: yeah. I mean I still love him to bits but I think it's just being me, being paranoid... I don't know. I know he wouldn't go off or anything. I mean it's coming up for a year since I had the cardiac arrest and the new year when I had the ICD and I think will it happen again. And I know I shouldn't think like that

I: are you doing everything you used to do in the house, taken on your roles as mother, wife, grandmother?

J: I prefer to be in the house, feel safer

I: what about alone

J: as long as I've got somebody with me I feel safer ... since I had the ICD in case it goes off ... but I know I've got my card with me all the time, you know, so people don't think they have to look for a number or something, they can see I've got the card there. I should get one of them talisman bracelets or something ... sort of just in case ... I do get frustrated. Like 'husband' will say something to me, and ten minutes later I'll ask him a question related to what he'd just asked me .....

I: but overall, your family has been helpful to your recovery?

J: yes. But sometimes I found it a bit over powering

I: over protective?

J: yeah but that's cos I've always been overprotective of them. You know, it's sort of swings and roundabouts really, they never used to .... very overprotective

I: and is it any better now, are you able to do what you want?

J: oh, they've eased off ... but because of the arthritis as well, I found it difficult to carry things ... so going into town, 'give it here, what you doing carrying it? Give it here now'. And if I don't do it, I know my daughter will tell on me with the boys and I'll get a row

I: do you find that frustrating?

J: sometimes, yeah. If i'm having an off day, I think it's about time somebody's doing something for me instead of me doing it for them.

I: in a week, how many off days do you get?

J: about four or five.

I: is today an off day?

J: started off. But then 'no, pull out of it, you're alright'.

I: you talk yourself out of it?

J: yeah but as I say, I still moments of frustration and then I think 'stop, get a life, you've been given that second chance'. It's like one person saying that to me and the other person, you know like the- sometimes you get the devil and the angel like. And the other one is like 'no you don't want to be doing that'. And at the moment, the devil's winning

I: so what's the devil telling you to do?

J: um, he's sort of putting me on that downer, that depression. You know, I'll go and do this and it's 'oh you don't want to be doing that' and I say 'come on, it's got to be done' . And I'll do it and I'll feel good I've done it. You know, it's 'I haven't listened to that one (bad), I've listened to this one (good).

I: It's a constant battle is it?

J: yeah. It's like .. I don't know how to explain it without sounding stupid ... oh I don't know, it's gone
(Long pause) ... It's so frustrating for me at times, very frustrating

Transcript for N17
Female aged 58 years.
Bundle Branch Block
In line with ethics, participant's name has been changed to 'Sophie' (S)
'I' stands for interviewer
EP stands for Consultant Electrophysiologist

I: I usually ask patients, if you can give me a brief background as to why you have your ICD

S: well I had problems anyway, cos I got arti(not audible)

I: you got what sorry?

D: artificial valves and on operation was done 2007. I have been having what seem to be low blood pressure problems and taken to 'hospital'

I: were you passing out?

S: no, just very dizzy, I haven't passed out, thank goodness. But then, I think it was about March, I was home on my own and I felt my heart beating very rapidly and that was something I hadn't experienced before, I have felt sick and dizzy but I haven't felt that. I wasn't sure what to do, so I phoned the doctor, spoke to the receptionist and she said 'oh, I'll speak to the doctor' and she came back and said just lie down a while and if you don't feel any better contact NHS direct. Um, that didn't fill me with confidence, cos I felt pretty bad so I phoned my husband at work and he came home. And I couldn't sit still ... it was sort of thumping so much, I couldn't sit down and I was walking around sort of concerned about it. So we phoned NHS direct, explained what had happened and we went in and I was seen by various people and then I saw Dr EP. He went through what I was doing, what I felt and explained everything (cough). And I gradually calmed down but he wanted to keep me in hospital, which he did for a week

I: so your heart rate lowered by itself

S: It came down by itself, so I stayed in hospital for a week and nothing much was being done. I was in under observation I suppose, blood pressure taken, blood taken, but I didn't actually see a consultant for a week, the week I was in there, which upset me a bit. Because I thought I'm blocking beds and I'm not even sure I need to be here. So I had to ask the nurses on the ward when I was going to see somebody. I eventually did, I saw my own cardiologist and I also saw the EP again and what they decided to do, was put a device on me to record my heart

I: and all this time you were an inpatient

S: yeah, so on the Friday I was fitted with this device and I had to take it back a week later , which I did, and I felt ok, I didn't think there were any problems, you know, I didn't feel dizzy, and I didn't have this heart problem again. So I took it back after a week and obviously you have to wait for the results and I thought everything was fine, we were both quite happy, we knew what my problem was previously

I: so when you say 'we'

S: erm my husband .... so we weren't expecting any real problems and we went to see the EP but he said there were things going on in the background that were being recorded that i wouldn't have been aware of but suggested there was a problem. And that's really when he said I should have this ICD. He explained it was a pacemaker and also the defibrillator (cough). But he was ... neither of us were very happy about being told this, very matter of fact and straightforward which when you're being told something like this is ... you need a bit more sympathy and we didn't feel as if we got that. And because they were told that is was very straightforward, it was so much and totally unexpected that we didn't even think of questions to ask at that stage

I: so you were taking it all in

S: yeah, trying to yeah. Um and what he said was, that because of my-my original problem which is that the left side of my heart is weaker than my right and that goes into the rhythm changes, this device, the pacemaker will help to sort that out. But it won't cure it because the muscle is weak and he said if you should-obviously the defib is in there just in case I do have an episode again.' It's possible you won't but it's there as a backup if you like'. So, that was a bit of a shock. He said 'I'll implant it' and June I had it done and I was seen within two months I think it was.

I: so you had it done in June? And in between you came home?

S: yeah so when I had it fitted I came home and carried on as normal.

I: so was there a period when you hadn't had it fitted, and you had to wait for two months?

S: yeah, yeah, it was about two months

I: and what was that period like?

S: well, it wasn't very pleasant, cos when we got home, we were both really shocked and had a cry, I suppose ... (starts to cry)

I: ok, yeah hard ... stop whenever you want to (gives participant tissue)

S: so, just discussing it and you know, just had to get on with it really and accept it. But as I say it was only till later, that we thought of things to ask but we didn't think-we didn't think there was anybody to ask about what he'd said, an explanation. 'This is the best thing for you and that's what we'll do'. But it was a shock and it did affect us

I: How did it affect you?

S: well ... just expecting something to happen

I: this is before the ICD? While you were waiting to have it done?

S: We were both concerned, because it sounded like it was something I had to have, there was no choice. It brings it home to you how serious the problem is, which isn't very nice to hear. That your heart is absolute rubbish, which I think mine is at the moment – I've got a lot of scaffolding (small laugh), which is there but if you didn't have it ... I think it was 'husband', he was obviously concerned about me, and he wanted to keep checking I was ok. I was thinking the same thing, I didn't want to say much 'cos I didn't want to upset him

I: right, so did you hold things back?

S: oh a little bit. I mean he was upset anyway but he was rather I'd told him if there was a problem or not. But yeah, it was a long wait for it to be fitted and of course you wonder what's going to happen afterwards. It's a sort of shock, I mean the EP explained what would happen, the ICD gives you an electric shock which sounded very unpleasant. He said I might not have it, might not happen but then why is he fitting it. You know there must be a chance it is going to happen, cos it's an expensive piece of equipment. And then I started thinking, what would happen to me, the physical affect, would it be painful, how long would it last, would there be a pre-warning

I: so these are all the questions that you wished you'd asked?

S: Mmm. Yeah, you just think yourself, how are you going to cope with it, how my husband would cope, would I be on my own when it happened. Trying to reconcile all this in my mind, trying to accept it, just get on with it, if you like. You know that period wasn't very pleasant but then I had it fitted in June. It was on a Friday, I was out on Saturday. And it wasn't-it wasn't painful but it-it was alien – this lump of metal in your chest. I didn't know how to cope with that, because obviously it affected me physically, things I couldn't do things, things I had to be aware of. And seeing the lump in my chest as well, I haven't got much flesh up here so it was pretty obvious but I mean gradually you get over that. I am aware of it all the time

I: are you? Constantly?

S: yeah. It's something you can't ignore. I can't. Perhaps that's a problem I've got. But still, it can be in the back of your mind then I will think what's going to happen, if my heart starts a peculiar rhythm, what am I looking at, is this it? If it starts getting really painful, what do I do? And it's just constantly in your mind, it's always there, what's going to happen.

I: so if your heart rate was to increase now, say for example, how would you feel?

S: um ... frightened probably. You don't know what's going to happen, you know, how far is it going to go, cos it might- it just might be an arrhythmia where the pacemaker will work it out, it's doing what is called pacing to try and get it back into a normal rhythm. And that's happened a couple of times, and that's unpleasant. But being pessimistic, you always think beyond – the next stage if you like. How's that going to affect you

I: you're talking about the shock, if you were to have one, what do you think it would be like?

S: well having read the literature and listening to what's going on, what's being done, I've been told it can be just like a thump in the chest, kick in the chest and if you sit down and have a cup of tea, you'll be fine, which is sort of reassuring. But then me being me, I- I just think of it quite often.

I: when you say you being you, what do you mean?

S: I'm a pessimist

I: are you a worrier?

S: absolutely, always have been. So something like this would prey on my mind. My husband is amazing. He's the total opposite to me, always looks on the bright side, always happy. So I think he does a lot to keep me going but I'm aware that's it's preying on his mind ... he doesn't show it, but urm, amazing man.

I: how long have you been married (I asked this because for some reason I thought they were newly weds)

S: It's our 40th in 2015.

I: so you've been together for a while. So what kind of things were you holding back from him?

S: well if there was anything going on. If the heart was doing strange things, I wouldn't tell at the time. I might say something later. It was probably a stupid thing to do, but at the time, I was feeling very-very strange, I wasn't really sure what was happening, I just knew something was, I'm not sure what so I just keep quiet and try and keep calm.

I: and this is after the ICD

S: yeah, sorry, yeah. But I'm very quick to calm down and get back to normal and I might tell 'husband' later. Because it's happened a couple of times, I've sort of- not happy with it, but I know what to expect in that case.

I: And what do you do to calm down

S: there was one time, this time it happened I was watching Dr Who (small laugh), which is not the best thing for the heart and I assumed that what was happening so I felt a strange rhythm and it was a bit unpleasant, just made me feel a little bit weak. And a bit wobbly, so I sat quietly and waited for it to calm down. I just told myself 'you must just let it happen, obviously something is going on and this is what this device is designed to do, to get back to normal'. So i just kept telling myself I was fine and it resolved itself out, which after about an hour it did.

I: so where is the fear coming from about the shock?

S: well anybody would if you think your heart is going to suddenly, well either beat too fast or stop. It's strange but your heart beating is sort of irrelevant, I think beyond that – I think ok, your heart stops, there's a silence and it's that I'm afraid of. That's the way i see it. Is there something I can do about it. You know, can I do anything. And of course you can't, your device is supposed to

I: how do you feel about the device doing that?

S: well I suppose, you're glad you've got it but then you think, your heart can't be in a great state as you've got one, which obviously suggests that things will go wrong or can go wrong. It's going to be pretty serious. Well an optimist would say 'well I've got this now, so I'll be fine'. You know, and I think I've got it because something's wrong – I'd rather not have it.

I: so that's how you interpret the situation, which I guess is part of your personality?

S: yeah. I know a far few people have had ICDs so it isn't rare and you know people have them and as far as I know, things are fine, people get on with them. And I know I should (small laugh) be feeling that

I: why do you think you should?

S: cos any surgery, anything you have done to improve your health, you should feel better about it, shouldn't you?

I: ok, you said you had a valve replacement, did you feel better after?

S: um, yes because I was able to do more. You know, it had actually restricted my movements because I got very tired. And that frightened me but I knew I would be better able to live life a lot better than I was, so that was a bit frightening but not as scary as this, for some strange reason, I don't know why.

I think it was there I assumed, well I had that done and that was it, my problems would be solved. You know, my heart is-has been looked after, if you like, and that's it. So, when I was told I had to have this device to keep my heart going, I thought perhaps my heart wasn't as good as I thought it was – it needs all this extra help to keep going. It's the fact that I think my heart isn't very strong

I: is that you thinking that, or have you asked?

S: no that's me

I: it's your thinking

S: well it's .. well if you think of what I've had, two valve replacements, not just repairs, they had to be replaced. My heart itself is not beating properly anyway, because of the left side being weak so that doesn't help. And also one other thing that the EP told us when we were speaking to him, he explained in more detail that something else could go wrong and he said 'what we're going to do, the device we're going to put in has an extra terminal. So he said that in the future he might have to put another wire in and that didn't help either.

I: did you only have the EP to talk to?

S: No, to be fair the nurses have been fantastic, and said anytime I wanted to speak to them I could but I didn't do too much of that.

I: why

S: I was in a state of shock and then I was thinking, I was going to have to go in and have it all done again, the extra bit

I: is that the extra lead

S: yeah. He explained it, but when he explained that it was another problem, it just made things worse

I: did he use the word 'problem'?

S: no, don't think so. Should i explain what it was or doesn't it matter?

I: well it would help I guess

S: well he said I had a bundle branch block, because he started talking you can have three or two wires and we looked at each other and thought 'wires, what are they?' As far as I know, i haven't got any wires in my heart. And my husband asked, and he explained what it was. They obviously are organic wires that generate impulses and he said most people have three or two and get along fine, he said you got three but two are broken.

I: he said you got three, but two are broken?

S: so he said, when they put the extra device in, so that if it should go, he can put another lead in. He said there was an extra facility with the ICD to do that and there was a probability that it would go. And again when he said that, that just made it worse, obviously cos you're going to think what's going to go next. Which is why i said, my heart isn't very strong and that's hard to accept .... But you know, you just get on with it, cos there's nothing you can do.

I: when the EP told you about your heart, did you go away and research it?

S: um yes.

I: and how did you cope with that information?

S: um ... well it was a bit frightening. I brought up bundle branch block on the internet and I started reading it and I realised that was happening to me. Again, it explained what was happening or could happen, but it also made it more real. You know, it was something and it did happen to people, you know it's not just words, it's not just a description of what could happen, it became real to me, that it could happen to me.

I: how did that affect you?

S: well ... um ... well at least I knew what he meant when he was talking about it, but it was just another problem on top of the other problems

I: like one after the other

S: yeah, yeah. But he said it's something that can be dealt with and this is why he put the extra device in. He said he'd rather that than it going again and putting the whole thing in. So, that was ok, that was fine. So, it's there in case i need it. But again, it's the extra problem with the heart . I mean, most of the time ... most of time-when I'm occupied I forget it. But when I sit down quietly thoughts go round my head-it's always in the back of my mind.

I: what kind of thoughts go round your head?

S: well, that I don't know what's going to happen, when it will happen, how it will affect me, will it hurt, will there be more than one

I; so you think about the shock, that may never happen, but it's real to you?

S: yeah, it's bound to. They wouldn't put it in if there wasn't a risk

I: has it stopped you doing anything, has it affected your life to the extent that you've stopped doing things

S: No, it's mainly about going away on holiday. Going abroad.

I: because?

S: well in case something happens. Will there be people around who can help, will there by a specialist hospital somewhere, will there be someone there to, you know, do something about it. Would I be on an aeroplane, you know 1000's of feet above the Atlantic. And if something happened, what would happen. All these thoughts

I: what would the worst thing that could happen

S: well that I'd have a heart attack, nowhere near help

I: not a cardiac arrest then? That your defib would shock you out of? But a heart attack

S: yeah, yeah anything like that

I: you're very sensitive about your heart in general

S: absolutely, I am now (small laugh)

I: are you very aware now of your heart beat and

S: I suppose I am yes, when I'm doing something strenuous, I keep telling myself 'you must pace yourself'. Cos if it starts-if it starts going too fast, too quickly there could be a problem, so you must pace yourself, so that is there as well.

I: so it's affected your day to day life in the fact you try to slow down?

S: mmm. ... But I also think people that have these things live normal lives, they keep fit, they jog and whatever they do, and they go abroad. Now I'm aware of all that, like people do marathons, that's the upbeat side of it and it makes sense to do that, but me being me (small laugh). Whenever I think I'd do this, but then I think you shouldn't really. I don't think I'm going to change in that way

I: why not?

S: that's just me as a person and I can't see myself becoming optimistic with all this going on to be honest. It's always going to be a problem

I: how has it affected your relationship?

S; it hasn't

I: what not at at all?

S: Well only that he is more caring, you know, making sure I'm ok, checking up on me to make sure I'm fine, there's no problem. And if we go anywhere, do anything, he um, just makes sure I'm not overdoing things. If I start to do a lot he'll say just take it easy.

I: how does that make you feel?

S: um, sometimes it's irritating. You know, cos I want to be able to do things without feeling he's looking out for me all the time. Cos it's a strain on him.

I: such as?

S: well he's worrying about it

I: what kind of things would you like to do?

S: um ... in what way?

I: you said you find it irritating cos you'd like to do ... something without him worrying

S: oh just general things, general day-to-day life. You know just making sure I don't overdo it, but it's also a comfort. Looking out for me really.

I: so how do you feel when you're at home and he's not?

S: yeah, I'm fine with that

I: what about going shopping on your own

S; that's ok, yeah... that's ok. It's just being aware that I can't- shouldn't carry too much shopping. I had to be careful for the heart valves but I got used to it but now I'm a bit more weary now doing that, which is silly, carrying shopping (small laugh). It's not a problem for most people and it shouldn't be for me. But if I feel a drag on my arm, my heart is going a bit faster, then I think about it. If I walk too fast, which I tend to do, I have to tell myself to slow down. It's a conscious effort to do it.

I: and this is to avoid ..

S: the potential of a shock. The main problem really was the attitude of the EP. He was just very cold. He gave statistics of what could happen but emotionally it was traumatic

I: so at what point did he talk to you? Was it when you were in hospital?

S: yeah, we didn't know what was going on, and this is when he said he would wire you up, then we went to see him when we gave it back and to you know, to check through it. It was then. I was frightened but he was telling us what was wrong and what was going to be done about it ... We just weren't expecting it, so it was doubly difficult. It was just the heart, you know I knew it was weak anyway but I assumed it was just that (episode), just one of these things, and nothing like this, it was totally different, unexpected, extremely insetting

I: so how do you feel about him now?

S: I mean from what I gather, he was one of the main people who input devices you know, and with lots of experience. He did it and he said once he discharged me from hospital I go back to my cardiologist, so I won't see him again, which is fair enough (small laugh)

I: I presume if you have an arrhythmia problem you'd see the arrhythmia nurse?

S: yeah. There was one time I thought I'd had a shock. But not knowing what actually happens when you have a shock. I was at home on my own-it was like a heart-a double heartbeat, strong. And I thought 'urgh', that didn't feel right at all, so I phoned the arrhythmia nurses and they said ok, come straight away if you're not sure . And it was checked at that stage, and it was fine, it wasn't a- it was just my heart playing tricks ... as usual (small laugh), doing things it's not meant to. It's not a regular rhythm. But they keep an eye on me, they check me, which is fantastic, if you're very-it's comforting to know they're looking after you to make sure everything is ok. So that's great you know, it's going to be a regular check up

I: you mentioned before that you wondered whether the ICD was your best option, do you believe it was your best option?

S; I think it was. I mean, I don't know, I think you have to-to trust the people who died (?) to tell you what you need. I mean this was an expensive device, and I don't think they would use it unless it was necessary, so as far as that's concerned, yes.... I was surprised it was so expensive. And with budgets and costs to hospitals, it just reinforced that I do need this

I: how did that make you feel

S: it's a double-edged sword isn't it. If you need it, that's great, it will help you, it's going to help your heart. But at the same time because it's such an expensive device, it's worrying that you have to have it, you know, you're thinking of the two things at the same time. Your heart's terrible, pathetic but this device is there to help you. You know I got this device, but it's because your heart's irregular, it's like thinking of the two at the same time

I: which thought tends to dominate?

S: um .... the fact that I have to have it

I: do you feel a bit depressed?

S: no, I don't feel depressed

I: it's just the way you think

S: yes, I get on my own nerves at times (laughs)

I: ok, lastly the literature you were given to read about the ICD, do you think there was anything missing?

S: no, i dont' think there was. There was a lot of information to read and you had the knowledge that if you wanted to speak to anyone, you could – at any time speak to one of the nurses, which I found initially very comforting. You know, you don't know how you're going to feel, you don't know what's going to happen to you. You don't know how to cope with what's going on, so to speak to somebody who's an expert in their field .... I have spoken to them, and I felt better after speaking to them, so I think that's a great help

Transcript for N18
Female aged 30 years. Post partum cardiomyopathy
Participant = P
Interviewer = I
Doctor = EP
Has had the ICD for a year.

Patient wanted her mother in the room, but in the end the mother went out but kept coming in, so transcribing has been minimised to cover the actual part of the interview that focuses on the ICD when the mother was not influencing the conversation

I: So, how do you feel about the ICD?

P: Fine

I: any worries or concerns?

P: no I wouldn't say worries or concerns, but I do have that feeling and I have explained it to the nurses, that it flickers a couple of times, like it's coming into beat? But apart from that, obviously at times, it's a little sore around the area, but it's all to do with the healing process .... I forget sometimes it's there.

(Missed out a large chunk of interview as not pertinent in any way to the ICD)

P: the left side [left ventricle] wasn't exactly doing exactly what it should have done, so what he wanted to do was he wanted to try and take the pressure of the heart of the right side, and put equal amount of pressure on both so that's what he wanted-came up with then. He wanted to try improve it back to what it should be ... whether it was going to work (ICD), he didn't really know but. Last test was a 45% increase, it's improving every time. He [EP] is just ecstatic of the fact that somebody of my age, having found I got this heart problem and putting a defibrillator that I have increased as much as I have. Don' t get me wrong I have my days where I get down, my breathing, panic attacks

I: when you say panic attacks, what do you mean?

P: Panic attacks

I: can you think of what causes them

P: change. It changes completely. For example, I had a letter from the job centre, just the littlest thing possible. Well actually it wasn't little, they sent me a letter saying they were stopping my money. They sent me for a medical, well I don't think someone like that can understand what I've been through the past year. We went, my mam had to come with me. I have to have my mam there as I need someone to assist me with my walking as my back, it do so painful, I've got to have someone there just to grab hold of. I also use a walking stick ...

I: so the stress of the letter?

P: The stress of the letter triggered it. Then I had to sit there and actually speak to them on the phone, which made me ten times worse, which resulted in me having to give my husband the phone to speak to them. Cos I couldn't breathe, well I could breathe but I was having that panic attack where ... It's changes like that. Before that I was fine. It wouldn't even have bothered me whatsoever but lately ever since I've found out that I've had a heart problem and the struggle I've had with the baby and what have you, it's put a toll, and it's there. I don't care what anybody says to me, it's got to me mentally, it does get to you, play with your mind.

It makes me feel I don't know what's in front of me, I have three chances in life, that's how I see it. I had my first chance with leukaemia and as I said to you, where the baby was concerned I physically thought I was a goner (details of the birth have not been transcribed), that was my second chance and then obviously my third chance was getting through this. And it has hit, it has. It's taken a big toll, big time.

(Missed out a large chunk of interview as not pertinent in any way to the ICD)

P: the [physical] restrictions I have nothing to do with the ICD. If anything the ICD has given me a different outlook on life, completely, it's changed my life and I'm-don't get me wrong I was restricted for 6 weeks, it's not long is it when you think 6 weeks ... I'm used to being independent and I feel I've lost my independence, I do. To be truthful now with you, if I was – right at the minute there's a conflict going on with this particular girl in the street. And before, do you know, I would not give two monkeys whatsoever, I'd stand there and fill her gob completely and that was me. You know, if you say to someone, [they would say] 'that was the old (name), she's changed. She was always the type of person to put up with no shit' and I'm going to say it how it is cos it's the truth 'no shit, she'd stand up for herself and then nobody would try an back her down'. And now I can't

I: what's changed?

P: because I'm afraid I'm going to set myself off ... I'm afraid I could have an attack or have a shock, it will get too much for me that way.

... I'm too afraid to go that extra mile, to stand my ground like I used to.

I: so how has that affected you as a person?

P: Annoyed, pissed off ... to think that other people got to fight my battles for me and I have never, ever, ever, I've never been like that where other people have had to fight my battles. I've always stood on my own two feet and I've always got my own way and I've always been able to do it myself. But for my friends to say to me 'look you can't do this because of your heart, we don't want anything happening to you' you know, 'we'll sort it out for you'. And you got (husband) as well, he says 'I can't put up with this no more, you can't do this, you can't ... ' and I think I'm not an invalid, I'm not a cripple, I might have had a heart operation but I'm still me. But I'm not ..... I don't feel the same person I was, a year ago.

Transcript for N19
Male aged 30, husband of ICD recipient due to Long QT Syndrome
Participant = P
Interviewer = I
Doctor = EP

I: can you tell me please why your wife had an ICD fitted?

P: she had a cardiac arrest, because of Long QT syndrome, this is what they diagnosed her with- we didn't know before.

I: where did it happen?

P: here at home. I was here, if I wasn't, she wouldn't' be here

I: how does that make you feel?

P: um, not so much bad now but first of all after it happened I was a little bit worried about continuously leaving her on her own

I: was there a period when she didn't have the ICD?

P: she didn't leave the hospital without it, but when she first got home, I was still a bit ... I still am. Not so much leaving her on her own but I do actually check her occasionally, you know like prod (laughs)

I: like if she's asleep or something

P: yes if she's asleep but it's more reassuring that she actually has got this thing. But um, it's still dubious whether this thing will actually-will actually work. She's never had a shock from it. It picks up episodes, I think they call them, which every time she goes [to check up], there are quite a lot of them.

I: is that the pacing?

P: well, they haven't really explained that. I have asked them but they said it's just when it picks up some sort of irregularity .. it could be her just walking up the stairs but when the heart rate is raised though. It just seems a bit odd the way they-because they got concerned one day when she was having a check, with the amount of episodes she was having .. But I don't know, they don't seem to explain, when they're having these tests, explain what all these things they're saying are. They come out with all these numbers and figures. You can understand a lot of it, but still think they could give you a lot more information.

I: do you speak with the nurse after?

P: Sometimes. We had done twice I think and that was a concern with a beta-blocker that she's on. She's always nervous about going, because once she went down, they wouldn't let he leave, cos the cable had moved so they kept her in and redone it. It made her even more nervous the next time she went down. Because she was afraid, cos they did a really tidy job of the scar the first time, not so good the second time and she's got a lot of worries about the next time they do it, the battery change, cos she felt everything they done. She was actually talking to them halfway through it as well and she said she wanted to be knocked out completely when they do it and they said she would, but obviously she wasn't so next time she goes down [to hospital] it's not going to be easy.

I: is this something you're worried about?

P: it's something I'm worried about yes.

I: you're worried about it, why?

P: because she won't have it done. She was that traumatised by it that she won't-she will not have it done. She made me promise her that I would be with her and make sure that she's actually out before they take her in [to theatre] or she is not going in. Which is difficult when you're down there [hospital] cos they don't work that way (laughs). The anaesthetist come to see her and promised her she would be out but she wasn't. She opened her eyes and was talking to them 'I'm still awake, mind'... 'oh you're ok, you're ok' and then she drifted off and then woke back up and they were still prodding around in her, which I wouldn't want that myself to be honest, not at all. She'd prefer to go to sleep and not know anything about it and wake up and it's all done. Which so would I if it was me.

I: so how does that make you feel as a partner? Listening to her worries and fears.

P: I think that is her biggest worry, the unit in itself, I don't think has bothered her that much, it's more the case of she's more worried about having it done or having anything re-done with it .... That's her worry, my worry is the fact that she's got to have it and if she doesn't have it ... Cos I know when the cable was moved, she created that much in the hospital that the consultant let her come home for two hours as long as she promised to come back. She really created, and there was no reason why, she was saying she had to get (daughters) stuff ready, to get all her clothes ready but it was nothing to do with that, she just simply needed to get out of there.... Fair play to the consultant he did let her leave but that was because she was panicking so much, she just wasn't going to stay there.

I: so seriously then, are you concerned that she may refuse the battery replacement?

P: she will refuse it unless she's out, she needs to be out, otherwise I don't know what will happen.

I: so for you, what are the benefits of the ICD?

P: I wouldn't want her to go through having a cardiac arrest again, because it was out of the blue, I resuscitated her ... it was just talking to her one minute and she was on the floor the next and it was just sheer luck .. cos I come downstairs and I heard a bang upstairs and I wondered what it was. And that does worry me, that if something happens again that somebody won't be around to-it does help that the ICD is there

I: do you trust it [ICD]?

P: no ..... I think the biggest problem is that I tend to look at things on the net and stuff like that which I shouldn't, so you don't always trust ... I know they have got a very good success rate but still they're not ...

I: so you are a little bit cautious about ... do you think you would feel relived if she had a shock and you'd know it was working or would that not make any difference?

P: that's a difficult one that is, cos if she had a shock she'd have to have another-another .. I'd prefer her not to have a shock actually.

I: ok, what would she have to have if she had a shock?

P: with this long QT syndrome with this miss firing or arrhythmia whatever , I'd prefer her not to have that really and risk the unit not going off. She's under the impression that she doesn't need it [ICD] cos she feels fine now, but like I said to her 'you went 28 years feeling fine', there's nothing to say that it won't happen again and at least you got this thing to make a difference.

I: have you told your wife your worries about ICD?

P: no, I've not told her. I just say 'you got this thing and you'll be fine' but I'm not comfortable that it will do its job.

I: that sounds like a strain on you

P: it comes in .. some months I go without even thinking about it. And then other times, I think well, especially if she feels unwell, you start thinking of it even more then. We did go down the hospital once because she thought that she'd had a shock and when you have your first shock, you're supposed to go down but as it turned out, she hadn't had a shock. But they had set the unit up to pace her so ... I don't know, it's like ... you can be thinking about it but then she's good with it, she dismisses it so then I think it helps me dismiss it. When she doesn't think about it, she doesn't dwell on it and to be honest what she went through, I wouldn't be the same. I'd be completely different.

I: are you more a worrier?

P: I worry about it more, I think than she does or she just keeps it well hidden.

I: but you don't tell her how you feel?

P: no, no. We don't really talk about it much in that way. It's like doing this study now, it was me that wanted to do it, not her ... I'm sort of an information gatherer, if something's happening, I'll want to find out everything we can about it, which I found pretty difficult when it come to this ICD ...

I: what kind of things did you want to know?

P: well everything, I wanted to know everything about her condition. I wanted to know about the unit, what it done but reading it, and when you're reading from multiple different sources, it's not the same as having it from a hospital or even a consultant telling you. Although I know they're busy people but they only have a certain amount of time to actually just quickly tell you something, whereas I think it would be far better if they sort of just sat you down and seen you afterwards about any concerns, which they don't . So, they just 'yeah, you got this unit now, you're all fine, on your way', in the way that they do it. I think five minutes of their time, a couple of months down the line will do a lot. (timing of info, cannot predict worries)

I: would that have to come from a consultant?

P: yes, I think it needs to come from a consultant not a nurse. Because they are the person ultimately decided that they needed this thing. I trust the EP, I believe what he says. I think .. she trusts the consultants more too than she trusts anybody-cos she had a few problems when she was in hospital as well ... I was on the phone to her and she actually collapsed and one of her things [heart monitor leads] was already off .. patches, was already off her ..

I: so they didn't pick it up

P: they didn't pick up the fact that the patch is off and she was sort of unconscious on the floor and I was on the phone to her and it must have been 30 secs, 45 seconds later she come back to the phone and said 'I think I just passed out'. And I said, well ring the buzzer on the bed, so she said 'I can't find the buzzer'. She was very disorientated so I said 'well pull the things off your chest' you know, to raise the alarm. Hopefully to alarm them, she wasn't in a ward see, she was in her own room so hopefully the alarm would go off. Then the phone went quiet, it all went quiet. Phone went dead. Then I had a phone call about 15, 20 minutes later off the doctor saying something had happened and um, and she's fine. But they moved her then from-I was on my way down anyway. They said 'there's no need' but I said, no I'm on my way down. So they moved her then from the ward she was on back up to ... not intensive care, the heart intensive care

I: coronary care?

P: coronary care, which is sort of the next one down from intensive care. Cos I know she was in intensive care and then they moved to that one. And the nurse there, the next day gave me a row, she said 'did you tell her to take the patches off the chest?' and I said yes, because she couldn't get to the alarm on the bed, she was trying to raise .. to get hold of somebody. And she said because of that it didn't record the information but whatever had happened had already happened. I said, this was after the event, not before ... But the reason they didn't record the information is that the patch was already off. Already the day before, i had already told the nurse twice while I was there, that her thing was off. ... When she was in hospital I didn't really feel comfortable, not so much when she was in the coronary place, cos they really looked after her there but when she went down to this ward and they put her in a side room, I thought well anything could happen to her in there and they don't even .... I know there was a big uproar about it and the doctor ... (wife) said the doctor, and I know one of the consultants had a head fit with all the nurses wondering what was going on. He said, 'I want to know why none of this information has been recorded'. Because something had happened afterwards, I was a bit ... you know, thinking, well is she going to be alright ..

I: so how are you in yourself now?

P: I'm fine. Yeah, I just get on with it really. I worry about her more than I do about me. I worry about my daughter as well, because she's so young, I do worry about (wife) being with her. Not all the time but ..

I: in what way?

P: if anything happens to her. If anything happens to (wife) and I got a three-year old

I: so you're talking about if anything happens like?

P: well (daughter) was there when it happened the first time, when she had the cardiac arrest. I just be worried about if anything happened to (wife) and the unit didn't go off or leaving a three year old on her own ... I know this sounds a bit ... but I do worry a bit about that

I: Has it made you see life differently?

P: completely. Absolutely, completely, definitely.

I: how has it affected your relationship?

P: um, I don't know ... not, not bad ... but um obviously .. my feelings-not my feelings towards her, cos my feelings haven't changed, they've got more if anything, but we have come a little bit distant at times. Not all the time but I don't know, it's hard to explain actually.

I: you say distant, emotionally or physically?

P: emotionally .. and physically. Physically more I think, first of all it was fear, not so much now. I know straight afterwards I was very worried about ... triggering it. But I still occasionally now like I said .. when she's sleeping or if I don't hear anything, hear a bump-if I hear a bump or anything like that it's 'are you alright?'

I: so if you heard a bump now, you'd fly up the stairs?

P: I'd fly up the stairs yes. It's strange, cos I know she's a bit-not clumsy but it wouldn't be the first time I'd heard a bump or bang but that day, i don't know what it was, I just heard that bump and I just knew there was something wrong. Which was lucky, lucky in a lot of ways .. it was unlucky to happen in the first place but lucky.. she'd literally only been in the house 10 minutes ... so she'd been walking my daughter home from playgroup, which is about half a mile away. So, if it had happened any of the time walking up here, the outcome would have been very different.

I; do you think about it a lot?

P: It does and it doesn't. When she played up coming from the hospital the second time, we got in the car and we were coming home and I said why do you need to come home, I can sort out any .. She said 'oh, I don't know what the bother is, I'm fine' she said 'you're with me'. Hold up I said, first time I said, you were lucky, I was there yes, the ambulance was very quick, but there's nothing to say that would happen again and I would be able to do that. I said, I'd prefer you to be in the hospital, cos you're safer in the hospital. It must have sounded terrible to her, more of a worry to her but because I saved her the first time, she thinks I can save her every time .... I can't be there, can't be there all the time and even if I was there, there's nothing to say I could do it a second time, especially when the consultant said it's only one in 20 people survive having a cardiac arrest like that. Because she wanted to leave hospital as well see, before she had the ICD

I: she didn't see a need for it?

P: she didn't see a need for it, she couldn't even understand why she was in hospital .. she was 'oh I'm fine now, I can go'. And the consultant he told her basically 'you're a very lucky girl and you can't leave until you have this'

I: was she happy to have it? Consent to having it?

P: That's very weird, cos she just went a long with whatever. She hasn't questioned it, which I found very, very strange ... It's as if she's denied even having it ... it's there, it's

I: has she tried to talk about it?

P: well, I've tried .. first of all she didn't want to talk about anything about the hospital at all, but then I'd be talking to somebody else and it would come up in conversation about (wife) and she'd say, 'I didn't know that, you haven't told me that'. But every time I brought it up, she'd make it not very easy to talk about.

I: why's that do you think?

P: I don't think she wants to know. I think she just prefers to keep it the way it is and don't want to know the ins and outs of it.

I: perhaps that's her way of coping

P: her way of coping, yeah, I think it is, which is why I haven't really pushed her with it. I'm the opposite, I like to know everything.

I: do you have any worries or concerns about the actual ICD?

P: only where she goes and what she does. Cos sometimes she forget that she's got this and I've had to-like we went to Asda's one day and she stopped and she talking to somebody in the doorway with these security things and I pushed her and said if you want to have a conversation, have a conversation over there'. But she do forget about these things. We went to a pub and they had a karaoke and they got these big speakers and I said you can't stand over there and she says 'why?' Her friend works in a magnet factory of all places and i said you can't go and see her at work and she says 'why?' and I say you can't go anywhere near magnets love. Of all the places for a friend to work mind, she works in a magnet factory.

I: so do you find yourself ...

P: feel more responsible yes. I'm constantly looking for stuff like that, but not consciously looking but automatically I do see things ..... (talks about holiday)... Gatwick wasn't as bad but still bad .. you still have to queue to go through it [security] even though I kept saying we can't, well, she can't go through it. Then they want to know why, the card .. well they don't take no notice, you have to justify why you can't go through it and it's bad enough having it without having to justify why you can't go through, they should do something about that. Before you even got there, so you could go to another desk, you know same as a disabled person. I know she's not disabled but .. it wouldn't be difficult if she [check in girl] put a tick here for a reason why you can't go through security.

I: is that a big issue?

P; that's the biggest issue we've had

I: how does it make you feel?

P: it's more I don't know what would happen if she did [go through security] ... You know, she's not supposed to go near speakers and that but why? What exactly would happen if she did?

I: so you'd find that information ..

P: yes, yes. And it's not information that I've been able to find. What exactly does happen then, does it switch the unit off ... because I know they can switch the unit off with a magnet. So, how do you know if it's not? Cos she doesn't know if it's working or it's not. I said they should put a light on it to show that it's working but that is a worry on my part, whether it actually is working. Cos you only know it's working, when you go for a check up and they tell you it's working.

And when she went for her 3-month check up they found a problem, well if anything had happened in that three months, the unit wouldn't have worked... or it might have been her 6-week check-up, then it went to three months, now she's on six months... But it is a worry for me, whether it is actually working or not....

I: how often do you think about that?

P: less so now. First it happened, all the time but less so now, especially now she's had a few checkups. It does get better, like the last check-up was the first check-up I didn't actually go with her ... that's cos she didn't tell me (laughs). Every check-up she's told me but the last one she didn't mention it.

I: why was that do you think?

P: oh she said, there's nothing to worry about, you're busy enough in the shop she said. That was her answer. So, I said, well I still like to know, so give me the choice of whether I come with you or not. But in her mind, she's probably thinking 'he'll feel compelled to come with me'.. but it was only a check-up and she's obviously feeling more comfortable.

I: does that make you feel more comfortable?

P: when she's more comfortable with it yes. The trouble with her, is that she doesn't take any notice of what's they're saying

I: is this new? Since the cardiac arrest or is this just her?

P: a bit of both actually. She doesn't take no notice of such anyway with things that are happening but more so with that. She could be in the room and she won't have a clue what they just said. I don't know, she just goes in there and switches off. And this is since the cardiac arrest. I know she had memory stuff and such when it first happened, it cracked me up, she had short-term memory loss and the first two or three days I was completely repeating myself every ten or 15 minutes. She was asking me where she was and I said she was in hospital and I said I'd have to repeat it ... I'd go for a cup of coffee and when I got back, she'd think I'd just come (laughing)

I: so you can laugh about it, could you laugh at the time

P: at the time no, because the thought that if she was going to be like that, that would crack me up because-actually it made me think more about people caring for people with Alzheimer's, because their life must be hell. And I only had it for a couple of days. But it makes you feel differently, because with Alzheimer's you think differently ... not so much for the person with the Alzheimer but for the people who are actually caring for them. Cos it must be very frustrating. Well it just done my head in and that was only a couple of days of it.

I: do you tell this to (wife)?

P: yes, we laugh about it, cos some of the things she done crack me up like her sister came in the morning, and had a break and come back and when she went she said 'huh, she bothered to come and see me then' and I thought 'she's been there all day!' So it's little things like that which made you laugh.

But lots of things, like when she had the cardiac arrest, one of the neighbours-cos (daughter) was with me and paramedics turned up and the first thing I grabbed (daughter) and run across the street to one of my neighbours. And we laugh because one the neighbours thought there was something wrong with me because I'd spend the last like seven minutes giving her chest compressions so I had sweat coming down me. I was in a right mess. And they thought there was something wrong with me, and she laughs about that as well.

I: that must have been awful

P: yeah, strange actually, you go on autopilot. I remember talking to the nurse in intensive care and she said, 'I don't know if I could do that to someone I know- to my partner', but to be honest, didn't even think of it. Didn't even think about it, just done it.

I: and you knew what to do?

P: funnily enough, I'd done a divers rescue course six months before so I done the CPR and everything but you still don't believe, at the time, you still don't believe that, that is what's with her. And I'd been taught in the CPR course to do all these things and ... has she fallen, she was wrapped around a chair as well so because of the bump I wasn't sure she hadn't fallen off the chair.

Talks about CPR

She was defibrillated three times, once upstairs, once in the ambulance and once in (hospital)
I probably shouldn't say this but I was talking to my neighbour, he works down accident and emergency at the (hospital) and he was talking to the paramedics and they said they didnt' think she'd make it

I: I can't imagine what that's like

P: no, it's not something I'd want to go through again. That's what the unit's there for

I; so where does this mistrust that it may not work come from?

P: It's not the unit that won't work, because she had a problem with the cable it's more a case of is the unit actually working ... because of that one problem you think ... you know, the cable is less likely to move now cos it's bedded in properly but it still makes you think 'is everything plugged in properly, is everything working, they test the unit when they put it in, but they don't test it fully, they just expect it to work. And I work in computers ... and they're expecting it to work but it doesn't always happen does it?

I: have you told your concerns to the doctor or nurses?

P: well you don't really get to see a doctor and whenever I see (arrhythmia nurse), (wife) is always with me .... I know the chances are the unit will work completely fine, but still there's this ... being an electronic device it can go wrong. The trouble is Medtronic were taken to court over their cables and this is the first thing that comes up when you put it in to search ... obviously that was a few years ago now but it makes you think, how do they know they got it right now?

The EP said to (wife) 'you will die of a cardiac arrest' but because of what happened I think is he just telling her that ... you know, is he just saying that to make her feel not so worried about having this unit .. which is why I think it would be nice if there was a follow up with a doctor .. you know, I've never seen him since. It's not a good thing cos any worries you have got, it's not the same coming off a nurse and not a doctor.

When you're told she has to have this ICD it's the first time that you've heard of this thing that she's having and any questions-well, you haven't got any questions, because you don't know anything about it. So, it would be nice just a couple of months down the line to just have time, with somebody-not somebody, the EP or a doctor. I'm not being nasty about the nurses, they are wonderful but like in intensive care, I asked one of the nurses what the difference was between a cardiac arrest and a heart attack and she said 'I thought they were the same thing'. And I said no, so she said she'd find out cos she was curious about it herself, I mean that's intensive care! And then she come back and explained the difference between them. And these are people looking after her [wife]... it doesn't fill you with confidence.

Talks at length about the NHS and its failings – very critical of his wife's experience in hospital

I; so you were relieved to get home were you?

P: I was relieved to get her from there yeah.

I: so what were the first few days like?

P: she just got with it ... she just wanted to carry on as normal

I: so she wanted to get back to normal, what about you?

P: well I know for the first week or two, I was afraid of leaving her at all... I remember the first day I went to work, I took her down my mother's cos I wouldn't leave her on her own but gradually that gets better and you think less of it really. But I know the first few weeks were bad, even to go the toilet I'd be shouting 'are you alright?'

I: ok, can I go back to something you said about the shock, you said you wouldn't like her to have a shock because of the long QT, what do you mean?

P: I'd rather she didn't have a shock, cos it means that something's not right that made her have a shock .... For starters the drug that she's on is supposed to control it anyway ... that's another thing that worries me, she lacks sometimes taking the drug ... she doesn't forget, she does it on purpose, which I don't understand

I: perhaps that's something you should tell arrhythmia nurse

P: I think I did and she (wife) said she hadn't taken it for three days and I just looked at her horrified. And I said well I wouldn't want to go through, resuscitating you cos you haven't taken your bloody tablets. I was annoyed, I was. But she said it made her tired and .. which is why we spoke to Arrhythmia nurse and they've halved her dose. But I give her a row and such and said you're being a bit selfish .. you've got a three year old. It's not for me, you got to take your tablets cos they could be keeping you alive. 'But I feel fine now' Uh! This is when 'you were fine for 28 years, it doesn't mean ...

I: do you think she is in denial or she really isn't concerned about it?

P: well if she is concerned about it, she doesn't't' say anything to me. I know the first sort of little niggle she had when she first had it, she'd say something. But I suppose if you got a foreign thing in your body, it's going to take time to get used to it anyway..... There's times I think she worries about it but doesn't say anything, you can tell sometimes with her mood ... you can see she's thinking of something

I: is that when you say you're a bit more distant?

P: yeah. I suppose it is yes, but for me, it's difficult for me to just bring that up because it's me that's always mentioning it-the unit so if she doesn't want to talk about it I don't force her ... it's a barrier, she doesn't want to talk about it so I don't force her to talk about it .... but then I don't think she's come to terms with having it in the first place. Or if she has, she's brilliant but I don't think that's the case. She just pretends it's there and carries on.

I: hopefully I will find out

P: hopefully, maybe she'll talk to you more than she'll talk to me.

I: yeah, I sometimes think maybe it's harder for the partner

P: yeah, because I've actually said to her 'you don't know anything about it', she was out, she don't know anything about it. When she woke up she was in hospital and she doesn't know about anything that's happened. I find that really strange, although it happened to her, the trauma's left with me. That might be why she is ... as far as she's concerned, she woke up in hospital, nothing really ... I did take a picture of her in hospital in intensive care and she was very shocked at that

Talks about his wife's memory again and gives a funny story about her and the EP.

P: because of her memory, she can't remember anything that they said to her so I'd go in and 'yeah fine' but she didn't know anything and I didn't know unless I asked which is why I think the partner should be there. I know it's difficult with their rounds and stuff but if he was coming to see her if I was there or even if the nurse said, oh the doctors been down today and he said this 'blah, blah, blah' and then cos of her memory thing, I could tell what's happening ... I'd just get there and be none the wiser.

I: how did it make you feel?

P: out of control actually. I'm used to our family life where I do and that and when she's in somewhere like that [hospital] I didn't have any control over what was happening. She's in somebody else's hands and you're trusting him to do the right thing, which as it happened we had a number of different problems with .... but I think the biggest thing that would help people is information, which is why I wanted to do this [study] because we had a lack of information. I know they give you a little book with an ICD explained ... but it doesn't tell you anything

I: so you'd like to have known things like why you should stay away from shop doorways

P: yes, cos they tell you mustn't do this and you must stay away from this but they don't tell you why and what would happen if you did ... And that is the biggest thing I think. If she goes through a shop doorway, does it switch off, does she drop to the floor, what?

I: and what else would you have like to have known? What do you think it would be helpful for partners to know

P: well giving you a little book about a unit that you're fitting in their body doesn't really tell you much ... I don't know exactly what information I'd want but the book didn't actually do it – it just explained what the unit is. It doesn't explain living with one and why she actually needs it. Not just that but with the Long QT syndrome there's not a lot of information about that which I think-cos the book they give you about arrhythmia covers a number of different subjects and you get confused then from one condition to another and then you read the whole book which is not relevant to you.

We've also got worries about (daughter), a lot of worries about (daughter), to think there's a 50% chance that (daughter) could have what (wife) has got. She had an ECG done (daughter) a couple of month later to see whether she had it Long QT syndrome and they said no, she's fine. And I said well tell me something cos when (wife) was in, the fortnight she was in, she had ECGs done every day and they were always abnormal but one day she had an ECG and they were absolutely fine .. and so I said, you're trying to tell me that (daughter) is fine, but (wife) had an ECG and it was also fine. So, (daughter) could just be on a lucky day.

I: what did they say?

P: well they said the only way to tell is a DNA test, which there's no funding for and I said well I'll pay for a DNA test, and they said you're not able to pay for it. And I thought what type of crazy place are we living in and I said well how much did it cost to keep wife in intensive care and all the stuff that we've had in hospital compared to doing an DNA test. It just doesn't make any sense to me, it's all backwards, they got a way of possibly preventing something with (daughter) ... but yet there's no funding for it ..... But we do worry about daughter, not so much now cos we know Long QT affects them in their early teens ... but I just can't understand this DNA, I really can't. It just doesn't make any sense whatsoever.... I think our biggest worry is (daughter) more than (wife)and hers too .. and it is annoying cos there is something they can actually do but they don't

I: has it affected how you treat your daughter?

P: no, no. Cos of her age we don't have to worry about that now, we've got 8 or 9 years yet before we have to start worrying about it.

Talks about the heart condition Long QT syndrome, cot death etc.

I: do you belong to any support groups or go to any talks?

P: no not really, because we don't talk about it. This study is the first thing we've done and it was because I wanted to do it. We don't go because she gives the impression that she doesn't need support ... And another concern is that once when (wife) for a check-up she was called down the next day, and that was only because the EP had looked at the test results and saw something was wrong so it makes you think, are they just printing results, do they know if something's wrong, it doesn't fill you with confidence ... . You know you say 'is everything fine' yeah everything's fine, then they call you back down after ... so everything wasn't fine ... it just doesn't give you confidence.

Transcript for S23
Female patient
Aged 55
Long QT Syndrome
I= Interviewer
EP = Electrophysiologist
ANS = Arrhythmia Nurse Specialist
P= participant

I: So how long have you had your ICD for?

P: Um I got to think now, I think three years it's coming up ... maybe 2, I don't keep track.

I: right .... how many shocks have you had?

P: just one and that was in January (month previous) yeah.

I: well, first of all I usually ask people why they've got an ICD .. have you got an ICD or a CRT-D?

P: I've got a pacemaker and a defibrillator. I've got long QT syndrome and it was discovered after a series of collapses, and they said if I did not have it obviously I could just drop dead, so that's why I've had one put in

I: so it was identified when you were an adult?

P: yes, it's only been identified a few years ago. I was fine up until that point . But I was on holiday in China of all places, when I collapsed on three consecutive days. And on the third day they took me to hospital. They said they had a problem with my heart that they couldn't fix but I'd have to have it looked at when I came home. When I came back, the doctor seemed to think I'd had some kind of fit. And he sent me to see a specialist for fits, who said no, you need to see a heart specialist. So it took some time to diagnose it cos I went to a heart specialist who dealt with the pipes rather than the electricity part of the heart. He told me there was nothing wrong with me at all but transferred me when I said 'look I know there is, cos I've collapsed again, there's got to be something'. Then he said, he'll send me to the EP. So as soon as I saw him he knew what was wrong. And I had a week long, where they put a monitor on your heart? And I took that back on the Friday, they looked at it on the Monday and told me I had to go straight in.

And he said 'do you know why I've called you in?' and I said no. And he said 'cos you could drop dead at any moment'.

I: and what that like to hear that?

P: it was really shocking, you know 'cos he was so blunt. So that made me afraid then. And he said I had to have this pacemaker and defibrillator and I was relieved then to think well at least that would sort it out.

I: so he told you that before you were going to have it. He didn't' send you home? Kept you in? So up until then, when you fainted before, you didn't think it was that serious?

P: No, no I didn't, cos I was in China and I thought maybe, maybe it was a busy schedule cos we travelled all over China and we'd had three or four flights as well so that was the first one. Then the second one (faint) I did start to get a bit worried and the third time I was sat on a plane going to Tibet and collapsed in the chair. And because I was sat up, the lack of oxygen imitated a fit because I wasn't able to lie down. And I had what they thought was a fit so why they initially sent me to see that specialist. But I got off the plane, they took me to a Chinese hospital and they did lots of tests, but they didn't recognise Long QT. They recognised that I had arrhythmia but when I told the doctor at home - I brought all my medical notes back with me - and give my doctor the notes and I said they think I got arrhythmia and she said, oh we'll ignore all, we'll do our own tests. And she sent me to see a specialist about fits

I: so you said you were in shock, you were frightened ..

P: yes I was ... initially the only way I could cope was thinking 'he got it wrong, it couldn't be that', i'd better have this (ICD) just in case because he said but it was disbelief really. And that's how I coped .. I feel upset ... (participant begins to cry)

I: you stop whenever you want ... do you want a tissue (Participant is up and looking for a tissue)
Is it bringing it all back? .... do you get a chance to talk about it?

P: i'm sorry .... yeah it were a shock but that was the only way I could deal with it. I think it would have been better if they'd had some sort of patient who'd been through it – cos I'd never heard of it before. It was only when I looked on the internet, I realised how bad it was cos when he first said, you got Long QT, I thought great, you can sort me out and I'll be on my way. You know I didn't realise exactly what it was.

I; so you started to find out about it did you?

P: yeah ... (Participants sobs)

I: are you ok? Have you talked about it with anyone before ... no ..

P: i'll be alright now.... (blows her nose) ... didn't think I'd get upset

I: what do you think is making you so upset?

P: I don't know. I think at the time, I kept it down and then it keeps popping up .. the shock of it I think

I: the shock of ..

P: him telling me .. of realising my family might have it, my children, my grandchildren so I coped alright by thinking, he might- he probably got this wrong , cos it made it easier.

I: how long did you cope like that?

P: oh I just kept it going cos it was easier. And if anybody asked I'd say 'oh well' you know, just get on with it, i'll be alright. But I think if there had been somebody there, like me now, who could go and sit, you know 'it's ok, you can live with this' and it'll be alright. And it's not, cos they said we're just going to pop this in (ICD) but you need somebody to tell you who's actually been through it I think. For them to say, well yeah you will get a bit of discomfort or you know, you will feel upset or nervous doing a lot things

I: is that how you felt?

P: I was in hospital waiting to have it done, cos you have it done and come out the next day, so I was in about a fortnight I think. And then when I went back for my follow up the nurse-you know my daughter came with me because she was going to be tested and my husband was there. And they said (to me) are you alright about it? But you don't actually want to say how you really feel, cos they are worried enough as it is. And like I went to the clinic this week about my arrhythmia and I said to (husband), 'you stay over there now, I won't be long'. And she said (ANS) 'oh come in, come in'. And sometimes I think you know, you want to be on your own cos you don't want to worry them. With what you would think oh it's silly to think that.

I: that's a very good point

P: you know they got their own worries, so you got to feel 'oh don't worry, everything's going to be ok'. I didn't want my daughter-my daughter has got it, so I didn't want her worrying about it. So, it was 'oh look at me, I'm doing fine, it hasn't affected me really and if comes to you (ICD) you'll be the same'

I: so you're kind of putting on a front the whole time

P: yeah, yeah.

I: is that why you're so upset now? ... (participant crying again) .. I guess it's hard trying to protect everyone

P: (sobbing) yeah, I thought about this this morning .. I'm alright. I think it's important that you're on your own to talk about things.

I: yes that's why we interview separately

P: yes, I was hoping you would. You would get a different story if they were sitting there cos you don't want them to know how worried you are about it. And there are still questions I'd like to ask but I feel silly about it ... Because you know, I don't know like I've hardly driven since I had it done.

I: why not?

P: because I got this fear, cos it comes so sudden. How will I manage if I'm driving and then it goes off, you've only got like a 20 second warning or something. You feel very-only once it's gone off mind. You just feel extremely dizzy, you know that was me and you can feel it revving up in your shoulder and then bang- you know it felt like somebody had hit you with a hammer. How would I cope driving? So I'm very nervous about driving. I've driven for a number of years, and you know, driven a lot of places but I just don't feel confident enough.

I: what was the shock like? Was it how you expected?

P: Yeah, I did think about what it would be like cos there was a man in (town), my daughter's friend' husband, he had it and he'd had a couple of shocks, but men are like 'oh don't worry it'll be alright.2 He said 'when I had it, being at its worst, it's really knocking me around the place'. I was like horrified, you see, you need to speak to someone who's sensible, who's perhaps had a shock and I expect everybody to be different but you know, it would give you some sense of expectation. But when it happened-I thought I'd lose consciousness just before it went off or something you know, but it worked like that. And it just felt like I'd been hit on the head with a hammer. Literally. And I felt scared.

I: that was your first feeling – did you realise it was that?

P: yeah, well no. First of all, I didn't know what had happened. I couldn't work out what it was, cos it had never happened before. I was like 'what was that??' I just felt stunned but then I thought it got to be my defib-defibrillator. And then I felt frightened that something else was going to happen. 'Why did that go off now?' 'Did my heart stop?'

I: that's what you were thinking was it?

P: yeah.

I: what did you do?

P: I just said to my husband ' you better phone for an ambulance'.
And I just went in to have it checked. (participant starts crying again)

I: it's ok, you've been through an awful lot. Do you want to stop?

P: usually, I just get on with things you know. But I think it's quite
shocking . It is a lot-I think somebody needs to explain more in
detail to you. 'Don't worry this'll go off, that'll happen, you'll be
fine', you got any worries, just ring her. You know they try and
reassure you but you need a bit more in-depth conversation on your
own, not with your partner or children or whoever you're with.
Because it's just silly things you want to know about – sex for
instance. You know, this records everything that happens you know.
How much does it record you know. How do you go and ask that
with your daughter sat there, you know?

I: so it that part of your marriage resumed?

I: back to normal?

P: yeah, yeah. Back to normal, yeah it's fine. But there's other
questions you want to ask, so I think it's really important that time is
set aside for just you.

I: so you'd find it helpful if you could have a chat with ANS on your
own?

P: not now, I'm alright now. C-cos I've rung her a couple of times cos
I've had problems with arrhythmia and they're 'oh don't worry, you
can't die, you got a defibrillator.' But it's not the worry about dying,
it's the coping with ...

I: coping with?

P: um .. going out and you think it's all going to go wrong
(participant bursts into tears again)

I: right, ok, ok. Do you want to stop?

P: I feel silly for feeling like that (sobbing)

I: it's ok, many patients have cried when they didn't they would

P: I thought it had all gone. Taking part in this interview I thought I'd
be honest ... but I don't think I thought I'd be this upset

I: have you been thinking about the interview?

P: no, I thought if I'm going to take part, just be honest about the way it was and it will help somebody else in that position. I didn't think I'd get so emotional (sobbing)

I: what's stopped you from telling your husband how you're feeling?

P: I just think they got enough on their plates just seeing me like this. You know, like none of them will leave me on my own. I can't go anywhere on my own. 'You can't go, you can't go on your own'. I mean my daughter, she lives in the street and my son and they'll say 'and where's 'husband'?' – he's their step-father, and they'll say 'where's 'husband' then, what's he doing leaving you on your own?' So, you've lost your independence as well (sobbing more)

I: how does that make you feel, the fact they won't leave you on your own?

P: I'm not an invalid but it makes me feel like that. And it makes me feel- and I feel embarrassed- but I think a lot about dying. Which I've never thought about before. I'm not scared to die because I believe in afterlife and all that so I'm not scared. But it makes me think a lot about it like.

I: what in particular makes you think about dying?

P: I can't get over the fact that this (ICD) is just there as a standby, it's like a marker to say 'right, you're nearing the end of your time'

I: that's how you see it, is it?

P: um ... yep. At first it was funny looking back on it .. (inaudible) well coming through it, I feel I'm on my last legs now and I thought, I wonder how long I'll last now. Cos it's such a shock as well. On the same hand I'm saying I might be wrong and then two weeks after it came on, they sent me an appointment for a year's time. And I was thinking 'what are they doing, sending me a card for a year's time?' And then I thought, if he thinks-the specialist-if he thinks I'm still going to be here in a year's time, then I probably will be. But you need to be told that. You need to be told this isn't an end, it's a new beginning for you. This is a safety net.

I: but is wasn't put across like that?

P: Well I dunno. Perhaps my way of coping, cos everybody copes differently don't they. I was very quite blasé and all- people were saying 'how you coping with this? Shocking news? 'Ooh don't worry, I'm alright, take it as it comes .... 'Get on with it, that's what everybody got to do'. But inside I was quite scared. And I kept saying 'well, it's just as well that they found out that I've got it, so I can make sure my children and my grandchildren are alright. And that was a sort of compensation thing for me. You know, they'd be ok, despite everything. But it's-it's a bumpy ride (big sniff)

I: so, what's made you actually think like this? Is it worse since you had a shock?

P: No.

I: it's not?

P: no.

I: has it made any difference?

P: No, not really. You know I think it was the initial of having it all done was the worst you know. And realising it was something serious. It wasn't as if I'd ever been ill. I've had Crones ... I just think it's a case of 'oh God, it's my heart', you know ...

I: so how do you cope now then?

P: I tend to just get on with it. It's been worrying me since Christmas, cos the arrhythmia been playing me up and then of course this went off so it has made me a bit nervous 'oh god I can feel my heart-I'm very aware of it as well, my heart rhythm. So when it goes, I think 'oh here we go, something bloody else' you know how it is, but I still just try to get on with it. It's always that niggling thought

I: do you ever forget it?

P: yeah, yeah I do. I don't walk around conscious of it ... it's just when I feel my heart starting to beat faster, cos I got this arrhythmia thing, but er .. it's a constant reminder then but apart from that I just get on with, forget about it's there. Cos you can't feel it in there. I can't sleep on my side as I always did but I've learnt to sleep on my back, cos I can't sleep on my side

I: can you sleep on your other side?

P: no, cos then it feels as if it moves and if I sleep there I can feel it poking me and if I turn on that side, I can feel it moving out like that, if you see what I mean, cos it does. ... Some days, it's under my arm and then other days, I can feel it up here. Like today, it's tucked in under my arm and then other days, I can feel it there [points to chest] you know. So, it moves around. That's another thing that worries me as well. I mean I'm used to it now, but initially I was like 'how's it moving?' If it moves, will it move the wire in my heart? You know? So, you know they say you got to be careful not to raise your arm and all that for the first six weeks. And when I said why, they said cos the wire could pierce your heart .. Well that's a massive worry isn't it?

I: is that what they said?

P: yeah. They said don't put your arms up above your head ... I'm sure it was ANS or one of them. They said you got to keep left arm down. Cos I even went as far as to sow my sleeve on my pyjamas cos I sleep like that [puts arm above head] naturally, you know. Is that right then? And I'm sure I read it one of the books as well.

I: well I know you're not supposed to cos the wires are trying to 'bed' so you're giving it time to bed. But to say it would pierce your heart ...

P: maybe I got that wrong. May be it was when EP said 'when we put the wire in, there's a chance we could pierce your heart'... so yeah. Maybe I got that mixed up now, now you've said it. So yeah, maybe I got that mixed up. But yeah, it is a worry about it moving. And I think-cos they renew it every five years don't they?

I: five to seven years

P: is it five to seven years?

I: yeah they just take the box out, and put a new one in. How do you feel about that?

P: I don't mind that, no, no. I'm not a baby when it comes to having stuff done, I can manage all that. Because I've been there over the years with crones, I've had to put up with loads of different bits ...

I: so it wasn't the medical procedure, it was the meaning behind it?

P: yeah, yeah .... yeah

I: and you were saying you've not been out on your own since?

P: no, no

I: and would you like to?

P: I'm 50/ 50 now. Because (participant starts crying again). I've always been supported by someone, you get to the point where ..(sobbing) ...

I: I guess you can used to that?

P: yes, and I was so very independent, you know. Cos my husband worked away, he was only home weekends anyway

I: I see, so you were in charge Monday to Friday

P: yeah. I'd be out and about, and I'd drive up to London where he was working you know, so it was like .. then suddenly nothing

I: so was that until your ICD? Up until that point that's how you were living were you? And then after your ICD ....

P: yeah, cos he retired after and we went to China as our big holiday .. you know, from his retirement. And then things changed then, it was a year after mind. So, I just carried on as normal. And then I had my ICD and then everything changed after that

I: what other things have changed?

P: I've put on loads of weight because I'm not as active as I was. I don't smoke, I don't drink. We don't go anywhere really much .. to the pub, cos that's not my thing

I: did you smoke before the ICD?

P: I did smoke years ago, I gave up mind.

I: you've never drank alcohol?

P: no, I've never been interested in ... just one of those things you know

I: so you just stopped being as active?

P: yeah. I mean, we used to go out every weekend and we stopped doing that

I: why did you stop doing that?

P: well I had a problem with arrhythmia as well, about walking very far .. breathless, so it's a big effort you know. Sometimes it's climbing the stairs is difficult, cos I have put on weight. And my heart beat was racing on and off. It was very unstable for about a year. So, it was like oh it was too much effort. And then I'd start worrying about 'would I be breathless, would I feel embarrassed you know.

I: how does that feel? I assume that's when it's pacing is it?

P: no, the arrhythmia is um, well you know what arrhythmia is don't you. If it drops under 70 now, it was 60 before. If it drops under 60 it will just kick in and .. but my heartbeat was raising all the time and I was aware of that, like a racing heart beat . And it comes in sessions, like if it started we could be just sat doing nothing and it would start and um, I've forgotten what I was saying now .. oh yeah, it would start and it would just last for hours. And that was worrying me as well, 'why is that doing that now?' So, it has made me worried I suppose

I: so when it does start, and you can feel your heart racing, what do you do?

P: Well, I just sit down then and try and take things a bit easier. I spoke to the nurse about it this week. Because some of the doctors said if you feel it racing 'just sit down and take it easy'. Then others have said 'just carry on as normal' and some have said and somebody else, Dr EP said 'if you fiddle with the vein in your neck and all that, it'll interrupt the rhythm. Oh I don't know, I said 'they said all this to me' she said 'just carry on as normal' so I have been trying to just get on with it.

I: so you feel that you're trying to ignore it?

P: yeah, yeah.

I: is it working .. you know, that coping strategy

P: yeah, well it's only this week that I've not thought 'oh God' cos you do get a rhythm and you think 'oh god, what's going on?'

I: are you waiting for something to happen?

P: I think it was starting to worry me about going out. Like I was in 'supermarket' a couple of weeks back and I felt that dizzy, I had to come home, leave the shop (crying) and come home. And then you get to the stage when you think 'oh god, well I better not go'.

I: what do you think the dizzy spell was then?

P: I dunno, it wasn't a panic attack cos I'm not a panicer . I'm quite practical even though I coped initially by thinking 'he must have this wrong now', you know. Sort of you know, trying to smooth it over, (sobbing)
I: so what happened in 'supermarket'? Do you want to tell me about it?

P: I was just walking around and suddenly the room started spinning and I stopped and normally I just take a few deep breaths and then carry on, but I just couldn't. Every time I tried to do that it was spinning even more.

I: do you know what triggered it?

P: no, they said it was probably a drop in blood pressure, so I don't know. I haven't had it like that since. That was the first one.

I: and your reaction was to come home. And how did you feel when you got home?

P: (sobbing) I felt upset. Cos I don't go anywhere anyway. I don't know why I'm being so upset, I think it's cos I haven't spoken to anybody about it before (big sniff)

I: you haven't spoken to anyone at all?

P: No, I'm quite a shy person really ... I wouldn't want to. I wouldn't mind a one to one. You know, with someone who knows how I feel

I: can I tell ANS that you'd like to speak to someone, one to one?

P: no, it's a bit too late now. I think initially it would have been fine

I: you sure you wouldn't just like to talk about how you feel to someone?

P: no, no, I got over the worst of feeling like that. I think it's just by saying it out loud now, I feel quite upset about it.

I: and you don't want to talk about it with your kids. And you say your daughter has got it?

P: yeah she's got it, she's on beta blockers at the moment and they're keeping an eye on her. And everybody else, they've been ok.

I: do you know where you got yours from?

P: no, but I think I've worked it out. I got it from my mother, she was 62 when she died. She had heart problems coming up to her death. And they said it was .. um, I can't think of it now. She had like an uneven heartbeat, they didn't recognise it as Long QT. And her brother had died, he was in his 30s. And they had found him on the road in the morning and he was walking home from the pub. You know and he died and someone discovered him. And they thought maybe he'd been sick and choked or something. But then because he'd died so young, we'd lost contact with-he'd had two children. And his son died in his 40s and he had heart problems but they didn't recognised Long QT with him. And his daughter had died as well. So it must be on my mother's side, you know.

I: and how does that make you feel?

P: It's just pot luck. You get whatever you know, it's one of them things. But my only concern is my kids haven't got it, that's the main thing, but my daughter has. But at least they can monitor her. I've got five grandchildren and so far, so good. That was my main concern, the kids and the grandchildren. My sister now, her children hasn't got any .. children if you know what I mean

I: your sister?

P: my sister, they don't think she's got it but they're unsure. So they did put her daughter on beta blockers but they're still not sure whether she's got it or not. But then they're worried about having children. I mean it's too late for ours, they've all got kids

I: do you think it's a reason to not have kids?

P: I don't but she does think it would be ... because it's something they can sort out now. It's not like you're going to drop on the spot ... it's not like it's like the very devastating and debilitating things is it?

I: like Huntington's?

P: yeah like that, you wouldn't want to pass that on

I: so have there been any benefits to you with this ICD?

P: well it's reassuring to know if I do have a heart attack or something that you wouldn't have to run for a defibrillator but I think that's the only benefit

I: and the disadvantages have been quite profound

P: yeah, yeah, yes I think so. Yet it saved my life you know. But it's also changed things (cries) .. sorry. I feel silly for feeling upset

I: no, you didn't think you'd feel this upset did you?

P: no

I: is there anything in particular that's made you upset? Any thought you've tried not to think of

P: I tried to keep it down you know. Thinking 'don't worry about it'. You can't live your life worrying all the time but then to say it out loud makes it more real then ... But I don't want to talk to anybody else

I: you don't want to

P: no, I think oh I managed this long now

I: what about if ANS came to see you?

P: no, no .... you tend to keep it all in then

I: is that because you're a private person or protect people?

P: half and half, I don't want my family to know how upset I am about it, because I think they got enough to deal with, watching me you know.

I: don't you think they would like to be able to help you?

P: no, I don't no. But I think initially if I'd had the chance perhaps, with there being such a strong feeling about it, I might have better to have let it all blurt out initially rather than hold it all in now. It's just the way I am. I coped by thinking, well they might be wrong, knowing in my heart of hearts I knew it wasn't but that was my way of coping.

I: so how else has your life changed? You said you've lost your independence?

P: my confidence, it's knocked my confidence. And I can't have-like I got a grandchild who's only two and a half and like I've always had the kids for my son to work. And I had the kids for my daughter to work and now this new one that came along just about the time when this all happened. And I can't manage him. I can't get up and run around with him. And so I feel disappointed I can't support her with the baby. Like I have with everybody else. So, that is disappointing and before we've always travelled a lot you know. And we've been all over the world, and I would like to go to Israel but I don't feel confident enough to go. I think what would happen if I was ill over there or .. So I has stopped our plans for travelling the long haul now husband is retired sort of thing. And we had saved for that, you know so we could go on all these exciting holidays that were too long to go on when he was working.

I: what do you think could go wrong in Israel?

P: what if I died in Israel? You know I have said to him 'what if I become ill?' but that is the main reason. If I went abroad on holidays, what if something really drastic happened, while I was out there you know? I know I wouldn't know anything about it, and it'd be somebody else's problem but I just don't feel confident enough to go.

I: so you don't think the ICD is a lifesaver then?

P: no, I don't think I do really. You know, I know it's there like a safe-guard but I still got Long QT and I know it only affects you by stopping your heart or whatever but I don't know. I think it's because I've had arrhythmia as well and it's made me worry about having an unstable heart, which is the main ingredient for life isn't it? So, it has affected my confidence and our plans and what we were going to do and my ability to help the family. So things have changed a lot.

I: you still spend time with your grandchildren.

P; oh yes, of course but I can't run round with him. And I always had the kids over night. I have the big ones over night, cos they're big, it's easier but I'd have the baby over night, to give them a break. And if we were going anywhere, we'd take them with us. To help out and what have you and I was very grandchild orientated you know. You know what I mean? I'd try and help then cos it's hard work when you got little ones and you do need that break. And I'd try and give them that break so life was easier for them. But now she's got one of those jobs who's really busy and I can't have the baby for her. We take him out shopping with us but then the other day when I thought I was going to faint in 'supermarket', he said- he always insist on bringing the baby and he said 'what if we'd brought the baby?' And I said oh yeah (big sniff), but we still take him anyway.... I mean we still go out to supermarkets and we went to the beach on days out but I still worry

I: so it's affected you as a mother and grandmother, what about being a wife?

P: We've swapped roles. I always did everything, you know he didn't even know how to switch on the washing machine. But now he does a lot of cleaning with me. I do what I can but I can't mop the floor or you know-it makes me very tired to do stuff like that. So he does a lot of cleaning and he learned to cook more. So it's sort of-we've split the role, if I can't do it, he'll do it. So it has changed. So the dynamics of the family has changed-he's looking after me more whereas I'd always looked after him. And he never did anything, not cleaning or whatever. It was the old fashioned, he worked and I did everything. But that's sort of changed now and that's ok. And he's very good 'you've always looked after me, it's my turn now to look after you'. So you know that's fine. So that doesn't bother me much, we just get on with it. Luckily he's very practical, he's a bit older than me. And erm, he's just gone along with it. Easy going sort, that's ok.

I: Are you ok? (patient looks about the cry again)

P: yeah, fine, I'll be alright now. Is that it now?

I: yes unless there's anything you'd like to say?

P: well no but just that if they ask you if you're ok, you need to be on your own. Even this last week when I went down, I had to fill in a questionnaire and she said to him 'come on in, you're alright' and he was sitting there watching what I was ticking in and whatever ... so that's it really. You need privacy. And they got enough to worry about, you don't want to worry them.

(husband walks in)

Transcript for S01.1.
Female aged 66.
Husband has ICD for Primary prevention
In line with ethics, the Participant's Name has been changed to 'Liz'. 'I' stands for the interviewer.

I: So it's your husband who's got the defibrillator.

Liz: yes, yes

I: How did you feel when the doctor said, or when you realised that he had to have a defibrillator?

Liz: um .. I think we were relieved that at last they had found out what was the matter.

I: Right? So, you felt relief.

Liz: Yes

I: Ok, so for you what are the advantages of your husband having it?

Liz: well, the symptoms that he had before have gone away.

I: Right ...

Liz: erm ....

I: what were they?

Liz: he kept um ... he kept er... not passing out, but I mean it got worse towards the end when he was taken into hospital in May. He'd had .. he'd got a monitor on ... to um, to try because he'd kept going to see the specialist because they knew he had atrial fibrillation ...

I: right ...

Liz: But and we'd gone back a few times to the specialist, so you know we were paying for that .. which was getting a little bit worrying because ... anyway, they didn't come up with ... they didn't seem to realise that these um .. um .. episodes that he was having ... they thought that it was possibly anxiety or .. they didn't come up with .. you know, what's the word .. the diagnosis really ... so, I'm um .. so I feel quite strongly ... you know initially didn't have .. you know .. a diagnosis of what it was ... so um ... in April, May he kept having a lot of um .. times when he would just fall over .. you know um ...

I: right ...

Liz: so, err, it was only when he was fitted with this .. thankfully he had this monitor on for 48 hours and in that first 20 ... because he had had a monitor on before and to be fair to them nothing had come on those but .. at that time, a few years, he was only having them occasionally .. you know having had the atrial fibrillation diagnosed. So, err ... err ... at the point ... luckily as I said, having it on for 48 hours, luckily in that first 24 hours he had a few really bad .. because it was getting worse, passing out all the time ... so err ... they were able to ... um ... you know, take away and realise and he went straight into hospital then. And was on a ... you know ... completely monitored the whole time until they um ... actually fitted the pacemaker ...

I: so, he's got atrial fibrillation?

Liz: He's got atrial fibrillation. And then now he's got um ... ventricular tachycardia

I: right ...

Liz: .. is what he was diagnosed with. So, um ... luckily he's got a healthy heart ... yes, well it's the electrics that ... he had no clogging, his arteries were ....

I: right ...

Liz: ... didn't have any problem. And you know, we walk a lot, he plays golf and never had any problem with breathlessness or anything, anything like that, so maybe it was ... maybe I'm being hard on them the doctors, maybe it was difficult to diagnose .. I don't know, but anyway ....

I: so, how are you feeling about that episode? Are you feeling ..

Liz: What? What episode?

I: when he was trying to get a diagnosis?

Liz: Well, it was quite worrying. Because I went with him one appointment ... um ... I can remember saying to the doctor, 'well you know, he's having ... what do I do when he does this?' It wasn't, ... it was a worrying experience, very worrying, so it was really 'oh he'll be fine, he'll be fine'. I mean bearing in mind they didn't diagnose what he had .. so in fact, looking back saying 'he'll be fine, he'll be fine, just leave him ' was not a very, err .. well in hindsight you know ... if you look back on things you know ... but we didn't know and I was told you know, it wasn't a problem. You know 'let him relax, he'll be alright after a while'. So, it was ... looking back on it, I'm probably more angry about it now, I mean it was very concerning every time it happened because it wasn't a nice experience.

I: So, how long has he had it fitted?

Liz: he had it fitted in June ... since then he's been absolutely fine .. you know other than the once it went off ... so, erm ... it's doing its job, it's stopping it from ... it's based at 40 and 200

I: ok, do you know what that means?

Liz: well, its ... well I believe its ... err ... the 200 is the beats that its going, you know if it's going too fast, if it goes over the 200 ... and 40, its too .. if it goes below 40 it's probably too low and I think , you know, that's as far as I ...

I: ok

Liz: I mean I can understand what .. what it's doing .. It's allowing ...

I: and are you conscious of those limits each day like when you go for a walk?

Liz: no, no ... I mean I .. I .. I .. bearing in mind that I've been concerned for a long time and you when he was getting ... before he was diagnosed with this in June ... before then ... so, I have been concerned for a number of years that something might happen. I mean .. I .. I .. I used to know sometimes I'd see him .. so if he stood like this (puts shoulders and head down) then I would ... you know .. begin to worry that something was occurring so ... so, I suppose erm, .. so I used to worry and I probably still worry at the moment that something is going to go ... so ...

I: so, what are your worries about at the moment?

Liz: erm ... well I suppose I worry that the thing's not going to work. You know, I don't think my worries are valid worries because ..

I: but they are worrries ...

Liz: but you know ... I mean, it's just something you ... you know ... you just erm ... so along with really ... I think it's erm ...

I: your husband has had a shock?

Liz: He's had a shock yes.

I: and how did that make you feel?

Liz: Erm ... cross initially, erm ... you know, flipping heck, that's another six-months he's not going to be able to – to drive ... erm ... but in fact erm ... it didn't ... you know ... when we rang up ... I wasn't worried because he was .. he was fine

I: ok?

Liz: so, I mean, I think we were both shocked by it ... and erm ....

I: Do you remember what he was doing at the time?

Liz: yes, yes, we were ... we were in bed at the time so erm ... it was at that ... so it ... so actually because we were lying down it was ... I mean, I'm sure if you speak to him ... he seemed utterly fine to me. Now whether he was being fine to me ... you know whether he was putting on an act ... But nevertheless, we didn't have to ... you know ... I didn't have to go and get him cups of sweet tea or anything, which was something that was said you had to do ... I think we were both shocked and cross that it had happened. But as they've said .. that's something that ... I for the life of me I can't think what the word is they used for it ... but it's ok, that's an ok thing to have

I: an appropriate one?

Liz: appropriate, right. I was an appropriate .. because we were away and he went in to have it looked at as he's obviously got to and erm ... so before, it would have been four weeks but that four weeks is in this ... was in this ... 13th December ... that's in that fall, it's about 3 weeks ago so it's fine. So, it obviously works ...

I: does that help? Does that help you?

Liz: Well yes, I suppose it's .. it's um ...

I: But you say still you're worried?

Liz: yes, I think that's just something I've got to ... you know, I've been worried for such a while and worried not about him having a pacemaker but worried about these funny turns he was having. So, err .. you know ... I think when you've been doing that for a few years, it takes a little while to erm .. probably calm down about it.

I: right ...

Liz: you know, I don't go around standing behind him and you know, doing anything stupid like that but erm, he can still go like that (hunches over) and I will .. I will think 'oh gosh!' because that's something that I'm used to being aware of.

I: So, how do you feel like about leaving him .. for half a day?

Liz: Oh, I'm erm ... I mean initially, I wasn't quite sure what was expected of us, ...

I: of you ... of you as a couple?

Liz: yes, I didn't know whether I was supposed to be with him 24-7 ..

I: right?

Liz: but obviously, I don't have to be with him 24-7. He goes and does his thing and I go and I go and do mine. I erm ... erm .. I suppose initially that's something you might worry about. Well you do worry, you think right ... but erm ... erm ... No, it's just you know, it's just carry on life as normal really.

I: Ok, so apart from the driving that your husband can't do, has life returned to normality?

Liz: yes, yes, I mean the driving is a big thing ... cos he's reliant on me to ...

I: was your husband working?

Liz: Well, we were working .. we've got our own business, erm .... I mean obviously we're at retirement age anyway ... we were trying to get out ... we're in manufacturing so, .. that's been a constant worry ... but my son is involved with the business ... so ... as it's happened erm ... I think ... I think we've seen how they're getting on with it.

I: You're overseeing it?

Liz: Yes, we'll just see what happens.

I: so, as regards everyday activities, you carry on as you have done?

Liz: Yes, yes ... you know the initial ... probably the couple of weeks after he had it fitted ... you know I wasn't sure whether I should be with him all the time or not ...

I: So, is that something you'd like clarified?

Liz: Well, yes, they do .. they do ... I mean I have to say the erm ... erm ... the ... the ... the nurses .. what do you call them ?

I: the ICD nurse specialist?

Liz: yes, they're very, they're very good ... erm ... but I do think they give them so many books to read that its ... and books make it , for me, more worrying, because there's too much information ... and I just found there was too much information. Probably because everyone is so different, they like to put everything, you know they have to put everything into these booklets.

I: So, what would you like to have had?

Liz: I think just more simplified ..but then I don't know that ... you know that's unfair if there are so many different areas that ... every patient can have a different erm ... you know .. problem. And of course, we're all different anyway. Some people will love to be reading this book .. you know ... whereas I'm a very sort of ... you know 'let's just see' (she makes three claps as though to emphasise life goes on). And you know, ... I mean if it's just the simple things that erm ...erm ... I mean you are worried, you do worry to start with so you know .... but this is something different.

I: did the literature calm your worries?

Liz: well sometimes, but sometimes it was 'oh gosh, what does that mean?' And don't ask me to say an example, cos I've not looked at a book ... one of those booklets ... they've gone away.

I: You've put them away have you?

Liz: Oh yes, I've put them ... I don't wish ... you know, I don't see the point in ... I could be wrong ... you know someone could say 'you should ...', but no, I don't think so erm ... erm ... we're getting on with our life. He has been told, you know, he's to carry on .. as normal. So, if there is something he shouldn't do or can't do, we would be told. You know so that's ... you know, that's my feeling that we just carry on, that that was a blip then and hopefully ... I don't know what the future holds do I?

I: None of us do ...

Liz: none of us do.

I: So, the activity that you were doing when your husband had a shock, would that stop you from...

Liz: erm, it might do (laughs) simply because it would ... I mean we're an older couple, we're not a young couple. So, a young couple, it would be more erm ... I suppose it might ... it might concern a younger couple more than it would concern ...

I: But it would stop you from ...

Liz: Well, we've refrained from it for the moment so that was probably about three weeks ago now so ... I think know he had to stop four weeks driving again, might stop Tony (name of husband has been changed) now ... I don't know ... you know .. we've sort of laughed about it and erm ... you know.. that's where it's stayed at the moment .... But it could alter a young couple's

I: But you're saying it's more the inconvenience of not being able to drive and not the shock?

Liz: yes, I think so. Actually, it's quite nice, well not nice ... we'v e got over ... we've got that over with ... it's happened, I mean he had one so I know ... I know ... I was quite close to him and I felt it and erm ... that's fine that's ... I say it's fine, but it was no big deal and I think it was a worry for Tony really not for me ... so erm ... I think it was probably a good thing we were lying down cos there was no .... but having had it ... you know.... I mean I think they said it shouldn't happen so possibly if it occurred more they would maybe regulate it and I suppose as a younger couple, they would try and ... you know ... sort that out .. I don't know. So, having got it over with, it is 'right, we've done that'.

I: So, what do you attribute the shock to? Do you think it was the heart rate?

Liz: well, yes obviously it was the heart rate. I don't think there was any other reason.

I: Ok, thank you.

Liz: ok? So I don't think there is anything else I can say.

I: So, for you, you feel reassured that your husband has been diagnosed that is in effect treatable?

Liz: yes, yes, I mean I don't know if there are any hidden secrets that we are unaware of but ...

I: Oh no, we're just trying to understand from the partner's point of view because you know, when your husband was in hospital and he was surrounded by nurses and then suddenly you come home ...

Liz: Yes, but you worry but then there isn't. There again, I don't know, individual cases could be different. I'm trying to be very simplistic about it but if-if ... there is that worry that things are going to change and how are you going to cope with it, what are you going to do, but in fact they don't change, I mean hopefully they don't change for other people ... hopefully they don't change for the worse for Tony ... but you know, I think there is that worry that you know ... there's this something that's not natural, you know, he's got this thing in this chest .. and you do think .. you know that you are going to be a full-time carer but in fact you're not.

I: That was your initial fear?

Liz: yes, of course, you just don't know. When anyone is in hospital they are very vulnerable .. the strongest person becomes a very vulnerable person in hospital I think. So, yes, it's a traumatic time for everybody really but in fact, it's ok. You know, I don't know whether I'm being simplistic about this and something awful is going to happen, but that's how I... that's how I see it, if somebody is having one of these fitted that you can worry unnecessarily and you can be worried unnecessarily by all the books you're given. But in fact it's not as bad as ... 'you'll be ok, don't worry'. That's how I'd put it.

I: That's really interesting .... I sensed that you were a little reluctant to give this interview, is it because you're trying not to think about the ICD?

Liz: yes, I don't erm ... I don't erm ... erm no obviously I don't think about it ... I mean Tony is so much better now he's got this ... I'm cross that he didn't have one earlier actually, you know, a couple of years ago, he should have been having it. But then you know, it's his fault as well, I was, he was convinced he was stressed by work ... it was part of it, you know, having your own business .. manufacturing is you know .. it's a very .. you know, it's quite a stressful .. having your own business is stressful anyway so yes, it could have .. I think he ... I think perhaps that masked the .. so maybe it's not the doctor's fault. So, now I erm ... 'let's get on with it'. I'm not unhappy to talk to you about it but I do find talking about it stressful actually, it sort of erm ...

I: Is there anyone you can talk to about it? Do you and Tony talk together about it?

Liz: yes, I mean, we're just getting on with life now so ... but thankfully nothing has happened that apart from when the shock went off, that I've needed to talk to anyone about it. The feeling that I've been given is that he is much better protected now than he was before. So, therefore, that's got to be good. So, I think you've got to, from the initial being diagnosed then you've got a period of being worried about it all, and then you get through that and hope that everything will be ok.

Female aged mid to late forties
Wife of primary prevention ICD recipient (ARVC)
In line with ethics, all names appearing have been changed and participant's name has been changed to 'Karen'.
'I' stands for Interviewer.

I: so, your husband was telling me how he fainted after his run .. it must have been frightening ..

Karen: Yes, yes, we thought he must be messing about to start off with ... but ... I was driving 'cos Tom was on call and the heart rate was going quite high .. so I was driving and sort of keeping an eye on him as well and I could still see him rubbing his chest and one thing and another and as we got to the Harriers in Llandough, bottom on Llandough Hill ... erm, I turned and sort of 'are you ok, are you ok?' I seen him then, his head sort of moving back and fore, back and fore, just as the car was moving and I thought he was messing about ... and my boy was in the back and .. When I shook him, his head was just flopping and I knew then that he'd actually blacked out .. So I was like, automatic pilot I suppose, pull over quick, shook him, couldn't get him to come around so I just did a U-turn in the road, pulled into the car park and thought then 'well sod's law or whatever, he's going into this hospital whether he likes it or not' .. um .. pulled into the ... course they've changed the ... they are doing works down there, major works .. and they've changed the car park bit slightly so I pulled in there and he come around. 'No, no, can't go in, can't go in there, got to be in an ambulance to go in ..' and all the rest of it, 'let me lie down' and he was hot, then he was cold, cold and clammy and then the first aid was coming back 'that could be heart' or what have you and he was already being checked down in the (name of hospital) for heart stuff ..

I: oh right?

Karen: cos , oh God, three, four years ago he'd come home from work and said, 'oh I've a pain in the chest and of course three weeks later down the doctors to sort it out ... you know, what they're (men) like ... and then we were going back and fore to the(hospital), where he had one of those 'up the groin' tests .. but it had come back all clear ... um .. so, this had come about cos Tom was due to go in for a hernia operation ... and when they went up to do the checks on him, you know the medical checks beforehand, they discovered that this heart problem was still there, nothing had been sorted out .. and we had just thought 'oh it's alright, it's been sorted, people just forgot about it like, so of course that was how it all started, where he was going down to be checked and one thing and another and then Doctor P then was keeping an eye on him and one thing and another .. But what happened then, when Tom came out of hospital with the ICD and everything, Dr P's hospital got in touch with us to go down to speak to Dr P. So we said, he's had this attack, he's got the ICD fitted and everything else and the receptionist said 'oh, that's alright then, we'll take you off the books' ' oh, no, no' cos Dr P wanted to know what was causing the problem. So, we said we'd go down and have a chat to him. So, we went down, it was a normal appointment, they were checking him over and one thing and another and we went into the room and we started talking to him, like what you doing to yourself now .. and he was shaking his head and he said that what I was going to tell you could happen. But he already had, and that was in the August and he'd had the actual attack and everything in the July ...

I: and how did that make you feel?

Karen: annoyed in one respect cos I thought 'well, he could have ....' but that actually happened on the Wednesday when he had his attack and on the Monday .. cos of the running he was doing .. he was running along the Taff Trail .. on his own .. nobody around and I .. then .. you talk to people afterwards who live along the Taff Trail or walk along it quite regularly and they say they do find people just drop dead .. on the trail, and I'm thinking that could have been Tom and I'm thinking 'you knew of it, so why haven't you contacted us before now, you know'. So, I was frustrated and annoyed more than anything .. but I'm just grateful it happened when .. when it did and the action I took .. it was the right thing. Cos Tom wanted to come home 'oh, it'll be alright, we'll call out the .. er.. the doctor on call and everything and I thought 'fricking hell, you going boy, it doesn't matter what you say! You're going in' (laughs).

And I took him into the hospital and that bit was quite difficult, cos I had my son with me as well and it was sort of ... the-the the nurse when he first went in was sort of like aww, what are you coming in here for, you're a youngster with shorts and trainers' .. no, not trainers, he didn't have his trainers on, he took his trainers off .. but shorts on and he was 'what the hell you two playing about' type of thing . But of course, when they got .. I helped him on the bed with the nurse, and when they put all the pads and stuff on and then suddenly hell broke out ... I was looking around to see if the television cameras from Casualty was there, cos it was exactly like an episode on Casualty like, the bed goes down, and they wheel him off .. through the double doors and walking behind .. 'oh, no visitors and no family' and nothing was being explained, that was the difficult bit. And then we were told there to go to the Family Room, and that's when sort of 'hang on a minute, that's not me .. or time, or err .. It was very ... I suppose they weren't sure what it was either, but you know, there were just little bits coming .. and you weren't quite putting it all together type of thing .. It was like, 'alright, you can go and see him now' .. and he's lying in the Special side, all wired up and mask on and God knows what like, and it was that bit 'well, what the hell's going on' . And at the time, thank God, I didn't understand what the computer bits were, cos I think if I'd realised .. it was 218 when I looked at it .. and er .. I think if I'd realised what it was then .. I would have been a bit more panicking that what I was ...

I: How do you feel about the ICD?

Karen: Um .. I think it's helped having young children .. in that we've .. it's (the ICD) a part of the family. So what we did, cos we had to come home and I had to explain to the all of them what it was all about .. cos we didn't want to scare them ..

I: how old are your children sorry?

Karen: Daughter's 19 now and son's 16 .. so they're an age where they can understand but they're at that age where you don't want to scare them. And especially then you're finding out it's hereditary .. they got to be checked and everything like that ... So, we've changed the initials around and we call it 'CID' .. It's a person as far as .. it's a 24 hour paramedic and you know like. It's there to save his life if it needs to go off. How did your children feel about the ICD? Were they worried about any aspect of it?

I: So, that's what you call it do you?

Karen: yeah, we call it CID.

I: That's excellent!

Karen: That' s the only way we can accept it ...

I: Did you see that written down somewhere?

Karen: No, no, it's just a family thing, it's just an extra member of the family .. as well as the dog .. he's there as a 24 hour paramedic .. but you know .. it's helped *us* understand it *more*, you know, but er .. And as I say, the stuff we've had through the British Heart Foundation, the little booklets and stuff like that have been brilliant.

Was there anything else in the booklets you'd like to have read about? Was there anything particularly good or worrying that you read about? Was it informative enough?

I: Is there anything you'd like to have seen?

Karen: I think what has helped is that we've continued to go to the support groups ... because the Arrhythmia nurses, (names) and er .. can't remember the other one, have set up a support group ... and er .. through my work I went to monitor a group of heart patients, who were going to a Cardiac Rehab exercise class and what have you, and one of the patients .. clients, came up to me and said 'please don't take the money away'. And I said 'oh, no, no, no, I'm not here to take the money away .. I'm just making sure you're enjoying yourself' and what have you. And she came over to me afterwards and said 'please don't take it away' she said, cos she said 'I still got this heart problem' she said 'and I-I .. everybody here *understands* what I'm going through' she said 'people, my family will say to me 'you alright?' and you'll say 'yeah, fine' and they'll say 'oh, ok' but you want to talk a bit more about it. And I thought, yeah the support group is there for that type of thing you know, for people all in the same boat and you've got the partners there as well and you're just generally trying to help each other with that little bit of support .. and 'it's not just me' , that type of thing. But I found them very use-.. very, very good, in that it gives you that little bit of extra knowledge. Because sometimes I think, if you go onto the web-sites, you don't get the true pictures?

I: In what way?

Karen: Like there was a lady, and her defib had actually gone off and she was able then to explain .. truthfully, and I appreciate it must have been really difficult for her to go through that experience, cos it was going off quite regular, and the confidence she'd lost through it going off. She was a walker, she could walk up mountains and she'd stopped doing that cos this was going off and one thing and another, you know. So, learning and listening to other people's experiences has given us a bit of .. more confidence then .. you know, touch wood, hopefully it don't go off, but you've just got that in the back of your mind that if you know that happened ... it's normal then, it's a normal function. It's the talking bit ..

I: so, you got a lot of reassurance from that? WHY WAS THAT REASSURING? WHAT ELSE WAS REASSURING?

Karen: yes, yes, (breaks off to talk about the ICD support group and Cardiomyopathy group). Again, (the defib support group) was good for having it explained .. we'd seen the different sizes, like when Tom was first told he was having the defib fitted you know .. and you know they used to fit them in the stomach and stuff like that .. and that was useful to go and listen to that side of it ...

WHY IS IT USEFUL TO LISTEN TO THAT?

I: How often do you go to get it checked?

Karen: It's every six-months now

I: Do you go with Tom?

Karen: Um .. I was going ... he went the last one on his own .. he's due to go January 17th/18th to have his six-month check again. But I was going down with him before, because he couldn't drive until the February .. so that was hard going but good in another respect .. cos (daughter) had just passed her test and she was able to drive my car and I was driving Tom's car .. my car .. our car .. but it was that bit was quite hard .. Cos he'd signed up to do a college course in (nearby town) as well, which was great when he could drive, cos he'd go to work, drive from (Town) to (nearby town) what have you. But his employer then was giving him the morning off so he could catch the train from (town) to (town), and then one of the boys in college then was bringing him as far as (town), and then I was picking him up then from there so that ... it worked out .. yeah .. and it was nice for him then, cos he made good friends with a couple of the boys quicker, cos they were helping him out and stuff ..

I: So, do you see any disadvantages in having the ICD? For the family, or for you as a partner? Has it affected the physical side of your relationship?

Karen: no, no

I: has it stopped you doing anything?

Karen: no, no, it was ha- .. it was difficult in the beginning to get the confidence and ... not understanding what it's there for but what if it goes off, what'll happen then, what .. what .. you know, how's he going to feel, when is it going to happen ..

I: you're talking about the shock?

Karen: the actual shock of it, yeah. So, I wasn't ... that side of it was a little bit apprehensive but ..

I: how long did that last for do you think?

Karen: Um .. oh a good six to eight months I would say. Yeah, especially with him not driving .. so I was having to make .. take .. cos he wasn't always on his own then type of thing .. cos he wasn't driving. If you're driving, you're on your own .. so if it went off .. you'd be in a worse state .. but because I was always with him all the time, I felt I was constantly baby-sitting or watching .. make sure he was alright and .. you know, when he said he was going back out running and what have you like, it was 'oh God, is he going to be ok' ... But because I've taken charge making sure he's got his tablets, I feel .. I .. I'm in control as well has him, type of thing .. So I'm doing my little bit, to make sure he's safe and ok like, you know.

I: So, how do you feel about him running on his own? Did you ask him not to?

Karen: For Christmas I bought him a dog-tag (laughs). A heart-shaped dog-tag, he'll kill me for it, I know ... his name, ICD, and a telephone number ... but I was doing that type of thing before he was ill, cos with his running ... he'll always tell me where he goes .. take a mobile phone with him or anything like that .. But he did go running a couple of months ago and didn't have anything on him at all and a van missed him by inches .. But I wasn't too pleased when I found out he didn't have a phone on him, he'd changed the route he'd told me he was going to go ... and it's just little things like that ... it's .. it's always there ..... don't live with it day in, day out, but you're always conscious that he's got the defib ..

I: the shock seems to be an alarming element to you?

Karen: um .... It's just there ... I can't say I'm worrying about it or anything like that ... but you're just conscious that if something does happen .. or what will it be like if it does happen .. what effect will it have on him and stuff like that ..

I: when you say 'effect on him' what do you actually mean? WHAT DO YOU THINK IT WILL BE LIKE?

Karen: is it going to knock him back .. his confidence back ... are they going to start questioning it in work .. or should he be doing that type of thing .. you know, classic like, he out clearing snow, clearing snow for neighbours and he clearing our drive and a comment from my mother was 'should he be doing that' .. Well, until she'd asked me 'should he be doing that' .. yeah, he's done it and he's still there like, you know. So, sometimes it's other people who put doubt in your mind or starts questioning .. 'oh perhaps he shouldn't be doing it, perhaps he should be putting his feet up', do you know what I mean? It's a funny one to try and get the right balance. How do you feel when people say things like that? What do you do about it? But you know, when he had the attack, you know everybody, everybody, every single person we knew said 'that's the running done that, the running's caused that'. So, of course meeting with Arrhythmia Nurse when we had the talk about the effects of the ICD being implanted and what have you and ... she said the running actually saved your life .. it's like 'yes!' That type of thing you know and that .. anybody that comes back with that comment 'oh, no, no, no, it saved his life, hasn't killed him or nearly killed him, or caused it, it's hereditary and learning more about the Cardiomyopathy side of it does also help to talk to .. to make other people understand what the condition is all about you know.

I: So, your husband's family didn't have any symptoms of Cardiomyopathy?

Karen: no, no, his dad has got .. um .. they all suffer from low blood pressure .. but he's got an older brother, he hasn't taken up the test .. his mother died, but it was put down to pneumonia but as we say, we don't know what the true cause could have been ... His younger brother and sister have been tested .. his sister has got a bundle .. So they've picked that up in the heart but that isn't life-threatening .. but it's something she's got to be aware of .. she's happy about that, not happy, happy, but you know .. But she knows it's

something. And his younger brother has been fine. We've had the children checked and they're all ok. But they have said if daughter notices anything .. any children she has in the future to bear in mind that her father had had this and it could be that .. so you know, it's just making people .. Well, its educating, making people aware of it and not being scared of it you know .. It's there for a purpose ....
How did you feel about learning it was hereditary? How was it waiting for the results of the testing? How did you cope? How were your children affected?

I: how do you feel about remote monitored ICDs?

Karen: I wouldn't mind ... but I'd still want .. say a yearly check .. actually going down and speaking to somebody .. cos I think if then you've experienced or had something you want to ask a question .. that makes life a little bit easier to .. when you're actually talking face to face with somebody rather than the computer . Um ... I think it's a good thing if yer .. if .... there's no problem with the person with the ICD .. you know, like with Tom, he's getting on with his life and he's fine .. but I don't think it should be totally .. to be honest ..

I: you need some contact?

Karen: yeah, yeah definitely ... But I think that its fortunate, the way that he accepted it .. has been a real positive .. you know, I don't know we would be if he'd accepted it like you heard about other people and its then like going to the support group, you realise how lucky he's been and also other people .. you know.. 'it's this thing' 'get it out of me' comments that we've heard from people who just cannot accept it ... There's one character in there, in the support group .. he's .. he's really been hard done by .. you know, and *every time* you go to the support meeting , he doesn't look on the bright side, like your glass is half-full, it's always half-empty and he's really down and stuff like that .. And when I think what Tom has been doing and going through and everything else, I think 'well you're not the only one like this you know'.

I: Your husband said he hasn't run a marathon since ..

Karen: No, no

I: How would you feel if he were to?

Karen: I'd be ok about it, yeah, yeah ... I think now he's gone the full 12-months and nothing has happened (why is 12-months important?) and now this and this has been tested and you're learning more about it all the time, it's there and I think you've got to think of it as well .. it's been picked up .. he's safer now then when he did his first marathon in which he could have dropped dead on the spot .. you know, as some of them have .. um .. I know

that he'd have to go down to the hospital to have it programmed ..
So they can change the maximum and minimum for it, and then he'd
go back down on the Monday and have it altered back to normal,
heart rate and stuff like that .. so I think that's been a good thing to
understand .. And I'm nosy anyway, as you can tell ... you know, I
want to know what they put it up to and I think he'd want to wear a
heart monitor himself .. a heart rate monitor to make sure that he's
not going to go over that ..
But I think his attitude towards marathon running is now totally
different to what it was when he was running before .. it's a
challenge just to complete the distance rather that do in a certain
time like it was years ago like, you know ... it's better when he's
running (laughs) .. he's out of the way (laughs) ..

I: do you find yourself watching your husband, like say if he came
home from work and said he was really tired ...

Karen: mm ... I have .. he does ... it's a standing joke with us in the
family, he got the family disease where he falls asleep anywhere ..
his sister and his brother, they're all the same .. one minute, you're
talking t him and next minute you're sleeping your know ... He has
said about being tired, but I don't know if that's .. he's still doing the
college course, you know he's working full-time ..

I: So you don't automatically attribute it to the heart?

Karen: no, no, no, I look at other things first. If he was coming just
straight in from work, which i know that he isn't as active in work as
he used to be .. then I think .. but that is more a psychological thing
in 'well, let's step a little bit', not because of this .. no this is stopping
him doing certain things in work .. he's not allowed to go near MRI
scanners and stuff like that .. but I think he's thought 'why am I
running about like a fool, when there are other people here who are
getting paid to do it .. that type of thing you know.

I: has that been easy for him to let go ...... the responsibility?

Karen: um .. he seems to be ok with it .. he still gets involved with
different work and what have you. With the course he's doing, will
give him a management grade so that he will then be able to go up
the ladder .. promotional wise, you know. But I think he just looks at
it in a different way ... I think it's been a good thing, in that its
calmed him down a bit as he was trying to do 150 things in one go
whereas it really is delegate and stuff like that, you know. ... but I
don't think its affected him that much. It's just more paper work
than actually going and looking at a job and taking boys, the
workmen when they come back and understanding what the job is
all about rather than going to go look at it himself, that type of
thing, that's what he's cut down a lot more on. But what I think the
tiredness is.. you're coming home and doing more work, deadlines,
and you know what it's like, you're trying to do the family bit .. the

work bit, the college bit on top ... just sometimes it (big sigh) beats you doesn't it ... I did tell him, when he goes for his check in January, just to mention it .. that he's feeling tired and stuff like that .... and if they come back and say 'you're doing too much with the computer, you know this, that and the other, .. I don't put it down as being the defib .. I think it's something he's doing or we're doing ... you know that's causing that

Additional Interview

I: Did you have a good New Year?

Karen: Yeah, yeah .. quiet .. normally go up (name of town) .. there's a road race, they have all different ages and they an elite and then they have a club run .. fireworks, a funfair and all this. Years ago, they used to do .. they started in the old year and finished the race in the new year. And with health and safety, they don't allow it now .. they do it all on the 31st.

I: Did your husband run?

Karen: No, no, he done in the past ..

I: Would you have liked your husband to have done it?

Karen: Yeah, yeah

I: Sorry, when did he have the ICD fitted?

Karen: August 2009 .. yeah, 13th July was the attack and then the 1st August was it was actually, when the ICD was fitted. It was done on the Friday afternoon, last thing and he come out on the Saturday morning ...

I: Was it nerve-racking?

Karen: yeah .. cos we waited all day for when, when he was actually going to go down, when he was going to go up, so I'd made arrangements to go down .. the children didn't go down that night, I just went down on my own and visiting was 6 to 8 or whatever it was, and as I had arrived Tom had literally just come out from theatre ... and I think that experience wasn't a pleasant .. that was a bit off-putting .. for him, he didn't like that bit at all .. being awake, it's like having teeth pulled I suppose .. you know what's going on and you think things .. a bit over the top sometimes .. but as I was saying, he was as bright as a button when he come around ...

Interruption –

I: ok, so when you got home on the Saturday with Tom was that hard?

Karen: Hmmm ... yeah, cos the thing was, it was sort of .. you'd had three weeks of being .. looked after, I suppose and questions and answers and stuff like that and then coming back home, that was a little bit 'oh, my God, what happens now?' type of thing ... And its like when you have a baby, I remember bringing (daughter) and it was 'oh my God, I've got to do this on my own now'. It's that sort of thing. We got a system together then with ... because the 12-months beforehand, he'd had a hernia operation .. so it was doing, like covering the area .. scar bit .. for him to have a shower .. So, we altered it, so we were covering the scar so he could have a shower, but then I'd stand with him in the shower .. not literally in the shower .. you know, and if he found it difficult to bend to wipe, stuff like that, so I was there to support him as far as that was concerned ..

I: did you feel you had to stay with him all the time?

Karen: yeah, yeah, um you're very, very ..um cautious. Didn't go out. I remember the first time we went for a walk, I said 'leave the dog', cos the dog tends to pull and what have you and I said 'it's only round the block, it doesn't matter, we need to get out for some fresh air' and stuff like that and ...

I: Was that your idea or his?

Karen: um ... I can't remember, cos it was .. after the op done it was the August time, the weather was nice, and I would make him go outside and sit out in the sun rather than sitting in here .. so had the cap, the cover on .. the umbrella so .. cos his colouring doesn't help, .. Um cos I remember his sister came down to see him the one day and he was sitting outside in the sun .. It was nice, cos he was in the shade and he seemed to be um .. not his confidence but a bit in the shell a little bit .. you know, a little bit quiet ... Not that he wouldn't talk about it .. but a bit oh, don't know .. 'what's going to happen' .. you know, 'what's the next step?' 'Are we going with this ..?' and that type of thing and as we went on the walk and as he was walking he was 'oh, oh' and I said 'what's the matter?' .. And every time he was putting his foot down he felt as if he could feel it moving and I think that was the biggest thing with it .. cos they tell him not to raise his elbow so far (lifts elbow up to shoulder height) cos of the wires and the stuff like that and it was these little things that played upon his mind the most ...

I: So, how long was it before you went for a walk?

Karen: Must have been about 4, 5 days perhaps ..

I: before you left the house?

Karen: yes, yeah ... But um .. people were coming up here so it was um .. people going through the house, you know. There was plenty of people he was seeing and stuff like that.

Don't think we went out in the car .... coming back from hospital, cos the seat-belt was going to come over .. he wouldn't sit in the front seat, he sat in the back, behind me ... which was a bit difficult, cos I had daughter sitting in the back, which is the oldest child, keeping an eye on him type of thing, whilst I was concentrating driving, and then Jonathan was sitting in the front with me ... It was like the walking bit ..

I: So, the first few weeks, you were kind of waiting for something to happen?

Karen: Yeah, yeah, and the uncertainty I suppose. It's difficult I think for the arrhythmia nurses or other .. surgeons and stuff like that .. to actually to know what it was like if the warning signs .. they tell you the warning signs but actually they don't say, ' well the pain is like .. ', or 'this sensation is like ..', I think that was the uncertainty type of thing ..

I: They said that to you did they?

Karen: Well, no, if you said 'well, what's it going to be like if it goes off?' and I always remember (arrhythmia nurse) saying 'I can't answer that question'. And in one of the support meetings we went to .. to the arrhythmia one, erm sorry, the ICD one, I remember she actually went over .... this lady came in late... and she actually went over to her and said something. And what it was, she wanted her to tell the class, type of thing, the experience that she'd had, so it was interesting there actually listening to someone who'd actually gone through it thinking 'right, this is what would happen if it did go off type of thing'... You know ... you'll just watch the um .. the telly, and look at like Casino Royale, where he's trying to defib himself .. and you think 'it's going to be like that' but because he hasn't had that type of thing or haven't seen anybody going through it .. it's what people are telling you .. and I did get concerned that the lady was telling us what would happen was that .. that her confidence, it really, really set her back .. Because she used to do a lot of hill walking, going out and doing a lot of things on her own ... wherein when it started then, she wasn't going out walking .. stuff like that ..

I: you actually said that you'd found that reassuring .. so what was reassuring about listening to someone else's experience?

Karen: that she'd come out of the other end. That she is still alive to tell the story, that she's still active, I think what happens is, it's what more happens up here (points to head/mind). I know with meeting other people in the groups I've been very lucky with Tom, his attitude is 'well, get on with it now' type of thing. Whereas a lot of people just go within their selves and they don't want to bother you .. you know .. But having some idea, you know, they sort of said it'll give a couple of warning signs first .. if the heart rate goes high, it'll give a little 'flick' and the defib will 'flick' the heart to get it back into its normal rhythm. If it doesn't listen, it'll give it another one, and if it doesn't listen to that one, that's when the full pelt comes in, to make it really, you know, 'do as you're told' type of thing. And when Tom gets that sensation, it is to really to 'make safe' .. get into a safe situation .. if he's up a ladder, get off the ladder .. sit down ... and this is what I said to him in work .. 'you should let them know in work what could happen'. You know, we had some sort of sheet, you know, it said 'if it goes off, you don't have to ring 999' .. this mobile and stuff like that ... Just for work to be aware, if it does happen there, at least they know what to do rather than just 'oh God, he's having another ... heart attack', type of thing , you know ...

I: um ... another thing you said ... at the support group you were shown the different sizes of the ICDs

Karen: ICDs yeah,

I: .. the chap was telling you about how they used to be implanted in the stomach area ... and you said that was useful?

Karen: I think because they done all the different research on and stuff like that, I think it was reassuring that .... the evening we were told he was having this defibrillator fitted by the person changing the bed next to him, *that* gave us enough time to find out and ask more questions .. and she showed us then the defibrillator .. so you had it in your hand, you could feel how heavy it was, what the size was .. And to have that then explained later on ... if the guy had come and said 'this size and we'll fit it here ' and all the rest of it, it was a bit too soon really to have digested anything ... so to hear about it later was useful ... with having the nurse telling us before the consultant did, and with the two of us being there at the same time, it's helped us prepare ..... Cos Tom used to have like a note book, he'd write all the questions down that he wanted to ask the consultant when he come around and knowing that prior to him coming and saying 'you're having a defibrillator fitted' I felt very useful. And then just learning about the history and stuff you know, how it's developed, and science and .. you mentioned about doing it through the computer (REMOTE MONITORING), having checks and stuff like that, it's just progress ...

I: And you found that reassuring?

Karen: Yeah, yeah, yeah.

I: That's great. Can I just go back ... you said you'd told your children .. 'CID' to lessen the anxiety, how did your children react to the ICD? Were they worried about it?

Karen: No, no, no. I think when he came home then and we showed him where it was .. I think what was Tom was a little bit apprehensive about was how far it was sticking out ... cos when it was explained to us that a pocket was going to be cut .. the battery was going to be fitted into that and this type of thing, we thought it was going to be a lot more further back in the chest .. cavity .. wall .. I dunno, that type of thing ... and that played on his mind for a long, long time .. about how far it was sticking out .. Cos he was conscious that it was there .. having the seat belt coming over it

I: conscious as in ...

Karen: It was moving it and pulling the fnow, 'don't lift your arm above' .. this type of thing ... I know he was very conscious of it, how far it was sticking out .. he's used to it now like ... It's a party act it is 'show everybody' 'there it is' ... and other members of the family have said how .. well you can see the shape of it under the skin.. that was the one thing, but the children took it very well.

We explained it's not through anything he's eaten or anything he's done .. it's hereditary, we don't know if it's come from Bampi or it's come from his mother .. we explained to them then we had to have the tests carried out .. it wouldn't be any .. no operations or nothing like that .. we just went ... can't remember ..... be like an ECG, have to keep it on, the 24 hour tape .. I explained all that to them and I think cos they were at that age where .. (daughter) had done PE, so she'd done the body .. So she understood a little about that side .. (son) is at that age where he is football mad, bodies and stuff like that so he could understand a bit more ... I don't know how they would have taken it if they'd been younger ...

I: So, waiting for the genetic test, they weren't worried?

Karen: No, I think (son) .. when we went down to the paediatrician and he did (son's) tests and he did the ECG one ...... and when we were talking to the consultant then ... and he asked Tom's history of what had actually happened .. And when Tom started to tell him what had happened, he wanted (son) to take a stress test, which he hadn't asked for before he found out it was after the run or whatever ... So we had to go down again with (son) to do the stress test .. but yeah, he was fine ..

I: what about you, how did you feel through this?

Karen: Well ... the only difficulty I get with it is we go through all this .. we've understood that it doesn't skip a generation, so one or other of them have got it somewhere and it's like .. I suppose it's like a murder mystery, you want to know where it's come from .. Like his mum has died, put down to pneumonia, but could she have been the carrier? You know? Erm .. it's sort of ... funny enough we were talking about it this week ..'oh, it's alright me, I'm alright' .. 'but you still got to have the tests' ... His sister was saying about it this week, 'yeah but you still got to have the tests' .. we've been talking ,cos we've been away on training we have, and I said to her 'yeah, but there are tell-tale signs that you need to be keeping an eye on .. like fainting. Tom was very, very .. faint at the drop of the hat and I said, 'I know you all got low blood pressure' but I said ' don't always put it down to the low blood pressure .... I think it's that bit of the doubt bit, that is not quite right with me. But there's no funding for the genetics but yet that works out cheaper than doing all the ECG, treadmill and everything else you know. When I think, if they could just pick out that gene .. sounds selfish, but then you know that the whole family, not just our family, but the whole family then could be tested and it would be 'yes, you've got it' 'you haven't' type of thing, you know. So, it's that uncertainty and what in the future type of thing ... I think that's the only thing that's the biggest frustration, for want of a better word, more than anything ...

I: You said, you found the British Heart Foundation booklets 'brilliant'

Karen: At the time it was more of .. one of the questions was 'how was they going to fit it in' and it's just going to be a cut, a cut of the muscle and I remember that quite clearly being told, and then wires were going to go in and that's going to trip the heart .. and all the rest of it .. So, they told us that basic stuff .. . But I don't think .. um ... they could have told us then perhaps how much it was going to be .. you can see it .. like in the summer time, with the shirt off, you can actually see the shape and stuff like that you know, ... but one of the girls in training calls him the bionic man (laughs) ... But I think, for what it was published for, I think it serves the purpose, it doesn't scare you and it doesn't make you feel 'oh my God, what is going to happen ..' type thing ...

I: So, when you were discharged you were given these booklets.

Karen: We had those booklets the time before, before we actually had the ICD was fitted ... I still carry it around with me now .. cos if I think of something or I want to show .. th-that's what helpful as well, I was able to ... cos it was in simple English, simple drawings .. I continued to work, cos I had to have something to take my mind off .. I was going into work and showing people 'this is what Tom ..'. I don't think at the time, it had actually sunk in how serious it was .. it was like 'oh, he's going to have this fitted ...' , 'it's going to do this, that and the other like', you know, but I think we've been fortunate that he's hasn't had an attack or .. he hasn't lost his confidence or stuff, you know.

I: One comment you made was you were pleased he had finished the first 12-months .. why was 12-months important? ... I think it was in context of running a marathon ... you said you wouldn't mind him running a marathon because he'd gone the 12 months.

Karen: I think you got to ... I think the first 6-months is like a 'hype' type of thing ...

I: Like a what sorry?

Karen: Like a hype. Everybody comes to see him, everybody wants to know how he is. I'm constantly ferrying one or t'other around ... the interest, for want of a better word, is still *there*. And then he was able to drive himself .. that was his 6-months to prove to everybody that he was ok, do you know what I mean?

I: Ok, ok

Karen: It's like the first 6-months, he's still a patient for want of a better word, cos he can't drive so I need to pick him up, or whatever the case may be. Like we booked a caravan holiday and Tom wanted to cancel it and I said 'no' and that I would tow the caravan .. petrified of doing it, but I did it .. and 'I got to prove to you' .. cos I remember saying to him 'what *if,* it happened when we were away', you know 'how would I get the caravan back'. It was a 6-month of learning for both of us .. you know, I can do things as well as him, and he can do things as well as me, type of thing ... I think then, cos we come to the full 12-months, it was proving to everybody out there that he's fine, he can do what he wants, he can go where he wants, he goes out running on his own ...

I: Can I ask ... this is a bit sensitive, you don't have to answer if you don't want to ... has it affected the physical side of your relationship?

Karen: no, no, not at all .. Because again, in that little book, it explained it quite simple and I think .. I'm sure once somebody brought it up ... I can't remember but I remember them (arrhythmia nurses) saying that it's not going to affect anything in that respect. The only thing is we are lying on the opposite of the bed, but it's comfort more than anything (because of implant site)

I: ok, initially when he said he wanted to go out running again, how did you feel?

Karen: Nervous, very nervous ...

I: Did you ask him not to go?

Karen: No, I said I'd come or go with him .. so I used to go with the dog, or the bike ... he'd run on, and I'd just peddle behind ...

I: How long did that go on for?

Karen: I suppose up until the 6-months when he was then able to drive and I could see that he was getting back on his feet and coming stronger and stuff like that ... I think if he'd come in and said, 'right I'm going to start running' and he hadn't done it before, I'd be very, very sceptical ... sceptical of him going out on his own then but well, all the time since we've been married, he's done road running and stuff like that .. I'm not saying I'm a specialist at it, but I know what's good and what's bad and what limits he got and stuff like that ... I think it goes back to the initial diagnosis, it's hereditary, it's not the exercise and I think I kept that in the back of my mind all the time ... the sooner he could start getting physically fit again, whether it's swimming .. he don't like swimming .. or cycling or running or something that he enjoys, the better for him, cos psychologically as well, that's building his confidence .. ' well, it hasn't gone off, I can still do it' type of thing .. So it was like proving to the both of us really that it wasn't going to stop life as it is like, you know.

I: But initially you were a bit nervous?

Karen: Oh yes, yeah .. I can remember down at the hospital saying about it 'oh, he'll be alright' 'oh, no, no, no'. Because I think what was at the back of my mind all the time was he ran home on the Monday .... along the Taff Trail, so I'd gone down to pick him up ....and then the .. well, not the next day but the following day he has this, where if nobody had been around he would have gone, you know. Then you think 'hang on, he's here for a purpose .. could have happened on a Monday but it didn't .. he's got it but we still got to keep doing normal things .. things that you enjoy .. you can't stop cos you've got this (touches site where ICD would be) and i think his attitude to it as well .. that's made it more .. 'come on, lets get it done like, you know' ....

I: what do you tell yourself when people put doubts in your mind about what Tom is doing?

Karen: I'm a realistic person .. I don't know what I'd be like if Tom's attitude towards it was different .... I've been very, very fortunate in that his attitude hasn't changed pre-ICD to post- ICD ... I'll give it two seconds of thought and then 'no, this is a normal thing .. life', you know.

Female aged 65
Wife of primary prevention ICD recipient (Chronic Heart Failure)
In line with ethics, all names appearing have been changed and participant's name has been changed to 'Dot'
'I' stands for Interviewer.

I: so, your husband's told me the reason for his ICD .. how do you feel about the ICD?

Dot: Well, you know, at the time when they said .. they didn't give us any choice really, cos they said he was into chronic heart failure, and to be honest, we wanted it as quickly as possible .. whatever it was, you know, ... if he'd known what was going to happen after, I don't think he would have had it but then it's not always the case with everybody like, you know .. I mean they did say he would get 30% more than what he had but it didn't happen straight away .. it took a long time .. and we thought it was never going to happen ... yeah I was happy with it, you know.

I: that must have been quite a shock to know he had chronic heart failure

Dot: I mean the doctor down in the .. (name of hospital) .. oh, what's his name .. (name) .. he didn't pull any punches at all you know ... short of him saying 'he's going to die' like.. you know that's the only thing he didn't quite say and it was like 'well, it's very bad ... it's chronic .. his heart is into .. failure' you know. As I said, he didn't pull any punches and .. frightened us to death like. I mean, I'll be truthful, I would rather have the truth you know anyway, but it was a shock ... you know when he first started saying he couldn't breathe, he was saying 'oh, it's your weight' you know, cos he was nearly 18-stone .. and so we thought 'huh, I don't know, maybe it is, maybe it is the weight' so when we went to (name of place) we were sure they were going to say, you know, 'you need to get your weight down, that's why you can't breathe' but when they actually gave us ... they did this .. scans and everything, it said he was into heart failure, it was a shock, I must admit that yeah.

Because when he had the by-pass, the surgeon said '20-odd years at least, you'll have no problem at all' . But he didn't have any follow-up. You know personally, i know we had to go private but we should have been referred to (city) on a yearly basis really ..no, no, never saw anybody. Never saw anybody at all. He just carried on taking the tablets, what he was told to take and that was it. No follow up whatsoever, you know.

I: How do you feel about that now?

Dot: I'm disgusted 'cos they probably could have found out before his heart got so weak, you know. We didn't find out till it was chronic heart failure, you know. We should have found out long before that but we didn't. And my husband is not one to sit down ... if we had even thought .. I have to admit long before he did go into hospital me and my daughter .. I could see the colour .. the colour on his face but the trouble is you're helpless ..... his colour wasn't right, I knew .. his colour wasn't right, it was like .. pasty .. he never had rosy cheeks, I've always had rosy cheeks me, but I could see but you know there isn't anything you can do about it. Do you know what I mean? Because he wasn't complaining .. it wasn't until he couldn't breathe, they had to rush him in .. I thought 'I've seen this coming on' .. but I didn't know, I didn't know about it. So it could have been caught a lot earlier, so I mean I'm not happy about that and when we went to see Dr (name) even then he said 'we'd like to fit this defibrillator because that's the only chance he's got, but it's entirely up to you whether you want to have it or not'. He gave us the 'you would have 30%, there are drawbacks' although he didn't say many drawbacks only that if it went off, this is what they told us, that you could be flung out of your chair .. that you know, we weren't very happy about that but at the same time that was the only thing they could do for him, you know. So, we were quite happy to have it. But when we went it was like in .. in the end of October, I think it was .. I said 'right, ok, how long is this now .. just a couple of weeks?' 'Oh, dear me no, not till January' .. I said 'excuse me, you've just told me that without this device you know ..' in so many words, 'he's not going to last'. 'Yes, well you know, we've got a list'. I wasn't happy about it and said 'you know, I don't' think this is right. You're telling me that he needs this and he needs this as soon as possible and you're saying three months'. They did take him in, I think a month before, which was in the December .. either the 9th or the 11th of December before Christmas .. So was a bit happy about that, but it was still two months in between.

Now I personally thought, because of the state of his heart, they should done it straight away, you know .. and he said 'do you know how much these cost?' So I said 'no I don't know how much they cost, it cost us £18,000 just to get a by-pass I said, because we waited so long. And he kept telling us he was the top of the list so I know. 'Oh, it's £25,000'. I thought, well you know, when you're in a bad state like that .. he's worked in the pit and you know, he's paid in all his money, why shouldn't we have had it straight away, that was my belief anyway ...

I: So, when your husband had the ICD, how did you feel then?

Dot: well, we were quite happy about having it ... it was just *after* ... it .. it .. everything changed .. he was so ill .. He wasn't that ill before he had it put in .. he was just so ill ..

I: Ill in what way?

Dot: He was ill in that he couldn't eat anything and erm .. er .. sleeping .. like he never sleeps in front of the television, you know that's just one thing .. he couldn't keep awake .. he didn't ... he never wears .. he gets up straight in the morning, he washes, gets ... he never stays in his pyjamas .. he wasn't getting out of his pyjamas and at night .. oh! I never had a night sleep because ... and I don't know what it is, I said he snores but he doesn't .. only when he's missed his afternoon nap does he sometimes snore ..... but noises he was making in the night .. it was terrible, it was like a (deep groaning sounds) you know, it wasn't a snore ... I mean I'm a terrible sleeper anyway .. I was out of bed at 4 o'clock this morning ... but he was like sitting up in the bed, he couldn't breathe .. he had all these pillows, we bought a special back thing ... and you know, I had to keep putting the light on .. because he was sitting up in bed but what he was doing sitting up in bed, he was falling asleep then ... he was sat up at the edge of the bed and I could see him and he was going like that (demonstrates head falling forward asleep) you know ... And I had to tell him 'you're going to fall off the bed' so he used to come down here and sleep on his arms. He used to sit at that table (points to dining table) and get the pillows and he used to sleep with his head down ... and that went on for ages ... we just never, ever thought he was going to come out of it.

And then his legs .. they were up like .. his feet .. and he's never suffered from swollen legs .. his feet and legs were swollen .. I mean, I used to cream them and I could see, you know, that spots were coming that were going to break out .. they were so enormous ... They had him on a lot of tablets you know, ... I said to my son, I can't go on any longer cos dad's so ill ... he's getting worse, so he called the doctor in and he said 'well, I can send you to the hospital (name) now' but we didn't want to go to (name of hospital) .. so he said 'the best thing you can do is take him to A&E in (hospital name)' and of course they kept him in and .. they kept him in for about 3 or 4 days and they said 'oh no problem, we'll give you a different tablet' they were worse, they did not work. On the last day, my husband said 'look, I'm going home' .. he hates hospitals, he's terrible, he is awful .. he said 'i'll go now' . 'Look Mr X' said Mr (name of doctor) 'we'll send you home with this water tablet and see if that works' ... Well it did start to work, very slowly, then they put him on another one (name of drug) and the legs went down, you know .. But it took a good six-months or more .. you know he felt .. oh it was just horrendous ... It was horrendous, I have to be honest ... But as I say, they didn't say that to us ... I mean, i know in every patient, they're different .. you know, each patient is different .. but what they said to us was 'with this now you will have 30% more than what you've got now' so, he could walk up the road .. and he couldn't (now) so we thought 'that's good' but it seemed as if he had to get really bad for it to get better ... you know, we were back and fore to the doctors, well, not the doctors, the hospital all the time cos he just wasn't getting any better, you know .. They twiddled about with it (ICD) you know, and as I say, gradually then he got better ...

I: but it took longer than you thought ..

Dot: yeah, it took longer than we thought because we never thought ... If they'd said to us you know, 'you might get worse to get better' we would have known what to expect ...

I: Did they give you any literature to read?

Dot: sorry?

I: Give they give you any literature to read?

Dot: yes, they give us the literature but there was nothing in there really, you know. But you know at the end of the day, his heart was very, very weak .. they kept telling us that 'your heart's very, very weak' you know .... they didn't actually say .. you know .. 'you're going to die' like .. but they may as well cos that's what they kept on telling us 'you're *very, very* weak' not 'you're just into heart failure' .. it was 'you're into *chronic* heart failure' and 'it's very, very weak' you know .... Maybe that was why, because it was so weak .. I don't know, that he had those side-effects .. i don't know .. Well, it had to get into rhythm didn't it .. his heart just wasn't in rhythm and .. you know, but I could see the change in him, in the colour in him ..

I: so how did you feel when your husband came home from hospital?

Dot: when he came home from hospital? Oh i was .. I didn't cry in front of him .. I'm going to get emotional now .. my youngest son, he was with us all the time you know ... and he was on the phone all the time you know, so I used to tell him how I felt .. he kept asking how's dad .. he was so worried his dad was going to die like ... I got to be honest like, I was crying all the time .. because I could see nothing was happening .. it was getting worse .. you know that's what I could see, and I was living with him and we were getting no sleep at night .. he was down here, or he'd sit here .. it was, it was just really traumatic really ... But as I said, I expect my husband has told you, we are Christians and we do believe ... we believe that it's the Lord that done it cos we just feel that he was so, so bad that it was only the Lord that could help him .. and you know, that's what we believe and as I said .. I mean obviously he's still got the weak heart, and he always going to have unless he gets a transplant or the Lord gives him a new heart ... but we take every day as it comes now

He's very faddy with his food, he drives me mad ..

I: he says he's lost his appetite

Dot: well, it's .... I-I wouldn't say he's lost his appetite .. he would .. he's say he's lost his appetite .. because he's snacking on things, which is worse for him you know. Like we could go to McDonalds with the Children .. he could eat a burger .. I mean yesterday I did a lovely beef dinner .. he couldn't eat the beef .. he actually got up, was heaving .. he did manage to eat the sprouts, he didn't eat much veg .. did eat sprouts .. it's so different for me cos he would always eat everything .. anything and everything .. never choosy or picky ... he liked his cheese .. I used to stop buying that cos he's always been a cheese fan .... Since he was on the first tablet since he had the first heart attack, you know, things slowed down then and he could never – although he's not one to sit down – the only time he sits is up on his computer and even then he's (squirms) ... but he never sits. He's up and usually doing work around the house or we're out, we have the grandchildren .. so no, he doesn't like sitting but it doesn't lose him any weight cos everything's slowed down .... He's on so many tablets, I've just picked them all up this morning .. I mean they do their job but they slow him down and that's what it does .. and of course over Christmas now he's put the weight on ... And trouble is, I've been on so many diets ... I've dieted all my life .. I've never been excessively big .. I mean I've just got back down to my 14 .. last year I was 16 ..

Pork scratchings .. that's the bag down there .. my son bought him it ... he doesn't realise how many calories are in there .. and they get cross when you tell them 'oh it's only a little bag' you know ...

I: so when did his diet change? Was it since the ICD?

Dot: sorry? ... his snacking's increased cos he don't want to sit down to eating a dinner ..... and he would always eat dinner, loved his dinners with gravy .. doesn't like gravy now ... It's the tablets, all through the day .. he'd never be sick but heaving .. I'm presuming it's the tablets .. his body trying to get used to the tablets ... and we did tell them and they said 'well, you really do need to get over it' cos the tablets he was on, they didn't want to change like, you know. And I mean, there's side effects on all tablets ..

I: so his snacking has increased since the ICD ..

Dot: oh yes, and another thing is he wants things .. he wants something (to eat) and we buy it and then he says 'I won't have that yet' .. you know, he likes it, likes it a lot, go out and get it, and then he's 'oh, I don't want them anymore ... I'm finding it very hard .. he don't like a plate-full of food and it's changed .. I mean, I've been married 45 years and he's always loved his food ... but in any case when you get older, you need to cut down on your food anyway .. They've told him don't have Oxos cos of the salt but 'you've had a drink' 'yeah, oxo' ... It's the food, that's the only thing I find hard, but it's not a big problem really ..

I: Are you worried about shocks?

Dot: I'll be honest with you .. I put that to the back of my mind, because if I .. If I thought about it I'd ... I don't think I would cope with it, do you know what I mean? We never talk .. well, we talk about .. we laughed about it when he first had it done but I think as time's gone by .. it's a year now .. you just don't put it into your life ... we don't 'oh don't get him worked up, he might have a shock' .. we don't do any of that, no we don't we

I: Did you think that at the beginning?

Dot: well, we never really thought about that .. what was on our mind was, he's had it cos he's feeling better .. if he needs to have a shock, it means his heart has stopped .. so really we just took it in our stride to be honest ... I mean, they did say he had shocks but I don't believe that .. no, no, I think when um .. when they said he had the shocks, it was the time when he was very, very ill .. when he couldn't do anything .. he was tired all the time you know.. he didn't feel he had any shocks and I mean how can we tell them, if we don't know ourselves? I mean, he would have known, he would have known if he'd had a shock .. but as I said, it was at a time when he was really down .. in his health .. he wasn't down, he's not a down person ... but his health was .. he was sleeping all the time

I: this was the first six-months?

Dot: yes, this was the first six-months .. yeah after that, he picked up you know and we just take things from day to day now ... I mean we have the nurse .. she does call .. she was calling every couple of weeks .. then it come to monthly and then three-monthly so you know so over time we progressed. She said 'oh Derek, you're doing really well'. They still call, the cardiac nurses, but it's not so often ..

I: She speaks with you as well?

Dot: Yeah

I: having that contact is it important?

Dot: yeah I think so, she explained everything .. about how the heart was working you know .. I mean she came when his legs were all swollen .. so she used to check on his progress and that ..

I: you said the literature they gave you, wasn't really helpful?

Dot: no, no, I mean it didn't tell us ... we actually spoke to someone last summer, we were at the children's sports day .. and there was a man there who'd had it done .. and he said exactly the same thing .. he said he couldn't eat .. he was hungry but once the dinner was in front of him and he couldn't eat it ... and they were like conferring and um ... he had nearly the same as my husband .. he had the defibrillator fitted and what have you .. so it does seem as if .. I mean it can be worse in some patients ..

So, we go out .. with the scooter .. we wouldn't get very far without that .. we thought 'come on, you're only in your 60s, don't want to just sit on a couch' you know, he wouldn't want to do that .. we'd rather be out, doing .. we don't do anything strenuous .... and yet you can't worry about this going off ...

I: so what are the benefits of having this ICD?

Dot: well, since he.. like after the six-months, he done sleeping normal, you know those noises stopped and he sleeps doing ok .. he wasn't doing this before he had this fitted ..

I: what are the benefits for you?

Dot: the benefits I see .. Well, it's hard to explain really because he couldn't walk all that far before we knew that something was wrong .. but what I will say, is he doesn't get out of breath or anything you know, he doesn't walk too far, but he walks ... I do say to the nurse I say 'do we every day, walk up and down the street' and she said 'no, no'.... I was surprised she'd said that to be honest .. she said 'no, he gets plenty of exercise going up and down stairs, walking around' you know that .. that for the condition that she got, she seemed to think that was enough ... I said he's out on his scooter and she said 'no that is fine, he's got to get out to the car .. he's got to get out the car so it's not as if he's sat, not having no exercise .. she said the exercise he's having is enough .. you know .. so we're quite happy with that ... we have got a treadmill out there (points to garage) and she did say if he wants to have a couple of minutes on it ... you know .. for his own benefit ... but they don't seem to want him to have .. they don't want him to stretch it ... you know .. what he's doing, because he's being so good .. they seem to think everything we're doing is ok. I do worry about his weight, I do worry about that .. that's the only thing I worry about .... I do worry about his weight cos it makes his heart work harder doesn't it.. and the other we just take in our stride and thank the Lord that he's still here at 68, you know ...

I: do you see any major disadvantage since you had the ICD?

Dot: major disadvantage? .... No not really cos .... there wouldn't have been anything that would have helped him .. I mean he was into .. is into .. chronic heart failure

I: how much do you know about his heart condition?

Dot: How much do I know? Well how she explained it was, the one side wasn't working .... He only had half the heart working anyway because when he had the first heart attack, the doctor didn't give him the right injection on the way to the hospital .. the medics on the ambulance were really cross with him cos he came to the house and he didn't have this injection .. whatever it was, so he was in pain all the way to the hospital and they couldn't give him (injection) that till they got to the hospital and in that case, the heart damaged .. so the first heart attack damaged the heart ...

I: Did you know his heart was damaged afterwards?

Dot: yes, yes we did .. but what can you do about it .. And then the second heart attack .. he was having side effects to .. like a sort of neuralgia on the face .. and we phoned up the doctor and he just said 'oh stop taking that tablet'. But it was a main tablet that he needed to take .. and within three-months he had another heart attack. But fortunately, he had .. they gave him that injection straight away on the ambulance so that didn't do any more damage ... well it wasn't then till we went to Spain, we were going to Spain, we bought a place out there .. he was having trouble then, he was using the nitro spray cos *a lot* while we were in Spain .. he couldn't .. he'd have to stop and spray you know, and someone said to us, 'you need to go home, you need to check, even if you got to pay for it .. get an angiogram' you know.

Well then we came home .. we paid to get this angiogram and they said you know 'he needs a triple by-pass' but you know, it'll only be about four and half months .. but it wasn't, it was over a year .. Well then we kept phoning up 'oh he's at the top of the list' until in the end we went private anyway and he told us only 20% of the heart was working then and one side was dead. But he still said to us that the side that they were able to do .. still got 20 years of life you know , no problem at all. But then of course you see, as I said to you in the beginning, he didn't have no follow up .. and when the surgeon said '20 years no problem', we thought 'that's it, no problem there' you know ... And I suppose we should have .. but we thought 'oh, he's ok now' ... But they did, thinking about it after .. they should have followed it up .. every year they should have .. and then they would have seen how the heart was getting on ... but obviously they didn't until it was too late .. and the only thing they could offer us was this defibrillator, which we jumped at because there wasn't anything else we could do ... I mean obviously we did have a choice but at the same time, we didn't have a choice because they kept telling us that it is chronic ...

I: and what does that mean?

Dot: well, they just said it is chronic – heart – failure ..... I'm presuming they couldn't have just said you're into heart failure but they kept saying 'it is very, *very* .. your heart is very, *very* weak'

I: Did you look up about it?

Dot: well my husband went on the internet and that you know ....
the thing is at the time we didn't want to know .. too much you
know .. because .. I mean when me and my son went in .. we
listened to the doctors you know, you sort of look at each other and
think you know 'they're not saying ... that it's so ... you can go
anytime' she said you don't want to talk about but that's how we
felt that they were in so many words were saying to us you know ..

I: have you ever said that to the nurses and told them how you felt?

Dot: oh yeah we did, yeah we did .... well she said you know,
again she said she's read up all of the notes and you know she said
it is chronic heart failure .. you know, they have told you how it is ..
they haven't smoothed over it .. they've told you how it is. But I
would rather that, and my husband would rather that you know ..
but it was a shock cos erm ... we had no idea ..no idea. We just
thought it was the weight he'd put on and he just needed to ... well,
that's what we thought. We did not think for one minute the heart
.. there was anything wrong with the heart because it was only
about .. what was it .. five years since he had the by-pass .. so you
know, we thought it can't be the heart .. it's ok, he told us it was ok.

I mean the nurse .. she was very nice, she is very nice but you know,
she didn't smooth it over either. She ... cos I kept saying 'he's not
eating healthy' and she kept saying 'oh well, you know ... he's got to
eat a bit what he wants to eat because of this ' but I thought, you
know, ... So really she was saying 'he's got this condition now' you
know, 'it's pointless cutting this out, cutting that out ..'. That's the
impression I got .. and as I said, she was very very kind but she – she
.. she wasn't as blunt as the doctors , she just said you know 'he ..
his heart as the doctor said is not good but with this we're going to
bring him .. with these tablets ..' .. I mean he was trying all these
different tablets .. he's still trying them now, he was put on another
one about four – five months ago, which again ... amiodarone .. he
said ' this is a dangerous tablet' .. and i was thinking ' if it's
dangerous, why we having to take it?' But that was the words they
said ... We used to come out of there and my son used to say 'don't
take any notice of them mum .. you got to go, do the checkups just
don't take any notice .. dad's going to be ok, he's got the Lord'.
When he took that tablet, and Derek was a little bit .. wary of taking
it .. he was taking it in the afternoon and then he wasn't taking it
and then she came (nurse) and sometimes he would miss Lisinopril
in the night .. 'I didn't take that one cos I thought my blood pressure
..' we got the blood pressure thing down there (points to it) he said
'I'm feeling ok, I didn't think I needed it'. She said 'Derek, you need
that one, it's imperative you take the Lisinopril cos it works with the
other one, and it does the job for the heart' and with the other
tablet, she said 'Derek, it's all working to get the heart health .. wo-
.. it can help the heart, can't make it better, but can help the heart '.
So I got all the tablets .. give him when he has it .. she was very good
explained it all to us ... drew pictures for us how the lisinopril helped

with the beta-blocker and how this new tablet's going to help .... so she 's been very very good.

I: do you think you focus more on the drug side of it rather than the defib?

Dot: erm yeah we .. as I said, my husband has got it and he says sometimes ' ooh ooh, look how big that is' (ICD) but otherwise no we don't , the tablets we know we got to take and they stress to us that these tablets help ... they have got the heart into sync .. it does half the job and the tablets do the other half .. so if they hadn't explained it to us like that ... my husband was getting to the state where he didn't want to take all these tablets, especially the ones that brought his blood pressure down too low ..

I: Is there anything the doctors or nurses could have given you to read that would have helped .. helped how you were feeling?

Dot: no not really .. I'm with him when he goes to the doctors, I'm listening to what they say .. and I'm able to give them a little bit more information that what he did cos I can see what is happening ... no, not really ... all in all they've been pretty good ....

My husband was worried that if he did die, this thing you know, would go off and keep bringing him back .. if it goes off he has to go in .. she said it goes off once but then it has to be reset .. this is why I couldn't understand when they said 'ooh, it's gone off two, three times' .... they were a little bit vague about that .. and (name of nurse) did say a patient of hers went off 36 times and he didn't know ... but as I said, we understood that when it goes off, you got to go in and have it reset .. he's got to get back on the machine and do it .. I don't know ...

I: Are you worried about the shock aspect?

Dot: no, no, mind .. we haven't had one yet ... but no

I: So you don't live day to day thinking about it?

Dot: no, no .. I don't think you'd get on with your life .. because you'd be thinking 'oh, we don't want to put stress on him' .. no we don't ... he's very good, he knows how he feels .. if he wakes up and 'don't feel so good today' he'll take it easy .. it's usually when his blood pressure is low ..

I: so when he wakes up and says he doesn't feel well, you check his blood pressure?

Dot: yes we do usually, yes that's what we do ... that's what he normally does ... but doesn't happen very often .. we went to London, went on the train, got taxis, we coped with all that .. you know we don't see the point in sitting here 'oh don't want to overdo myself' that's not living .. not living ... this is why he had no quality of life before ...before he had it (ICD) put it then, it was getting we had no quality of life and that's why we decided to have it done .. unfortunately as I said, it took six-months to kick it ...

I: has it been worthwhile now?

Dot: *I* think so, I think so, yeah yeah .. as I said, I don't know what he said, did he say it's been worthwhile? Worthwhile or ...?

I: well, we didn't have exactly the same conversation but I think on the whole yes ..

(receives phone call from heart failure nurse)

Dot: we liaise more with the heart failure nurse than the arrhythmia nurse .. they are always there at the end of the phone .. if I need them they are there but luckily we haven't needed them .. has that helped you?

I: Yes, it's been interesting. Can I go back to something you said, you said that when they told you your husband had chronic heart failure and needed and ICD you didn't really want to know too much. What about now, has this changed? Would you like to know more now?

Dot: I think it would have been good for them ... as far as we were concerned .. you know, that they would like to fit this device ... it sounded to us that without it .. you know, your heart's in a very bad way but of course they said 'it's your choice but we would advise you ..' you know 'that's what we can do for you to get your heart back into sync.' I think they could have said, told us that while this device is getting your heart into sync .. cos it didn't do it straight away, no it didn't .. well it couldn't cos it was in too bad a way ... They should have warned us a little bit more .. well you know, 'you might feel worse cos of what's happening in your body with this erm .. device ... I think if they had forewarned us a little bit ... you know if they had said you might feel quite poorly, I don't think it would have put us off having it because we're not stupid, we do realise that's all that they could do .. and you know .. things would not have got any better .. it would only have got worse, breathing and everything else you know. So, I'm sure we would have had it put in, but it would have been nice if they had forewarned us a little bit .. like your appetite and stuff like that might go .. they didn't tell us any of that and the literature doesn't tell you any of that either ... I know everybody's different but they have done lots of operations so they have the results of lots of different people so they could have said 'you might not get these side-effects, but you might get these side-effects' ... like with the swollen legs and feet, that was chronic .. that was terrible.

I: Do you think it was maybe trial and error as to which drugs worked?

Dot: We didn't realise that that (ICD) did half the work and the drugs the other half and that was trial and error ... I would recommend it (ICD) to people but rather that they know it doesn't work (straight away) ... cos it was *horrendous* ... with those noises in the night, you know we did not have a good night's sleep for about six-months

Transcript for S05.1

Female aged 40
Husband has ICD for Idiopathic Dilated Cardiomyopathy (secondary prevention)
In line with ethics, the Participant's name has been changed to 'Charlotte' (C) and 'I' stands for the interviewer.

I: Do you want to tell me about your husband, what happened to your husband?

C: yeah, sure .. there were no symptoms of his cardiomyopathy at all ...

I: what type of cardiomyopathy has he got?

C: Idiopathic dilated ... we were out one day, lunch time it was June 22nd .. I can remember dates .. and we'd been out for lunch, he'd picked me up from work .. and we were driving back to my work on X Road and we must have been about 2 minutes away and he suddenly said 'I don't feel very well'. He went white, started sweating ... anyway, we stopped at the lights .... and he said 'your work's literally 30 seconds away, we'll get to your work and I'll have a glass of water ... we were in the inside lane and the car swerved to the outside lane .. I looked over to say 'what on earth are you doing?' and he was collapsed on the steering wheel. And the car went into the central reservation, knocking a lamppost over onto the other dual carriageway hitting two cars and a van .. we had two cars hit us and we hit another car in front ... basically it was just chaos (small laugh) .. on a Monday lunchtime and then ... I got out the car, Joseph (name changed) was still unconscious .. and .. um .. fortunately lots of people around cos it was Monday lunchtime .. I started to get a bit hysterical, Joseph came to and the focus was on me and I said 'No, it's my husband .. he collapsed at the wheel and the ambulance came .. it's a good place to crash, cos it's handy for all the emergency services .. took us to hospital and that's when all the investigations began and they realised that he had these arrhythmias. So, what had happened was he'd had these sustained VT and that causes .. basically he died at the wheel .. heart failure .. but the impact of the lamppost defibbed him back, that's what the consultant believes so. He only popped out for half an hour and he was gone for two weeks .. our joke ...

I: that must have been so frightening ...

C: it was yeah ... i think one was the shock of the crash .. cos I was awake the whole time it happened .. and secondly was Joseph being diagnosed .. I remember thinking I was going to pass out when the consultant told us .. cos we'd just got engaged ... so it was all like .. a lot of things all happening at once .. So he was in the hospital on B

Ward for two weeks ... did the tests, diagnosed him with dilated cardiomyopathy and then the ICD, cos the VTs are quite .. his arrhythmia's pretty bad ..

I: I believe he's had some shocks?

C: He had two shocks before Christmas yeah, about 21st December I believe ..

I: And is that the first one he's had since the ICD?

C: yes

I: how did you cope with that?

C: Pretty ... Not very well, I wanted to phone the ambulance, I was very scared ... afraid

I: What actually happened, do you mind me asking?

C: No, not at all, I was at the Christmas Party and he was coming to collect me .. um ... and um .. basically messed up where we were meeting each other so he was wandering around looking for me and it went off and hit him when he was on his own .. and it hit him twice .. but Joseph will be able to tell you more about the events because I wasn't with him at the time.

I: So did that upset you?

C: Yeah .. he went to the hospital the next day to have it checked out .. but it was all fine. They thought it might be over sensitive but he ... it's weird at the hospital cos he went in and he came back and said 'no, no it's fine .. it's over sensitive'. And yet we went to see the consultant about two weeks ago .. Dr Y ... and he said 'Joseph you're a very lucky man .. if you didn't have it, you'd be dead now'... So, you kind of get mixed messages from the hospital sometimes ... you know, it's like they're not playing straight with you sometimes, which I don't like ...

I: You'd rather know?

C: I'd rather know ... and the technicians just seem to do their job with the electronics, they don't do the actual .. you know, tell you what's actually gone on. And of the two of us, I'm the one who's far more inquisitive .. So, If Joseph's on his own, he just lets things happen, whereas I'm there, I can badger them .. say this 'what's going on here, why's this happening? 'Don't tell me it's life-threatening, what do the trace show?' ... I need to know these things .. I don't like bland statements, I need to know what's happening and why it's happening ..

I: So, you want to know as much as possible ..

C: I do, yeah. And effectively, he had sustained VT again, which led to the device going off .. so it's doing its job, which is a good thing, but I guess ... also .... but when it happens, it makes me more anxious about Joseph dying .. thinking, he nearly went then, what if it doesn't work properly sort of thing ..

I: that goes through your mind?

C: yeah

I: how do you cope with those fears?

C: hum ... . interesting I don't really tell Joseph about those .. you know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful so I keep it to myself and rationalise it away .. he has the device, it works, it's been checked

I: and does it take the fear away?

C: the fact it's checked?

I: when you rationalise it

C: uh .. I think because he's doing so well with his cardiomyopathy, it's like a reminder that he has got a serious condition .. it's more of a jolt in that way .. and we haven't yet established what caused it, what the ... he's not being treated for it .. at the moment the tablets are maintaining the disease, not curing it. So, when it goes off, it makes you more aware of his mortality .. that it's a life threatening condition

I: ok ... do you think it could be controlled, the cardiomyopathy?

C: It can't be cured, it can be controlled with drugs to ensure the heart doesn't work so hard .. the beta-blockers, the ace inhibitors all help in that regard .... Well it's not .... every patient's different, you know some patients improve, some don't, some deteriorate quite rapidly .. and the prognosis of the disease is very different between people ... so, you never know how things are going to pan out ..

I: you seem to have done a lot of background research into this condition ...

C: yes I have, yes, ... So, Joseph has enrolled to become part of a stem cell trial in London ... that's an area of my interest, stem cell research .... and I've read a lot about it and it's the only thing that's offering any help for patients at the moment .. so he's enrolled on that. But we've had to postpone it because the ICD went off, we want to find out more about what's causing the arrhythmia and whether anything can be done .. So, there's two possible outcomes, these tests, he's undergone a myocardiopathy infusion test and that will show if there are any blockages to the branch arteries to the heart causing a lack of oxygen to the muscle, therefore causing cardiomyopathy, which can ameliorated a bit with a stent. And if that's not the case then ... he's having the tests now

I: eighteen months down the line?

C: yes, it's a bit fractured I have to say .. cardiomyopathy treatment is quite strange .. you know I would have thought you would have a patient, get them on an ICD, stabilise them and then investigate what the causes are and go from there ... There's two reasons, one is if there is something that can be done about it, it's good to be done earlier, secondly if it does look like it's genetic, you get the genetic tests done quickly, cos Joseph has two children from his first marriage and they could .. you know .. be carriers of those genes, so I would have thought for many reasons, it's good to find out sooner rather than later .... So, it does seem to be a bit haphazard the treatment .. I find.

I: How does that make you feel?

C: um ... I get frustrated .. I feel not enough information is given to patients, I don't know if it's the scientist in me but I almost want a flow chart with 'this is what he has, these are the possible reasons, this is what we're going to do for each one, and these are the outcomes .. and we're going to follow this here time-table' ... But it doesn't happen like that .. part of it is it's the NHS and also Joseph's cardiomyopathy .. he's coping so well with it ..

I: when you say he's coping so well, what do you mean?

C: Well I know a lot of patients with cardiomyopathy have trouble breathing, doing normal tasks. Joseph's got property and he does a lot of outside work ... you know just tree surgery, guttering, you know all kinds of active outdoor work ... and even though he might be slower than he was and although he can't do so much, he can still do it. Which, we've been told is fairly unusual . And we put it down to, he was very very fit before he had the attacks, he used to play a lot of rugby and to his mindset 'I'm not going to be beaten by this'. But he does get tired in between, but the fact that ... you know .... when he first came out of hospital, he started running with me again, short of breath ..

I: how long after?

C: about er .. four or five months after ... the first six months were the worst then after that it got better ...

I: the first six months were the worst?

C: um adjusting to what'd happened ... I think for both of us just getting used to it, Joseph was suddenly drained of energy, you got to get used to drugs, they make you sleepy, they tire you out. They make you very dizzy, you get hypertension so when you stand up you feel dizzy .. and it takes a lot of getting used to and you .. and he was very down for a long time .. although he'd probably say he wasn't, he was ...

I: did you ask him?

C: yeah, we'd talk about how he was feeling, and he would just shrug his shoulders and just say it was one of those things 'I just got to get on with it'

I: would it be fair to say in the first six months there was lack of talking about how you were feeling?

C: yeah probably, we were dealing with it in different ways .. he came out of hospital in July, got married in the November, so we had wedding things to do as well .. it was good .. we had a great wedding, great honeymoon, he was really well, so it was like he stored up all his energy for that and when we got back, we started running together.

But the first six months I was like .... I was so scared ... every time he felt dizzy, I thought he was going to collapse on me or die. I'd be like a cat, you know .. if he said he felt unwell, I could feel my whole nervous system kicking in .. adrenalin .. and I'd be so anxious, worried about it

I: so what's changed .. after six months?

C: because I got used to it, that's all it was ... just got used to the fact he was dizzy and what it meant.. it didn't mean he was going to collapse, it was part of his treatment. And also I read a hell of a lot. I researched the hell out of cardiomyopathy .. so read lots of papers, went on the cardiomyopathy site, went to forums, saw how other people were coping. And I realised by reading other people's experiences, this was normal

I: and that's what made you feel assured?

C: yes, the experiences and the symptoms they had, they were what Joseph had ... so it's universal for cardiomyopathy sufferers .. but going back to your study (we had a long chat before interview about the study), this kind information is not there ... for patients and partners. When you go, it's kind of slap your ICD in, shake your hand and out you go

I: what would you like to see more of?

C: I think there could be more support for patients, certainly the first six months to a year, in terms of you know, someone the partners and patients can talk to about their worries, that isn't you know, a cardio-technician, a consultant, but on the kind of quality of life side. So, I could pick up the phone and 'it's completely normal, we understand your fears .. don't worry it's part and parcel of taking the tablets'

I: you've never felt able to speak to the ICD nurse?

C: no, I didn't think it was an option for a partner to do that ... so I just kind of learned everything myself ... certainly knowing things were normal kind of took away my fear ... I think everyone who has this (ICD) is different and you have different relationships but it's kind of understanding they are going to be tired all the time, feel dizzy. You know I ask Joe to describe how it feels, you know, it's hard to imagine. And you get to know your partner. After eating Joe's always felt more dizzy, more tired. So, these things, you kind of pick up cues from your partner and as I said because I research, it got me a bit more relaxed.

So, from the moment the consultant told me the condition Joe had, I was immediately researching it (laughs) .. lifelong geek! And in terms of the ICD, Joe's always been .. because he's quite muscular, it's quite proud and the wires are prominent and they're kind of worried about it breaking through at some point .. so he's got to keep an eye on that. So, he's very conscious .. I've got used to it now, I don't even notice it's there cos its .. part of our life, it's there, I've grown used to it. And the ICD when we were back in hospital ... it's hard for a partner to get information in the cardio ward ... they seemed quite off-hand. I wanted to sit down and talk to them about Joe's illness .. they weren't really forthcoming with info .. and it was basically, we're going to put an ICD in .. spoke to the ICD nurse about what an ICD was and they show you one, tell you about the procedure, what's going to happen, how it works that kind of stuff. ... And then they put one in and then you go. So, it's kind of .. you know .. the consultant said 'right, you can live a normal life now .. you're fine, off you go' kind of thing. It was all a bit kind of brusque and dismissive almost. And I remember for quite a few months I was worried about it going off .. 'would it go off when I was next to him? "would it go off when we were in bed?' 'how would I react?'

I: so when you felt these fears, it was the first what three months?

C: yeah, until it kind of hasn't gone off, and then you forget to worry about it, if that makes sense because ...

I: what do you do when you are worried?

C: nothing really I don't think. You just worry about it, there's nothing you can do.

I: Does it stop you doing anything?

C: I suppose you have a worry when you hug people, you think 'what if it goes off and I feel it?'

I: so were you worried about yourself?

C: well I was worried about what would happen to Joe, 'how would I cope?'. 'If it went off, how would it affect us?' you know, all rational, irrational fears I guess

I: And now it has gone off, how do you feel?

C: I mean, I wasn't there .. Joe has described it being punched in the back very hard ... I guess one thing is that it works, which in a strange twisted way is kind of good .. it was there to do the job and it did the job, so that makes you feel safer in some respects .. but because Joe described quite well how he felt before it went off .. certain times he's felt unwell recently, I've thought is it going to go off again and he worries a lot about that

I: and what do you do when he says he doesn't feel very well?

C: just be quiet for a while and see what happens ..sit down, relax until he feels better again. It's like a dangling sword hanging over you waiting for it, but it hasn't gone off thank goodness.

I: what is your perception of the shock? What does it mean to you?

C: .... it's interesting because when Joe went the next day and they said it's over sensitive and then the doctor said it's saved your life .. it's not consistent. They said it might be over sensitive, went back to the technician and he said 'oh no, the settings are fine' .. I don't know. You don't get consistency between the technicians and the consultants ... You need more holistic .. he went for an echocardiogram, to give an idea of the ejection fraction and with the consultant, I actually had to ask what was the result of the ejection fraction and if I didn't ask, it wouldn't be relayed and actually it had improved, which was great news. So, 'why didn't you tell us this?'

And there's a lot of confusion between .. you know we went for the myocardial profusion test .. you're on a treadmill and you're all wired up and the ECG's going bananas .. so the consultant stops it thinking Joe's going to drop dead and the technician says 'on no, that's fine, that's just his pacer in his ICD kicking in .... So, it's not all kind of 'joined up' in some respects. I understand they're doing their best and it's very specialised but you kind of think they don't know what's going on really. And I don't know enough about it to know whether those shocks were due to a life-threatening VT or was just an inappropriate shock .. I've no idea.

My coping is I've got to know everything inside out, I'm sure it annoys Joe when I'm with him 'well, what does that mean? And how does that work? why are you doing that?' Whether that's more irritating or not, I'm not sure

I: but that's your way of coping ..

C: I think so. I need to know things. I think the information I've found on the web has been enormously helpful but I'd say the information .. certainly that you get verbally from the consultants and certainly the literature is kind of ... well it didn't really help in any way.

I: too basic?

C: far too basic. Yeah. Totally. So, more would have been good, and something like 'what to expect' something like that, you know a leaflet 'what to expect when you go home' , your partner, this is completely normal .. you know just what to expect both quantitatively, medically and from a psychological stand point. And then some links to say, if you want to find out any more about these things, here's where to find more info .. So, you can go deeper if you want to, to relevant sites you know, that kind of thing

I: that's useful to know

C: you know, that kind of fact sheet ...

I: which websites have you found most useful?

C: well i think because I'm a scientist, I go the peer-reviewed papers, so I go to Scopus and read all the latest papers on it. I'll email you the journals which I find particularly useful ... but also on the web you get contradictory information so it says, you know, '50% of patients are dead within 5 years, blah, blah, blah'. Then you read the peer-reviewed papers and find actually that's incorrect ... so although there's information on the web, unless you know how to dig deeper you'd actually think it was real. So, for people who go away and do research, it making sure you know what's fact and what's not fact and what the prognosis ...... No-one really talks about prognosis, you know, you go 'what's the prognosis?' and they just say 'oh you know, everyone's different' .. you know, it's just so vague.

I: would you find something on coping helpful?

C: Certainly something on leaving hospital and coping would be really helpful ... maybe the ICD nurses are accessible to partners, making it more .. making partners aware, yes she is there, yes you can phone her up for anything trivial or large, as you say the partner's important for helping the patient recover and if you're kind of feeling ok about things, you're more likely be able to help. So, that's why I find your study is very relevant to helping.

I: have you ever been to a support group meeting?

C: yes, we went to one, where they had people talking about ICDs and .. a talk by somebody and then you could ask questions. But this is going to sound awful but I found it really basic. And obviously people want to focus on themselves so ... people were just coming up with ridiculous things 'can't believe you just said that' ... it's moronic, you just have to sit there going (makes a grimace). So, it's just different things for different people isn't it. We've all got different ways we got to cope but ... the only thing I discovered from there was other people suffer from sleep issues, which are down to beta-blockers so that was a kind of handy bit of information and that was ... we haven't bothered going back to any more. Don't find them helpful. The way they're kind of put together and held are not ... maybe for other people, it's good to reach out and have .. meet people over a cup of tea who they can phone up and have a chat with them ... And the age gap. Most people in there were in the late 60s, 70s, and for me that age-gap is huge .. so for Joe and I we're young, Joe is 50, I'm 40 so it's kind of ... So, it's not so dynamic for us.

I: yeah I suppose there may be age related issues.

C: maybe ... So, we tried one and it didn't really work for us, so apart from that I just look as and when I need info. Especially on how your drugs work and what to expect, rather than me having to rifle through to see what you get in the boxes, you look them up. And the GPs God bless them, don't know. I wouldn't expect them to, you know I'm going 'how's an Ace Inhibitor work?' And they look 'I don't know'. And about dosing, they're talking about titrating Joe's dose on his ace inhibitor from what it is now ..... that's never happened. So, all these kind of little things .. you know, the care is not as holistic as I'd like it to be. And I don't know why that is

I: funding?

C: funding. That's why I say Joe's hoping to be .. you know there are probably people out there coping really poorly and need more input than Joe. You know, it's a really interesting point about quality of life cos when we went to the hospital in London, to have an interview to see if Joe met the inclusion criteria for the stem cell study and there were quantitative and qualitative outcomes and the qualitative outcomes were about quality of life and things like 'can you walk?' 'Can you do this and that?' And Joe said 'well, I can do all those things' so they were wondering whether to put him in the study. So, Joe said 'well before this I used to play rugby'. You know his level of having a life, is on a different scale

I: yeah thinking about some of the measures used for quality of life are like 'can you walk up the stairs?'

C: Yeah exactly. I mean Joe can run up the stairs, I mean it's just a different level of quality of life. I mean Joe can't play rugby anymore and when we went skiing at Christmas he was worried .. especially as his device had just gone off .. what would happen if his device went off in the mountains and how he'd cope, how his skiing might be affected. So, it's different, you know what I mean, it's a different kind of quality of life 'yes I can run up the stairs, but no I can't be so gung ho about my skiing and I can't play rugby'. You know, 'I can't run as fast as I used to'.. And I tell you, what scared Joe, was he was up a ladder the day his ICD went off, without a harness, doing some work, so he had to rethink the whole ladder thing .. it went off later in the day, but if it had gone off up the ladder, he'd be dead. Cos he would have been thrown off the ladder .. So It's a different quality of life, before he'd be up trees, up ladders not worrying about it, now he has to think about harnessing ... so you know, for him it was a different quality of life rather than be able to get around.

I: And how do you feel on holiday like when you're skiing? Because it was after the shocks.

C: yes, we went away on December 24th ... yeah I was worried about the driving there

I: do you do the driving?

C: No Joe's got his license back .. we both share the driving and we were worrying about how he'd be with the skiing and whether it would spoil the enjoyment of the holiday, cos he was worried about the device going off.

I: How do your children cope? (children's toys all around)

C: Oh he's fine with it, he's mine from my previous marriage, he's known Joe for two years .. but no, he's fine with it ... (laughs) morbidly fascinated about it 'tell me about your heart failure again Joe'. 'When you're out, you're not going to crash the car again are you Joe', that sort of thing .. take the mick out of him. Because Joe's not ... you know we do normal things, go out as a family

I: Is there anything you don't do now because it's affected you?

C: erm ... trying to think ... probably don't as much things .. I think the only thing that's been affected per se is we don't do as much cos Joe's always gets tired ... It's like ying and yang. He's working hard say for a few days on a job then at the weekend he could be really tired, not want to do much.

I: How does that affect you?

C: um .. I get a bit bored. You know, I wish we could do a bit more things but I understand ... I'm understanding that Joe doesn't want to do it cos he's tired .. it's his work, you know, I know why he's tired, and I know it's taken it out of him and I say perhaps we ought to look at what you do as his job and think about doing something else, but he can't .. he loves it. I think if he stopped doing what he enjoyed, that would be it, you know. That would take away any kind of purpose in life so ..

I: (inaudible)

C: Oh I just off and do things, you know. It would just be nice to do more things. I guess .. I've know Joe more with the ICD than I've known him without it. So, it gets .. you kind of get normalised don't you.

Apart from that I can't think of anything that's been affected per se by ... the device. But as I said information for parents .. parents? I mean partners and patients on the quality of life side would be good .. just some vague statements about being more tired and not being able to walk would be good.

I: How about your sex life?

C: Sex life? No, it's fine. Not been affected at all.

Transcript for N06.1
Female aged 50
Husband has ICD for secondary prevention; survived a massive MI and cardiac arrest.
In line with ethics, participant's name has been changed to Sheryl (S). 'I' stands for Interviewer

I: your husband was telling about his heart attack ....

S: he don't remember nothing but I remember it all ... remember it all ... he was at the hospital everything, cos he was just on the bed .... pumping and pumping, nothing you know ... shocking him, pumping him cos ... when the paramedics took him from here they said 'oh nothing to worry about, just .. no rush, just follow us down .. go to CCU'. So, I was going to go down on my own but my daughter, I got one living with me and her little girl and I've got another living up the top here, phoned her .. she came down with me .. we got down to A&E and told them about my husband, and they told me to go to CCU .. they phoned .. 'yes, go down to CCU' .. We started walking down to CCU and this young boy come running after us, Mrs X quickly come back ... why? ... 'come back innit ... very bad .. very bad'. So I thought 'bad', you know they told us it was just indigestion. We rushed, got back, took us in a little room ....

[interrupted by her nephew who also had been fitted with ICD, but leaves shortly after realising she is in the middle of an interview]

.... so we got back then, they took us in a little room and there was a doctor and a nurse there and she said 'your husband, very bad, very bad'. And me silly, 'yes, ok, where is he? Where is he?' 'No, you're not listening to me Mrs X she said, 'your husband is clinically dead' 'No, no'. So he said 'come and see him'. My daughter wouldn't, she was worked up innit. So, sorry .... [begins to cry] I'm always like this .... sorry ... and I went and he was there .. on the bed .. the staff were fantastic .. they were ... they were pumping and pumping .. they said 'there's nothing' so I said ... fair play to the nurse, she was holding my hand and going 'come on, come on' like that .. And she said to me 'shout at him' ...'pardon?' ... she said 'shout at him ... I believe in it she said, shout at him'... So, I thought 'right' and I shouted 'Sam! (name changed) you ain't leaving me like this', so I said 'come on!' So she said 'come on, I'll take you back' And I turned and I walked about .. say about 10 steps .. they said 'we got a heartbeat, we got a pulse, he's back, he's back!'

Then we had to wait then while they took him up to ... to um, have a stent put in .. through the groin .. they said it was the critical time because two arteries to the heart was blocked .... so they had to get him up to theatre to get a stent put in and so I thought 'right' ... We waited and waited, they told me I had to get his father who is 80, 81

... how the heck do you tell an 81 year old man? So, his sister lives up by (in England) and I said 'right, I'll have to phone her' so I phoned her, fair play she come straight down. She said 'don't tell dad, I'll bring him down with me'. So I thought 'right'. I got my other son to come ... they [doctors] come then and said 'everything went fine. He was up in intensive care but was still touch and go'. I said 'right-on'. Well we went up there, he said 'he's fine' ... one doctor said his heart had stopped for 20 minutes', so I thought 'that's not too bad'. Then the head one came and said 'has anyone explained to you what's happened?' Well I said 'no, nobody has explained to me what's happened'.

'Right' he said. 'Your husband has had a massive heart attack' he said. 'The two valves to the heart was blocked. We've reopened them and put a stent in .. but your husband's heart stopped for 45 minutes so we are worried now that he might have brain damage .. we want to take him off the ventilator, we want to see if he's got all his faculties'.

Well, they took his ventilator off him, and he come around .. he asked a few questions like my husband normally does and they said 'is he alright?' And I said 'to me his functions are right for what he's saying'. Then of course then, he took a turn for the worst .. all his kidneys collapsed, his oxygen that went down .. so they had to re-vent him again .. they had to put him on dialysis machine and take him then from one ward which was the one after, into to the real ICU ... where there was 24 hours looking after him ... but they thought he wouldn't pull through but he's a strong man and he did.

I: very determined ..

S: oh he's very, very determined. There was a 'silence of the lamb's' mask well, he wouldn't put it on .. 'you put that on me, and I'm off' he said. Doctor said 'very, very strong willed man' he said. I said 'that's me husband'. And touch wood, he's come well. He has come very well. It's been a lot of hard work, but this box [ICD] is sort of giving him gip ... It's more .. like I explained to Dr .. who we went down to see ... it's more my peace of mind, cos I am ... how can I explain, I'm frightened, I don't sleep .. because I'm watching him all the time .. and I'm frightened something .. 'boy' I said ' when you putting that box in, you're putting my mind at ease .. I know if something happens to his heart, that will shock him and I know something's happening. That's the way I feel, but he' s a bit now, he said to me 'I want it out' like ... but I don't want him to take him it out

I: so for you the box is ...

S: is a good thing. It is a good thing, cos it puts my mind at ease. Cos my daughter come home the other week and sometimes Sam, on a Friday he goes up to bed for an hour, if he's tired and he might be up there for a while ... and you know, my daughter , she turned to her little girl and she's seven now, 'go and wait Dadu up' and I'm like 'NO!' I said 'no!' She looked at me, and said 'what's happening' 'well he's been up there a while on his own ... and I'm petrified ... cos a lot of people have said 'you have a heart attack, you gone' ... when I see Sam on that bed [in hospital], there was nothing .. and I don't want my granddaughter to see it ... do you understand? [S finding it clearly difficult to talk – was asked if she would like to stop the interview] .... That's what frightens me

I: you're still frightened?

S: yep .. still now [sobbing] ... sorry

[S asked again if she would prefer to stop]

S: no, I am like this anyway ...

I: it must be very frightening ..

S: 'indigestion' he was going .. 'the pain, the pain' and he's stubborn see 'let me phone the ambulance .. 'no, no' ... then one o'clock when I come down by here .. cos my daughter, she said 'mum, he's in a hell of a state' ... 'look I'm not arguing with you, I'm phoning the ambulance' and the doctor said 'you're a very lucky man' he said. 'If your wife hadn't phoned that ambulance, you would not be here' ... but he can't remember nothing about it .. nothing at all. The only thing he remembers was waking up in the hospital. Two weeks it was, you know for him to come around to know what was happening.

I: so you said the ICD makes you feel assured

S: What he said, what Dr said, it won't prevent it .. heart attack, it won't *prevent* that but it will ... it gives you a warning ... do you understand? If Sam has a shock then that's telling you that's something wrong with that heart ... so it's given you *a warning*, and that's what's put my mind at ease ... so I think, well at least I'll have a warning ... there'll be no ... going upstairs and finding your husband dead in bed as they say ...

I: but you say you still worry?

S: I still worry ... I do still worry about it. But I said to Dr but I am sc- ... when [ICD nurse], she was talking to us whatever, and I said 'it's not my decision, it's not body, it's his decision' but at the end of the day, I wanted him to have the box. I said, at least then, I know there's something there that's going to give you a warning plus me a warning ...

I: this was when you were first told about it ...

S: yes .. we went down and he had to have tests done and you know they took him into the room .. cos my husband .. how can explain .. he's [chronic medical disability] and from the age when he was born up until the age he was 21 .. it was operations on the legs, back and fore hospitals and he hates hospitals. When i was having my children .. he come in, two minutes sat down, 'right I got to go', he hates hospitals but fair play to him you know, he's been good to this and he knows he's got to do it .. he's got to. He turned to the doctor and said 'well look, what good is this box to me?' And he said, 'well, it won't stop the heart attack, you know, it'll give you a warning Sam'. So, he said 'what'd you recommend?' 'Well I'd recommend you to have' he said. So, he said 'so, you're saying if I want to see my granddaughter getting married and grown up I'm to have it done'. 'Yes' he said. And that's why he decided to have it done. And it is, he done the box ... when he does things, he don't like doing them on his own...

I: when he does what sorry?

S: when he does the box, the reading and that, it's like Thursday now when he goes to the hospital, he won't go on his own ... I've got to go with him.

I: Has he always been like that or is this a change?

S: always been like that ...

I: is it because it's a hospital?

S: Hospital. If it was him had to go on his own, he wouldn't go. He'd say 'no, I won't bother'. But this time, he *made* the appointment ... he phoned [Nurse] and made the appointment about the box ... when we talking to [name of man who'd walked in earlier], he's a bigger boy, bigger up here [points to chest] so the defib is there and he has had no trouble with it. Now Sam's now, seems to be moving so i think the smaller you are, the less muscle you got to hold it in. And that's the only trouble he's had with it ... he hasn't had no shocks or nothing with it

I: so the benefits for you are you feel he's safe?

S: you feel ... you do feel a lot bett-safer .. cos you do worry. I do anyway, I'm terrible. I am a worrier like ..

I: have you always been like that?

S: no, the only time I been .. I've had bad nerves ... but my brother .. go back three years ago, he hung himself in my mother's house, and I had to cut him down .... so of course, now I panic, I'm terrible ... I panic terrible and within a year you can say, I had my brother and then I had Sam who had a big, massive heart attack. So, I had two people dead on me that I couldn't understand so, this box to me, is my lifeline ... I know he's got it in there and its going to show me if anything's going to happen and it's a good thing for that. The worse thing is when he's in bed and he goes to move 'urgh' and then you get the noises you know, 'oooh' 'aagh' and I panic then. I say ' is there something wrong, is there something wrong?' And he goes "No, I'm alright, I'm alright'. 'Have you had a shock?'

I: inaudible

S: that .. that's what the nurse said 'if he'd had a shock, you'd know it .. it would knock him' she said because I do tease him. I got the weight up .. the magnet up there .. 'you play up and you'll have it' .. 'don't you dare come near me with that' here's the box ... [walks over to stairs where the box to send readings was]

I: your husband was telling me, he'd rather see someone face to face? What about you?

S: with Sam, he panics .. what I said was with [nurse] you can phone her, fair play you can phone her, but maybe she's off and then of course you've got to wait. As soon as she gets the message, she phone's back straight away but you need someone you can get in touch with to talk ... you know, is this right? Is this supposed to be happening? You know and that what he is ... this now, you take it to my mother's, plug it in to the telephone and it do what they said would happen to it .. marvellous .. but I think you just need someone to .. how do I explain it .. cos when you go down, they don't talk .. they don't think of the partner .. what the partner would like ... Sam do say to me 'oh don't be silly, don't be silly .. it's not going to happen again, it's not going to happen again' but .. it's in your mind and it is constantly in your mind .. 'well is it going to happen again',' what's going to happen' .. it's there.

I: what do mean?

S: the heart ... you're frightened that the heart is going to block again ... because it frightened me so much , my husband hasn't smoked since that day .... and I give up ... he give up on 16th January and when he was better, everything fine I give up on 1st February and I haven't touched a fag since .. it does frighten you. My sister smokes now, and my daughter. My son give up, my son give up the week that it happened ... they seen what he went through

I: do you think the smoking attributed to the heart attack?

S: yes I do .. because i got to explain, when my husband was in intensive care .. they had .. behind him they had jugs .. which they had down his throat .. cos his chest was bad see, he had to have a pipe put down to clean, clean the chest, the lungs. And I look like that and I said to my son .. he said 'what's that mammy?' 'that's what's coming off your father's chest ' I said, 'that's through smoking' and it was black like tar .. he smoked from the age of 15 .. and it was black ... and I turned to my son and I said 'I'm not going to put you through this .. so I give up. So, he give up, he got two boys he has .. I said 'it's up to you, but you remember you got two children' ...

I: so, it was a massive wake-up call to the whole family ...

S: Oh I tell you the truth, if somebody had said to me .. cos I was a heavy smoker, I was heavier than my husband ... and if somebody had said 'you'll give up fags' and I'll had said 'no' ... because even the doctor tell me 'you got to give up .. give up smoking' .. 'no, no' ... After seeing that I did ... I'm healthier and my husband is healthier for it ... before, I couldn't walk out of there .. I'd be 'huuh, huuh' [deep breath sighs] but now, I can walk up the school with my granddaughter .. it's marvellous, it's marvellous.

I: so come good has come from it ...

S: some good has come out of it

I: so how do you cope with it ... you know you said, your husband goes upstairs and he has a lot of sleep ... and you're worried it may happen again, especially as you're worried about what a shock will be like , so what do you tell yourself? What do you do?

S: well I ask a lot of questions. Sam doesn't. When I went down to the nurse she said 'if this keeps on shocking him, the defib, you got to put the magnet on and I said 'yeah, you put the magnet on, but if Sam's on the floor, do you keep the magnet on?' 'No, no' but it's still shocking him then, that's what I don't understand .. what do you do ... there's not enough to tell you .. do you understand? If this happens, this is what you do ...

I: have you read any of the books they gave you, BHF books

S: no, well we read them ones, the little, little book that Nurse put his name on, I've read them ... but ... fair play the Nurse was good, when we went down and she explained about the box and this and that and you think 'right, ok' that's what you do' but you still worry. I think .. what is in my mind is, 'am I going to do the right thing?' and panic, you know when somebody's on the floor , what do you do, what do you do? Do you put the magnet on then? Do you leave it, do you phone? Do you get touch with ... ? You don't understand .. like 'Do I phone the ambulance straight away cos it says get in touch with the ambulance cos the paramedics know what to do. You got to explain to them that he has got a defib in, and they know what to do ... you know .. I'm frightened in case I don't do the right thing

And he says 'it's ok, it's been a year now and I haven't had another pull' 'Yes Sam, it's good'. Now, I think now, in the first year now when now he's there now and I know he's alright .. you can accept it .. he's not going to have another heart attack, but it's still in the back of your mind. Like we went down my friend's house last Friday and of course we were going to bed and he was getting up and he was making heavy breathing and that's not Sam. And I thought 'what's happening, something's happening' ... but it wasn't, he had a blocked nose, that's why he was breathing funny. It's the same with my daughter, I was upstairs cleaning and she said 'Mammy you better get down, Daddy's not very well and that was on January, 16th again and I thought 'it's a year now, oh no not again .. here we go again'. And that's what's in my mind. But what'd he'd done, cos he's [name of condition], he had twisted and his hip had gone out. So, I knew then, 'oh it's alright, it's only that' like.

I: so you fear the worst?

S: you do, you fear the worst. It's constantly ... and my husband is not ... how can I explain .. he don't tell you. If he's hurting, he won't tell you. Instead of saying ... like he said 'oh indigestion', he didn't say 'oh I got a pain in my chest' ... that's why we didn't even know it was a heart attack. Like when he was in intensive care .. the nurse took the telly off him cos she said 'no, you're not telling me you're in pain Sam and how can we know if you're not telling us?' And that's when he started telling us, 'yes, I am having pain'. And he had the angina spray. But he will not, he's terrible, terrible he is.

I: he said when you talk you share everything

S: yep, yes

I: but you feel he is holding stuff back?

S: yep, yeah he does

I: and that worries you?

S: that's it. I'd rather he say to me 'oh, I got a pain in my chest' or 'this is hurting me' because then I'd know. The other week, he did say to me, 'love, have a look at this for me' and he showed me .. now where his scar is .. where they put the defib in, it was down .. but it had moved up .. you know more over here [points with hand]. It's more over on the arm ... but with him, I think it's resting on a nerve with him .. so that's why he's getting trouble ... the doctors [GPs] sort of up here, don't know anything about these defib boxes. GPs don't. He went to Dr X and Dr X said 'well, it must be something to do with the box'. 'Well' he said 'can't you tell me?' 'No I can't cos I know nothing about it' she said. Well, to me they should .. they should know about it

Now Dr Y [GP], he's a totally different doctor .. he does know, he goes into everything .. he's a good doctor, he's a really good doctor ...

I: and what did he say?

S: he explained everything to me ... oh here he comes

[interruption as Sam walks in and then out again]

S: yes, he [Sam] doesn't .. keeps a lot back, doesn't open out .. always been like that .. but since he's had his heart attack, I got to say, he is more .. to let you know that it's hurting him .. we've gone, how to explain .. we've gone more together [become closer] ... more together than separate, cos his father said 'you're lucky' and he said 'I am, she's been through a lot'. It's like he said 'I didn't know what was happening to me but she did, she seen it all

I like him to go with the phone, he's terrible ... don't take his phone and I ... fair play to him now, he goes to work every day and in-between 10 and 12, he'll phone me and I go 'are you alright' cos he leaves- he's up at five'. Well if I don't hear from him, I panic .. I'll worry, I'll phone work and ask them 'is he alright?' 'yes'

[she receives phone call]

S: The children are terrible, they do watch him ... terrible you know, if he goes to do something, 'you're not allowed, you're not allowed'. Because when Sam had his heart attack, his sister, his father , all the children, they were there. 'You've got to tell him that he's not to smoke, he's not to drink, he's not to go out' and I turned and I said 'you can't do that'. How can I tell a 53 year old man that he can't do it ... and my husband is more .. if you tell him 'no', he'll do it. I said, it's got to be his decision. Then when he come around he said 'no more fags', he said 'I'm not smoking' and fair play, he hasn't touched on. As for drink, he has cut down on his drink and as for going out, he does go out. And he goes for a little walk, and he comes back.

I: do you go with him?

S: I go with him normally nine times out of 10.

I: did you used to go with him?

S: no, no... my husband was a couch potato ... come home from work, sit on the couch, watch telly, never move very far ... go up to the club- car, car back ... that's how he was, now he will walk. I say to him 'come on, you've got to move, you've got to get up and you've got to keep going'. We go up around the pond ... there's a lake around there [points out of window] and that's where we walk around ...

I: He said he's hoping to go fishing again?

S: yes, we've bought him boots, I've bought him a jacket, and trousers and I told him, 'you're not going unless you're warm' . So he's had new waterproofs and I've bought him tidy boots for him to walk. I've told him to go over the pond there and have a little go, so he can get his arm working ... but he's still a bit .. I think he's waiting until the 17th now to see what they tell him down there .. so I don't know.

I: how do you feel about him going fishing?

S: alright, as long as he takes his phone with him ... it's just that little phone call, just knowing .. puts your mind at ease ..

I: and you say it's got easier over the year?

S: it's got easier. In the first ... when they were putting the defib in and everything like that ... before that box was put in, I was terrible .. I was more worried. Since the box has gone in, I've mellowed. I think well that box is there ... and he's got a card that he carries in his wallet .... if anything happens and I'm not with him, that's in his wallet. And I say 'you got to carry that with you, cos they'll know then that that's there'. To me, it's a life saver .. that's the way I look at it .. that's the way I look at this box ... it's mine and his life saver. That's how I feel ... 'well, that's in there, that'll give me notification that something is not right with his heart' ... if anything happens to his heart, that will show me there's something wrong ... and I do say to my husband, 'if you get pain, or you get anything, you got to tell me .... and then I know then'. 'Right' he says 'I promise you' But it is marvellous ..

I: you day you've become closer as a couple?

S: yes, since the heart attack. I mean we've always been close ... mean we've been married 30, well 32 years this year we been married .. I was 16/17 and he was 26 when we got married. Many people, they say 'oh it won't last, cos my husband was [medical condition]. We had our arguments, we had our quarrels, my husband used to be a drinker .. out ... I'd be in the house with the babies, he'd be out drinking ... since he's had the heart attack he don't drink so much, he's more content I'd say and I'm more content cos he say to me 'well, you go out' 'why do I want to go out?' 'Ok then we'll get a Chinese and stay in' and that's what we'll do.

I: It is quite a big change in your lifestyle

S: it is a very big change .. for the better ... but it has brought us closer .. as a family and as husband and wife .... but before, I was sort of .. my children come first, and my husband come second ... but since the heart attack and this [points to chest], he comes first, and they know it. My husband comes first, he's the most important. My mother, she's 76, she lives next door. I see to her, I clean for her, I cook for her .. I see to her. But she knows, if Sam's bad, Sam comes first.

I: what about the physical side of your relationship, has it stayed the same?

S: no, no. Sam gets problems .. down below. We got closer emotionally .. where sex is involved with me and Sam .. Sam don't talk about it ... [but] now we do ... now we do ... but I do say 'it doesn't matter' 'it does matter' he said. Funny that, last week he was kissing me before he went to work and kissing me when he come home from work .. 'alright' I said 'who's your fancy woman?' I said. 'what' he said, 'you know I love you' he said 'she's accusing me of a fancy woman, I can't keep up with you, let alone a fancy woman' ... but that's what in his mind, that I'm going to go, cos he cannot ... have an erection ... 'I was always fine before' 'but it's to do with the tablets you're on' they said 'and there's nothing you can do about it' .... He went to Doctor [GP] and he explained ... now my husband, how can I explain, now he's very embarrassed ... he don't like talking about .. sex .. like with me ... we went down to see the doctor ..now .. how can I can explain .. I said to him now .. 'no, you're not taking this Viagra now until I know you're safe to take it ... because to me-I read up about it .. and they said it puts the pulse faster to put the blood to the penis .. well I said, if they're making your pulse faster that means your heart's going faster ... And when we went down [hospital] , the nurse got the magnet and she said 'is there anything you want to ask?' and Sam. And I said 'yes, you want to ask about these tablets Sam' So, he said 'I buy Viagra, is it alright to take them?' And the doctor said 'as long as you don't over exert yourself, like pick up a wardrobe .. yes' he said ' take one, and make sure you're alright before you do anything he said' ... So I said 'now I know it's safe, you can take it' ... but he don't like having to plan to take them

Tape ran out ...

Transcript for N07.1
Male aged 65
Wife has ICD implanted for primary prevention: undiagnosed cardiomyopathy.
In line with ethics, participant's name has been changed to Doug.
'I' stands for Interviewer. EP stands for Electro physiologist or Consultant

I: your wife's filled me in about why she's got an ICD ... how do you feel about it?

Doug: pleased .. well because what happened with her brother, I felt this could prevent it happening to Jane .. that's my interpretation of it.

I: so you're very positive about it?

Doug: oh yeah. I would have done it a long time ago, but Mr [EP] .. he just wanted confirmation I think, what he was planning on doing .. well, we went to the heart hospital, London, and they said that's exactly what they would do so ..

I: so when Jane first had her palpitations were you worried?

Doug: oh flip, aye. She didn't tell me .. twice .. I'd been drinking, I'd been to football one night .. so I couldn't drive so that time I got the ambulance and the time before she went and drove herself, she wouldn't let me call the ambulance but touch wood, it was ok.

I: so you were worried ...

Doug: yeah, yeah cos although they couldn't find anything wrong with the heart .. there was still something not quite right there so ... I know this thing [ICD] is not for the palpitations but ... (inaudible)

I: what do you think the machine's there for?

Doug: um .. if the heart rate drops below a certain-it'll kick back in and if it goes above, it'll bring back down .. simple

I: do you have any concerns at all?

Doug: No, I'm glad she had it. Being a nurse .... and it's her call, it's not up to her GP about it ..

I: did you talk about it?

Doug: Yeah, I was all for it a long time ago .. you know, 'why can't they do it?' 'why can't they do it?' ... 'they can't, they got to make sure .. make sure of this, that'

I: so, what was that waiting period like for you?

Doug: It's strange but you don't think about it ... because you've been with it for so long ... I remember it years ago now, she went down to Hospital for a scan, and I remember sitting in the room with the doctor and I could see her heart in all different colours .. years ago ... th-the trace was really abnormal .. what she's been told up till now, is 'the abnormal trace you have is normal for you', if that makes sense ... when we were sitting out in the waiting room after this thing, waiting for the results and who should walk in but X [name of rugby player] and he said 'oh I feel better, look at your trace, mine's better than yours' (small laugh) .... So, all those years we've lived with it so, it's in the back of my mind

I: so, it has stayed in the back of your mind?

Doug: oh yeah. You don't worry everyday about it .. you know what I mean? Cos you think you're invincible don't you? We do, don't we, I mean we're all going to die – just don't die just yet.

I: so, when you were told she had to have the defib how did you feel?

Doug: relieved .. positive.

I: did you want to know all about it?

Doug: Well I knew what it would do .. I mean pacemakers's the common thing but this is a bit different to that isn't it ... Mr [EP] said .. when he was sitting in with us .. he was telling Jane .. the bit I caught on was if the heart drops below a certain rate, set it up 50 I think it was and if it goes above a certain rate it will kick in .. so that's my interpretation .. if she gets a cardiac arrest ..

I: how do you feel about the shock element of the ICD? Does that cross your mind?

Doug: No.

I: What was it like leaving her when you brought her back from the hospital and you returned to work?

Doug: Ahem ... Mr [EP] is very, very good .. he's a nice guy you know, and he speaks to you in plain language ... we can understand it .. I mean when we were in that day ward waiting for it to be put in .. talking to patients either side, one was coming in for a check up for some procedure .. and you could hear what was going on .. not that I was particularly interested ... and there was another woman there, getting her nerve ends burnt off? Is that right, to stop her having palpitations .. so that was interesting .. I think she was 3 or 4 to have the procedure so of course when I got to go, I may as well go, I can't do anything .. I went back to work, and they phoned me-I phoned them ..... I phoned at ..... 4 o'clock or they phoned me 'she's back, she's ok .. she's drowsy so pop up'. I popped up and yeah she was fine .. and when she woke I was sitting there sort of thing

That was a big-I wasn't worried about the procedure because of what Mr [EP] said .. do you know what I mean, he does allay your fears to a certain extent .. that's me that is, I'm not saying everybody would take the same ... Yes, I've no worries at all and I'm glad she had it. Slow her down, wouldn't stop her having palpitations .. she'll still have them .. I mean I have palpitations, I think we all get palpitations but when Jane's last for hours and hours and she doesn't tell you till 3 hours down the line ... and in fairness, people criticise the health service but it was good, really was good .. really good ..

I: so, when you say Jane doesn't tell your till 3 hours down the line ... would you prefer to know at the beginning?

Doug: Yes.

I: And have you asked her to tell you?

Doug: well, she won't tell me ... no she won't tell me 'there's nothing you can do' ... because over the years she's had palpitations, sometimes they last a couple of minutes .. go away fine and sometimes they last 10 minutes, she probably thinks there's no point in telling me 'no point worrying you'... but when she has them for 3 or 4 hours and she's does all these things .. blow in bag, hold her nose whatever .. nothing worked you know, and even in the hospital .. I think last time she had it I think he gave her 3 injections ..

I: Does she still have palpitations now?

Doug: No, not to my knowledge.. she may have them for say, 2 minutes spells but she- nothing prolonged. If she has she hasn't told me.

I: Like she's going off to the gym now, and you're quite happy?

Doug: yeah, yeah

I: and would you be as happy if she didn't have the ICD?

Doug: No, I'm glad she's got it ..

I: so what does the ICD mean for you?

Doug: well that if she has a cardiac arrest, it will keep her going again ... that's my interpretation of it and ...

I: everything positive?

Doug: I mean if her brother had it 25 years ago, maybe he'd be with us today .. we don't know that, but if it was there, there is a chance he would have survived.

I: How do you feel about the implications for your boys?

Doug: erm, concern for them .. I think [eldest] is ok, [the younger one] he's er ... concerned for him I think he got the gene I think .. I think he's got to go for the tests

I: And how does that make you feel?

Doug: bit more concerned for them, because they got their children and they got their lives ahead haven't they? But it's different .. different with them.

I: so it's different with your wife and your son?

Doug: yeah to a certain extent yeah. It's not that I love Jane any less it's er ... do you know what I mean? I'm used to it with Jane, I'm used to it, cos we've worried about it for years, she's got this funny heart beat but when you see its hereditary and ... I think [eldest] is ok, I think they've both been for tests .. I think [eldest] is ok, and [youngest] needs further tests. So, what the implications are, I don't know ..

I: How often do you think about it?

Doug: not all the time .. but we talk about it ... when its talked about it [youngest] tends to pooh-pooh it you know ...... he will go for the tests .. just time he needs ... makes sense?

I: absolutely, so really to sum up, the benefit of the ICD is that it would bring her back to life

Doug: yeah, keep her going

I: And are there any downsides?

Doug: Don't think so, I think they're all plusses .. she could be on her own and have it, she could be with somebody ... you don't know do you, at least she's got this thing and it will do something for her, and keep her going ... that's my interpretation .. yeah, very positive about it, think it's good. It's expensive but it keeps her going, doesn't it?

I: have you been worried about her since ICD implant?

Doug: No, no, really I am not worried, because God forbid, if anything did happen this thing would help ... simple as that

I: what did you think of the literature you were sent home with?

Doug: yeah, it was alright .... some of it, the terminology was to a bit-not being a medical person

I: was it hard to understand? What would you have liked?

Doug: oh no ... whoa ..whoa .. . well .... the implant is there to get the heart going .. that's all I need to know, all around the peripheries, I don't really need to know that do I? Simplify it. Even when you are in heart hospital they're using medical terms for the heart and things .. all these words are new to you .. I mean you catch on .. the left ventricle to the heart, the right ventricle .. you know these things but when people talk about it in front of you it's er ... you're fascinated about their jobs, how clever they are ..what people are, what people do

I: your wife was saying she had it done in November and her first check up was April and she was saying she felt it was a bit of a gap, do you feel the same?

Doug: er .. no... the cardiac nurse .. she's very good, Jane's got a lot of faith in her ... she's very helpful, but when they sent her home on the day, she came home she said 'I'll see you in 3 months' whatever, and I presumed that's time for it to settle down and no point looking at it beforehand because maybe things haven't settled down and maybe you'd have a better picture 3 months down the line.

I: if you were worried what would you do?

Doug: phone 999

I: oh yeah sorry, if you had a concern not a 999 ...

Doug: oh ... there's a number on there to phone .. phone them

I: and you would?

Doug: oh yes.

I: some participant's have felt as partners they couldn't ring the nurse but you don't feel like that?

Doug: well no, she may not be in a position to ring her .. but if she was in that position I would ring the ambulance ... I mean Jane has spoken with Arrhythmia Nurse Specialist and she likes her ... before the procedure if she spoke with her, she was quite informative ...

I: did you go with her?

Doug: no, Jane don't take me everywhere (laughs)

I: would you go in April? [first check up]

Doug: er.. probably ... because every time she's seen Mr [EP] I've been with her ... so I'd probably go with her to see Mr [EP] yes. It's pretty mind boggling all this isn't it?

I: I just can't imagine how you must be feeling

Doug: I'm pretty laid back believe it or not ... if you worry too much .. it doesn't help to worry too much .. it drags you down a bit, I think ..

I: do you talk openly about the defibrillator?

Doug: oh yeah, yeah, it's not a secret

I: no sorry, I meant the cardiomyopathy?

Doug: no, she has it now.. we've had ten years to think about it .. next step now is to try and work out the telephone line

I: yes, the remote monitoring reading

Doug: yes, it's very sophisticated

I: how do you feel about that?

Doug: yeah, yeah .. if it saves the hospital, saves tying them up, does the job ... yeah, got no issues with that .. we'll all grown up, and if that's what we're supposed to do, we'll do it.

I: Going back, I know you waited a year for the defibrillator, what was that year like?

Doug: erm .. I did think at one stage .. erm .. what if she has a heart attack before this .. it'll be too late you know what I mean ... 12 months, 11 months, ten, nine month, eight, the closer you get to the date .. if something happen in between you-

I: so you sound anxious during this time ...

Doug: not all the time you know ... we were scheduled to have this procedure carried out and erm ... and hope nothing happens before it does ..

N08 Transcript: ICD Study

I – Going back to the beginning, can you tell me a little bit about the circumstances leading up to the fitting of the ICD?

Jill – Umm, I had a cardiac arrest, went to bed, perfectly fine, went to the bathroom. My husband takes a cup of tea to bed with him, watching television and apparently I came back in from the bathroom, got back into bed and made a funny noise. And that's it. I don't remember anything at all, there was no...well I'm presuming I had no pain because I got no recollection now, for at least...I don't know.....three weeks, a month before.

I – Really...

Jill – I can't remember... it was my birthday a week before, and you know, obviously I had presents given me, the first night I came home from hospital, I walked up the stairs and I said to Terry (husband – name changed), where did that candle come from? He said, well Mary (name changed), my friend, gave it to me for my birthday, which was the week before. And I got no recollection at all...nothing. So I can't tell you whether I had any pain, because I can't remember anything, the only thing I remember is um... being in the hospital, not even intensive care, I didn't see nothing, until I went on the ward, I've got no recollection at all.

I – Do you worry about that?

Jill – No not really, cause you know, I said this to Jo (the specialist arrhythmia nurse – name changed), and she said, are you bothered about this, because, perhaps its best that you don't, I said well, no, I've got... for me, it was fine ... got no recollection at all...

I – Mmm. Maybe it is for the best then...

Jill – you know, I mean, I just can't tell you whether I had any pain (tearful), or anything 'cos I just don't know.

I – very frightening for you...

Jill – well no .... for me, no. For everybody else.... yes.

I – So how does your husband feel about that then?

Transcript: ICD Study

Interview 1: ICD Partner NS (name changed) – Terry

I – Starting as I did with your wife, could we go back to the beginning. Could you just tell me about the circumstances surrounding the fitting of the ICD?

Terry – it all started, we went to bed one night and I was in bed just drinking a cup of tea, habit I've got into, having a cup of tea before bed. Jill (wife, name changed) doesn't drink tea or, never has. I was just drinking my cup of tea and watching the news on the telly and Jill was in the bathroom doing what ladies do, and she got into bed next to me and that was it, gone. I noticed a change in the sound of a breathing, and she wasn't responding to me so I just rang 999 and the rest is history. She had the arrest, I mean she was breathing when I went downstairs, to let the paramedics in. But obviously she wasn't by the time they got up there. Then they shocked her back, and before we knew it we were in intensive care for a few days, and the upshot of it was you know the fitting of the ICD.

I – And obviously your wife says she can't remember ....

Terry – No, she can't remember anything, well I mean obviously, she was unconscious from almost immediately that she got into bed and the three or four days she was in intensive care, she was out of it anyway, so she has no real recollection until she got back into the ward. Quite strange really, she doesn't seem to be able to remember anything for a few days previous to that either, that week if you like is a bit of a blank. Not a bad thing I don't think because you know she hasn't had any lasting trauma, if you like, from the event because she can't remember anything. But once she got back to the main Ward, that's when she started taking notice and I think realising for the first time what had happened and how grave the situation all could have been. But she seems to have got over that now and copes very well.

I – And what were your feelings at the time?

Terry – Well, feelings of uselessness really, you know, you know, once I had dialled 999, I ... You know, couldn't do anything, I was completely you know .... And when the paramedics came ... How they got here so quick I don't know, they must have been the end of the road or something, it's amazing how quickly they got here. And, you know, while they were working on her upstairs it's just a feeling of uselessness, of looking on and can't do anything, you just feel useless.

I – So you were downstairs ....

Terry – No, no I was upstairs with her,

I – I see, so you saw everything that happened ....

Terry – Oh yes, yes ....

I – So do you and your wife talk about what happened?

Terry – Well we have done yes, you know when she asked me what happened obviously I told her, but we don't talk about it now, you know, that's gone and finished. To be honest I don't really think about it now, the fact that she's got this fitted now is sort of .... It just doesn't come into my head and we carry on as normal, and I don't see any difference in Jill, apart from she probably gets, towards the end of the evening, tired, more tired than normally. But we've never been late to bed people you know so, I just noticed that sometimes when we're watching telly you know, nine o'clock comes and she's flagging a bit, which is a little earlier than normal. But I, I, you know, don't notice any difference.

I – So do you worry?

Terry – No, I mean everything ... um, everything was explained and um, you know, Jo was saying that lifespan was, will be no different to normal and to carry on doing the activities she was doing, and more. So I feel now that because she's got this, she's probably safer than the rest of the family (laughs), you know, um, so I don't worry at all.

I – So you find it reassuring?

Terry – Yes, yes. Because you know, they don't know what happened really, they don't know why it happened, um, they, um, (the surgeon) said it might never happen again, but if it does then she's got this and ... I just, I, I'm not worried about it at all.

I – So I see you find that reassuring, do you ever worry about the fact that it may go off?

Terry – I've never thought about it honestly. Um, I just feel that you know if it does go off then great because it's doing its job, I just feel confident that if should something happen again, then, you know the device is there to shock the heart back. But I honestly don't think about it.

I – During your time at the hospital and the fitting of the device do you feel that you were included in the process?

Terry – Oh yes, everything from start to finish, yes. I mean nothing was said to Jill on her own we were spoken to together, there's no problems there at all, the care was fantastic.

I – You feel it was important that you were included?

Terry – Oh yes, it was important to know what was going on. Because initially I think Jill was still ... For the first couple of days when she got back to the Ward, she was still a little bit mixed up, you know, I noticed that she was talking a lot and talking quickly, and obviously I think this was a realisation of what could have happened and was a nervous reaction to that. But as the days went by, that passed off, and um, you know she got back to her normal self. But everything was discussed openly and I mean when her mum and dad were there they were included, we were asked if we minded obviously, but nothing was sort of undercover it was very, very open. It's good for everybody to know you know.

I – Aes it is important as you may think of asking things that Jill may not ...

Terry – Yes, you know different things, the whole process was ... Simple and reassuring. But now it's behind us and we just carry on ....

I – Very forward looking then ...

Terry – Yes, as I say you know I think she's safer than any of us now (laughs).

I – So how would you describe the main benefits of Jill having this device, obviously you've described it as reassuring ..... Anything else?

Terry – Well, to me that is the only benefit, that's all that matters, it's our insurance policy. There's no other tangible benefits, but I mean, what other benefits do you want? That's the only one you want isn't it, she is no better or worse than she was before, it's just reassurance. That's the only benefit isn't it?

I – Yes, yes ... Looking on the flipside then, are there any disadvantages?

Terry – No, no everything is .... Everything seems now .... You know once we'd got over the shock, it, it is now as it was before, um, I don't see any difference, I don't notice any difference in Jill's behaviour, um, I don't notice .... I don't think about it I really don't, and I don't think she does that much either, um, I mean the only time we think about it really, is, because of where the device is she says ... ooh my bra rubs, she says, that's the only thing. Because I said to her, sort of tongue in cheek, I said, be grateful that you're here to feel the bra rubbing (laughs).

I – And you feel your wife has the same positive attitude .....

Terry – Yes that's right, I mean, as I say life is almost as if it never happened.

I – Was there a time when the device was first fitted that you will more worried?

Terry – (pause) .... No, no. Once she was in hospital and we got over those first days when she was very ill you know, the Dr says to me you know, here is well (indicates with hands), here is critical, well Jill at the moment is about here (indicates with hands again), so you know for a few days we didn't know what was happening, you know we didn't know whether .. We didn't know how long she'd stopped breathing and we didn't know whether there'd be any brain damage, but I mean the signs were good and they didn't think there would be, but we couldn't be certain, um, but after that, um, when they said right we're going to fit this ICD ..... Once we got over that I was happy then that everything was going to be okay, and once we got over those initial few days I was pretty confident, and you know certainly once they'd actually fitted it I felt even more confident. So once she'd had the procedure, um, I felt that we were over the hill and we could start getting over it and go home and back to normal.

I – And in the early weeks when you first came home did you find you talked about it a lot?

Terry – A little bit, I wouldn't say we talked about it a lot. Um she was a little bit tearful because you know we've got a little grandson, and they told her, you know for six weeks you mustn't use your hands so it means she couldn't pick him up, of course with a grandson that age the first thing he wants to do is be picked up, and of course that made her a bit tearful. But you know, we got over that and we just don't think about it anymore and she is back to normal now, lifting him, you know so we're over that and, and again it's in the back of the mind.

I – And if she was worried she would let you know .....

Terry – Yes, she wouldn't hide it. No, we don't hide anything from each other, and never have done you know, no. If she had any worries she would tell me. So I'm confident that, uh, you know there's no underlying psychological worry there because she would tell me. And I would know, I would know if there was something worrying her, I would know.

I – You feel you know her well enough .....

Terry – Oh yes, and vice versa, so you know what I mean there's no, there's no doubt about that.

I – That sounds very positive, moving on I wanted to talk about the driving issue, but of course your wife explained .....

Terry – Yes she can't drive anyway because of a back you see, and whilst she's got a licence, a valid licence she hasn't driven for ... 13 14 15 years.

I – So it's not something that has happened to change ....

Terry – No, it's got nothing to do with, uh, with uh, what's happened to her heart I mean it's her back that prevented her from driving.

I – Are you still working?

Terry – No, I'm finished, well, I do a couple of hours a week in a (gives name of a business) in town. Officially I work on Wednesday and Thursday, in practice it's a Thursday morning (laughs), no I finished full-time work six years last January.

I – Because obviously something that we ask people, is if it has affected their employment or their work?

Terry – No, no it didn't affect me, but I don't see why it would anyway, once that initial first few weeks is over, especially when the first six weeks were over and she could do more, um, I don't see really why it would affect work. Mind you I suppose it would depend on your attitude, and the way you think about things I suppose. I mean it would be easy just to sit in a chair and worry about it wouldn't it? But we're not like that, so I mean, no. Even if I was working, after those first few weeks I don't think it would have had any effect at all.

I – You wouldn't have worried about leaving her at all?

Terry – Oh no, as they say after the initial period I wouldn't have worried at all.

I – And your wife attends the cardiac rehabilitation ... Is she enjoying that, finding it useful?

Terry – Yes, yes, I think ..... I mean she can't do much of the exercises because of her back but I think she enjoys the involvement with other people with similar problems, you know, and I think ... I mean she's only been twice, yes I think she, I think she enjoys going for a chat, yeah.

I – Don't we all ...

Terry –(laughs) .... Yes of course we do

I – What about the support group at the hospital, where partners can go along as well ....

Terry – Yes, well I haven't been to any, I don't know when that is but a mean I would imagine it is something we would take advantage of, if it's available you know, if it's there, let's have it.

I – Yes, because obviously the partners can go along to that. Do you think you would find it beneficial?

Terry – Well, I don't know, I will certainly give it a go. Whether I'd find it beneficial I don't know, because .... I don't feel as if it's changed anything really, you know, I mean apart from the ongoing six monthly appointments, um, you know it doesn't affect our lives any more.

I – So do you find the appointments reassuring as well?

Terry – Yeah, I mean you know, initially when she went after six weeks, once we knew everything was fine, uh, the read outs from the ICD were all normal, nothing irregular had happened in that period, which is what they told us would probably happen. But I mean once .... Well it's just reassuring isn't it?

I- So in your opinion, is it useful to attend these appointments?

Terry – Oh I think so, you know even if it's to say right the device is working, and nothing's happened well that's great isn't it?

I - Absolutely, do you find it useful to see the nurse in person, have contact with the nurse?

Terry –Um, well we don't have contact really other than when we go for the appointments. That is, I mean you know I've got Jo's (cadiac specialist nurse, name changed) card in my wallet and if there was anything we could ring her and if we've got any concerns, but honestly we haven't felt the need to do that. But it's nice to know in the back of your mind that it's there if you do need it. So you know, seriously it doesn't affect our lives any more.

I – So you don't have worries about physical health, you just feel reassured, is that right?

Terry – Oh yes, that's right.

I – Is there anything you would like to ask or add to what we have said?

Terry – Honestly, no. I mean life is good and normal, you know and obviously we are thankful for that, it could have been a lot worse couldn't it? I mean, at one stage I thought I had lost her, I really did. You know I thought she had gone, (appears tearful), but as I say once we got over that, those first few days, and they told us what was going to happen, and when it did happen, after that .... I mean you know, I'm just confident everything is fine. And as I say, other than we're chatting now, or if somebody, you know, asks how are you, and wants to know the ins and outs, we don't think about it ..... Which is the way it should be I suppose.

I – You appear to be very positive .....

Terry – I think that's half the battle isn't it, you know, if you're going to dwell on these things ... And I mean some people ... Well we're not all the same are we? And, um, we are fortunate in that we have got a positive attitude and uh, as I say it's an episode which is gone now and we don't even think about it.... Might do though now we've bought it back to the forefront, or like when we are due for appointment, you know you might think, hope everything is all right now, but that the good bit of going there, because you get no reassurance. But other than that, it doesn't impinge on our lives at all.

I – Your wife mentioned that and appears very positive as well, but that she may think about, when going somewhere, whether there is a phone or a hospital nearby ....

Terry –Mmm, well, no I don't think about it. Because we've always got a phone anyway, with mobiles today, everybody's got mobiles so we've always got phones, um, and, we know that with the way the thing works, um, you know that should something happen then we've got time to get to hospital, it's not going to be as critical as it was. You know so, so, you know I don't think about it.

I – Yes I see it self-sufficient, amazing really ....

Terry – Yes, it is amazing, clever (laughs), it really is clever.... Until it happened I'd never heard of it, I'd heard of pacemakers but I mean I had, I didn't know any such thing existed, so it's nice to know, you know, if things do happen the NHS, you know when it's needed the NHS kicks in very quickly and efficiently. You know, you've got waiting lists for non-urgent things, but when you need them ... I still can't believe how quickly they got here, it's amazing, literally minutes. I mean I was ringing 999 and talking to the girl on the phone and they were there, honestly. I said they must have been at the bottom of the road, they were there so quick, because I mean another minute and it would have been too late. I still can't believe how quick they were. Now it's happened well, I don't know if you know the area but what we call xxxxxx Road (gives directions) ... Well I've seen, I've noticed that, the car, you know the paramedics car, parked in a lay-by there, so it could have been obviously waiting for a call or something, it could have been that they were there that night, which is literally at the bottom of the road. Because there is an ambulance station in xxxxxxxx (gives name of nearby area) as well, but I mean I don't think they even had time to come from there. Because I have seen the paramedics parked there on various occasions, funny thing I haven't seen them since but I do remember seeing them there before. And I think that could have been where they were that night. Just luck of the draw I suppose, I just think they could have been there which would account for why they got here so quickly. It is absolutely amazing how efficient they are ..... It is amazing, I mean it's something you take for granted until you need it.

I – I'm glad you've had a positive experience ...

Terry – Oh yes, I mean with everything .... It could have been such a tragic event really, I mean everything just seemed to go for us, from the paramedics getting here so quickly through to everything. As I say, you know, life is normal now. It doesn't cross my mind, it really doesn't. I mean we just don't think about it, other than when we're chatting like this and obviously when someone says, oh what happened, you know we go through the story ... But other than that, we don't think about it.

I – So you wouldn't say you ever feel anxious ....

Terry – No not at all. I feel confident now that if anything happens, this is there and you know will put it right until we get to the hospital, and that's what it's there for. Wish I had one (laughs). So yes I feel perfectly at ease, you know, as I say I don't think about it. That's what it's all about isn't it?

I – Yes, that's very forward thinking. We don't know how people feel and are trying to find that out ....

Terry – Well, I mean different people may have different experiences, it depends about this doesn't it (points to head), it's the mental attitude.

I – Yes that's right, how do you feel your attitude has helped you? Is it being optimistic?

Terry – Yes, probably yes. Being positive you know, about most things helps doesn't it, and it's the same with this. It's just something that happened, she's got it, fantastic, get on with life.

I – Great, just one more minor point, some new devices being fitted now are remote, which basically means you do not need to go to the hospital for your appointments, you can sort of scan in your own bedroom ....

Terry – Yes that's right, they told us that ...

I – Yes, and the hospital are interested in whether people value their appointments or if they would prefer to stay at home.

Terry – Personally I would prefer to go to the hospital because, just going there and seeing the monitor and the machine churning out all of these charts, and the nurse saying oh that's fine, there's been no irregularity ... I find that, uh, reassuring. I suppose, you could get the same thing from doing it remotely except there would be a delay in that I suppose, you know from doing it then I suppose somebody's got to ring you back to say everything is fine but when you're there it's instant isn't it? But again, if that's the way it was going to be then it wouldn't worry us, it wouldn't worry me.... It's the same, well our youngest boy, now when he was five he had Hodgkin's disease, and he has no problems with that now, but when he had the radiation it was in the area of the thyroid, so every couple of years he has test for his thyroid. Well he's 30 now, this was 25 years ago, um, but going to the hospital with him was just reassuring, and you know ... Well he's got to go every few years now for the rest of his life, and I think that's great because you know if there is any problem, it's picked up straightaway. So I think, I like the reassurance it gives.

I – And do you think it's valuable that you can both attend these appointments?

Terry – Oh yes, definitely, definite. Um, for the simple reason, if we are both listening to the same conversation and, uh, if only one listens to it you wonder then has she (Jill) told me everything, not because she would hide anything but what if there was something she had left out or forgotten, but if we are both there I think it's much better. If there was anything wrong with me, I'd certainly want Jill there you know, at any sort of meetings and vice versa. I think that's important, very important. We are both in on everything, yeah.

I – The value of the support you can give each other is .....

Terry – Oh yes, it's immeasurable...... yeah, life is great.

I – Well, unless there is anything at all you wish to add we can end here, thank you.

Terry – No, everything is fine. As I say, um, other than having a conversation now I don't think about it.

I – Okay thank you, I'll stop the interview there.

Transcript for N10.1
Female aged 44
Husband has ICD for secondary prevention; hypertrophic cardiomyopathy
In line with ethics, participant's name has been changed to Mary.
'I' stands for interviewer.

I: your husband has been telling me how he came to have the ICD fitted. How did you feel when you found out he had to have an ICD?

Mary: delighted. Because the fact that his brother had died .. so suddenly without even knowing he had- .. which was very, very tragic and the fact that his dad was found to actually be the carrier. There wasn't any doubt myself, and myself, I have health problems and with the children .. he didn't want to have it and I actually felt was very selfish of him, cos I said 'if your brother had been given this chance, he would have like to see his child grow up .. you have become a grandfather, I need him, the children need him .. erm you know, I want to grow old with him' and I said, if I had to end up going for an operation that could be coming to me very soon ... is the fact that if they try to remove my tumour, I could be left paralysed but because I want to live, I said I will go for it ... I still have my head, my brain, my thoughts, my love for the children and for him and I said 'there wouldn't be a doubt in my mind cos I couldn't leave you' and I said 'I want you to have this'.

And he did ... Yes he's .. well he's not really coped .. he is coping with it .. there are times when he'll say to me .. you know in the middle of the night .. cos I actually said to him last night .. he's probably told you already .. I lie on this side of the bed, so his defibrillators here and I don't like lying on that shoulder ... I try and lie there but I feel 'oh, am i going to hurt him' or 'will I set it all off'... So, I actually said to him this morning 'I do want to cuddle you, I just don't want to cuddle you on that side'. We're going to have to swap where we sleep and I said 'at least when I roll into you I won't' ... 'cos even in my sleep .. I'm conscious of it, and I turn back, even if i have to waken myself cos I'm so afraid of hurting it or hurting him, but it's only because he finds it now and again, it's er 'I hate this thing, I hate this thing' you know but at the end of the day he knows why it's there. And in a way, he glad he's got it you know, cos he knows ... My son was asking in the car what you were coming to see us about and I explained to him about daddy .. and God love him, he says 'but Mammy if he had a heart attack, that saves his life'. And you know, as I said, it's that is the basic honest truth .. yeah that is the truth. And this is the way I put it to him .. God love him, when he is feeling down about it I just say 'if [brother] had had that chance .. you know, he'd still be seeing [son] at school, he'd still be with [wife] and you know your mum and dad' ... You know basically that woman died with he died .. she was a shell of the person she was .

thing on our phone too, that we press against ICE ... all I do is press that number and it comes up to the computer to the ambulance, all Steve's details, all I do is press that .. and someone is here within minutes .. because it'll go to the closest, they know where their ambulances are .. and-but again, this [ICD] kicks in .. saves his life ... My father died of a massive heart attack at 47, and that's another reason I said to him .. cos my father never got to see his grandchildren, his 17 grandchildren .. never got to see them, worked hard all his life .. all his life and the same thing happened as happened to [Steve's brother[] .. keeled over and died. Which is very, very sad, cos my mum, I mean she still only 64 and she's such a young widow .. there were six of us .. and as we began to leave home and things were getting easier for them, he died. And that is the saddest thing, and again that's hard so I was saying to Steve, I couldn't put a child through that ... I'm very positive and I'm sure he told you, he often wakes up in the middle of the night .. and I actually go down and make coffee, cos he wants to talk about it

I: does that happen a lot?

Mary: a lot, a lot .. it happened this morning, I've been awake since 4 o'clock, if he can't sleep or 'this things digging in me' or such and he said cuddle into him and I said 'I don't want to cuddle that side' and he went 'oh right' (in a huff). And I said 'I don't mean, It doesn't' mean I don't want to cuddle into you darling' but I had to change sides so that when I cuddle in ... but he took it as 'ooh, it's this thing' and I said it's not that, it's the fact that I'm squeamish about hurting him ... mmm but you know, it doesn't affect me every day at all, I've nothing but positive things. Cos I've read up ..

I: you can't think of anything negative?

Mary: the only negative thing is the way he gets himself down about it. He thinks he's too young, he could have lived a perfectly long life without it, 'how do these people know this .. blah, blah' 'how did they know I was going to have a heart attack, how's this and how's that'. And I said 'yes, but what if?' 'you're driving down the road and God forbid you drive into a family' .. it's not your fault, because you had a heart attack ... I know that's not a very nice way to put it .. to put the guilt on, it's more or less to say this could happen, you know what I mean. No, I see everything positive, everything positive except for the fact, as I said, it makes him down sometimes and that makes me down but I always have him up again, cos I always have to say 'look at what we got'

I: so how do you cope with him when he's down?

Mary: I tell him straight away .. up in the bed, whether it's 4 o'clock in the morning, 2 o'clock .. we're up, I put on the nightlight and we chat about it, otherwise he'd be twisting and turning, twisting and turning and it's on his mind .. I know he wants to talk about it and he says 'oh it doesn't matter' and I say 'no, I'm up now'

I: what kind of things does he want to talk about?

Mary: if he could get it out ... you know what I mean. And I say you can't. Cos what they said was .. when he enquired .. they could switch it off, but it has to stay in there. And I said 'it's better in there switched on that in there switched off .. you can't remove it Steve'. And the fact, when he went through that operation that day .. I was up in that hospital, all day on my own ... climbing the walls with worry and one of the nurses came over to chat to me about it ... and I said I was so interested in finding out everything ... thought I knew everything about the operation ... up and coming operation and everything, and this nurse said to me that they stop his heart .... and that was it for me. I was 'please, no-one told me this'. Maybe I missed it, but I never heard that ... I was completely calm until that and the fact if he got it out and had to have his heart stopped again .. that's not right. It's been done once, and that's it, I don't want it done again.

I wouldn't let him ... but at the end of the day, it's his decision ... but I'm all positive for it. I'll say it to him, like I'll go up to those meetings with him ... you know so partners go so we can talk about it, cos it is *our* thing, you know what I mean

I: do you find them useful?

Mary: I haven't been, Steve's been. I said, if he wants to go to them because he is down, wouldn't be down for long, but he'd still be down about it. And then we talk about it and then he's fine again. I say you've got 4 beautiful grandchildren, he's walking our first daughter down the aisle in four weeks, you know what I mean, we've got such a beautiful future ... and as I said, if I had to walk around with a box on the side of my head or a bag on my side .. if I'm here, [alive] I'm happy enough, you know what I mean. I'm secure in the love he has for me if anything happened to me, and he knows the same you know what I mean. You know what I mean there's no negatives for me, none at all. I would actually advise women or men if vice versa .. I don't know if women get these things, we were actually talking about that .. And Steve said, there was a man at the meeting and his wife had it and she died. And I said it's an awful thing but the fact that it's going to save his life is good for me ... Cos the heart thing is in my family and I've seen my own father die and he's exactly the same age as my dad. And I've actually said that to him ..... you know, children are beginning to leave home, grandchildren coming, daughter getting married, little [boy] turning 13 in June, you know, we're only beginning our life .. you know in a different chapter. Grandchildren adore him, the children just love him so you know what I mean. And his father needs him so much, that's another thing ... as I said to him I don't think his father could cope with losing another child. And I said that to him, there's only him and Steve.

Of course I'm the mother of the family now .. I'm the one who organises everything you know but I've become really the daughter ... more than the daughter in law, the daughter. You know it's' me who brings him to the hospital appointments, it's me who takes him to the dentist ... it's me who cleans the house, it's me ... you know what I mean. He wouldn't' cope with losing another child, he's lost his wife and his child ... he couldn't, he couldn't, he's [Steve] his life. He lives and breathes that man.

I know it's all about me, but I'm telling you how I cope with helping him ... I don't beat about the bush .. I say it as it is. And sometimes, I have said, 'do you know what, you're actually selfish, that's what you are to me, you've got a life' and it works. He actually thanked me 'do you know what, I'm just sorry Mary' and I said 'oh but it just breaks my heart that they [brother's family] didn't have this chance. You know Steve, it could have been you, it may not have been your brother', it could have been you and we'd never had grandchildren, you'd never see grandchildren. I'm very strict but I wouldn't hurt him cos I'm very comforting and very, very affectionate and very loving towards him and I'm actually over the top because of my life .... we have a good life, we're in bed by Emmerdale, we read, I read magazines, we're not drinkers, we don't socialise unless it's with family ... we love our life and I don't know what I'd do without him.

No, I'm so positive and I would advise anyone to get their partner's- just get it done ..

I: do you worry about him when he goes out on his own?

Mary: no, never, never, I don't have to

I: but you would if he didn't have it?

Mary: oh yes, as soon as he found out he had, it was .. to be honest with you it was .. sitting next to him as a passenger in the car, taking our son to football it was- but not since he got this [ICD]. This has helped me.

I: was there a gap between being diagnosed and having it fitted?

Mary: not very long, not very long thank goodness. That's why he'll say he didn't have much time to think about it ... I think that was a good thing, I really do believe that. You know, I think that if Steve had thought and spoke to other people and everything, I'd have a hard job getting him to do it. I'm not saying I made him do it. I had the options there .. you know, these are the possibilities .... this is where we'd have a *life*, you know what I mean .... I said I'd have to move back to Ireland, the three eldest have moved there, there's only [youngest son] and [son] and I said I'd have to move back to be with my family, and what about his dad then? Not that I would, but these were little things that I would say, I mean I need my family if I don't have a husband.

I don't know what went on with you and him talking but I really do think that sometimes he's you know, just feeling a wee bit sorry for himself. To be honest with you. I think sometimes he just sees the negatives of this things, but I wouldn't. If I had something, to be honest I'd just be glad somebody had saved me. I would have loved my father to have had it.

I: so you're a very positive person, how about Steve, how would you describe him?

Mary: not positive, not about money, [Mary's attitude]if we lose the house we'll move house, we'll live on the side of the road, that's what we'll do ... [youngest son] hasn't got leukaemia or cancer or anything, or got hurt in an accident I expect most families have to face so, so what if we lose the house. So what? You know what I mean, we'll get a smaller house, blah blah di blah, we'll have one car instead of two ... no, I don't see nothing like that ... there's nothing like that that would make me feel- ... I think we're very lucky, very lucky, you know I think we're very lucky in everything that we've got. We've perfectly healthy children, grandchildren, you know what I mean, yes, there's been sad stories .. terrible, but you ... don't get over it, but you know what I mean.

When he [Steve] worries, it worries me cos I think that's like a strain, you know ..

I: so, you're worried when Steve worries because you're worried the strain may cause him to ...

Mary: yes, that's why I get him out of it quickly, if it's 4 o'clock in the morning, 2 o'clock, he will lie awake and stress himself out and things get worse ..... If we sat up and spoke for half an hour, if we chat for half an hour, he'll be snoring within 5 minutes and we lie down again, you know what I mean? And he'll be like 'oh thanks Mary for that' and I'll be like 'it's the truth Steve, I haven't done anything, I've just told you what we actually have' and things like that. I always think the worst thing that can happen is something happen to one of the children and I always think that is the worst ... I wouldn't care if I didn't have nice clothes to wear or nice house to live in, it don't matter to me, never did ... he'll tell you himself, that's how he fell in love with me.

And if I can't sit up and chat to him when he's going through this .. even though I think to myself 'oh, here he goes again' .. in my head now .. this is important and I can't have him feeling down, I: are you a bit worried about the potential of a shock?

Mary: My son asked me that .. he asked what happens to dad if he has an attack when he's driving and I said he will have a chance to pull over ... a chance to put on his brakes, cos they told me .. he will feel something before it actually does it ... they told me it will be enough to stun him .. you know, for him to think there's something not right, so you know, it's not just going to happen .. it could just be mild ones but they need to know about it ... so even if we think it's a mild one [shock] we still have to let them know. He will still have to be checked, which is good and is what we'll do ... you know what I mean, I know exactly what to do. But no I don't worry about him, cos he knows as well that's what happens, he will get something ..... As I said to Steve, if you're on the motorway, off you go, you know what I mean ... Cos the last thing you want to do is head into someone else. You know, he takes the child to football and stuff so this question is very important to me .. you know, that [son] is safe with him as well. I nag him about going too fast, but never even thought about that [shock during driving] ever, never .. and that's the truth until you mentioned it.

Obviously I knew in my head what the process would be if it did happen ... so no, I'm ok with it ... I know it's not happening to me but .. I feel like it is sometimes .. but that is part of being a wife and supporting him ... no, no, I'm glad he has it .. and I think he is too, really to be honest with you. I think because of the size of it and that's the truth .. he has said that to me. They may get smaller in years to come, remember the first mobile phone? But it will eventually sink in, it's been in nearly two years now, the skin will grow over it and it will like, sink in a bit more, or if he was to put on weight .. so it's not going to be stuck there forever, you know ... or up in his face, as he says ... the fact if he moves it's there, it reminds him that it's there ... but no, he's grand with it. If was affecting him every day, I would have already contacted someone, because you know, it's obvious that I'm not helping him, so he would need better help than me.

I: how often does he wake up worried? Maybe in a week?

Mary: about ... well, i'd say about ... I'd say definitely about once in a fortnight.... and he'd go on about it, and then he wouldn't mention it again, you know what I mean. But it wouldn't be a good sit down and listen to him ... but if he said, 'Mary I need to talk about this' then I'd sit down and listen to me ... but that wouldn't' be that often

I: do you think he's accepting it more?

Mary: yep. Yep definitely do. Definitely do, yep.

I: How's your son been with it?

Mary: He's been great with it. Obviously the whole family were worried when he had to have it but the fact that [brother] died everyone was so delighted, just glad the operation was over. Everybody was worried before, like again my father, I know that's nothing to do with Steve, but it's to do with 'heart'. When he had the operation and we knew it was in, then everybody was relieved .. it was when he didn't have it and we found out he had the-the disease, that's when everybody was scared ... I was scared, I had sleepless nights, I was really worried, scared, you know checking on his breathing and yet if I hadn't had known I wouldn't have done those things, but i knew .. that he had it ... but I would have nothing negative to say about it, it's a great thing, it's a great thing, cos it's given him a life.

Transcript for N11.1
Female aged mid- 60s
Husband has ICD for secondary prevention.
In line with ethics, participant's name has been changed to Elaine (E). 'I' stands for interviewer. EP stands for Electrophysiologist or Consultant.

I: firstly thanks very much for doing this under the circumstances, it can't be easy ...

E: no, not the best of times no,

I: are you sure you're happy to do this? If you don't want to that's fine ..

E: It's ok, I just don't know how helpful it's going to be .. because um .. no, carry on ..

I: ok, so can you tell me a little about your husband's ICD ...

E: he hasn't had a shock, in fact when he first had it, he went back in it had .. you know, the pre-shock situation had happened and that had happened several times, and they changed his medication and nothing's happened since, it's been fine .. but I think initially it was a bit difficult, cos he was nervous going out, and I was nervous of him going out as well .. 'have you got your mobile phone' all these sorts of thing ..

I: so, you were nervous him going out on his own?

E: yes, not now but I was yes.

I: and how long did that last for?

E: erm ... it was a really complicated situation because as he went into hospital his brother came in from NZ a few days later ... he hadn't been over for 7 years or something .. so it's difficult to get the timing right because then he couldn't drive for six months and I was driving him round ... forgot what the original question was now um .. how nervous was? Um .. I think after he'd been out once or twice I was ok really .. I was ok, ya .. but after .. after he came back and had the ok from the nurse ... that it hadn't really, hadn't really gone off .. nothing had happened, and then we felt a bit more confident about it really .. so yeah ...

I: so, if it had gone off because of the heart, how would you have felt then?

E: well, I would have contacted the hospital, I think I'm a fairly calm person, I wouldn't have gone crazy, I would have actually rung the hospital and taken him in I suppose ..

I: I see, can you tell me about your husband's condition, why's he's had to have the ICD

E: how he had it in the first place? ... um .... well prior to that he'd been working- he was playing badminton and felt strange, just went down on his knees and he went to the doctor but couldn't get an appointment for ages and actually after that he went to work in Berlin for three months and walked and cycled and did all sorts of things .. And we were on the 5th floor, the flat was on the 5th floor with no lift .. so we didn't realise there was any problem.

I: And you were with him at the time?

E: I was with him a lot of the time ... I was going back and forth a bit, because there was another grandchild born and so I came home ... but yeah, we didn't really- when he went to the doctor then, they said maybe it was something to do with blood pressure, they didn't actually suggest it was anything .. major .. it took a long time to actually get the diagnosis. And then when we came back from Berlin ... when would that have been-May, June, quite frequently then when we went out for a walk he said 'oh, I've got to stop' and there was one particular occasion when we were having a meal and I was going to take him into A&E but he said 'no'... he-he .. we didn't know what was wrong just that he wasn't feeling himself and it was probably something to do with his blood pressure, we thought.

I: so, how did you feel when you heard the diagnosis?

E: um ... trying to think when I heard the diagnosis ... it took quite a while to get the final diagnosis .. they thought it was other things first of all .. they were talking about heart failure, they were talking about enlarged heart , all sorts of things he might have had for years and we started thinking 'was there anything years ago that'd happened' ... um, I suppose relieved in the sense when he had the diagnosis and we realised something could be done that would probably make it ok ... I think going through the diagnosis was difficult because they kept coming up with more and more things and it just wasn't clear what was happening ...

I: Can I ask what the diagnosis was?

E: Originally? Well, he went to a different-he went to- he was under a different consultant, I can't remember his name .. because they were talking about an enlarged heart and um ... just trying to think of what the original diagnosis was ... it was an arrhythmia, that was the final diagnosis, a ventricular arrhythmia- fibrillation ...

I: sustained fibrillation?

E: yeah, yeah .. um, I mean it was quite frightening when we knew what it was, because of all those times when he had been feeling not right .. any of those times, he could.. have gone wrong but they were behind us, and the system was in place, so it was relief I suppose.

I: So, how do you feel about the ICD?

E: Now? .. He just seems to be as he was really .. apart from having things like cold hands and feet and he's back cycling ... He hasn't been walking up mountains yet, he's been on walks but he's ... and i wouldn't be happy about him being on his own on a walk, which he has done in the past ...

I: not even with a mobile phone?

E: well, they don't always- they don't always get a signal and I mean, some of the walking was in Spain so it just makes it a little bit more .. uncertain. We know the situation here, you know how to deal with the hospitals but you don't necessarily in Spain, well, I would know, the first time we went I made sure I had all the phone numbers to hand, now I feel a bit more confident really because nothing has happened for .. for a year. He's had nothing, not even had the initial stages ...

I: so, when your husband wanted to go out, initially those first few times, and you said you weren't too happy about it, did you talk about it? Did he know you weren't very happy?

E: yeah. We were both nervous about it really but he had to do it, I drove for the first six months anyway but on a Friday night, he generally goes into town on the train, has some drinks with friends .. and so the first once or twice he did that it was a little bit .. he was a bit nervous about it ...

I: you didn't stop him going?

E: oh, no, no. No, because he wouldn't have done it unless he felt he could cope with it ..

I: you encouraged him?

E: yes, I think I was supportive of him, yes. I don't think I could have stopped him actually (laughs)... No, I mean he didn't do it straight away .. he didn't do it until he felt a bit more confident about things anyway. I think going out first of all, was a little bit 'um, if this goes off ..' But I knew what I was going to do if it had gone off so ...

I: can you remember the first few months that your husband had it? Can you remember if have had any particular worries about the ICD? Any concerns?

E: .... well, I was a bit concerned that he wouldn't be able to get back to doing the things that he loved to do ... and I think that would have made life pretty ... miserable for him. I mean he liked walking, playing badminton, he used to do quite a lot before so ... And he'd been working abroad quite a lot and I thought 'well, we're not ...' well, he'd come to the end of that .. I think he had come to the end of that anyway... but I don't think we would have done that again afterwards ...

I: and has your husband started to do these things again?

E: yes, but not .. walking but not very long walks, but he has been out once or twice now with the group since ..

I: Badminton?

E: no, because it's explosive .. it's an explosive sport isn't it .. badminton? The way you (mimics playing badminton) ..play, it was suggested not badminton because it's that (demonstrates swiping) .. very much .. although I guess at some age he's got to stop but ... I think he misses that ... And the group he was with were very competitive so you couldn't play at a lower level, you know, you had to go for it. So, yeah .. he misses that and he would have missed the cycling if he couldn't cycle again .. actually six months later he fell off his bike and had a slight skull fracture, so he'd just started driving and I think two days later, he fell off his bike ... didn't have a helmet on, but he wears one now .. all the time ..

I: was that related to the ICD?

E: nothing to do with that, they did ask lots of questions but I think, I mean when we saw where he'd come off .. it was very .. loose stones, it was skiddy and there was a bus coming and it wasn't .. he doesn't remember exactly what happened, but they were satisfied it wasn't anything to do with that

I: when you heard he'd fallen off his bike, did you think it was related to the ICD?

E: no, I didn't no ... no, it wasn't until afterwards when they asked all the questions .. no, I didn't ... I think if you cycle a lot, you're quite likely to fall off ... and where it was, when I saw where it was .. I think when it happened, I was so 'getting him to hospital' that I didn't no... I didn't think about that particularly no. I don't think he did either really ... well, he didn't tell me he did anyway...

I: do you talk openly with each other about the ICD?

E: oh yes, but it doesn't really- .... the biggest worry really is if he's remembered to take his tablets ... I don't think he likes having it ...

when you swim a lot and you've got this thing stuck there, it doesn't look wonderful but ...

I: your husband swims a lot?

E: yes, he swims for exercise .. he swims, cycles, wants to keep fit

I: were you surprised at the size of it?

E: at the size of it? Yes, I suppose I was, and of course he's also quite slim so it probably stands out more than .. you know, it would to a larger person... And he did look-just looked so well, that was a surprise to everyone, he just looked so well ..

I: yes, he does look fit

E: he'd probably say no, but he is yes. But we do have .. my daughter's a doctor, my son's a dentist ... you know, I think they also um .. they are aware of things as well, we can always ask them 'can you find out ...' you know, if we didn't know, they were very helpful.

I: mm, so what do you think the downsides to having the ICD are? If any?

E: downsides?

I: mm you said your husband's not happy about it?

I: I think the thought of having wires through to his heart .. it doesn't feel-it's an invasion isn't it, of your body really, I think ... he misses doing certain things, and the fact you're living on tablets for the rest of your life and things like that .. and maybe the walking, maybe he doesn't do as much as he would have done ... he doesn't do the high mountains and stuff anymore you know ... so, I don't know how helpful this is, because it hasn't really interfered with our lives probably as much with some people, because it very rapidly ... because by the time he got onto the medication, it hasn't really bothered him since then. Apart from being there, it hasn't really interfered with a lot .. except the more strenuous exercise ...

I: How do you feel your husband's coped .. you know, he can't play badminton ...

E: He's been fine ... I mean my son said 'Dad might get a bit depressed' but I haven't- I can't say I particularly .. I mean he isn't the sort of person who shows his depression, he tends to internalise things ... he's coped with it ..

I: so, if he was depressed, would you know?

E: I know him fairly well, I think I'd know if he was different yes, he never has been, so it's very much .. he's very much on an even keel so

I: has he always been like that?

E: yes, always ... I think we're both sort of .. calm .. we deal with things, just get on with it really

I: And how are you feeling?

E: well not great. I know there's no cure now this time ... this is the third time .. but he's been amazing since I came out of hospital .. he's been running around after me, but now I'm getting a bit better he's not running around quite so much ... No, I'm sort of er... I think in the early stages of these things, as with anything is you realise you're mortal ... and you somehow have to cope with that .. and then you have to get on with your life because .. that's what you have to do isn't it ... so, we're both on medication for life

I: I suppose for your husband with his ICD, this is perhaps the first time he faced he was mortal?

E: yes, exactly. Yes, he hadn't had any serious illness before. I think when he was in hospital is when he would have been ... maybe he didn't show us what he was feeling then ...

I: he's quite a private person is he?

E: yes, he doesn't like showing his ... it's not .. he doesn't like sharing his feelings ... as you will find out ... so, I don't know how helpful this has been. I suppose some people don't cope with it particularly well, but I think we have just got on with our lives now ...

I: I suppose having a diagnosis of cancer must have been such a shock, it must change your outlook on life ..

E: absolutely, I think that was the first- you know, our lives are not as settled as we thought they were but having said that since then, since the cancer we have worked and travelled in Germany and Austria, since then grandchildren have been born, so you have to put it behind you really and carry on ....

Transcript for N12.1
Female aged 60
Husband has ICD for secondary prevention: previous MI
In line with ethics participant's name has been changed to 'Kay'. 'I' stands for Interviewer and EP stands for Electrophysiologist or consultant

I: well, first of all, can you tell me a bit about why your husband has got his ICD?

Kay: um ... he had a heart attack, last um .. June, and they believe it's as a result of scarring from a previous heart attack he had in his late 20s. At that time, he had a period of rehabilitation and .. that was it really .. you know .. he's continued to work all of that time ... he doesn't work now of course because he's on dialysis ... but there certainly haven't appeared any problems within our married life ... I suppose the concentration has been on his polycystic kidneys more than his history of having had some event, you know with his heart.

I: right, ok, so .. so he had a heart attack and ...

Kay: he was hospitalised immediately .. because he arrested twice... and he was in coronary care for about three days and then he went into the general cardiac ward and it was during that time that he had the device implanted ..

I: right, and how did you feel when you knew he had to have this device?

Kay: um, I wasn't upset about the device ... I was upset about the whole incident more and I did become a bit emotional when we were interviewed about what the device was all about .. you know, why etc and what the longer term implications or consequences could be ... but other than that I've no problem with the device being implanted at all ...

I: you said you became a bit emotional ..

Kay: yes, because at that time we um .. we were then um .. [husband] had already started home dialysis so we had quite a few things going on. Initially the home dialysis had gone well and then we started to run into some problems .. and then on top of that he had the heart attack and so um ..

I: it was the culmination ..

Kay: It was the build up it was, of what was happening at that time ..

I: sorry did you say you felt worried by the implications?

Kay: no, no, I wasn't worried. I felt we'd had a full explanation of what was going to happen during the procedure ... what to expect following the procedure ... even being down to him not being able to drive and wh-what we needed to do to make sure all the paper work was completed. And what would happen if he didn't have another event and what would happen if he did have another event. So, I felt we were constantly in the loop ..

I: so what would happen if he didn't have another event?

Kay: well if that was in the 12-month period then I'd apply for him to have his license to be reinstated and there would have to be consultation from the cardiologist from the DVLA

I: and if there was another event?

Kay: well it would depend .. there's a possibility of a further extension .. well there would be, it wouldn't be possible, there would be a further extension of him not being able to drive, now I believe it was .. I can't remember whether it would be six months or 12 months .... And then it would be reviewed again and even after that there could be a further review and there would be two reviews following that before the decision would be made that his license would be cancelled altogether ...

I: and how did that make you feel?

Kay: well, it's not a problem because I drive anyway, so it's not a problem, I suppose it's just an inconvenience at times because I'm still working part-time and when I was working, [husband] could have the car and still go and do things ... as now, when I'm at work .. or again we are a little hindered by him being on dialysis as well ... then we find .. if I'm at work, he- the car is normally with me but in the past, he would have dropped me off and gone and done things. And now he can't. But it hasn't stopped us from doing what we need to do and I still work part time ..

I: ok, so would you say your life is similar before and after the ICD?

Kay: yes, yes.

I: so what are the advantages for you? As the partner, what are the advantages in your husband having the ICD?

Kay: well I suppose the fact ... well it gives me some peace of mind because the day that this thing happened to him I was at work, and I had to suddenly come home from work .. and call the ambulance and we were very grateful that he survived that initial attack and that he has gone onto have something .. have the device put in, which is not hindering him in any shape, form or fashion .... it's really not interfering with our lives in many ways .. it's not. And we have been fortunate, and fingers crossed, that he hasn't had any hiccups and the last time he saw-he went up for a review, they don't want to see him now for another six months, so that makes you feel very positive ... And I think there's a sense of security too, that he's still being monitored .. although we're not aware of it in a way .. you know, we have the little device at the side of the bed, the little box ..

I: the remote one?

Kay: yes, and that in some ways gives you a sense of security that somebody is monitoring it, even from a distance ... and I think that's absolutely marvellous that that can be done ... and you know, nobody has ever contacted us to say that there has been a problem .. a hiccup and as I say when he last saw the cardiologist, he doesn't want to see him for a another six months ... so it's all quite positive.

I: can you think of any disadvantages?

Kay: no.

I: none at all?

Kay: No. None at all.

I: that's good. Did you have any concerns when your husband first came home from hospital?

Kay: well, we just had a minor concern because his device seemed to be quite raised in his chest but you know, we contacted the Arrhythmia Nurse and she came out and reassured us that it was nothing dramatic, or nothing to be overly concerned about and the swelling would settle down-as it did. And you know, when he hasn't got a top on you can see the outline of the device, but we're not vain people so it doesn't (laughs) ... the fact that it is doing the job that it is meant to do ... and it's keeping him with us ... so anything else is really so secondary that we didn't even think about it.

I: ok, thank you. Can you tell me whether your husband does any activity to increase his heart rate

Kay: um .. he doesn't. Because he has polycystic kidneys and you know, he's been on home dialysis now for about 15, 16 months and we've had a few hiccups with that ... which are now starting to settle down a bit .. it's a bit of a balancing act, because with his kidney condition, he does get tired anyway .. And most weeks he would dialyse five days a week, for at least three to four hours each day ... so it takes up a portion of six hours of the day ... So, it's a big slice out of the day. But you know, this week now with the weather, we have been getting out into the garden ... we will walk the dogs and that-he seems to be able to cope with that ...

I: so when you say you take the dogs out and you work in the garden, are you aware of the ICD?

Kay: no, no,

I: you don't think about it?

Kay: no, I certainly don't anyway I must admit ... you know we do monitor him, there are periods when he does get breathless .. that's a balance whether it's his kidney condition or his heart condition, you know. And he's not foolish, and as it is now ... and I suppose in some ways, I must be honest I think that the problem that he had with his heart condition was a bit secondary to his kidney condition. That seemed to be the primary concern. You know, that's where we were having the hiccups you know .. and we have an absolutely brilliant service from the renal department and for months and months the renal sisters were coming out here five days a week because he was having trouble. So, again, not wanting to sound dismissive of it but at the same time, because it wasn't presenting a problem .. it didn't seem to be up ... up-in our minds really ... you know, because it wasn't becoming a problem to us. And again, the priority was to get his home dialysis settled down .. And the implant wasn't causing a problem, if it had been causing a problem, then it might have been in competition with the dialysis but it hasn't caused a problem, so we've been extremely fortunate.

I: do you think you're quite positive as people?

Kay: ... um ... yes. I think we are ... we've had to make some great adjustments in our lives ... me more than my husband .. and that's because of personalities ... because we've only returned to this country five years ago

[talks about life in another country]

... and we came home because of [husband's] renal condition. At the time he had his mum and sister out there but we never had any family of our own, because his condition is hereditary .... and he was becoming more unwell ... when he began to deteriorate, I thought we ought to return home because there, they were talking about a survival rate of five to seven years. So, we came home, and my husband adjusted superbly well and I didn't .... he adjusted well because of his personality.

[haven't continued to transcribe as 'Kay' continues to talk about life in another country and tends to focus more on the kidney condition than the ICD]

Transcript for S13.1

Female aged 60

Husband has ICD for primary prevention. MI scars and heart failure. Husband has constant fast heartbeat.

In line with ethics, participant's name has been changed to Jen. 'I' stands for Interviewer and EP for Electrophysiologist or Consultant.

I: so how do you feel about this ICD?

Jen: happy that he's had it done .. he-we're two different types of people, um .. I knew he would be nervous, he is because he's never had anything done like this before ... he is more of a nervous type ... After he had it done, he was a little bit worried ..if he'd move his arm or things like that .. he was a bit pathetic like, like most men are (laughs) and he was recovering well, taking his time, you know because he kept on thinking it was there [hand hovers over where an ICD would be placed] .. he shouldn't move his arm, so for the first month, he was quite ... nervous about it ... but after the month, he slowly started getting gradually better about it, and forgetting it was there, so he was beginning to get quite well,

I: good ..

Jen: yes, after the month he'd go out driving, he did start helping our son ... so yes, he was beginning to really forget about it ... Everything was going fine ...

I: what happened?

Jen: until he become ill ... I don't know whether it's cos the weather .. and whether that started off him being *constantly* in this irregular heart beat .. whether the pneumonia set it off or whether it was helping [son] .. something just set it off and it was constant .. instead of being irregular at times ... so I think that .. from-from February, beginning of February [few weeks previous] when he had the pneumonia, things just went downhill from then ... but he was getting so much better beforehand .. and he was obviously going to get worse at some stage .. it just so happened it was from February onwards [few weeks previous] and he could have gone *ages* before he got to this stage ..

I: and that was triggered by the pneumonia?

Jen: yes, and that started the constant irregular heartbeat

I: and what do the doctors suggest?

Jen: they suggest an ablation .. what they're saying is they do it twice and then if it doesn't work .. I've never heard of this before, a heart operation and they'll cut that part off ... you know, we haven't been down this road before, his father did have a by-pass but not a piece cut out-as I've said, I've not heard of this before

I: so until your husband had the defib, he's been remarkably healthy then?

Jen: yes, yes, yes, yes.

I: so this must all be quite a shock .. different

Jen: different .. completely different ... the defib didn't change our lives, it was after the first shock .. it's completely changed our lives .. cos he did all the driving, he used to do all the shopping... we'd go shopping together but sometimes if I was too busy he would go shopping on his own, so it's *completely* changed our lives .. since the shock ..

I: because he can't drive?

Jen: yes, yes. He can drive in six months as long as the ablation works, if it doesn't work .. but it depends .. but it has, the shock has changed our lives quite a bit ..

I: what about the actual shock itself, what was that like for you?

Jen: well I think because the doctor had actually shocked him a couple of times, to me it was just 'oh, another shock' but if it had happened at home when we were on our own for the first time then that would have been different ..

I: he was in hospital?

Jen: he was in hospital, and the doctors had already tried to shock him twice .. so when I went in they didn't tell me over the phone .. he [husband] wouldn't let them, so he told me when I went in ... i just took, because of the fact that he'd already been shocked twice by the doctor, so you know, it was just another shock to me at the time but .. I think if I had been on my own at home with him then-the first time, I would have coped .. as long as he didn't pass out, I'd panic if anybody passes out, don't ask me why ..

I: he would come round

Jen: yes

I: do you think about that a lot? Do you think about the shock?

Jen: no, no .... I was just-I don't think I'd worry too much ..

I: so it's really changed your life in the sense of not being able to drive ..

Jen: yes

I: How do you feel about that ...

Jen: It is a disadvantage but I wouldn't be without it ... I wouldn't say to him, you got to have it out .. no, he's got to have it and that's a fact of life that we have to put up with it

I: so for your the advantages are ..

Jen: he's still here .. otherwise he wouldn't be

I: do you leave him on his own?

Jen: yes, I do leave him .. I go out-well I have to, I go out quite a bit .. to do the shopping and to do different things yes,

I: how would you feel if he didn't have the defib?

Jen: not happy, I wouldn't be happy ... not at the moment no

I: what did you think about the literature they gave you?

Jen: I thought it very good, yes ... everything is very good ... the only thing I would query is ... um .. well, not query .. is the afterwards .. you come home and you're on your own basically aren't you?

I: that's how you feel is it?

Jen: yes, yes.

I: is that how your husband feels as well?

Jen: um .. don't know on that one, don't know ..

I: ok, but you felt it. Did you feel at a loss of what to do?

Jen: oh no, to me I'd just carry on and cope and then if I got a real question, I would ring them and ask them ... but I did feel .. it's like a cut-off .. come home from hospital isn't it ... you just got to get on wi-with it ..

I: what do you think may have helped that .. bridge?

Jen: not sure, perhaps a visit? I don't know.

I: but you said you coped ... how did you cope?

Jen: well you do, you .. you .. just carry on

I: ok, do you talk to each other about the defib?

Jen: yes, sometimes, yeah. Yes, in the beginning we did .. the more things .. and when things actually happen, everything falls into place .. when you go and read it [literature] .. what they've said, then sort of makes sense ...

I: ok, how has the defib changed your relationship?

Jen: no, I don't think it has changed, wouldn't have said so, no.

I: some couples have said it has brought them closer together ... some haven't .. some have

I: um ... well, I suppose, it's not just that it .. it's what's been happening .. what I've said, each step of .. since we started going to see the EP ... each realisation has perhaps brought us closer together .. the fact that his heart is wearing out, that's what the basically told him from the very beginning ... .. his heart is wearing out so perhaps, each individual step has brought up closer together yes, not just the defib ..

I: that must be hard ..

Jen: yes it is hard .. it brings an end to everything so yes it's quite hard ..

I: do you talk to each other about it?

Jen: I do try sometimes, but he would prefer not to .. not to talk too much about it

I: ok, so for you the defib is positive

Jen: oh yes, yes

I: ok, so how do you see the future .. you and your husband

I: mm yes, well there's two things going on at the moment, there's the fact he wears a defib .. there's the fact that at the moment his heart beats too fast .. so if they can't get that down .. then obviously we'll have to live a quieter life than what we did before ... Whereas with the defib, if his heart was alright-he had the irregular heartbeat but not constantly, so he could go ahead and do things, whereas-so with the defib it would be positive .. it's the positive side of it .. because we were planning to go abroad, which I had to cancel ... so with the defib fitted, we were flying aboard, we were planning a couple of holidays .. two of our children have got caravans, and we got the motor home .. so he was driving, we were going places .. so

that was the positive side of it .. But with the irregular heartbeat
constant .. we're sort of stuck at the moment .. can't plan anything

I: so the defib can't cope with the constant irregular heartbeat

Jen: no, well no the defib can, but his heart can't-can't cope with the
irregular heartbeat ... it's running at 105, 110 so at the moment ...
how long it's going to last .. the doctors can't tell us that .. They have
got one gentleman who has got-that's got an irregular heartbeat-I
don't know-he didn't say how fast it was running, but it's constant
as well ... but he's more prone to strokes, so he's decided not to do
anything about it ... so he is living his life quietly .. plays the
occasional round of golf, he said so, of course my question was how
long has he been going with this irregular heartbeat, and he said 'so
far, it's been a year' .. so, um, you just can't tell .. he said there has
been no study on that side of it .. and so .. er .. he said I just can't
give you an answer, how long ... so as I said, the defib side of it, it is
positive but at the moment, the irregular, the fast irregular
heartbeat s, isin't-is stopping our lives putting it that way .. He just
has to sit quiet ... Course he was one of these people that used to go
out, go out a lot .. he used to love going out .. whereas I would have
interests in the house .. go on the computer, I could read .. you
know I do lots of little things .. whereas he's got no interests ..
driving was one of his pleasures .. he's stuck ..

I: mm, that's hard ..... do you drive

Jen: I have got a license but I don't drive .. I walk, I walk everywhere
or bus

I: do you think you may start?

Jen: no, I did try .. I did try, my son took me out cos he's a driving
instructor and he said 'you're alright' and I said 'I know, I'm alright ..
but all I need to do is concentrate on going down the road, I can't
look at signs .. (laughing) .. I said, 'I'm fine driving but I can't see
anything at the side of the road '.. if anybody wanted to cross, that
would be it, they would be gone! (laughing)

I: perhaps you had better stick with the bus .... so the fact you don't
drive means it's even bigger ...

Jen: yes,

I: do you see yourselves in the future back to travelling?

Jen: well yes, hopefully yes ... this is what we're hoping for .. our
lives back to normal ... but we just got to wait and see ...

I: ok,

Jen: but on the other side of it, I'm not sure whether it's the tablets in the eve-in the night .. whether it's the build up of the tablets in the night .. with him sleeping or whether it's the fact it was the shock, I'm not sure whether he's ... um ... whether it's on his-on the back of his mind .. when he goes to bed. [need to read S13.2]

I: do you suspect it might be [on his mind]

Jen: yes, yes .. It could be the tablets mind .. different tablets do different things .. you don't know the side effects do you ... but it has been gradually getting worse, since he's been coming home from hospital recently .. cold sweats, and then he gets giddy, but the first time .. he said last week, it was like a choking effect ... so it's been gradually been getting worse ...... any other questions?

I: um, have you any concerns or worries about the defib?

Jen: no, no I think the defib is great really ... yes, that really is amazing.. to me it's a lifesaver .. we go in and they read it, and they can tell straight away .. so yeah, I think it's excellent

Transcript for N14.1
Female aged 56
Long-term Partner has ICD as he has Brugada Syndrome
In line with ethics, Participant's name has been changed to Meg.
'I' stands for Interviewer and EP stands for Electrophysiologist or Consultant

I: Your partner was telling me about what happened in [town near coast]

Meg: bit scary that was ... well very scary ... and ... annoying as well as scary but I wasn't annoyed till afterwards cos .. he'd been in hospital, and they said that he needed the ICD and then they sent him home to wait, until they called him back .. and .. I'd .. gone .. and spoken to .. a nurse to say you know ' is everything going to be alright? Can he do his normal stuff?' you know ... And he'd already told them that he was a walker and 'yeah no problem' [said nurse]... so I didn't think it was a problem taking him for a walk, you know ... take him for a walk (laughs) .. *going with* him for a walk and then of course all that happened. And it was very, very frightening .. More frightening for [Partner] cos I felt that-I felt that he was panicking .. exacerbating the situation ... because he's never been ill in his life .. you know, and I think because I have I see signs and stuff when people are getting up tight.

But yeah, it was very frightening and very annoying because I think they should have just kept him in and done it

I: have you talked about what happened with each other?

Meg: Oh yeah, we've talked about it .. at the time. At the time when they said he was going home, I didn't like that ... I just thought it's crazy really, cos they've got him all geared up now ... they should have just got on with it, instead of just leaving him you know .. worrying ..

I: so what was it like for you .. were you worrying? Did you return to work?

Meg: no, thankfully .... yes actually thinking about it, I did go back to work with the view that when he had it done, I'd want some time off ... so I decided to go back to work because they didn't give any indication that it was going to happen and I don't think they ever knew it was going to happen [it being the attack or episode]. So I went to work, thinking well let's just hope he gets done sooner rather than later

I: so you weren't particularly concerned at the time

Meg: oh I was concerned .. yeah definitely concerned because he needed an ICD .. although a part of me was absolutely amazed cos he was-55 he was I think .. 55 and this has just been diagnosed. And really the fear was a retrospective fear .. thinking 'oh God, anything could have happened at any time'. And I think there was a bit of 'crikey, this is my big, strong boy and he supposed to be looking after me' and he has always looked after me, very well ... and the tables have turned you know. That was quite hard to come to terms with .. that was-although I would always look after him .. It changed my whole perspective on our relationship

I: how has it changed?

Meg: well now, it hasn't really changed .. but at the time I thought that it possibly could change, hugely ..... and then when I read up on ICDs and all that, then I reassured myself ... And I'm just very thankful that they did find it and they done it cos now .. you know .. it's more a mental thing that we're going through rather than a physical thing ... You know, I'm not concerned at all about his physical well-being .. other than the norm, you know ... because he's got this thing now ... And it has changed things like I can't sleep with him any more .. he's just rolling around and I'm a bit of a 'roller-rounder' as well (laughs) ... so I've gone into the front bedroom now .. And I look at him and he looks healthy .. but I know in his heart he doesn't feel a hundred percent. You know, he's more .. hesitant I suppose than he used to be ...

And there are little things like um .. well for instance, the other day-he turns the water on and off for the front and out the back, cos of the frost and everything and he turned it on when I was in work the other day and when I came home he said 'I've turned all the taps on and everything and oh by the way .. there's a little red thing by the thingy in the shed' blah di blah' 'and what you do is ...'. He's telling me that in case I've got to turn them off in Oct-because he was saying I always turn them off before the frosts come .. you know, little things like that ... And I don't actually react to them at all because I know myself, nobody else can make him feel any different. He has to work it out himself .. he has to come to terms with everything ..

He's been having a lot of problems-he's probably told you-with work and getting paid and all that so .. it's kept him going I suppose really .. he's-everyday he says 'I've got to do this today' and I think .. it unfortunate his work involves the type of work he does and the people he was working for. Because you know, if he was working where I work-I'm a civil servant- this would all have been sorted ..

I: [inaudible]

Meg: yes and before-because this has been going on for a good few years really although without knowing ... you know when I first went to the hospital with him .. cos he said to me one time, I've been having palpitations so I said 'right' stopped cooking Sunday lunch and said 'right, let's go' and he said 'no, you stay here and cooked the lunch'. So, I said 'no you're having palpitations, I'll take you to hospital' but he said 'no, you're alright, I'd rather have my lunch when I come back'. And then I went in then, cos he hadn't come home for hours so I thought 'that's it I'm off' so I went into the hospital and they were doing ECGs and they said to me to-he said to me 'I've had all these ECGs and nobody knows what's going on'.

I went to find somebody to find out .. I'm a bit more au fait with things like this and they said 'well, we just don't know'.. You know they said to me the same thing when he had knee ops- he's had little knee ops .. and whenever they do the rounds and they take his temp-I can't remember-observations, they were saying he's like an athlete, he's so fit ... and they were saying the same thing that day.. And I was thinking well this is just bizarre .. and I said what's going to happen, and they said 'oh you can go home' but take this ECG reading with you'. And I said 'why?' And they said if anything happened to give it straight to the ambulance men .. now that's not very good is it?

I: no

Meg: what they said they'd do is give it to the Head Honcho, and that was the words, the Cardiologist the next day, and if the Cardiologist decided that he would needed to be seen, he would phone us ... they didn't phone us so for months and months and months, I was thinking it must just be a blip .. so I got used to it really and we just carried on ...

I: so what was it like finding out he needed an ICD?

Meg: well as I say, very odd for me because he's always been so fit and healthy .. he's very *strong,* very strong, he's one of those wiry fellows .. You know, strong, worked really hard .. I mean, thankfully I made him give up the tools I don't know, about three years ago, four years ago because I felt he was getting older and his body was wearing out quickly, and that's how he got into teaching and stuff like that ...So when, it's a weird thing, it's a weird thing ... I kept on thinking that it would be alright, because of the time level .. I thought this is only something very minor which they are keeping on top of then of course when he came back with this piece of paper saying that he had Brugada Syndrome and he told me the EP said tell your partner not to go on the computer ... And when I saw what it entailed then I was frightened. Then I got really frightened. I thought 'oh my God, it could happen any time, any place, anywhere' sort of thing ...

I: did they give you any literature about it?

Meg: no,

I: just the name?

Meg: Just the –he wrote it on a little piece of paper 'Brugada Syndrome', so I got on then on the internet ... I do understand that the internet is very..so I went on quite a few sites and stuff and took bits out of it and thought this is a bit of a problem then .. this needs to be done .. But then they didn't call him for another year ... then I was thinking how can someone have mild Brugada .. because that's what they had indicated to [partner] that it was mild-how can you have something that's mild like that, it either bangs in or it doesn't .. so I was reading all about that and the sodium and the potassium .. so I was thinking how can you have a little bit .. So I started to say 'you better get yourself sorted' .. you know, ask to see the Cardiologist .. and then I think out of the blue we had a letter .. and then it all sort of went in motion

But it was very, very strange the way they [EP] behaved I have to say because they more or less said to him 'we'll do a deal' you know, 'if we put you for this test now'-this was the one where um .. I can't remember what they do ...

I: is it when they stimulate the heart?

Meg: yeah, yeah ... um .. 'and if we find there's a problem, we'll give you one' ... Well hello... it's not a lottery .. well, it may be in the big, bad world but as far as I'm concerned it's not a lottery and um .. the way it was handled in that although in saying that, I wasn't there when they were saying this and [partner] does sometimes get the wrong end of the stick .. because you know what I mean, I'm a kidney patient and if I need something, they don't say 'well we'll do this test and see how bad it is and see if it's bad enough' you know what I mean ... (laughs) .. that's it really, I was just very, very relieved when he finally got it sorted.

I: so for you the advantages are .. as a partner they are

Meg: I feel safe ...

I: right

Meg: I just feel safer with it .. I've had some real strange day dreams ..... but I feel happier now that it's done .. And that couple of days where they sent him out .. I wouldn't have wanted him to go through anything that he went through but in a way, I'm glad he did, cos it got him in and they did it. I don't know what I would have been like if I'd had to wait a month, six weeks ... I think I might have got a bit heavy handed then you know, ordering him to sit down and stuff.

I: and now you know physically he ok

Meg: yep, I'm really glad he's got it .. the only thing I'm not happy with is the fact that it could .. you know .. it could have happened in those three years when he was being seen by an EP. I think if anybody has anything like that, it's no good saying to somebody 'oh you've got a mild case of something awful' .. it doesn't do the trick does it .. And especially people who know about hospitals and procedures .. cos that was my biggest concern .. you can't have something like that that's just mild ..

I: do you think if you hadn't pushed him he would still not have one?

Meg: no, I think it was at the back of his mind ... but he's not that way inclined ... if the doctor tells him something, he thinks the doctor knows what he's doing, and a lot of people are like that. And although I'm not saying they didn't know what they were doing.. they weren't on top of the case. I think it's just the physical-I mean it is physical because it has changed him, he's always been a great sleeper and stuff like that .. he's not sleeping and he says he can feel it ...

I: has it spoilt your relationship?

Meg: not really .. I think it's probably brought us closer together

I: in what way has it brought you closer together?

Meg: um ... well as I say, I had my kidney out .. my first big op, when I was about 17 so I've always been in this pattern that I've got .. ongoing problems .. always been .. very aware of *life* and [partner] never has .. he has always been very positive and he used to say things like- I used to say 'oh that'd be terrible' and he'd say 'oh it's alright, you only die once' and he'd put me in the ground, make sure the birds can eat me' and this palaver but that when he has that collapse in the park that was *it* and I saw him, and I looked at him and I knew it had changed everything; the way he looked at life .. that was the upsetting thing

[Participant begins to cry]

I: are you ok? Do you want to stop?

Meg: [shakes head no] .. I looked at him and I knew he'd changed .. which is .. not saying it's for the worst .. I saw the realisation hit him you know ... saw he now knows what you know, it's all about ..

I: I suppose up until then you'd been the 'patient' and he'd been the strong one

Meg: yeah, that's right you know .. oh thank you [Interviewer gives her a tissue] .. he started shouting, well not shouting, he could hardly speak .. and he sort of said to me, 'well you can talk to me' and I was thinking 'what the hell do you say to somebody' you know what? And all I was saying to him was 'breathe through your nose'... he was lying across this bench type thing, and I don't know whether he's told you because it was just bizarre .. cos he was there .. and I'd phoned the emergency services and they said they were coming but where was I. Well I didn't know where I was-I knew where I was, but I didn't know the name of the park blah di blah .. and there were people going back and fore and I was asking them .. nobody knew what the name of the park was ... so they just said they'd send someone out ... Well it was 20 minutes went past and he was going white and coming back and going .. and I'd taken my top clothes off, all I had on was a little t-shirt, a little strappy thing .. cos I'd wrapped everything around him. And when the paramedic came he drove past me [laughing] and what was happening I was standing in the middle of the road going like this [waves with arms]and I saw him going past me and I thought 'Jesus Christ, what more can I do' but in retrospect he thought I was exercising [laughs] .. this mad woman in the park ....

First of all they wouldn't take him to the hospital, we were near [name of hospital] and the ambulance man rang up and they wouldn't take him 'no, no, no, we don't want him if he's got Brugada, no, no'.. And they said try and get him into [name of another hospital] hospital and they wouldn't answer the bloody phone .. so in the end the paramedic was fantastic, he said 'I don't care what they said in .. I'm taking him in now'...

So I followed them and it was when I went in and he was there with them all around him and I saw his eyes and he was so scared .. it was just awful, [shivers] I didn't like seeing him scared and then I knew that he knew it was very serious and he had to get on with it. And then love him, he was in there for 10 days ...

I: have you been back to the park?

Meg: oh yeah, yeah we went a few weeks ago actually. I-I .. it was strange, cos I hadn't even thought about it .. because we do go, cos we like to have a little drive ..... and I said 'let's go to the park' and he said 'oh yeah, the fateful park, let's go there' 'Get it off'-can't remember the words he was saying but he was saying that he didn't want to go there but he didn't want it to become this place [puts hands in front of her like a cross] ... Cos when we'd gone there when it happened, we'd gone there and he'd insisted on driving .. 'You're not supposed to drive' um .... and he'd got out the car and we went a little way, and he said to me 'I don't feel very well' right nearest bench we'll just sit on it and I said to him 'look we'll just sit there till you feel better' you know, cos it does happen, if you sit down you get yourself together and all the rest of it ... Well we sat and sat and sat for ages and when we got up ...

But I don't know, I don't know, it was a really weird feeling when all that was going on .. because a part of me felt that .. he was panicking which I know from myself, you can't panic in situations like that .. you start panicking, your heart starts racing .. everything starts swimming, you know you've just got to try and bring yourself down. And I was trying to bring him down .. and as I was trying to bring him down, he was going whiter and whiter and I said 'I think I'd better get somebody' and he said yes. .... And I was thinking that I'd read on that bloody internet that you weren't allowed to give them normal CPR and I was thinking 'well what CPR so we give him' (laughing)... So I think, they should have given me information, they should have given me stuff so I knew what to do, cos I was the one that was going to do anything ... if anything was going to happen, it'd be me wouldn't it?

If it had been a normal situation, I'd have my head around it, but when you're not supposed to do normal CPR well ... So, I think now, it's just [partner] coming to terms with it, and me carrying on beside him ..

I: so how's your life changed ..

Meg: well, obviously he's not working

I: I know that's a huge part of his life, but apart from that? Apart from working? What about exercise

Meg: yes ... I thought a lot about you can't change your life to a great extent over something like this and him having had the procedure probably the best thing for him was to walk. Because even if something else got him, it wasn't going to be that [Brugada]... Because before the procedure .. before he'd gone into hospital, they said to him don't go walking the dog on your own, and stuff like that .. and I think it frightened him ... they had already put that doubt in his mind hadn't they .. so it was like conflicting .. conflicting advice really ... I don't know if he had a cardiac arrest ... they said if they'd had to shock him he couldn't drive, but they said he could drive, so I surmised that he hadn't had a cardiac arrest .. but that's me surmising not me knowing ..

I: ok,

Meg: but I think that's probably right and I'm just glad he's not going to have a cardiac arrest anywhere I'm going with him .. and he's going to be alright .. you know, that's how I feel about it .. I mean we've been together 30 years, we've had our big bust ups and all the rest of it, but we're very, very *together* now and whatever he wants to do, I'm there behind him. And the same goes for me, I know. His head needs to come together now

I: do you talk about it?

Meg: I talk about it with him .. I put in these little things for him to go away and think about himself .. cos there's never going to be a time when he listens to me and goes 'yep that's right', he's got to come to terms with it himself. So, obviously if he wants to talk about it, we'll talk about it ... you know I was quite happy when he was getting quite proud of his scar .. that's always good cos then you've come to terms then haven't you? .. And no doubt he'll come to terms with it a hundred percent, well never a hundred percent .. I suppose there's always going to be that thing in the back of your head isn't there 'I've got this thing'... Especially unfortunately because he can feel it .. I never thought he'd be able to feel it ... you know, I've got bits and pieces in me that aren't real and stuff but I can't feel them so they are real as far as I'm concerned. So, I think jutting it it's 'that's not what I was born with' kind of thing ... and if you can see it, it's a weird thing on his chest .. I was quite surprised at that .. no doubt in 30 years time, they'll be the size of a finger nail ... But I don't care-I do care obviously, but I'm just glad he's got it ... if it was a huge box like that [makes shape with hands] fine,

I: so it's keeping him alive

Meg: that's right, yeah

I: can you think of any disadvantages?

Meg: the only disadvantages are he can't sleep cos he feels it's moving around .. obviously a disadvantage he's got this flaming syndrome anyway but saying that, if he's got it, then that's what I want him to have .. and that's what he wants to have as well... He said at one point 'when it's time to go, you go' and I'm thinking 'oh God, it's only a box.. you're having it!' And it's a good job he doesn't listen to the Archers, do you listen to the Archers?

I: no,

Meg: well one of their characters in that has just had a defibrillator put in .

I: that's interesting, I'll have to start listening ..

Meg: yes in the last three weeks .. she's had one put in .. Elizabeth .. in fact if you google The Arches, you'll know all about it .. She's had a long going heart problem and she had an episode and I'm thinking this is absolutely amazing because they were talking to her .. her EPs were actually talking to her! And so I learned quite a bit of it you know

Yeah, I think it's absolutely fantastic

I: so for you it's all positive ... have you noticed a change in [partner]

Meg: have I noticed a change? He's a bit more philosophical now .. less 'gun ho'

I: do you think that's since the incident in [town by coast]?

Meg: yeah ... yeah, cos he's never been vulnerable before .. and he was vulnerable that day and it's just put a-a new slant on things really. You know if anything was going on, [partner] would be there, if somebody needed a fridge to be carried up to the top of that [points to house across street] .. up he'd go! And he wouldn't do it now ... thank God. So, it's just carry on now isn't it?

We did have some literature about what to do if it goes off and all that ..

I: do you ever think about that, about a shock?

Meg: mm. Yes, because it's not going to be very nice is it .. and I don't it to hurt him and I don't know where we got this but it says somewhere in those little books, that I may be able to feel it if I'm next to him in bed. Wouldn't quite fancy that myself. And I don't know how I'd react if it went off .. and then I think 'well you don't need to think about that, cos it hasn't gone off'. And it's a good chance, it'll never go off... so you know I have thought about it at times but you know , not in an over- you know I don't think about it much ...

I: some people are worried that if the heart rate increases a lot it could perhaps trigger a shock, say during sex ..

Meg: could it?

I: no, no, it wouldn't .. it would have to go up too high .. but some people avoid sex because of this fear ... some people are frightened of exerting their partner so it could affect their lives

Meg: haven't noticed that I'd have to say ..

I: please don't worry, it's an irrational fear

Meg: well I can understand that worry, that concern .. but it hasn't affected us .. I don't know whether [partner] said, did he say ...

I: no

Meg: oh, perhaps I should ask him ... No, I haven't noticed anything different

I: what about exerting himself as in going for a walk?

Meg: He's a sod.... In the beginning I thought he was taking it all very well cos he was being .. you know, 'I'll just do a bit of this and a bit of that' and a couple of weeks ago I came home from work, and he's chain-sawing bits of wood .. and there was a big pile ... and I said 'have you had a rest?' and he said 'no', so I said 'why don't you have a rest'. You know, he can't be sort of doing the whole bloody lot ... It's trying to allow him to so what he does and be himself and to just try and moderate it a little bit ... cos he was the type of person, before this happened, would work till he was so exhausted that he could sit on the settee grunting cos he was so exhausted... He's not one of those people who can 'temper' things very well .. I do usually let him get on with it, but I do temper him a bit now ..

I: inaudible

Meg: I know when he's worrying .. I know when he's in deep thought .. I know. And if that happens-if he's going down I try to bring him back up.. and vice versa .. we do work each other out quite well ... And in a good way, he listens to me a lot more than he ever did before .. and that's because of the vulnerability .. dare say, he'll be fine

I: inaudible

Meg; and I don't think sometimes being positive is a good thing because I wish I'd gone to the hospital the first time it happened, because then he wouldn't be hanging around for two years. And I'm a little bit annoyed with myself about that as well ..

I: with hindsight I guess we'd do a lot of things differently, at least he's got it now..

Meg: yes, but I can't understand why I didn't get it all sorted out when it all first happened ..

I: what don't you understand?

Meg: yes I didn't think 'hang on a minute, this is all a bit strange'... and I think it's because they told him he had 'mild' Brugada and I can't imagine why I thought mild Brugada was alright to have but .. it's like saying you've got mild meningitis isn't it? I have said to [partner] a few times I can't understand why I didn't - .. cos I'm pretty proactive .. I just don't understand why I didn't get proactive in the beginning. And I'm just glad he's got to where he's got really ..

I: you come across as being very positive and matter of fact, how do you think you've coped so well?

Meg: I am happy, I am *so* pleased that he's got this thing ... I mean he could be in the situation that he had something like this [Brugada] and there was nothing they could have done about it .... so great! I've had so much history, in and out myself that I know you've just got to be positive, no point in getting into the mire of things, just not good for you ... not saying I haven't on occasion .. I know it's so bad for you .. you have to be positive, you have to give him a resounding positive yes; 'this is what we do, this is what we got and this is how we deal with it'. ... I think I've got where I got through being positive and I'm going to be positive for him as well ...

I: thank you [I and Meg chat a bit]

Meg: This is another thing, [partner] has always worked, so it's strange having him sat at home ... I think he will try and get back to work .. I think he will drive himself insane if he stays home .. I can stay in, read , go on the computer .. but [partner's] not a reader .. I have taught him how to get on the internet now ... I think once he's sorted all this out with this company .. he'll get other things [work].... if he worked in a decent place, I would have been saying to him 'do a couple of days a week' you know gradually, but I can't do that with this [company]... so that's a bit of a bloody stumbling block you know ... but after he gets it all sorted out .. I mean people have come to him and offered him things .. teaching stuff, so I think he will go back eventually.

I: do you think he went back to early?

Meg: (big sigh) yes, but that was pressure you see .. from them. I felt it was too soon anyway .. because I felt he needed a bit of time to heal himself up here [points to head], which you do don't you, especially when you've always been very, very well ... you've got to come to terms with it, before you can go any further. And I felt he hadn't come to terms with it .. and poor bugger, he was bloody freezing and I-I wish he hadn't gone back in the first place ... Not nice having him home when I'm at work .. just not on! (laughs)

Transcript for S15.1
Female aged 64, wife to recipient due to MI and HF
Participant (p)
Interviewer (I)
Arrhythmia Nurse (AN)
Electrophysiologist (EP)
Husband has had ICD for 9 months

I: I've heard from your husband what happened, how was it for you as a partner?

P: oh what are we going back to now?

I: when he was taken in because his heart was tachycardic

P: oh yes, um .. quite daunting really, although I felt as though it wasn't really happening. You know, he'd had a heart attack before so when he said he wasn't well, I phoned 999 and just put everything in motion really ...

I: so when you say you didn't feel it was happening ...?

P: yes, I suppose I was-I'd gone along with all those years and thinking ah well, we can discount that now, he's fine so when it did happen it was quite a shock. And then you sort of get the ambulance and then think well best ring the family, but I'm sure I'm going to be worrying them unnecessarily. But at the back of your mind you're thinking well maybe it is-it is really happening again and um, yeah, you just get on and deal with it then. I went to the hospital with [husband] .. can't remember now. (Participant puts hands in hair as though thinking), went in the ambulance ... um ...

I: so when you found out your husband was having the ICD, how did you feel about that?

P: relieved, yes very relieved .. you know, obviously when he had his first heart attack, he had the two cardiac arrests and when he was in the hospital they said you know, his ventricles wasn't good. So, um, when we knew about the possibility of an ICD, I know I would have been very cross if he hadn't had it. Because it was obviously- when they spoke that he might need it, there must be a good reason. And um, that seemed the next step forward really,

I: so you're positive about it?

P: oh yes, very positive. Because unless it went off what would we have done. And although he's got it, psychologically for him and for me, you're aware there is something in his chest ... Well, you're just thankful I suppose that it could go off, because it needs to go off.

I: so how do you cope as a partner?

P: I just try and reassure him.

I: has it changed the way you live your life day by day?

P: I don't think it has, well it has for [husband], it has for [husband]. I mean after it went off for the first time, he lost confidence obviously. The week before it went off, he had been poorly. He'd been digging in the garden and I'd felt well he's doing a bit too much. But when it actually went off, whether that was because the heart was feeling a bit stressed, I don't know, but when it actually went off, he was doing nothing, which is a bit daunting. To be thinking well, you don't have to doing something for your heart to go in the wrong rhythm. I think it's made us reassess .. I think it's made [husband] reassess his capabilities-how much he should do at one time. And to listen to his body more, and if he gets tired-I've learnt there's no need for me to nag if he's getting tired, because he himself is adjusting. So, if he gets tired, 'well there's no point in pushing myself ...'

I: initially did you feel protective?

P: I'm sure I did, yes. I'm sure I did. But you got used to it. I liken it to childbirth, you know when it goes off, it's not nice but it's something you forget about. Whether you forget-he is aware that it's there I think, but I'm not as aware.

I: not as aware?

P: no, not as aware, when did it-May, June .. November, December, January, I suppose after the first four or five weeks, it does become a distant memory, for me more so than him. Because he can feel it there, and it irritates him sometimes

I: So how did it feel when it went off?

P: oh, I touched-I actually touched him, cos he was standing and he was .. I put my arms around him. We were in the kitchen and he stood up and I felt as he went 'urgh' and I thought 'oh' and I thought he was going to fall, never thinking it was this (touches where ICD would be on chest). So, I put arm round him 'are you alright' but as I said that it went off, and it did just go right through me. Because we were so close. And that was the only reason and I can remember thinking 'it's gone off, it's gone off 'and I really was ... And I think I reacted more because I'm getting the electric shock ...

I: was it painful?

P: no, it wasn't painful, it was just a nasty sensation ... have you ever had an electric shock?

I: No, well only from a car, you know, from static electricity, not a real one

P: oh yes, well it was just like that on my chest. Not sure if it went in my arm, I can't remember, but yes it did-that did frighten me actually and I did phone for an ambulance ... I was rushing round- I thought 'oh we need the magnet, we need the magnet' 'no no no we don't' [says husband] ... But it was nice to know that there was help coming.

I: so you felt like you needed someone?

P: well as it hadn't happened before, he hadn't been well and I thought well best ring for the ambulance. But now it's happened once, we will be more sort of calm about it, we'll just see how it goes, and we'll just expect him not to feel well for a couple of days. But oh no, I'm glad he's got it.

I: so, how has your life changed for you, living with somebody with an ICD?

P: well, first it was hard cos he was very 'down' and um ....

I: he's not normally down is he?

P: No, no, it's me that gets down ... I'm cheerful and bubbly on the outside ... [husband's] not bubbly, he's very (participant uses hands to show something level) .. level, you know he's um ...

I: you said you're not cheerful and bubbly ...

P: I *am* cheerful and bubbly but because I've got anxieties, I can-I can put a falseness on, you know to people, that I'm fine but I'm not. Um .. what was your question?

I: how you cope, so you felt anxious did you?

P: yes, I felt anxious about [husband], I felt anxious that he was feeling sad. You know he likes to play golf and when we were away in October, he took his golf clubs to the hotel and he had games of golf. He was very tired after each one but it was good he enjoyed it. And then initially he kept thinking 'all I can do is sit around at the moment, and this isn't very good'. And that affected me, cos I thought oh well, you've got to sort of think ahead and perhaps change your interests. You know, you're still-you're lucky this thing and it worked, we are getting older anyway – I mean we are in our sixties, so often life does has to change as we get older. So in one way I'm positive and I'm trying to lead him to be positive. But he has, I feel, come to terms with things and perhaps realises he's got this-he's the sort of person who has to have something to do, which is great, he's got lots of different interests, and it's just him accepting .. yes, you can play golf but .. it's ok to have a rest. You know, if you want to do it, we'll do it.

And I've had to drive, now that's the bit I don't like.. I didn't think I'd drive the campervan but I am. Can't say I'm enjoying it and the day he can drive again, hallelujah (laughs), I'll never touch the car again.

I: so you had to take on that role?

P: yes, and I can honestly say, I have never enjoyed driving so I suppose it's a necessity that I've accepted, graciously, accept when he moans (laughs)

I: ok going back to your anxieties, have you always been anxious?

P: yes, and I get depressed

I: was this triggered by ...

P: not triggered by the ICD no, no. I did a very silly thing. I don't know whether- I keep thinking about this .. When [husband] was ill, I decided to take myself of Sertraline. I had been on it for 10 years and I decided to .. I decided I didn't need it. I don't know why I decided it but in hindsight I think I can work through it. I stopped taking it and I was really glad I'd stopped taking it. I told [husband] and I told my family and .. and um, I didn't see the doctor and when I did see her, I told her I'd stopped it. And I shouldn't have stopped it. And I think I perhaps did it when [husband] was poorly-cos I could take control of something, I'm wondering. Cos I couldn't take control of his illness and make it alright for him but I could-I don't know what it was, I don't know if I done it for that reason, but it was part of my life that I thought 'I don't need those, I'm fine'

I: sorry when you say [husband] was ill .. what, what

P: when he was poorly, with his heart in May [date of defib]

I: when he had the ICD implanted?

P: no- oh yes, yes. But it was when he was in hospital, I decided i didn't need these things anymore, then he had his ICD.

I: so you felt the need to take charge of something?

P: yes, I think so. You know, his illness was sort of ... I don't know. I didn't think that then. It's with hindsight. I'm wondering if that's why I did it.

I: how did you cope without them?

P: I thought I was alright but I wasn't, I was going more and more down until Christmas and we were in [name of country] with the family and they drove me almost potty really. ... Then in October, I started with this eczema (shows her eczema on her hands and arms), it's on my hands and feet and I feel as though ... I'm back on the Sertraline and I think it's just starting to kick in. But I feel this [eczema] has been a reaction to an anxiety. Probably if I hadn't come off the pills, but we don't know whether I would have had it. But I think my anxiety has come out in this eczema ..

I: and you're feeling a bit better ...

P: I think they're kicking in, the tablets, and we're both ready to move forward.

I: right. So, how do you see your future? With the ICD, do you see it more positively?

P: Oh yes. [Husband] got to a stage last year, he didn't want to make any plans. Yes, I don't know if he remembered to tell you that, you forget lots of things, don't you but he didn't want to make any plans.

I: Was this about Kenya? {see other interview}

P: oh we cancelled Kenya because of the ICD. We thought that was probably quite sensible because we'd be on an island and you'd be on a boat and blah, blah, so that was disappointing but

I: but he didn't want to make plans?

P: oh no, it was nothing to do with Kenya, just every day, he couldn't think 'next week we'll do something cos 'maybe I won't be here to do it'. You know, he felt very negative

I: did he share that with you?

P: yes he did, he did, he did, yes.

I: was that hard to cope with?

P: well, I thought it was a normal reaction on his part really. But I suppose you try and spur somebody on don't you, and that probably takes more out of you than you realise. You know, it's a partnership and if one is down .... But then sometime I do think, [he's] very selfish ... And I think we've come out-well, we have come out, we've got plans for this year. In this country, we've got our motor home. He wanted a dog, I say 'he' cos I would never had dreamt of getting a dog but I went along happily. I'm not saying I'm a martyr I'm not, I said 'ok then'. I think it's a good positive thing, because he's making sure we go out for walks. You know in weather like this (gentle snow) you know you think .. So, it's healthy for him and healthy for myself. So that's an interest for both of us. We love walking, we got our motor home and I think we're just looking forward. And I mean none of us know what day we're going to die do we? We can be sat here and be fine so I don't think we-well I certainly don't think .... I think the ICD is going to be fine, stop the rhythms, you know, get him back if it goes wrong. The worrying part is his heart failure because that's not going to (get better)... I'm wondering over time, when he has his drug, the beta-blocker, you know that's strengthening his heart, but for how long? You know ... but I don't brood over it. But sometimes if he has a day-you know sometimes he looks brilliantly well and sometimes, he looks a bit cyanosed and that kind of reminds you. But it's all about living, living with what you got isn't it? You know living each day, and [husband] appreciates that as well. It's getting off negative thoughts, which I don't have about him. Just living each day and getting on with it and thanking God for such a device. Because 20 years ago, he probably wouldn't be here. So, it's amazing really.

I: your worries about the heart failure side of it, do you share that with [husband]?

P: no, no I don't .. you know, I was a nurse, so I'm aware of things ... and of course my father died of heart failure at 62 but then that's talking about 20 years ago. But things have changed so much

I: Is that a niggle at the back of your mind?

P: um, I think it was more a niggle for when I got to 62, I used to think I'd drop dead but now I'm 65 nearly (laughs). But no obviously, the heart failure is- .. no, I just think we got to get the best out of life while we're both-while he's healthy and move on. And [husband] is ready to do that, I mean he is back taking services at church and he's wanting to do it, feels worn out after it.

I: how long's he been back doing it?

P: actually it's only the last few weeks, (name of Priest) has been on holiday and after his ICD went off, you know the family pressure 'Dad, you mustn't be doing this, you mustn't be doing that', but he is enjoying doing it but I think he does get tired. And I think it has changed his energy levels by the evening, he's had enough.

I: his tiredness, do you think it's the drugs or the ICD?

P: I think it's a combination, certainly when he went on the beta-blockers, they seemed to knock him out. You know, make his dizzy and what have you. They're being increased gradually by [HF nurse]. Oh she's a great 'boon' as well, she's lovely and so was AN-they're both lovely. This will be a real job, cos I go to one thing from the next (referring to her jumpy thoughts). But having the nurses to talk to is a brilliant help for [husband] and myself. You know if he has an increase in pills and feeling dizzy and she says 'well, you don't do everything in one day! ("jolly voice") You need to drink more, cos your blood pressure's a bit low and you know, it's nice to be able to talk to someone, got that reassurance. The GP is very good, but she doesn't have the expertise that the specialised nurse has got understanding these diseases. But no, I think we're getting on very well. That's all I can say really.

I: ok, one last thing, when your husband goes for walks do you worry?

P: no, no, I don't worry, no.

I: would you be worried if he didn't have the ICD?

P: Oh yes, I think the ICD is nothing but positive. You can't get away from what you got can you? You've got to be thankful you've got a device that can- it's ridiculously incredible. You know at hospital they could tell when he had that thing, the time. It takes us an hour and a half to get to hospital and it makes you laugh when you read in papers that people in cities complain when their A&E hospital has moved and they've got to go four miles further on (laughs)

Transcript for N16.1

Male aged 54 years.

Wife had Multiple Cardiac Arrests during routine hysterectomy

In line with ethics, participant's name has been changed to 'Den'

'I' stands for interviewer

I: your wife was telling me about what happened last year, and the cardiac arrests, that sounds like it was a traumatic time

D: yes it was horrendous at the time, very difficult to understand why and there are still no answers to why it happened, they tested the family and none of them have showed anything. So, they just don't know. So, the reason they fitted the ICD was just in case it happens again. And I asked them was it to do with the anaesthetic and they said no. And they said if we done an epidural to do it, it would have still been exactly the same. So, it didn't matter which anaesthetic you had, the outcome would have been the same. So, they said they eliminated that before they started the other research like. They don't know, they don't know now ... But when she did finally come home ... her memory loss ... she goes to town and she forgets what she's gone for and she comes back with nothing. And she goes into town, she can go three times in a day .... But when I asked the Arrhythmia nurse, and she said yeah, when they shock you every time, when they shock you, you lose a brain cell ... Cos the body's not functioning normal, they got to get the body to function normal again and she said it can occur but normally it's a longer period that they've been waiting to be shocked. She said it does damage in some people and it doesn't in others.

She won't go out and she'll have just put the cooker on, and she forgets and goes upstairs or something. And I'll be there following, you know like a little child, you follow them around ... and this is all since the cardiac arrest, before this she was fine, remembering and doing things. Her chest has always been, over the past two years it's gone down, they don't know what it is. And she won't go out . if she goes to town, she specifically say quarter past eleven and then she's got to be back on the 12 o'clock. I don't know why. I ask her, you know, 'what's the rush? Why have you got to get on that bus? What will happen if you miss that bus?' You know .... and all she can answer is 'I'm frightened, I've got to be home. It's a comfort zone like. And if I go anywhere, and she's here on her own, she'll be on her own half a dozen times. 'Where are you? How long you gonna be?' So, although it's a comfort zone, she's not comfortable unless somebody's here, with her like.

She still has nightmares, we've had to separate the beds, because she's um ... she (inaudible) ... She's frightened of dying, she thinks she's going to die. And the reason why we separated the beds is that she was violent in bed and she didn't even know like. You know, she was sleeping and she was kicking me and punching me and I said, I can't cope with this. But it was very difficult to try and say to her, you know,' I've got to try and separate the beds'. But even though we're separated now, she still keeps me awake most nights. You know, I said, I don't want to go in another bedroom, you know, we've got enough bedrooms for us all to sleep in one – I don't want that, you know' for better or for worse' you're there for each other. Like I'm not a fit person, I got spine trouble and that and she's always been there, if I come out of operations, she's always done everything for me you know, so, it's the same. A marriage is to be together not separate like you know. But sometimes it's very difficult to try and get through to her. Like she'll give in to the little one a lot more and doing it behind my back. You know, if he says I want to be out till 8 o'clock and I've told him 'no you've got to be in half past 7, he'll phone his mother and she'll say ok and that he is doing something.

And I said, no, we're supposed to be one, you're supposed to be with a child. And she never used to do this, this is all since ....

I: do you think it's her memory?

D: I think a lot of it is to do with her memory. Probably she wasn't involved with him much before and now she's frightened she's not going to be here .. do you know what I mean, so she's ploughing as much into what little time she thinks she's got. And I've tried to explain, 'no, you've got a better bloody chance than we have because you've got something to trigger your heart back. None of us have got anything But she doesn't accept she's got something, she's knows it's there and she knows what it's going to do but she's frightened of it going off but she doesn't accept that it will save her like. It will bring her back, do you know what I mean if it does go off. And I don't know how to explain, I can't get through

I: so how does that make you feel?

D: Very frustrated. You know, sometimes, I just got to go out and take a walk and calm myself and think to myself do you know. It is very, very difficult and I find, and I don't know whether it is because of what has happened, but she's a lot slower than what I am now. Where I had the problem with arthritis and a bad spine ...

I: you're talking about walking?

D: walking ... she can't get around. So, all this ...

I: so things have changed

D: It's all changed, a lot and it's all come .... And I say 'come on! You should be jumping over my bloody head, you're six years younger than me. I know as you get older these things do happen. Like your body changes, you get arthritis, you get all these happening, but you don't accept. Now I always try to fight my way through whereas

'Jean' seems to accept it, 'oh I can't do this today and I can't ...' 'What do you mean? Of course you can do it, you've got to do it'. Because if you don't keep moving, you'll seize up completely, you've got to take a walk, you've got to do this, we've got to get shopping in, you know. And I just find it's very, very difficult

I: and how has that affected you> (participant didn't reply to this but carried on talking)

D: and she didn't accept that I was there every day because she'd lost a week. She was adamant 'no you haven't been here'. You know, the hospital phoned, we were there every day and she still says now, there were days when I didn't come. And you know, her own son has even said, her oldest son 'I took 'Den' down every day to see ya .. I had to use the 4 x 4 from work to get him there, he was there all day'. And we'd get home and 2 o'clock in the morning we'd have another phone call – you'd had another one. And we'd rush back down again. 'No you didn't come every day' she's say ' you left me there on me own'

I: and was she like this before?

D: No, if you told her the truth, she'd believe it like, now all of a sudden, she won't believe that we was there. And she'd be asking me questions 'what was she doing?'

I: so how does that make you feel?

D: inadequate really, as if you're not giving the full story. I said, I can only tell you what we actually saw. And she'd watch the hospital programmes and she'd say 'was I like that?' 'yes I'd say, you were on a life support'. And she'd want an explanation of why they done it. I said they done cos they needed to give your heart a rest. 'Your heart was overworked, so they put a balloon in give it a rest and they put you on a life support for a few days to try and give you a rest'. She remembers them taking the balloon out, she said it was very, very painful and she said she could remember them shocking her and feeling the shock. At one time she said she could ... a woman come to her or something, she didn't know if she was a nurse or what but she was a very light talker and stroking her. And I said it was probably a guardian angel or something because you wasn't um .. breathing and everything on your own ...

I: and that was when she was on life support?

D: when she was on life support, when she was going down to have the ICD and this person has appeared in the ward, so whether it was her mind playing with her or whatever but I don't know, you know. 'Cos it frightened the life out of me when she was telling me things like that and you know the doctor called me in the one day and said 'we don't think she's going to make it'. He said 'I got to give you the worst scenario, we can't keep shocking somebody indefinitely. He said you know, 'we've had to do it so many times, we just don't know what the outcome is going to be'. And I said 'oh she'll be alright, she'll fight 'because subconsciously she knows she's got a 10-year old

I: did you feel as confident as you sounded?

D: yes, yeah, I mean I would have been in a hell of a state I suppose if it would have been the worst scenario like, but I believe in the national health and I believe what they're telling you and I also believe they tell you the worst scenario of everything you know. So, I think the confidence was there

I: so how do you feel about the ICD?

D: I'm fine with it. I think it's .. it's a good thing she's got it because without it we don't know whether she would have another cardiac arrest or not like you know. I mean, 'the arrhythmia nurse' is very good. She's explained it all and said she will feel it- if it goes off, she will know about it like. I mean, another doctor have said 'no, you won't feel nothing .. it'll go off and you might just feel a twitch' and this was the local GP. Well I told 'the arrhythmia nurse' 'well the local GP said you won't' She said 'trust and believe, if that goes off, you will know-it'll be like somebody punching you straight in the middle of the chest. She said 'you will feel it'. So, I think that frightened Jean again. But I said 'wouldn't you rather know, than not know'. I'd rather know if I'm going to get a bloody big punch in the chest. And sometimes she'll be crying in her sleep and then she'll wake up heavy breathing. I've got to wake up and sit with her, calm her back down, 'breathe normally, you're alright, nothing's going to happen, you're fine'

I: so what is the fear?

D: the fear of dying and she'll break down. And it's quite, it's on a regular basis that's why 'the arrhythmia nurse' said you need to go to MIND or somebody that can deal with that side of it. In the national health, there's very little support ... you know, she said we can put you in touch with groups that have all got ICDs and you can all talk amongst yourselves but apart from that there is no carers out there, the best support is MIND. They started but then she was breaking down all the time and they said I think we should leave you for another month. But then when she saw 'the arrhythmia nurse' I think two or three weeks ago and she said 'no get back in touch with her, start it back off, you need it'. She said you'll have a worse scenario before you actually feel the benefit of going into MIND. They'll bring everything out of yer and bring you down but then they'll fetch-they'll build you back up with confidence, you know. She lacks confidence, 'cos you know, she was a manager of a shop... but she's got no confidence at all now

I: so what triggered this change?

D: It all started when she was made redundant ... I don't know if you've ever heard of 'name of shop chain'? Well, she was one of the shops in 'town'. It was the busiest shop they had and when they made her redundant, it took all of her confidence out of her and then the breathing problems started. She had all the tests everything, and nobody could find anything and that's why they said they would do the hys-hys

I: hysterectomy

D: hysterectomy. Because we can't find nothing wrong, nothing should go wrong. So they said, yeah we'll do the hysterectomy and that when it all come out, anyway they're still saying there's nothing wrong with her breathing and yet she can't walk any distance without stopping and being out of breath. She can get out of the chair to answer the phone, and you think she's run a marathon. You know, it just goes straight away like

I: straight to?

D: straight away, her breathing goes. She just can't breathe, she's very short of breath. They told her-she went to one, 'it's all in the mind'

I: what do you think it is?

D: well I don't know, I ... I said well if they can't find anything, there's got to be a bit of truth in what they're trying to say. Have you got into a routine of breathing like this, rather than breathing the right way. They said, there's no right way of breathing and there's no wrong way, cos anyway you're breathing, you're keeping your heart going. But they said, we'd rather you try and do it this way but it still didn't make any difference. So, I don't know. I just don't know what the answer is ... she doesn't do half of what you'd expect. I know she's in pain and she's taking medication and that

I: so who does the running of the house?

D: I try to do the bills and everything because since she's had the cardiac arrests, she'll tell me she's paid something and then I'll find out it's not paid ...

I: and that's what she used to do before?

D: She used to do it all, but again it's caused a lot of stress and arguing 'why am I doing it, why can't she do it?' And how do you explain to somebody, you're forgetting everything. You think you paid something and you've not. I mean, I thought she'd paid the rent and this had been going on for about 5 or 6 months, cos she'd always paid the rent, so I assumed everything was normal. The phone went last Monday and he said is it ok for me to come and call for the rent, cos it comes on the first of the month. And I said yes. And he said will your arrears be there? And I went 'what arrears?' Oh he said, Jean's been missing something every month, there's £480 outstanding . I think he understood. I said I'm sorry i don't know nothing about it. He said I can hear in your tone you didn't know. He said, it's not a problem, I just didn't want it to get any higher. So, I said I will pay you the rent from now on and I said I can't do anything this side of Christmas but after Christmas, we'll try and pay you a sufficient amount to bring the arrears down. And he was quite tidy and 'no problem'. So, I said to her 'where's the money gone then?' She can't answer. She doesn't know. She said she's been buying food, but I said, we've always had food you know what I mean, I mean we're not buying something we don't normally have. And she just doesn't know and I can't answer where she's spent it like. So, I said, right I'll have to take over the rent. And 'oh I'm not capable anymore am I?' and this nonsense. 'It's not you're not capable, you're not in the right frame of mind – you can't remember so until I've a bit more trust in you taking it back on' you know what I mean? I don't like taking everything away from her but it's the only to keep a positive lifestyle then. I mean, everybody's still got to be paid ..

I: so, ok ... that's really the cardiac arrests isn't it ... what about the ICD?

D: erm I think the ICD .. well she's had it checked a few times and everything's fine. They tested it last month when we went down and they turned it up or they turned it down to test it and she could feel it, and she knew and she thought she was going into another cardiac arrest. And they turned it back down, and she had to stay there for some time because she was still fearful it was going to go off.

I: And how do you cope with that?

D: I just try to tell her, they got to do these things. They know what they're doing, have more faith in them. I feel confident that they know what they're doing. But if they didn't do it, they'd never know whether it's working or not. You know what I mean, and then she- she accepts what I tell her like

I: how do you feel?

D: oh I'm happy with it. I just accept that it's there to keep her going.

I: Like when Jean gets upset, like in the- when they're testing it and she stops it, does it make you feel frustrated?

D: erm yes in a sense, cos I think she should trust them a bit more

I: you got 100%

D: I got 100% trust in what they-they know what they're working with to do these things so they know, you know. Now she's got the fear 'oh I've got to have it changed after 5 or 10 years, oh I've got to have it changed'. I said 'why you worrying about tomorrow? This is the day you got to worry about

I: is that part of her personality?

D: her first marriage was negative. Her first husband oh he used to give her the negative of everything. Now I'm the opposite, there's no such thing as a negative in life, it's only what you make a negative. You can make a positive out of anything you deal with and I always try to look for the positive in everybody. 'I can't do this, I can't do that' Why?? And jean never had that. When she started working in the shop, her husband put her down 'oh you can't do it, you'll never stick it' and all this. And then when she got out of that marriage and come in with me, she was in the shop and they offered her assistant manager and she was 'oh no I can't' And I said 'why can't you do it? Go for it, the sky's the limit, you can do anything you want to do. 'If you want it so bad, you can do it'. And that's the same in everything, the ICD, I don't want to know the negatives about it, if there is any, you know. All I want to know is the positives. And that's what I try to put through to Jean, it's all positive.

I: you said she can't accept it

D: she won't accept-the barrier's there. I suppose when you've had 35 years of negative, negative, it's going to take some time to get the positive attitude in life you know. I've always been brought up with positive so I think that is probably where all the negative is coming from. She knows it's there, she knows what it can do, she don't accept that it will- I don't know whether it will change if it goes off and that would give her the confidence, do you know. 'Oh yeah they were right, it does work and I am fine'. And I think that's the only time she will accept it. Even if 100 people are telling you it's working fine

I: so that's the fear

D: I think that's where the fear comes from, is it going to work when I need it to go ... I think that is the only way she will get the confidence herself, to live life to the full again, you know. Rather than feeling down all the time and having the negative feelings. If it goes off, they know it's working and (b), I'm still here to say yes I know.

I: do you encourage Jean to go out and do things?

D: I try to but she won't do anything on her own

I: is she back driving?

D: she has driven a couple of times. The first time she took the car out, it wasn't her fault, you know, somebody run into the car and I thought bloody hell, you've only had the car one day, you've only gone to Tesco ... but it was stationary the car was, the person admitted it. But it still didn't give me the confidence then with Jean .... I've never said to her you can't drive. I said to 'the arrhythmia nurse' I'm not happy with her driving, not because of the ICD but because of her memory. Because of the cardiac arrests and what it's done to her memory, I'm frightened. I mean she can go to town and forgotten what she's come for and come back so what saying, she took the car out and forgets where she put it? I don't know, you know what I mean. I mean I've got to pick the pieces up whatever. And she said well the DVLA don't look at things like that and as long as she says she's healthy in so far as her heart is ticking over ok, she can drive. And I said fine, enough said and when Jean said she's going into town and she taking the car, I've said yes, if that's what you want but 90% of the time, she'll go on the bus.

I: are you happy with that?

D: I feel more contented that nothing's going to happen to her with driving because I don't think she would react quick enough. She can be thinking of something and there's a car in front of her and she hasn't seen that bloody car, do you know what I mean, so I'm more happier. If she has a problem, she has a panic attack, she's got her mobile, she rings me and I will go straight away in the car.

I: how often does that happen?

D: I've had it a few times. She goes to town, she's only been out half hour or something, she's gone into a shop and she thinks the magnets on the bloody clothes have set her alarm off so she starts thinking, she's panicking over it. She phones me, 'right I'll come and pick you up'. We were in the Coop the one day, together, and she went looking at clothes there and she said 'oh I got to get out the shop. I was in the food side of the shop, she threw these clothes to me and I think they'll think you're bloody pinching them, cos Peacocks is down the other end, so I had to run to Peacocks 'I'm awful sorry, she hasn't pinched them'.... So, I paid for them. 'What's the matter then?' 'My machine went funny

I: the ICD?

D: the ICD. She said, I can feel it going, it's the magnets on the clothes. Well, when I asked the 'arrhythmia nurse', she said no, she said she told Jean, it won't happen like that. She said the only magnets you got to be worried about is on these moveable escalators ... it's the ones that holds the trolleys, it's the magnet underneath that hold the trolley. They're very powerful the ones on the escalators but the ones on the bloody clothes, they're fine, they're only a little magnet, they won't do nothing to you. And she said the only other place is the airport, you're not allowed to go through security . She did say about the shops, if you go into supermarkets, don't hover at the doorways. If you want to talk to somebody, get in the shop and tell them to talk to you or come out of the shop and talk outside. Don't hover in the door ways, cos there's all magnets around them. But thats the only things you need to be really worried about you know.

I: are you worried about them?

D: I wasn't so much worried about the clothes I didn't think. I mean me son has got a metal detector and Jean said 'oh get it out' and so we had to switch it off and took the batteries out and I forgot to ask the arrhythmia nurse whether that would-she reckons that was making her funny but I said I don't know (metal detector). Cos she wasn't actually holding it, you know, she was in the room, she was probably over there or something (waves to corner of room) and he was going like this (imaginary swinging arm). I was throwing something on the floor and see if he could find it but he wasn't allowed to play with it, so it's still upstairs in the box like, you know. Would they?

I: you'd have to ask your arrhythmia nurse

D: I mean Jean remembers I don't, if we're in Tesco, we got to use the lift, she won't go on an escalator, she stays clear of them

I: even the ones with steps (stepped escalators are ok for ICD patients)

D: yeah, she won't go on either of them, she'd rather walk up a normal flight of stairs or if there's a lift, she'll get a lift of something.

I: so how's that affected your day to day life?

D: you have to change the way you do things, you have to think a bit more. Now I like to prepare things, so for tomorrow I think now what do we have to eat tomorrow. Jean does none of that. If I'm not well, and I'm in bed or something , I'd be panicking, what you going to feed the kids, they're coming today, what will they eat. But Jean 'I'll do it later'

I: Is this new?

D: yeah, this is new. She was like me, I never had to worry. I'm more worried now. I tell her we need milk , we're running short of milk and something, nothing out of the ordinary, a bottle of tomato sauce or something, but main things like sugar, bread, milk, butter, she'll completely forget. I said, you can see in the fridge, you can see what's there. I've even given her a list. Right, if you can't remember, write it down. And still last week, she went to town, come back, no bread. And we got one son that works so we got to have bread for him for sandwiches for work. Why didn't you get bread?? ' I don't know'. But it's on your list! 'yeah I know, but I haven't got it' . so, I have to go over the corner shop and pay double the amount, do you know what I mean? It's all frustrating things, silly little things, and it ends up escalating into a big argument. I don't mean to argue, but it just frustrates you, how can you forget to get the normal, everyday things that you've done since whenever, your first marriage, your second marriage? You've always had to get bread, milk ... she can't answer why, she don't know.

I: do you feel tempted to take over that side of it?

D: I have felt tempted, but I don't. Hopefully she will remember, I'll try and do other ways-I give her a list and then when she's in town, I'll say leave her for half hour, then phone 'where are you?' 'I'm in Tesco'. 'Have you got the bread? Have you got the milk'. She could be telling me she's got them, but I'm just asking her have you got them or she'll go around and get them.

I: that sounds like it is tiring for you?

D: very tiring. She always used to get up in the morning with the sun, because we do his lunchbox in the morning

I: the 10-year old?

D: No, he's 27. We got a 10-year old and a 27-year old living at home. He always likes his lunchbox made in the morning, he doesn't like it in the night. We got to do it in the morning before he goes to work. ... But she'll switch the alarm off or something in the middle of the night, so I'm constantly waking up every hour to see whether the alarm goes off. And then the other night, I go to bed about 10 o'clock, I'd switched the central heating off, locked the doors, all she had to do was turn the light off in the living room. Now I told her, before I went to bed, the doors locked, the windows locked, the central heating's off, just turn the TV off and the light, ok I'm going up.

I woke up at 4 o'clock in the morning and thought oh, it's bloody hot in here, I got out of bed, felt the radiators, she'd put the bloody heating on. So, in the morning, I said what did you do last night? 'I switched the central heating off', no you switched it on ... 'did I?' I said, yeah I turned it off-we can't afford to have the heating on all night. So when i told you I switched it off, it's off. 'Oh, I thought I had to switch it off'.... it's things you know, but you try and explain to people like the gas or the electricity I'm sorry I can't afford to pay you over what I give you, and build it up over the year ... They won't accept, 'no you got to pay this amount'. Whether or not you got to pay it, you got to pay it. Because I'm on disability and Jean on ESA, they don't give like the winter fuel allowance. We don't get anything .... you'd think, they give it to single parents but they don't give it to disability people, the government have stopped giving it to disability people

I: is that new?

D: no, last year this was (digresses to talk about benefits, strike, general social problems of Britain so didn't transcribe)

I: Can I ask, has it affected your relationship, the ICD that is

D: yes, sex wise I was frightened to-to have sex, in the beginning. Because I thought, all the excitement and everything, is that going to trigger the ICD off. But the arrhythmia nurse put us straight, 'no that's a different type of excitement'. The heart hasn't been excited by any movement that Jean was doing it was just going out of rhythm on its own, so that's why she had to have the ICD. She said you're quite safe to have a normal sex life again. Cos Jean wanted sex all the time, and I was – I push her away

I: is that new?

D: that was new, cos I was frightened

I: was her high sex drive new?

D: no, no she's always been highly sexed, but I mean up until then, we were both the same. I was the one who stopped and we've resumed. We're not back to normal but more sex, I have more of a sex drive than I had at the beginning, I was frightened to do anything. But 'the arrhythmia nurse' said that's normal, that's nothing out of the ordinary, she said everybody's says the same like so that was the only difference. I've accepted it now, and that's why I wish Jean would accept that she's got this to save her life. It's nothing- it's there for a reason but there's nothing stopping you from having a normal life, you just got an extra thing, what will keep you going. Even if you have a normal heart attack or something, it will trigger the heart back, so you will live longer than probably we will, you know .... She can't accept that no. I'm hoping when she goes back to MIND, they will give her some more confidence to accept, to try and forget about it. It's there, but forget it. You don't think about your heart every 2 minutes or your kidneys, or your liver, you accept that they're a part of you so take this machine as a part of you

I: Is she more afraid of the shock, or the heart, has she separated them both or are they all

D: no, the whole thing is one upsetting thing which she's frightened of. And I said, you're not going to die any sooner than you would anyway. You know I believe we're all given a number, when you're born, you're born on such a date, you will live such a life and you will die at such a time. And whatever happens in-between, you won't go until it's time. So when you got an ICD, if it shocks you 100 times before then, this is the time it won't be able to shock you anymore ... that's my belief, it's planned out, except for ... no I wouldn't say an exception, a road accident, or any accident you have

I: do you think Jean believes that?

D: no, she thinks-she said she saw herself on the table and they were shocking her. And I believe she did, I don't disbelieve it, cos I've heard other people saying me spirit have left the body and I see myself there and they brought me back, it wasn't my time to go. But I don't know how long these ICD s have been fitted. Cos until you know somebody who's got one, you never think about it, do you know what I mean

Transcript for N17.1
Male aged 57 years.
Husband of patient with Bundle Branch Block
In line with ethics, participant's name has been changed to 'M'
'I' stands for interviewer
EP stands for Consultant Electrophysiologist

I: I was asking your wife about why she had her ICD and she was saying it was how the news was put over that upset her

M: yeah, we were both a little bit angry about that really. She had already had the valves-heart valves transplant a year or two before and she started having these, well they were sort of dizzy spells and that sort of thing and they tended to occur as these things tend to, in the middle of the night. So you rush over to-well, you rush over to A&E. It wasn't the first time, it was about the third time since she had the heart valve thing done. But usually we get sent home after a while so, for whatever reason, they make sure everything is ok, they bring the palpitations back down again or whatever it was and then we get sent home. But this time they decided they wanted to keep her in. Um, but then it was, almost a whole week went by with us not knowing at all what was going on. Even the nurses, the doctors on the ward didn't know was supposed to be dealing with it and who wasn't and they were getting quite concerned as well. And we explained she was already under the one heart surgeon, (gives name) but they said it was EP's name and we didn't know who EP was. As far as we were concerned he hadn't come to see us at all and all we had were one or two-well, we know now that they were some people working for the EP and they were some of his team.

And it transpires that he was supposed to have got in touch with Dr X and there was some communication breakdown and it was almost as though nothing was happening until 'wife' actually kicked up a fuss, and one of the nurses kicked up a fuss. In fairness to her, she tried to say whatever's happening, somebody's got to come down, somebody has got to come down and speak to the patient. And then when he did come, he just seemed to come all out of the blue, all of a sudden ..... No, no, that's what happened (participant getting his thoughts in order) .... one of his team had said something, he had come in at one stage then and said, you know we'd said we hadn't seen anybody. And one of his team came in and said you might need a pacemaker. That was just out of the blue at that stage, and 'for what?' 'why?' We didn't know anything. And then we spoke to Dr X and he came down, he's 'wife's' regular heart surgeon, he called in and said there is a possibility, that the EP thought you might want one (pacemaker), but I'm not sure, I need to look at whatever's going on.

And then 'wife' was let out of the hospital, we were let out. And then we went to see the EP about a week or two later, and he was just 'yes, you're going to need it'. He wasn't-I didn't think it was put across very well at all. It was very much .. I mean he started talking about this branch block, I can never get it right, the 3 bs anyway ... and he said, if we don't do anything about it, you got a 30% chance of surviving. You know, and he just started giving death rate figures to us all of a sudden. And I thought ... the problem is, when you're there with somebody, you know you also feel 'it's not me, it's 'wife', I'm here for support and it's not for me to-well, it is for me to ... it's a strange situation there when you're there supporting people. And although he was telling 'wife', you think 'hold on a minutes, just slow down a minute, tell us what's going on here'. But he virtually said, if you don't have it done, you're going to die.

I: that was your take home message?

M: yeah, that was it... And, um, perhaps it's being unfair but I also got it, that he was annoyed that we kicked up a fuss in the hospital and this was his way of ... you know, it's sounds a bit childish to say, but it felt almost like a retaliation thing. And that's how I felt about it, you know 'you kicked up a bit of a fuss in the hospital, I can't now be bothered with you, this is how I'm going to tell you'. You know, that's how it came across a bit

I: how do you feel about him now

M: I mean even now, I mean obviously he's done a good job and he knows his work, but I would say he's got a lot to work on, on personal skills and I think that was a major downfall, certainly. You know, I'm not resentful, cos he did a good job, it's there and 'wife' is ticking over, for want of a better phrase, quite nicely. You know, so I can't criticise the skills of the man, you know but I certainly wasn't happy about the personal skills

I: I see. So, how's the ICD affected you and 'wife'. How has it affected you as a partner?

M: .... I mean you're aware of it all the time now. If 'wife' wakes up in the middle of the night, you know I'm always-I don't think either of us sleep as well now as we used to. That's certainly something, um ..

I: in what way?

M: in as much as the-the depth of the sleep. I don't know, it's almost like um, if-if 'wife' wakes up, I'm almost sensitive to her waking up, you know 'why is she waking up?', you know. Since she's had it, she's felt one or two times when she's not felt very well and it's turned out to be something like indigestion or something but you're always aware of 'is something happening' or what is happening, and what is it. And in that respect, you know, it's always niggling away at the back of your mind, no matter what. If she starts getting a bit tired, or she sits down or she- you know, I'm always aware, you know 'is something going to happen now'

I: when you say, 'is something going to happen?'

M: is something going to kick in, are we expecting anything. Given that we've been told that inevitably something is going to happen, she's got a 30% chance of it happening this year and then gradually .. I can't remember the breakdown but it gets less each year.. So, then you start thinking, well the odds are that something's got to happen eventually, you know. You know it's always at the back of your mind, well not in the back of the mind, you're almost waiting really for something to happen in time. You know, you get periods, where it's not in the forefront but certainly it's at night when you're aware of it, maybe because whenever anything's happened, it's always in the night-time. So you're always aware that something is happening, so in that respect it's there. I think it has certainly affected us in as much as-, it's made us think about-, well certainly how we live our lives and what we do. You know, after she had the heart valve transplants and she was still getting the palpitations, you know I made the decision then you know, that I'd try and make the most of what we had left. So, I was going to retire, take early retirement, which I did. Once we knew about the- I knew I would take it in a few years but once she had the device fitted, then there was no doubt in my mind that I was definitely going , so took retirement in October (4 months previous) to spend a bit more time with her. So, obviously that's a major change that we've had in our lives.

I'm not overly happy about 'wife' being on her own, cos the whole idea of this thing (ICD) is that at some stage this is going to kick in. You know, we've been told it's going to be a big wallop across the room and you just want to be there when it happens. But at the same time, you're aware that you can't always be with her everywhere that she goes, so. So, I suppose what I try to do is try to increase the amount of time I'm with her, rather than leave her on her own. That's probably what I'm trying to do. But obviously, by the same token, you can't be hanging around everywhere she goes, she's got to have freedom to move around on her own or I mean, otherwise life becomes ridiculous, you know.

I: Who told you that 'wife' could be blown across the room?

M: um, this is what one of them, um (gives name) is it? The idea is- what happens is when this thing kicks, it could blow her across the room or something ... well perhaps I got it wrong, but I got the impression that when it does go, it's like a punch in the chest (smacks fist against hand), which in many instances could knock her- knock her down and frighten her- well they said it would be frightening, cos it would almost be like a punch in the chest. So the impression being it could knock her across the room, I mean I might be wrong, is that?

I: I think it can vary from person to person, some hardly feel it, and some feel a knock, it's how you interpret the shock and the unknown

M: yeah I think that's it, it's not knowing what's going to happen at one stage at any one time. And when it's going to happen, is the problem. So, it's affected us to that extent. We don't talk about it very much, I mean that's probably a fault with both of us. I mean because we spend so much time seeing doctors and things, we tend not to talk about it ourselves. We're aware, I'm aware that she's aware and she's aware that I'm aware. When you been married for a long time, there are some things you just don't talk about but you know it anyway. But yeah, we will mention it now and again, but we don't talk about it a great deal.

I: would it help to talk about it?

M: I don't think-no, not really I think... We don't tend to talk about it too much. It's just, I sometimes think I'm getting on her nerves if I say 'are you feeling ok?' if she's looking a bit .. you know. I sometimes just think I'm perhaps pushing a bit too hard and I am nagging-not nagging but it must be getting on her nerves if she hears me saying 'are you ok' all the time.

I: so you're feeling protective?

M: yeah, very much so, yeah.

I: do you try to stop her doing things?

M: um, well things like vacuuming and things, I've taken that over, rather than let her do it

I: for what reason?

M: mainly cos I don't want to see her exerting, carrying it around upstairs and things like that, so it's easier if I do it, but by the same token, I'm also aware I can't be over protective. So, sometimes I will just turn a blind eye and let her go ahead and do it downstairs. I say you go ahead and do it downstairs, and I say, I'll do upstairs rather than. But there is that-that constant 'not sure'. As I said, she's also got this BBB or whatever it is and we're not sure what affect that has either. We know that's why she's had the ICD, but that apparently is deteriorating as well, which we found out fairly recently. You know, they've increased her medication for that as well. So, you know it's not the ICD on its own, you're aware of the valve transplants, so it's the ICD itself, and there's the fact that there is a deterioration in the wall of the heart as well. So, all of these things tend to accumulate in your own mind. You know they're all related but at the same time, you tend to think of them-it tends to compound any issues you got as well. So, you're starting to think she's got the heart valve transplant, she's also got this ICD that will kick in if she has any other problems and I'm also aware there's a weakness in the heart wall .... so it's little things like that, you're always thinking, you know, if I can take some of the heavy work off her. And it does annoy her as well, cos she loves gardening, and she will start cutting back the bushes and the trees and I'll go out and start helping rather than stop her. I think it's being over protective is the thing that bothers me most really. I'm not particularly keen on gardening and I used to let her just get on with it but it's just a case of not over doing it.

I: do you think you're more concerned with the ICD and potential for shock or the underlying heart condition?

M: the underlying heart condition.

I: ok, just coming back to the ICD itself, how has that affected your relationship?

M: I don't think ... Um I don't know, if anything we're closer, I don't think it has affected the relationship in any way, as I said, if anything, we're a lot closer than before

I: emotionally closer?

M: yeah, yeah I think so. I think it's made me think-feel that I appreciate her even more now than I ever have before, which is a terrible thing to admit really I suppose. Again, that may be tied up with the fact that I've realised there's more to life than work. I've always worked, and worked hard but now I'd rather put my time and effort into just appreciating .. you know that's terrible, cos I keep thinking at the back of my mind it's always 'while she's here' and again, that's another thing that's bothering me. Now again, whether that's the device or the underlying heart thing, I'm not sure. I'm aware-what often brings it to mind is that I often hear it ticking at night and when you're lying in bed, you can actually hear. Well, I'm not sure whether it's that that's ticking or the heart valves, it's probably the heart valves, it could be that, but you're never quite sure, but you're aware of it all the time. Especially when it's quiet in bed at night as well.

I: mmm, not easy for a partner

M: yes, and I think the other thing is, is that you're never quite sure what to do. Certainly in-between the first heart operation and the device being fitted, when I used to get the sessions in the night, when the heart used to race, you're never quite sure ... there's a stage where you phone 999 and a stage where you don't phone 999.

And I seem to have over the last few years, had a few sessions at where I'm not sure I made that judgement call

I: is this when you knew you were going to have it but just waiting for it

M: yes, that's it. Though, you're not sure you know what to do and since she's had it, there's been one or two instances, where the heart has still carried on racing but 'wife' hasn't been sure whether something has happened or not. So, again, it's when do you make those judgement calls .. you know, she's had what we know now in retrospect turned out to be vertigo, but we didn't know about it at the time. So obviously when you're getting vertigo and she's dizzy and vomiting at what have you, you assume it's the same sort of thing. And that's always the problem, cos any minor illness, well not minor illness, any kind of illness

I: so any symptom

M: any symptom, you attribute to something going wrong and that's the big problem.... Up until then, until we knew there was any problem or before the device had been fitted, you know, if you were ill, you were ill. But now if you're ill, is there an underlying reason why you're ill? And should I be doing something about it.

I: do you feel responsible?

M: exactly that, I feel responsible and that's my biggest bug bare really. I'm afraid of making the wrong decision. Or not making a decision when I should be making a decision.

I: if you were a woman and 'wife' was a man, would you still feel responsible?

M: yes, (loud laugh) yes, probably.

I: that's just you

M: that's just me, yeah.

I: ok ... for you, are there any benefits to 'wife' having the ICD?

M: In retrospect yes. I know that if the heart does stop then this thing is going to kick in and if everything goes according to plan then-then it's not a case of having to get to the hospital as quickly as possible. As i understand it, once it kicks in, it generally kicks in the once and then we just make a phone call and let them know it's happened.

What I'm not sure about ... really this is something I should have clarified myself, is that the reason that she's had it is because of this branch block whatever. And what the EP said to us, was the three of these, there are four connections which are needed to keep the heart beating. Three have gone, and she's operating on the one, and eventually that's going to go. But what I'm not sure about, is when that does go and that's when this thing kicks in, then how does the heart keep going anyway? If the four things that cause the heart to beat

I: I see what you mean

M: if that kicks in, it's all very well it kicking in, but what keeps the heart beating after that? And that bothers me a little bit as well. I mean I'm not sure, but I assume you get the device fitted for many reasons, but for this particular reason, I'm not sure how the heart continues beating after. And I need to get that sorted out ....

I: well if it's worrying you, you must speak to someone. Do you find you just worry about things and just worry or ...

M: no, I usually try and sort something out. I just assumed I got the wrong end of the stick with this one but I've got it down as one of the things I'll need to ask next time we go and see the cardiologist ..... But it's just one of those things that niggles away at the back of my head. You know, I'm assuming-I also bow down to superior knowledge, and I'm assuming that they put it in knowing what the situation is and they know that particular thing doesn't work. It's just in my own mind, I'd like to clarify it. But I'm assuming the specialists don't worry, they put the device there so it will work. And it seems to be working so it's not a worry as such. I think it's just in my own mind, I like to have things sorted. So, I know what's going on really.

I: where does this feeling of responsibility come from? Was it from your former job?

M: I was an assistant head at a large secondary school, but I think it's the fact that it's just the two of us, we made that decision, that there would only be the two of us and we've always been very, very close, so I think it's that side of it really. That's the only reason I can think of. I don't think it's a general feeling of responsibility for everything, and I take the weight of the world on my shoulders, it's just that, it's just in this particular instance with 'wife' that's all. And she's been through a hard time, over the last few years, cos her father had died-sorry her mother had died then her father had died of Alzheimer's, and we had him living here with us for quite some time. You know, and I just feel she's had a fair old weight over the last few years and it's just trying to relieve that as much as possible.

I: 'wife' mentioned that she was a little bit wary about going abroad

M: yes, it's affected us in that respect. In fact we had arranged to go to Russia on a cruise and we'd half paid for it and everything else. And although you know, the Arrhythmia nurses give you a list of all the insurance companies and things like that, you know I could see that 'wife' wasn't happy about that ... You know, we'd only just started getting around to the idea of travelling abroad ... you know, after the valves, the open heart surgery, we couldn't have-for about 12 months we couldn't get any type of insurance at all but then after about 12 months we were able to go abroad. We were able to go to Ohio I think it was, Chicago, and then this year, we were going to cruise to Russia. And then we booked it all up and everything and then we found out about having to have the device fitted. And the device was fitted June (6 months previously) and we were due to go to Russia-the plan was to go end of September, early October. And although, as I said, we checked with the Arrhythmia Nurse and she said yes, she couldn't see any reason why we couldn't go abroad, we managed to get the insurance.

But, um, 'wife' wasn't happy about going abroad at all, and I can understand. She was afraid of something going wrong and when you're not in this country, it's bad enough when- you know, we're only five minutes away from (major hospital) .... But yes, she wasn't happy about going abroad at all, and I can understand that so we cancelled this year ... But I think it's a case of trying to get used to going abroad again and I think long distance could be out of the question for a year or two. It's just a case of getting used to going back over to Europe and then just building on that for a while ... You know, I think we might get her back to the States, you know fairly soon, I think she'll be fine in a year or two.

I think she's a bit-we haven't been through an airport since this has happened and I think that's part of the worry. We were starting to get to the stage where we were jaded about going through airports anyway, you know for terrorism reasons. It was becoming a real pain, you know and we've travelled a fair bit and it used to be so easy but now it's become. And I think she's worrying that with this fitted, that's going to cause even more problems. I know when we've booked seats, we've been told we need to keep away from large magnetic things, and I know when we go to concerts and things, she always says you know, we mustn't sit in the front stalls, we must sit in the mid-stalls or the back to-I mean she is aware of it. I don't know to what extent they make a difference, but she is aware of things like that, in fact she is more aware than I am. In fact the other day we were in town, and we split up and I said right we'll meet back outside M&S. And she said, well I won't meet you in the door way of M&S cos she was told she must keep away, you know it's little things like that that she is more aware of than I am. She thinks about those things more than I do really. Which is understandable really, cos it's her that's got the device ... I don't know to what extent she worries about those, magnets at concerts wouldn't cross my mind, but she's always aware.... So no matter how relaxed she seems, it's always in her mind

I: so are you optimistic about your future together?

M: oh yes, but it's a horrible thing to say, but you're almost waiting for that first one, just to get it out of the way, if you know what I mean.... When you know what it is, how it works, what happens after that then .. and yet then I feel guilty thinking like that. Because I think, no you don't want that to happen, you don't want that to kick in. But it's almost like, once it's happened, she'll know what it feels like and what's going to happen afterwards and then it'll ease your mind as far as that problem is concerned. That's the strange thing, you know a part of me is saying, the quicker it happens the better, at least we'll know but another part of me is saying, God, that's the last thing you want-for that to kick in and that to happen.

I: you trust it will kick in?

M: I do trust it will kick in, yes, and as far as our future together.. when they're talking about you have to change the batteries in 10 years, yes, I don't want her to go in there and have the batteries changed but then you're thinking if it will go for that length of time before they change the battery then they must think ... you know. So, that's sort of reassuring in that respect. She is aware of it physically at the moment ...

I: are you aware of it physically?

M: well obviously you are aware of it. When you're lying there in bed at night I can feel the outside, and sometimes she's aware ... you know, I'm quite a big bloke, so I'm aware I can be heavy handed and everything else, so now and again, it's a case of 'can you shift, move over a bit, you're lying on it a bit', or something along those lines. So, it is there.

I: so you feel closer emotionally, what about physically, has it hindered things?

M: no, I don't think so, no if anything, we're much closer in that respect as well. But certainly emotionally, definitely. But no, there's no hardship in that respect no.

I: ok, ... are there any disadvantages for you as partner do you think?

M: no, none at all. I think if I'm honest with you, I'm more concerned with the heart than the ICD, I've got real issues with that, you know I'm more concerned with what's going to happen to the heart. You know, cos it's something that just came out of the blue, it wasn't something we were expecting, it wasn't something long term ... we just thought 'wife' was getting tired, getting out of breath but it transpired there was this weakness in the heart, in the walls and a deterioration in the valves. I think naively we thought, when they replaced the heart valves, that was it really. And I think with the device having to be fitted, you know it was 'oh no, are we ever going to get rid of this' sort of thing. The answers no, we're going to have to live with it. Because my father, he had had a similar thing, he'd had his valves replaced and once he had it, he was fine, just carried on, and I think we thought it was similar thing. You know, yes, it was a major operation, but once you're over it ... but it just felt like a kick in the teeth and she had to go all through that again. But no, we live with it.

Transcript for N18.1
Male aged 30 years. Unemployed
Wife had postpartum hypertrophy. Damage to heart from childhood chemotherapy
Participant = P
Interviewer = I
Doctor = EP

I: Your wife's been telling me why she had the ICD fitted .. how have you coped?

P: um, it was hard, very hard, it was hard in the beginning, you know cos it was such a shock ...

I: shock?

P: well her getting ill so quickly

I: after the baby?

P: yeah, she was home two weeks then back in the hospital then like. But er, it is gerrin better. I can cope a lot better ..

I: right, so how were you coping before?

P: just support from my mother in law, father in law really.

I: And how do you feel about the ICD?

P: Um, I'm glad she's had it. I'm glad she's had it cos, you know, it's made such an improvement, you know, like she's a totally different person now than she was before. I mean obviously she's had some bad days like, but it's a hell of a lot better than it was.

I: when you say bad days ...?

P: like a panic attack ... her finding it hard to breathe but they're getting like rarer and rarer now

I: why do you think that is?

P: it's the ICD, definitely think so, I definitely think so.

I: so, how did you feel when she had the diagnosis, that there was something wrong with her heart?

P: um, frightened. Frightened I was going to lose her. It was just shock, total shock. I never expected, like but the people down (name of hospital) looked after her, well still are looking after her like. EP explained everything to us and went from there like

I: so what does the ICD mean for you as a partner?

P: um, I don't know, it's just peace of mind really. Peace of mind knowing that if something does happen, then the ICD can kick in and bring her back like.

I: so you trust it to?

P: yeah, definitely, definitely,

I: so how you coping at the moment?

P: Fine, fine, yeah, everything's good like. We're home, we got the baby like, she's always keeping us busy, takes your mind of things like, but yeah, we're coping really well. She's keeping us busy and because of the baby it's ... there's not time to sit around and think about things. It's taken the weight off my mind and (wife's) mind, you know, worrying about what's going to happen if something goes wrong. I'm not saying anything is going to go wrong, but you know ...

I: so you focussing on the baby?

P: on the baby, yeah

I: if you left your wife on her own, would you be worried?

P: well, yeah, well, if I was going out, not far, I would be alright with that but I always make sure my phone's on, and charged and you know. She's the same, if she needs me, she can just ring me like. I'm not far away anyway so. So, I think she's alright. I mean, me mum and dad are only 10 minutes away as well and her parents exactly the same and we got good neighbours. Fair play, they're really good as well. She's got plenty of support there like.

I: And you, do you feel you're supported?

P: yep. Yep I do. Yeah, I've had my-I've been through the mill a bit like, like gerrin there you know like.

I: so you had a better Christmas this year?

P: yeah, oh yeah, cos I mean, last Christmas Eve she was having the device fitted and everything went up in the air then, she was frightened, we were all worried sick as well

I: so you were worried about the procedure.

P: yeah, yeah we were, cos with surgery there's always a risk and (wife) was worried she'd go under and wouldn't come back.

I: she told you that?

P: she told me that yeah. And I'd always say 'oh it'll be alright, don't be silly babe', but it was in the back of my mind as well, what would happen if she didn't get out of it, sort of thing like. But this year, we can't wait for it (Christmas) especially with (baby) being that much older like.

I: ok, just one more thing, the literature you were given, the booklets, how did you find them?

P: um, yeah it was alright. It was pretty good cos anything we didn't understand, we could ask the heart nurses down the hospital and like, fair play if you need anything explaining, they'll explain it to you like. It was really good, fair play like. It answered a lot of things like. It was just the procedure we were worried with

I: did you have any concerns, when (wife) came out of hospital?

P: um, didn't know how long it'd take to recover, how well she'd cope and things like that but like I say, she has come on since she's had it fitted, really, really well. She's a different person. If you'd seen her before the op, she was constantly pale, tired and drawn. Basically she looked like death warmed up like but when she had this done, I say even from the first day she came home from hospital , obviously she was sore like, but the difference in her was-I mean she got her colour back. She was back to the old (wife). I think she's a lot more emotional, a lot more sensitive to things ...

I: is that the ICD or the baby do you think?

P: I think it's a bit of both. I think like, well she is still suffering post natal depression, all she's been through last 18 months, two years, it's all catching up with her ... to me, she's the same person anyway. She do get tired and she has to have a rest, but ... it's part of life you know .... It's going to take time I know, but she is getting there definitely .... she went down the (name of hospital) first cos they thought she had a problem with her liver or kidneys and if it wasn't for them, she wouldn't be here.

I: how does that make you feel?

P: It's upsetting I could have lost her, she was that close to going

I: do you think about that now?

P: um, sometimes, like when we have time on our own we'll think about it and (wife) will have a good cry like,

I: we take life for granted don't we?

P: yeah, as I say you got to live life to the full cos you don't know what's round the next corner.

I: do you think anything good has come out of what you've been through

P: yeah, definitely, cos I've never been in that situation before, never had a loved one so close to .. it. I didn't realise how much it would, well change both of us. I mean, I know every couple argues but since all this has come out with her heart thing, I've learned now to be a bit more sensitive, listen a bit more and you know, be supportive. If she needs me, she knows I'm there like

Transcript for N19.1
Female aged 28, ICD recipient due to Long QT Syndrome
Participant = P
Interviewer = I
Doctor = EP

I: I usually ask the patient all about why they have the ICD but I spoke with your husband first, so I know the details now

P: yeah he'll know better than me

I: It sounds like you've been through quite a traumatic time.

P: It wasn't-I felt like everyone else went through it, not me because I was just in a daze. I didn't really know what-what was going on and it was out of the blue so it was nothing

I: so how did you feel afterwards that you'd had a cardiac arrest?

P: um, it wasn't really until I got home, because they were telling me information and I think if I knew then, the thought of having something put in my chest would have frightened the life out of me, but I can't remember feeling frightened so I was just in a daze for ages. And the second time was worse ... I was petrified the second time.

I: why was that?

P: because I was awake. Um I can remember waking up first time while they were doing it. The second time when I went in .. I think because it was a check-up I didn't expect to be-I thought that's it, I was getting better and the thought of being away from the baby again, I just wanted to come home first. Just make sure everything was in place for another hospital stay. And of course I went into the operating theatre awake and they started cutting into me when I was still awake, so that, I never want to go through that again.

I: you felt pain?

P: yes, I could feel it, I I could feel it as they were cutting into me and then all of a sudden, I couldn't feel no more .. But it was .. horrible. And there was another part where I was awake, I was trying to open my eyes but I couldn't tell him I was awake. I couldn't feel no pain that time, but I could feel them tugging inside and I know I woke up and I can't remember if that was the first or the second, I think it was the second, I woke up and I was speaking to them. And I said 'you've finished have you?' and he wasn't, he was just attaching the cable. Cos he was talking to me about ipads but I couldn't feel no pain then

I: so you'd rather just be out?

P: oh Christ yes. Before I even go in the operating theatre- I'm not going in again unless I'm out [unconscious] somehow

I: so you're thinking about your battery change already are you?

P: yes. Only because of what happened last time. Anything else I can cope with, it's just that, the thought of that, it's frightening.

I: so how do you feel about the ICD itself?

P: um It hasn't really affected me really. I just carried on as normal and the scar doesn't bother me at all.

I: do you think about it?

P: yes I think about it but ... I don't try and cover it up at all, it's part of who I am and it just doesn't bother me. I'll take anyone's hand- they'll say 'what's that lump' and I say feel it, you can touch it. But that doesn't bother me at all ....

I: do you feel safer?

P: I feel safer with it, safer than most people I suppose. So, it's a good job it's in there. I obviously didn't expect me to just drop dead basically

I: are there any downsides to it [ICD]?

P: no, no not really. If, if I was in hospital and I was thinking I was having it I'd think, no I'm not having it put in. It sounds so daunting ...

I: what sounds daunting?

P: having something put in your chest, it's just scary isn't it, it's just really daunting. But er if I'd actually met somebody who'd had it and could see what scar you'd be left with or what it'd look like, then it's not so bad. But you just think of having this big, ugly scar.. and you're going to be cut all the way down here [points up and down chest]

I: so nobody told you where the scar would be?

P: probably, but I can't really remember. I can't remember certain conversations, the first two weeks, I can't remember anything at all, but the second two weeks it's like on and off. But in a way, I'm glad it happened in that way, that I didn't know. I was just lucky my husband took it all in and knew what was going on, cos he was brilliant, absolutely brilliant.

I: do you think about what happened a lot?

P: yes, because I think about my daughter. Because my husband can't remember where she was, because I was just about to bath her and I was upstairs. And I was told he palmed her off with neighbours but honesty I just can't remember anything ... Even now, two weeks ago, I heard new bits

I: so you're putting it all together?

P: yeah. I think about it all the time but it doesn't. Very rarely I get upset though thinking about it, I'm just lucky.

I: how has it affected you as a person?

P; um, diving

I: deep sea diving?

P: yeah. I can't dive anymore. Have another baby, but haven't said I couldn't have another baby but I just have to be careful. But that's not to do with the ICD, it's to do with Long QT, I think. But it has made me think about not having anymore. And I've got one child anyway. And I've put on so much weight since having it done, cos I couldn't do anything for a long time, like you couldn't even lift your arm for six weeks could you. And I am on beta-blockers which I've asked them to cut down cos I was tired all the time. But last couple of months I been going to the gym, I been going to the gym fine.

I: do you work up a sweat? Get your heart racing?

P: yes, yes. The first month I didn't, I was just doing the weights, gentle exercise, 30 minutes a day and up until two weeks ago I was going every day, just doing 30 minutes cardio a day and that was working up a sweat that was.

I: so you're not worried about ...

P: No, I know now, I know when I get the feeling enough is enough. And I don't push it too much, I just do about 30 minutes

I: do you monitor yourself?

P: no, because I can't actually hold on to them cos it sends a pulse. So unless you've got a portable device, which I haven't got

I: so how do you know when to stop?

P: I think I can feel it in myself. My heart beat-my heart beats fast, but then it can go like 'shaky' and that's when I stop yeah. I built it up slowly, I didn't just do work up a sweat and that was it. And I got to the point when I was coming in from the gym sweating and that's enough. I just wanted to do something about my weight and feel better about myself.

I: and do you?

P: yes, for the last two weeks mind, I haven't-I haven't been to the gym at all. Too busy with the accounts and everything so I'm going t wait till after Christmas now

I: ok, and how has the ICD affected your relationship? I suppose it's affected the fact you can't dive now

P: well (husband) doesn't dive now either ... We went to the Caribbean this year, (husband) went off diving for a couple of days. With (daughter) she's only young so we wouldn't both been diving anyway ..

I: so it's not a big thing

P: no, it's not major, it's a small price.

I: ok, and what about your relationship in general?

P: I think it's brought us closer, it has. Especially as he knows more about it than i do so I think he thinks he's got the upper hand in some ways. You know, he's like a dad in some ways, you know I can't do this, can't do that and then I ask his advice. Say standing next to speakers 'you can't go over there, you can't stand next to that big speaker'. Cos it doesn't affect me see? Day by day I just- I do go days without even thinking about it

I: are you deliberately not thinking about it?

P: No, it's just ... I think I'm ignorant in a lot of ways, I think I should pay more attention but I just ...

I: is that because (husband) there?

P: yeah, because I know (husband) is there ... If (husband) wasn't there then I would have to think about it myself ... I think it's cos he's always there for me

I: so you feel it's brought you closer together?

P: oh definitely, definitely, I mean we been married 12 years but it's brought us closer together

I: do you talk about it a lot?

P: um yeah. It was only Thursday, Thursday night, we'd both been out we had. We'd both been down the pub and we had a baby sitter, we come back and we were talking about it for two hours ... I just lay there and he just talks and talks and talks, tells me what happened, the part where I've got no memory ... but he can tell me over and over again. I do keep forgetting. So he keeps telling me. But he has been really, really good, brilliant.

I: close shave wasn't it

P: yes

I: does that worry you?

P: yes, it does. It worries me for (daughter)and I'm still waiting for her to be checked. She got to be checked every year. So she went last year and had an ECG but they couldn't get a proper reading cos she was screaming, she wouldn't keep still anyway, it did scare her a bit. But you know when I go for my check-ups, she'll go with me every time so she can see me having this and having this put on me and getting used to it.

I: so that's your main concern is it?

P: yeah, (daughter)

I: you're not concerned about yourself?

P: no, I just think I'm sorted now, now I got that [points to ICD], nothing else can happen can it?

I: so you're quite confident that the ICD will kick in?

P: yes. When I had ... I think it was after I had the second one, I went for the check-up, the pacemaker used to kick in every night, it was horrible, could feel it, you could feel it in your heart, it was a horrible feeling. ... Well you could feel it in your throat and then if I was having a lazy day on the sofa, you could feel it. And then when I went for a check-up they altered a few things and obviously they had the pace-maker set to go and to kick in if my heart rate dropped below a certain level. But with my condition, I don't need it to do that anyway, so I don't need the pacemaker side of it, I just need the defib side of it, I think ... they have kept the pacemaker there, it kicks in now and again but it's not every night, every day, it's like once a month or. ... Yeah that was horrible that was, ... can feel it in your throat.

I: well thanks, I can't think of anything else we haven't covered

P: that's why I sent my husband in first, to answer all the questions (laughs) cos I don't know, I can't remember.

I: does your memory bother you?

P: It does ... it doesn't actually ... again, if I was on my own and I didn't have my husband-my family were great as well ... But he do, he'd ring the hospital and he'd want to know the ins and outs of everything he did. So, I think if it wasn't for him, I'd be scared and I'd want to know a bit more but ... left-I put it all on him, I have.

I: but it's brought you closer

P: yeah, yeah definitely ... I think so, he might tell you otherwise (laughs)

Transcript for S23
Male Partner
Aged 68
Wife has Long QT Syndrome
I= Interviewer
EP = Electrophysiologist
ANS = Arrhythmia Nurse Specialist
P= participant

I: I've asked your wife about the condition so I know it's Long QT, so how was the diagnosis, how was it for you as a partner?

P: worrying. It happened three times in China. We were actually taxiing or starting to taxi out onto the runway and they stopped the plane. They got her off and took her back to the medical centre at the airport and then into hospital then from there.

I: and what was going through your mind at that time?

P: oh, 'what the hell am I going to do'. Cos out there -there was only broken English interpreters, so it was worrying. When we got into the hospital, it was more reassuring they were doing something for her.

I: how did you feel when she came back here and the EP said she had Long QT?

P: well, what was long QT? When I seen it on the print out on the graph then ... the ECG you could see it on there. Well once you been shown it, you can pick it up off anyone's whose ECG. If they got Long QT like. But it was worrying-she can feel her own heartbeat. Well, now and again, well more often than not it rises. Well, she's too aware of it I think. But er, there's not a lot you can do about that. We were out the front watching them after the fire (?), watching them do everything and she said 'oh I feel faint' so we came in, sat down by there and her defibrillator went off. Oh yeah, and it was just like (claps his hand loudly), just like that (claps hands again)

I: did you hear it?

P: yeah and then she looked-oh she looked like she was passing right out then ... but she didn't actually lose consciousness after the box went off, she was more dazed than anything. But it was the worry then 'what would they do now?'

I: what would who do now?

P: the hospital, the doctor, do now. Cos the box had gone off like.

I: what did you think would happen when it went off .. I'm just going to put this nearer you (moves recorder)

P: I knew it would kick start it back to life. But er .. wasn't quite sure what the procedure would be from there on. I was flapping like a headless chicken, getting everything together to go to hospital. She's always been very good like that, her case is always packed because she's been in and out of hospital for years ... there was one case for her nightie and dressing gown and such and another case for her stoma and stuff. And I had to gather all that up into her case as well.

I: so after the shock you rang for an ambulance, you were frightened were you?

P: oh yeah, yeah, the worry was, what happens next after the box went off.

I: so when you say, 'what would happen', what exactly do you mean?

P: what to do when the box goes off. We had no er .... didn't know what to do. I knew I had to phone for an ambulance and get her into hospital and er. No, there had been no explanation of what to do if the box did go off.

I: ok, so that would have helped if you'd known.

P: but yes, I'd read what the defibrillator was and read all about it, but there was nothing about procedure after it went off and kicked her back to life like. So, I was stuck then and worried like. Once they got her to hospital, they explained like, 'it's alright, don't worry, it'll kick you back to life, don't worry about it.' But it's alright saying don't worry, but you still worry.

I: so how do you feel about leaving your wife on her own?

P: oh, very, very wary. If I do go up the shed, I got some old cars up there , I like to go and play with .. but we got walkie talkies what erm-if I go up the shed for anything, even to get a stick of coal, I take the walkie talkie with me, so she can press the buzzer if she wants me like.

I: and do you ring her?

P: yes, to see if she's all right.

I: so how long do you leave it before you check?

P: five minutes, 10 minutes

I: so you're checking her every five or 10 minutes?

P: yeah, yeah. Cos it is a worry. Even when she goes to the toilet, if
she's out there-now and again she's out there changing herself
(stoma) and I'll go and say 'are you alright love?'

I: sounds like quite a strain.

P: well, it is really.

I: are there any times you forget about it?

P: no, no. Its constant. I mean she's alright now, she's next door with
her son and baby. He's good (son), he knows what to do if it goes
off. Nobody knew before what to do

I: so it's a worry for you as her partner so how do you cope?

P: It's alright, I cope.

I: what do you do to stop worrying?

P: oh, I have a glass of sherry in the night. But I can't have too much
in case I got to drive or in case something happens like. But I know
when her son is home, I might have-can't say I've always been a ..
not a heavy drinker, but I don't drink all day. I might have two or
three nights off a week, where I don't drink at all, but er so I'll drink
a bottle of sherry a night

I: a bottle?

P: yeah, a 72 litre

I: and that's when her son is home?

P: yeah. And alright, I'm quite alright after drinking a bottle of
sherry, like I don't get 'fall-y' over or er ... I can't afford to get 'fall-y'
over in case something happens.

I: so how has it changed your life? I believe you retired with the
expectation of lots of travelling.

P: well like I got two old cars out there I want do up. One is in the
shed, the other one is under a tarpaulin out the back. You know the
Wallace and Grommit car? It's the van like, not the car. But the
one's running, I got to recover the seats and do lots of bits and
pieces to it like ...

I: you're still able to do that are you?

P: no, not really. No, cos I'd be up there too long to leave 'wife' on her own like. So, it's-it's restricting in a way but I don't mind. I can't say it's my duty. I'd rather look after her than be up there pottering about the cars

I: if your wife didn't have long QT and a defibrillator would you be out there with your cars

P: Maybe for a few hours, not all the time

I: so what's changed?

P: . .... We used to be outgoing. If it was a nice day, we'd go out. We still go out, we go shopping

I: food shopping?

P: yeah, bits and pieces shopping like. We'd normally go out every-most days.... Even if it's just out to (town) and 'supermarket', pick up bread, milk and er paper- newspaper and then come back. It's a break from the house, for the pair of us.

I: so how far do you go these days? Your wife said you went to the beach in the summer?

P: yeah (name of beach) or (town)

I: what's it like going out the day?

P: oh great! She can't walk very far, she gets breathless ... yeah we go down. We found right at the top end of (beach), you can park the caravan, turn it round, put the nose of it against the sea wall and you can look out to sea then. Yeah, it's lovely down there. Peaceful and quiet. The nearest pub is a mile and a half, nearly two mile away

I: you don't feel worried about going to 'town' for the day?

P: oh no,no. As long as I'm with her. Stick her in the car and get to the first hospital.

I: ok, so what are the benefits for the ICD for you?

P: Well it's reassuring if she does pass out, it will kick her back to life

I: do you trust it?

P: yeah, yeah.

I: so why do you feel you need to check on your wife.

P: cos she'd collapse and she'd be on the floor if it went off. And I want to be there.

I: how does it feel now she's had a shock? Is it easier now she's had shock, you know what to expect?

P: No, no .. well it's about the same, still worrying. Will it go off like. I'm quite confident it'll work but what'll she be doing if it does go off? Like she had that – ooh about half a minute lapse, that she was feeling wobbly and dizzy but she had chance to sit down before it went off.

I: enough time to pull a car over?

P: yeah,

I: do you think she will start driving again?

P: yeah, more than likely. She was on about driving back before Christmas. But I said there's no need. Although she's got a little car, I got a jeep like but there's no point for her to drive cos we always together.....

I: how do you feel about her driving?

P: I don't like her driving but then she'll nag me when I'm driving.

I: I mean driving with the ICD?

P: Oh I don't mind. Just don't like her driving. Like when I was working away. If I was home, I would do the driving. Even-well no matter where we were going, I'd drive. She's not all that fussed on driving.

I: so it's not a big thing?

P: no I've driven all my life really

I: so the main benefit for you is that you've got that reassurance?

P; yeah.

I: what are the disadvantages? Things that have had to change that have been hard to cope with.

P: none really. Well, I've always been a faffer and a worrier but I can take the worry side in my stride more or less

I: the worry? So what things do you worry about?

P: ... about how long will she last. Or how long will ....

I: so you've had to think about things that you may not have? She mentioned she was younger than you?

P: yeah, 13 years ... so even more so. Alright, I'm still fit, well half fit anyway. But will I be fit enough in another five or six years to keep looking after her?

I: and you worry about that do you?

P: yeah, yeah. Like I'm still fit for my age. I was on the roof last year sorting out the chimney ... oooh that was a headache and a half that was (talks about the chimney at length)

I: going back then that is something you worry about, about coping in the future?

P: yeah.

I: has it been difficult physically?

P: no, no. I do most of the work. 'wife' will potter about, dust and that. I'll hoover and mop the floors and duvets

I: is that what you're worried about in 5 years time

P: No, I'll still be able to do that in 5 years time ... with a bit of luck.

I: have you any other worries?

P: no, no ... the only thing I had my hair off in the beginning and it's a bit worrying now, she won't disability. Well while she got the ileostomy and it's the pacemaker and defibrillator now and she still won't get disability allowance ... She can't get on invalidity. And I know one woman in 'town' and a man in 'town' and they get it. Her sister's got an ileostomy, she's gets it.... She won't appeal cos she's-she's worried about people knowing then.

I: about the ICD?

P: yeah.... It don't make no difference, we can't say we're well off but we're alright, comfortable. She might feel everything's always happening to her.

I: so how do you cope with your wife?

P: alright. Alright. I've always done personal little things for her. The ICD doesn't bother me at all, it's just the worry that when it goes off ... what to do.

I: you made a comment earlier that you were thinking how long she'd be here ...

P: yeah

I: you'd never thought of that before?

P: no, no. It's just since her heart has been playing up. It's like 'oh god'

I: what do you do with those thoughts?

P: put it in the back of my mind, back, out of the way. And then don't even worry about it then until er ...

I: so what makes you think about it again?

P: just every now and again, it just pops into my head and 'got to go, she'll be alright'. Like if the weather breaks, we'll go off in the caravan. Yeah it's alright. She do worry about the kids too much. We got four grandchildren and 'why don't we take them with us?' Never mind whether they are in school or not. 'Take them away for a week, as soon as the weather breaks'. (Laughs and shakes his head). Aye, she'll control the kids but I'll do all the cooking and well I'll do 90% of the cooking when we're away like.

I: why do you think she wants the kids around her?

P: oh, just to make sure they go on holidays – give them a break.

I: do you get much one to one time?

P: yeah, yeah. The kids will be here at ten past three, half past three, they'll come straight here. The daughter's living in the second house from the other end and her son's living next door like. They'll go home but they're not there long. The little ones, they're coming here, they're staying here tonight. Oh I'll do the cooking and the shouting at them

I: do you mind that?

P: no, I don't mind. I teach them to swear a bit (laughs).

I: is there anything you'd like to say as a partner?

P: no, not really. The defib's wonderful, fair play. The nurses down there are great, you can get on the phone to them. They come back to her practically straight away. The aftercare for it is marvellous. Seen EP, he's great, straight to the point ... I'd rather it be like that than er ... sugar coated..... There is an element of a lot of worry with it ... I don't tell wife to protect her more than anything. She'll say now and again 'you worried ain't you?' 'oh yeah, a little bit' but I play it down..... I can manage worry. You just put it to the back of your mind

I: do you see yourself travelling in the future?

P: yeah, if 'wife' is well enough, yeah... at the moment, she's too worried about the ICD ... Since the shock she's more aware of her heartbeat now. We went down yesterday, or the day before, down the 'hospital' because she was having fibrillations (palpitations I think). Well, I can't feel my heart, she can feel when her heart is beating fast and she's got a finger thing (shows me a gadget). She always keeps it there ... It monitors your heartbeat. Her son works for a medical company, he got it her.

I: I've never seen one before

P: it's in hospital, doctors use them an all. (Puts it on his finger to demonstrate) – that's its oxygen level, and that's the heartbeat. She uses it a lot and her blood pressure monitor. She's got one that goes on the arm as well. I'll be a doctor before long (laughs)... this is all since she's had the ICD.

I: so she seems very anxious

P: yeah. And they were saying 'oh don't worry about it, if anything happens it will kick you back to life'- bit you know

I: blasé?

P: yeah. Like we seen EP when we down after the box went off, and he said 'well, it's working then', he said it's one thing you can't die of, it'll kick you back to life. It's like 'well, I'm glad it does work'. I'll look after her for as long as I can.

I: Well thanks so much.

P: When we went to China we were going to go the rooftop of the world, but the airs that thin up there, they said it would have killed her.

I: And you didn't know that before?

P: no. So, I'm glad we didn't get that far ... That was the flight, she flaked out as we were taxiing.

I: how does that make you feel? These sorts of close encounters?

P: oh 'Christ, I hope she don't die'... When she collapsed the first time, I thought 'oh shit'. But it is an awful worry. Before we got the box fitted like because she had collapsed three times. So it's reassuring in one way, well she can't die but what else can go wrong? Cos she's having these fluttering, they say that's the electrics now- the top two chambers of the heart are playing up. See what they can do to sort that out and .... but we're both worriers, but I try and put my worries behind me 'oh it'll be alright, it'll be alright'

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"... don't like the idea of having anything stuck in my body ... it was an unpleasant idea and when I saw how big it was .. at first he said a matchbox, but there are matchboxes and matchboxes ... it was quite a big matchbox, more like a Swan-even bigger than a Swan Vesta box .. And also they said you wouldn't be able to see it. You can see how big it is, quite prominent really. I wasn't hugely affected by that but it does remind you that it's there all the time" (108-120) [N11] "... but this thing (ICD), every time I turn over in the night it's there like, you know what I mean? Sticking out of my shoulder, it's tough like ... my missus, my wife puts her head on my shoulder .. she's conscious of it, I'm conscious of it .." (50-59)[N10] "I feel it's [ICD] here ... Very, very heavy at first it was, don't seem so heavy now" (332-333)[N10] "In the beginning it was very awkward ... they said it would be below the collar bone, you know I expected it to be ... between the shoulder and the neck ... but it's literally over – by my arm .. so as soon as i start t move my arm, you start hitting it straight away, which I used to find very awkward ... but now, it doesn't bother me at all ... I think it's found its own pocket" (314-324)[N03] "it's annoying as much as anything else ... when I lie in bed and it twists itself and sometimes it's here and it's on one edge" (335-342) [N12] "I just know it's there and if you knock it ... you know it's there ... you think 'oh that bloody thing is in the way' ..." (130-131) [N12] ".. it feels like a stone in jelly .. and it moves in bed as well" (294)[N14] "I don't walk around conscious of it ... it's just when I feel my heart starting to beat faster, cos I got this arrhythmia thing .. it's a constant reminder then but apart from that I just get on with [it], forget it's there, cos you can't feel it in there .... "I've learned to sleep on my back, cos I can't sleep on my side ... it feels as it if it moves and if I sleep there I can feel it poking me and if I turn on that side, I can feel it moving out like that, if you see what I mean.... Some days it's under my arm and then other days, I can feel it up here. Like today, it's tucked in under my arm and then other days, I can feel it there [points to chest]. So, it moves around" (335-349)[S23] "It's not uncomfortable, I can feel it, I'm conscious of it ... It's just when you do that [you can feel it] [crosses one arm in front of the other] it's quite easy to move about [wiggles ICD box through his shirt] (25-32)[S01]	Physical Sensations of an ICD		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"You see, when the ICD is put in, you notice it all the time, you've got a constant reminder cos you can feel it all the time and sometimes it gets a bit itchy and rubbing it, so you're aware of it all the time. So that's a physical thing that's a constant reminder .. a constant reminder of the fact I've got one there, which then reminds you of why you got one .. But the very fact it is there is constant reminder" (410-422)[S15] "You can appreciate in January it was cold and my defibrillator, I don't know if you've had anyone else, it feels the cold ... it feels cold and it does feel hot in the hot weather" (153-159)[N14] "it hurts .. it wakes me up in the night if I'm sleeping .. If I turn over on that side (points to left side), I can't, it does wake me up and as I say movement in my arm in certain directions, it is really painful on the muscle. They give no warning of this whatsoever" (210-218)[N06]			
"And they had to shock me and ... but everybody tells me I shouldn't be here (tearful), really shouldn't .... [Nurse] said to me 'you know, you're very, very lucky, because you know, someone's watching over you ... everybody sort of says to me ... you are extremely lucky. I was talking to an ambulance driver on Sunday 'cos my mum was taken into hospital, and you know, she said to me 'it is so good' she said ' to see somebody whose actually had a cardiac arrest that's here to tell the tale" (42-57)[N08] ".. Although I'm not a doctor, I know in my mind there was a very thin line between me being here now and not being here" (398-400)[N14] ".. I appreciate now, this device is very expensive so I must have needed it badly for them to fit it ... and my heart was in a very serious condition, because I was told my heart rate could go up so fast it would begin f-f ... so it would be curtains as well ... I didn't realise I was that near .. of the end possibly" (343-352) [N11]	Trauma		Emotional consequences
"The first time we went away for a night was in December ... it was like ... a place where people have a retreat ... and my first thought when I went in to the door was, 'there's no phone', so if I need someone, there's no phone ... so 'I wonder where the nearest ambulance station is'. Because, I mean the ambulance station is close here, but when I came out of hospital, Terry said 'we'll go for a ride in the car, and we went down the Gower, and my first thought was 'they'd never have got to me in time' because there just didn't seem anywhere where there was an ambulance station. So, I suppose, you do sort of thing to yourself 'where's the nearest hospital? You know ... is it accessible for somebody to get to you?" (117-132)[N08]	Vulnerability & Uncertainty		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"... it's got to me mentally, it does get to you, play with your mind. It makes me feel I don't know what's in front of me, I have three chances in life, that's how I see it. I had my first chance with leukaemia... where the baby was concerned, I thought I was a goner , that was my second chance and then obviously my third chance has been getting through this" (66-69)[N18] "... I did say to him, I said 'I've got something to tell you now, and it's going to upset me more than perhaps you (very tearful) ... I said 'if anything happens to me, I don't want my good wedding ring on' I said, 'buy and cheap one and will you please .. 'cos I don't want to go to the crem (crematorium) with my good one .... And I said 'listen to what I'm saying now right, you know, 'it was so quick before, you just don't when you'd have time to say anything do you?' (425-435)[N08] "Cos it's like ... not that nobody cares but it's like you've a tooth out ... and it isn't really like you've had a tooth out ... it's something a bit bigger than that, do you know what I mean?" (429-432)[N07]			
"my confidence, it's knocked my confidence... I got a grandchild who's only two and a half ... I've always had the kids for my son to work. And I had the kids for my daughter to work ... I can't manage him [grandchild]. I can't get up and run around with him. And so I feel so disappointed I can't support her with the baby, like I have with everyone else" (627-633)[S23] "... it's a bolt out of the blue and as I say, I'm not the same fit person .. this [ICD] has changed my life (365-367)[N14] ".... (husband) he says '... you can't do this, you can't ...'And I think I'm not an invalid, I'm not a cripple, I might have had a heart operation but I'm still me. But I'm not .. I don't feel the same person I was a year ago' (114-117)[N18] "I used to be quite fit like, I used to go to boxercise, you know what I mean, and all that. I used to do a bit of boxing and all that, Gaelic football, you know what I mean, now I'm conscious of it .." (88-91)[N10]	Loss of Identity	Feelings of Loss	
"Disadvantages (of ICD) are I was going... well ahead in my career, especially at my age... I've achieved numerous certificates... To no avail now really 'cos I don't if I can get another job cos the way I feel and the defibrillator has to be renewed every four years doesn't it? ... if I'd be fortunate to have an interview with a college, I'd have to explain to them my condition, surely that would be a disadvantage, cos I have go this inser-insertion in me where if they were interviewing you, you haven't got one" (317-355)[N14]. "... I was always going to use that HGV license as a backup... if I wanted to get out of work and work two or 3 days a week... so my whole lifestyle had to alter.... I got to re-evaluate everything like ... I'm still working as I am like ... but that's not very good neither	Loss of Goals/ Dreams/ Future Self		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
like ... I was always going to fall back on driving ..' cos I love driving ... suddenly it's like somebody pulling the carpet from under your feet" (216-242) [N10]. "... You have an image of what's going to happen in the future, as vague as that might be and with mine it was obviously going to be quite active. And then you have that futuristic view changed ... if your active future is changed to sitting around in an arm chair all day, it might sound alright but when the reality is there, it does hit you and I think that's what happens to me every so often especially if I've done nothing but reading ... I think that image is becoming more concrete" (385-396)[S15] "... you feel ... not quite a waste of space but you're not doing anything constructive (work ethic). And so then you can start feeling 'oh, where are we going?' You know, what's in the future? If it's like this all the time, it's not my cup of tea" (343-346)[S15]			
"I'm used to being independent and I feel I've lost my independence ... Right at the minute there's a conflict going on with this particular girl in the street. And before, do you know, I would not give two monkeys whatsoever, I'd stand there and fill her gob completely and that was me. You know if you say to someone [the someone would say] 'that was the old 'N18', she's changed. She was always the type of person to put up with no shit. And I'm going to say it how it is, cos it's the truth, 'no, shit, she can stand up for herself ... and now I can't ... I have never, ever, ever, I've never been like that where other people have had to fight my battles..." (87-109)[N18] "... he is more caring you know making sure I'm ok, checking up on me to make sure I'm fine, ... And If we go anywhere, do anything he .. just sure I'm not overdoing things. If I start to do a lot, he'll say 'just take it easy' ...It's irritating. You know cos I want to be able to do things without feeling he's looking out for me all the time. Cos it's a strain on him" (434-443)[N17] "I felt I'd lost a bit of independence really, I couldn't just go out running when I want to ... you know, I'd have to 'oh what you got on [wife] any chance you could come out with me now' ... [or] one of the kids would escort me on their bike you know, and .. before, I could say 'right I'm off' ... it wouldn't have bothered me if I'd gone by myself ... it was more cos [wife] felt a lot happier doing it" (435-450)[N03] "I still have a problem taking the tablets, I don't mean in actually swallowing them but I-it's the old Type-A person again see, I don't like being reliant on anything really" (348-350)[S01] "I can't go anywhere on my own. 'You can't go, you can't go on your own'. I mean my daughter ... and my son .. they'll say 'where's 'husband'?' – he's their step-father, and they'll say 'where's husband then, what's he doing leaving you on your own?' So,	Loss of Independence/ autonomy		

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
you've lost your independence as well" (261-266)[S23] "In some respects, you realise you've come dependent on a machine, so things aren't of a natural process – I suppose if the machine breaks down, you're in trouble [laughs] but the monitor system and backup system is there, so everything is in order to actually safeguard your life" (496-500)[S15] "the fact I can't drive at the moment, means I'm limited ... if I suddenly feel like .... feel like going to [town] and going to a shop or something, I can't do so, unless [wife] takes me. That is a big, big thing" (285-291)[S15]			
"... But it [shock]certainly did leave me with this complete lack of confidence and I suppose the thought that I hadn't been doing anything and it happened – it just confirmed the idea that this could just actually happen at any time" (250-253)[S15] "My confidence suddenly went down ... It was the fact that my heart had gone into this rhythm and I hadn't been doing anything out of the ordinary. If I'd been wielding a pick axe or something like that, then I'd had said 'right the exertion had-it was my own stupid fault, it caused the heart to go like it is. But I'd actually spent the day doing very little, sitting around ... doing a bit of cooking which I'd hardly call strenuous. So, I could understand why the heart had gone into this rhythm. Certainly to me there was no outward sign as to why this should happen and that's the thing that unnerved me a lot." (213-226)[S15] "... logically, it should-... the logic behind it says yes, everything' as it was before and thing [ICD] is there. And in fact if it hadn't been there then I wouldn't be here now and it's done its job and all those logical things are there. It's the notion or whatever it is, it's certainly something that's affected my confidence, which is slowly coming back but it's taken quite a bit of time" (229-235)[S15] "I didn't know what had caused it ... because although I was rushing around and a bit stressed ... I'd been in that sort of circumstance before. I didn't understand why it had gone off, I thought maybe it was a fault with the machine.... I assumed it was the case with me but it wasn't, it was a very serious genuine shock ... Having since me the consultant ... confirming the fact it was necessary for this thing to go off, was a bit disconcerting really" (83-89) [S05]	Loss of Confidence		
"... I get sort of moments when I'm frightened of it [ICD], ... it's not so much in the body as having the first shock" (86-90)[N16]. ".... most of the time-when I'm occupied, I forget it. But when I sit down quietly thoughts go round my head-it's always at the back of my mind ... that I don't know what's going to happen, how it will affect me, will it hurt, will there be more than one ..." (363-	Anxiety and Fear of Shock		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
371)[N17]. "I'm a bit concerned ... I might precipitate this shock thing, which I don't really want to happen ... that's what would worry me, if I had this shock thing other than when it was induced in a test ... what would it mean? .. it's a bit dicey really, things are getting a bit dicey really if it's got to that level really .. the medicines are not doing their work, and things are getting worse" (209-219) [N11] "...It's strange because your heart beating is sort of irrelevant, I think beyond that – I think, Ok, your heart stops, there's a silence and it's that I'm afraid of" (236-238)[N17] "... if my heart starts a peculiar rhythm, what am I looking at, is this it? If it starts getting really painful, what do I do? And it's just constantly on your mind, it's always there, what's going to happen?" (162-165)[N17] "But when it [shock] happened .... And I felt scared ... I just felt stunned but then I thought it got to be my defib-defibrillator. And then I felt frightened that something else was going to happen. 'Why did that go off now?' 'Did my heart stop?' (186-198)[S23] "Two shocks ... I was trying to find somewhere to sit down and relax and of course the car was the obvious place ... and on the way to the car it hit me again .... I think for the week or two after that I was very apprehensive of it happening again" (60-78)[S05] "The horrible feeling just before the shock, shortly after it had happened .... I would dread more than the actual shock itself.... Cos it was a grotesque feeling, the whole body seemed to go [shivers] ... I can't really describe it ... But it's just this horrible feeling before the actual shock itself.... I didn't like the feeling [of shock] but it's only seconds" (239-248)[S15] ".... I got this fear, cos it [shock] comes so sudden. How will I manage if I'm driving and then it goes off, you've only got like a 20-second warning or something. ... You just feel extremely dizzy, you know that was me and you can feel it revving up in your shoulder and then bang-you know it felt like somebody had hit you with a hammer. How would I cope driving? So, I'm very nervous about driving. I've driven for a number of years ... driven lots of places but I just don't feel confident enough" (167-175)[S23]			
"... I suppose you're glad you've got it but then you think your heart can't be in a great state as you've got one, which obviously suggests that things will go wrong or can go wrong. It's going to be pretty serious. Well an optimist would say 'well I've got this now so I'll be fine', you know. And I think, I've got it because something's wrong – I'd rather not have it." (244-249)[N17] "I don't want to sound like a Jonah, some days I can ... thinking 'what do you do? Got this (ICD), out of work' (cries)	Pessimism		

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
I haven't been like this... it's just talking about it to you... it's all (begins to cry again) all my emotions, I keep to myself 'cos Meg's at work ... I'll be sitting in the garden, you think of things... Life ... I tend to keep things like this to myself... I don't want to worry my mother really, I don't want to worry Meg ... maybe I should have gone to ... it was in the booklet, you can go to a sort of club where other people have had it. I don't know ... like Alcoholics Anonymous, Defibrillators Anonymous" (443-495][N14] "And I've put a lot of stress through my husband, the children. My daughter, she phones everyday 'you all right mam? How you feeling today?' And if I say 'I'm not feeling too good today, she'll be back on the phone ... and I think oh, just leave me alone. ... But I've said to (husband) as well 'I'll just go, live somewhere else' I feel like I'm a burden to him" (341-347)[N16]			
"With hindsight I wonder whether it was worth it (ICD) ... there's worse things than dying you know, I ain't worried about that ... so like I said, because of my family really (I had ICD), they don't want to see me go that quickly" (188-191)[N04] "They painted such a picture of woe really, with hindsight now I probably would never have done it ... never had had it fitted ... why? 'Cos it hit me so bad. Like I said this time last year, I was ill and I thought I was on my way to be honest with you. I never had an ounce of energy... from being someone before the operation still feeling great ... " (27-43)[N04] ".. From a comfort point of view, (I would take it out)... I'd have to talk to my wife by I'd say 90% of me says 'take it out'. It's an uncomfortable-ness, an awkwardness. I'd said I'd have it out, but I'd have to talk to my wife... but I think this should have been done at the beginning like, like I said, if I'd been given the choice at the beginning I'd have chosen no." (429-434)[N10] "You can ask me this question, would I have had it if I'd had the choice of having it or not having it and if I'd gone by myself when I had those pains ... I probably wouldn't have had it in 'cos I wouldn't have known about it would I? But probably being a bit selfish, it could have kicked in, been taken out 'cos I've not got it (ICD)." (298-303)[N14]	Doubt and Regret Having the ICD		
"... the most difficult thing in actual fact, was people telling me to take it easy, including my wife. And everybody out of the best concern 'oh take it easy, don't do this and don't do that and sit down' ... that was frustrating, very frustrating, and just went against the grain, cos ... I just like being active" (113-233)[S15] "I find it frustrating cos there I was in April playing rugby, full 40 minutes each way, full contact, running about and then bang, in June this happened and ever since, I struggle to run. I can run but not very far and not very fast, whereas before I used to enjoy running, I used to enjoy extending myself. I find it frustrating now. I can't experience that cos it's a struggle to run, so for whatever	Frustration at others/ self and situation		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
reason, I can't do it" (117-123)[S05]			
"How I view life? I've been more aware.... I have always worked for the future ... so with things as difficult as they have been in the past couple of years, I think I have become more aware of my age, not because of anything medical but 'lucky to get over that one' .... 'Come on, you're 66, let's do something positive over the next 10 years" (601-609)[S01] ".... I think a lot about dying, which I've never thought about before. I'm not scared to die because I believe in an afterlife and all that so I'm not scared. But it makes me think a lot about it like ... I can't get over the fact that this [ICD] is just there as a standby, it's like a marker to say 'right, you're nearing the end of your time" (271-280)[S23] "... the fact it's [ICD] there and needs to be there, it is a kind of bereavement. Cos the life you've led before hand was free and easy without constraints, has suddenly transposed into the life you are leading now, which doesn't have too many constraints but it does have the awareness there and that's the thing you've got to come to terms with" (546-551)[S15]	Feeling Mortal		
"... Other times you think about it (shock) more, whereas before I'd think nothing of walking ... especially at the weekend ... I love walking, I love nature, I'd walk miles.. I wouldn't do it now... as I explained to you, I did walk sort of back to my normal walking area but I felt absolutely knackered, sat down and thought 'oh God, how am I going to get back', there's no one in the woods ... if something did happen and that's why I take the phone .. I might not get found for a couple of days to tell you the truth, I am-I am not the same fit person I was ..." (697-710)[N14] "... two weeks ago I was going every day, just doing 30 minutes cardio a day and that was working up a sweat that was.... I know when I get the feeling enough is enough. And I don't push it too much ... I can feel it in myself.... My heart beats fast, and then it can go like 'shaky' and that's when I stop ... I built it up slowly ... I just wanted to do something about my weight and feel better about myself" (135-156)[N19] "... I walk fast and sometimes if I'm late for something I'll run a bit... sometimes I'll go by train and sometimes if I leave the house a bit late, I'll run .. and sometimes I think 'I shouldn't be doing this', so I'm definitely watching my excesses .." (303-307)[N11] "... when I'm doing something strenuous, I keep telling myself 'you must pace yourself'. Cos if it starts-if it starts going too fast too quickly, there could be a problem, so you must pace yourself... If I feel a drag on my arm, my heart going a bit faster, then I think	Limiting Activity	Problem Focussed Coping	Coping with the ICD

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
about it. If I walk too fast, which I tend to do, I have to tell myself to slow down. It's a conscious effort to do it" (407-473)[N17] "I don't think I've changed at all ... I love my golf, go down the driving range. ... I'm aware sometimes, I've been digging in the garden and all the rest of it 'I think I'll stop now'. ... I went swimming this morning ... I do a length, 25-metres without breathing. And .. some days that's easy and I'll do eight or 10 spaced out .... other days 'no, don't like it this morning'. (317-325)[S01]			
"I went there once, to check after swimming once, I can't remember how many months, about six months, four months, five months that the thing was firing off properly ... so I went, and they gave me an anaesthetic and they tried it out and the shock was working" (150-153)[N11] "... I used to do up other houses; you know I wasn't afraid of working... I'd be very reluctant to lift up a concrete lintel which I probably would have done on my own before .. or a boiler hanging on a wall, I wouldn't do that now" (374-377)[N14] "I do swimming, I measure my pulse now, which I never used to do ... say after 20 lengths" (258-259)[N11] "That morning [of shock] I was on a double extension ladder, fully extended, right to the tope and I was doing some work on a fascia board and if I'd had know the shock was a severe as it was, I wouldn't have been up there. It would have thrown me off easily. [Have you been up since?] I have but not so high and with a safety thing on and all sorts of other precautions" (244-252)[S05] "I'm ok going for a walk, I'm building up now. I take a mobile phone with me, which is this area is probably more than useless really cos can't get the signals, so not really the best of things, but at least I got it there" (296-299)[S15] "... I do all the things that I used to do, hang out washing, sweep... go up ladders ... just be more careful... if I work, I make sure somebody's around, you know especially if it's manual sort of stuff, it it's only light stuff I'm alright" (102-111)[N12]	Protective Behaviours		
"We've swapped roles. I always did everything , you know he didn't even know how to switch on the washing machine ... I do what I can but I can't mop the floor or ... it makes me very tired to do stuff like that. So, he does a lot of cleaning and he learned to cook more. So it's sort of-we've split the role, if I can't do it, he'll do it. .... So the dynamics of the family have changed-he's looking after me more whereas I'd always looked after him.... he's very good 'you've always looked after me, it's my turn to look after you' " (683-694)[S23]	Re-assessing Role Identities		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"... it's very, very difficult for her ... she absolutely hates driving. She loathes it ... and of course she has to do all the driving now ... she hates the driving and hate being a passenger so it's not a very good combination" (367-375)[S15]			
"[it's stopped me from going abroad] in case something happens. Will there be people around who can help, will there be a specialist hospital somewhere, will there be someone there to, you know do something about it. Would I be on an aeroplane, you know 1000s of feet above the Atlantic ..." (385-388)[N17] "I think we've got a good relationship as a couple ... don't have sex often ... both a bit wary, bit worried ... to tell you the truth .... If anything could happen I suppose (are you thinking of shock?)... I do, but I don't mention it to Meg, cos I don't want to worry ... but I do think about it (shock) (263-278)[N14] "... I went to the hospital last week for a check-up with my arrhythmia nurse ... they wanted to check the machine [ICD]... when they put the one part over [ring], that was fine and they started to raise my heart and I said 'stop it! I don't like it'.... I tries to calm myself down cos I don't want it to go off" (300-313)[N16] "... I'm afraid I'm going to set myself off ... I'm afraid I could have an attack or have a shock, it will get too much for me that way ... I'm too afraid to go that extra mile, to stand my ground like I used to" (100-103)[N18] "We used to go out every weekend and we stopped doing that .... [why?] Well I had a problem with arrhythmia as well, about walking very far .. breathless ... Sometimes climbing the stairs is difficult cos I've put on weight. And my heartbeat was racing on and off. It was very unstable ... so it was like too much effort. And they I'd start worrying about would I be breathless, would I feel embarrassed you know" (435-446)[S23] "... Stress undoubtedly had affected me, and my son is having to shoulder it [family business] all now, which is still a stress. .... I haven't been in for 6-months now and I don't want to, which is a worry in itself because I've always been a Type-A person, get up and go for it" (215-220)[S01] "... before we've always travelled a lot ... we've been all over the world, and I would like to go to Israel but I don't feel confident enough to go. I think what would happen if I was ill over there? So, I stopped our plans for travelling long haul .... what if something really drastic happened, while i was out there you know? I know I wouldn't know anything about it, and it'd be someone else's problem but I just don't feel confident to go" (634-649) [S23]	Avoidant/ Restrictive Behaviours	Emotional focussed coping	

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"Yes probably [when asked if the shock would stop him from having sexual intercourse again] But because we're both 66 now, I don't think things are as important as they used to be ... there are lots of other ways of showing affection than ... having to .. complete the event ... I mean it was definitely that, there's absolutely no doubt, it was definitely that [sex] that caused it ... I think it would be very difficult to put that out of one's mind ... I mean if you knew one more drink would put you over the limit, you wouldn't have that drink, whatever the reason was" (265-387) [S01] "As I say, golf, I haven't played golf since this went off ...certainly initially it was the confidence thing. There are days when I can feel 'I don't fancy playing golf today anyway. I just don't feel up to doing things. .. the thing is, it could well be a kind of avoidance but it's bordering on the laziness 'oh I can't be bothered'. It's almost like a sort of depression, you know when you're depressed you just feel like doing nothing and it's that's kind of feeling in many ways" (300-325)[S15] "... We have a charity we support in Africa and over the last few years, we've been going ... to help with this charity.... We weren't going to cancel this until this went off and it's because this went off, we thought we'd not go ... we're not going ... where we go is a little island. By the time you get off that island, cross the water, get a vehicle the other side to take you to the nearest hospital- it's not much of a hospital, you wouldn't want to go there. You wouldn't even want to go to the toilet there let alone be a patient there ... the quickest is an hour and a quarter to get there ... Even after the ICD was put in, we still had it in mind to go there. It was after the shock, that we said no, can't go there, run this risk, not this time round" (515-534)[S15]			
"Cos it doesn't affect me see? Day by day I just-I do go days without even thinking about it ... I think I'm ignorant in a lot of ways. I think I should pay more attention but I just ...if (husband) wasn't there then I would have to think about it myself ... if I was on my own and I didn't have my husband ... he'd ring the hospital and he'd want to know the ins and outs of everything, he did. So, I think if it wasn't for him, I'd be scared and I'd want to know a bit more but ... left-I put it all on him, I have" (183-262)[N19] "Yeah, I have read up about it, but I really, I don't know if want to know about it truth like, does that sound strange like? To be quite honest, I still struggle with the idea of knowing you've got something, which alters your lifestyle, which there really is no cure for, you know what I mean? And I just think, maybe I'd be better off not knowing" (387-392)[N10] "I think I want to know [about ICD] but then I'll probably think 'do I really want to know that?' (553-554)[N16] "I had a booklet and I did look in the booklet and it did answer question. But at the time 'I just want to get through this', I didn't really want to know too much really ... I didn't want to read about it a lot, I wanted to know the basic idea but I didn't want to label myself	Cognitive Avoidance		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
as something awful... I tried to shake it off in a way I suppose, That's what I tried to do" (178-183) [N11] "... my wife being a nosy blighter, she reads them [doctors notes], and I'd rather not know ... Just get on with it, as long as it works ok, fine. If it don't work, I don't know what to expect .... If something is beneficial, that's fine, if it doesn't work, I didn't know about it anyway, so I'm not missing it, you know what I mean?" (239-249)[S13] [When asked if he had read the booklet on ICD] "quite a bit of it, the wife probably read more than I did. I'll be honest, I didn't really want to know what was going on, I got to be truthful to you" (415-416)[S13]			
"I'm not a worrier ... Probably my faith ... and that's why I said I probably wouldn't have had it done – I had it done cos of the family really ... more than me ... It's alright I don't even think about it to be honest with you ... very, very rare do I give it a thought ..When I have a twinge, I make it a little more comfortable, sometimes when I'm lying in bed, it's a bit uncomfortable, but apart from that I don't even know I've got it to be honest" (78-86)[N04] "Did I read it? (ICD literature) No. I'm terrible sometimes... Yes, of course I've read bits... I read before about the machine, I wanted to know what it did and I did all that, but I don't retain things... because I'm not interested" (336-339)[N04] "All of them had attacks or something like that like, so it was like a preventative measure (for me) like ... that brings me back to a sledgehammer to crack a peanut .. I just struggle with it.... "it's just there, I don't see the purpose of it really .... from a medical point of view, I can see like, but from a personal point of view, an emotional point of view, and a physical point of view, I'm really struggling with it" (71-108)[N10] "the only sadness for me would be to leave my family, you know .. Obviously, nobody wants to do that... but I'm quite happy when the time comes, and that really has been my attitude I suppose. I don't care what they put in... whether it's a machine or whatever it is, I'm going to go as long as the Lord kind of wants me to go and that the end of it, and I'm content with that" (325-330)[N04] "I think at the time, I kept it down and then it keeps popping up ... the shock of ... him telling me ... of realising my family might have it, my children, my grandchildren, so I coped by thinking, he might-he probably got this wrong, cos it made it easier ... [how long did you cope like that?] ... Oh I just kept it going cos it was easier. And if anybody asked I'd say 'oh well' you know, just get on with it, I'll be alright" (104-116)[S23] "Initially the only way I could cope was thinking 'he got it wrong, it couldn't be that, I'd better have this [ICD] just in case ... but it	Denial and Distraction		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
was disbelief really. And that's how I coped ... it were a shock but that was the only way I could deal with it" (77-87)[S23] "... we do talk things but I think the only way I can cope with it [shock during sex] .... was, I mean there's the classic old joke 'what a way to go!' so the expression is, which again is how I've managed to cope with a lot of these things ... I do prefer to joke" (297-305)[S01]			
"I have a faith, a really strong faith and I really believe that has kept me in good stead because I believe there is a time to be born and a time to die" (142-144) [N07]. "My faith makes a a big, big difference of course ... well, I know where I'm going ... the only sadness for me would be to leave my family, you know .. Obviously, nobody wants to do that... but I'm quite happy when the time comes, and that really has been my attitude I suppose. I don't care what they put in... whether it's a machine or whatever it is, I'm going to go as long as the Lord kind of wants me to go and that the end of it, and I'm content with that" (316-330)[N04].	Religious Coping		
"... But since I've had the ICD fitted, I'm getting a lot of trouble with my arm ... I'm saying it's the ICD that's causing this [pain] cos I've never had trouble with it before .. only since it's been inserted ..." (46-53) [N06] "... But I need to get back to doing my work for my own sake as well as the boys at work ... as I say, work has been great... they've been marvellous with me, but I'm just fed up just sitting around doing nothing .. it is boring and I need to get back to what I used to do before ... (397-401)[N06] "I wouldn't have had it, I would take it out tomorrow ... but they said they can't do that ... I don't think I was given the right information ... like with my father like, he was given the option 'ok, we'll do it on increased medication'. Now I'm on Atenenol 50 and he's on Atenenol half that strength... And they said they can do it on medication... but I wasn't given that choice, or I might ... 'cos what happened was, Dr EP he tried to convince me really ..." (112-124)[N10] "... I was always going to use that HGV license as a backup... if I wanted to get out of work and work 2 or 3 days a week... so my whole lifestyle had to alter.... I got to re-evaluate everything like ... I'm still working as I am like ... but that's not very good neither like ... I was always going to fall back on driving .. cos I love driving ... suddenly it's like somebody pulling the carpet from under your feet" (216-242) [N10]	Blaming and Venting		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"Disadvantages (of ICD) are I was going... well ahead in my career, especially at my age... I've achieved numerous certificates... To no avail now really 'cos I don't if I can get another job cos the way I feel and the defibrillator has to be renewed every four years doesn't it? ... if I'd be fortunate to have an interview with a college, I'd have to explain to them my condition, surely that would be a disadvantage, cos I have go this inser-insertion in me where if they were interviewing you, you haven't got one" (317-355)[N14] "I still get my moments when I think I can't cope with this anymore; I just want everything back to normal. You know, 'there's nothing wrong, I don't need this ICD' " (698-700)[N16]			
".. I thought maybe one of my blood vessels here had blocked up... they did all these tests, they said my arteries are pristine, which 'what a waste' I thought (small laugh)" (365-368)[N11] "I mean luckily I've never smoked and I've never drunk, so that baffled them for a start (laughs), 'cos that's normally one of the first things they ask ... 'Do you smoke? Do you drink?'... I said 'well I don't smoke, I don't drink, I don't drink tea or coffee so I've got no caffeine as such, you know ..." (356-360)[N08] "it was good to know that although I had a problem, if I'd also needed quadruple heart-by-pass as well cos I was all furred and clogged up-the fact that I wasn't, I've got you know, in very good nick, that was good you know. Yey! I'm pleased about that" (620-624)[S01]	Maintaining Self-Esteem		
"I mean when you got this stuck in where it is, I mean you can feel it so you know it's there, but I don't (think about ICD daily) ... because everybody seems to think .. and I've got it in my head, that I'm probably safer than everybody else now, because I've got it there ... when they said I had to have it, my first thought was 'well hurry up and put it in ... because I was afraid to go to sleep in case I didn't wake up" (67-75)[N08] "... like I've got a brother-in-law, he knows what his tablets are, he knows when he's got to have them ... you know what I'm trying to say? ... well, he's still walking around like an old man and I've had far more than him and I'm still far more active that he is." (341-345)[N04] "(I tell myself) ... well, I could be dead, but I'm alive ... lucky to be here is the end result ... I could be in Afghanistan, a child bombed for no reason... like that poor girl getting shot in London at her age and I'm 56 and I've lasted this long ... it puts things into perspective" (568-571)[N14]	Social Comparison		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"...I think the value of it is ... Knowing that I'm probably now in a better position that normal people are really ... if the same thing happened to Joe Bloggs ... say we were walking in some remote path ... the same thing happen to both of us .. I'd probably be the better off because I... got literally carrying around with me a paramedic ..." (277-286)[N03] " I was reading the paper .. about a woman, 30, she's had an ICD fitted. She's very fit, she's doing some marathon now ... six months after she's had it fitted she's training to raise money for the British Heart Foundation. You know, and I think 'oh my god, she's doing all these running and things ..." (365-370)[N16] "I've got an irregular heartbeat. And I'm told from the powers that be, that quite a few people go through life without having any problems whatsoever, named a few names, like Tony Blair and a few other people" (22-25)[S13] "Fiancée' started running when I started running and I should be able to comfortably beat her but she's leaving me behind, and that was worse in many ways. I used to go on the rowing machine and there was a competition and people had to put their results in. And I was pushing myself as hard as i could and I went to look at the results and they were probably half my age mind, but even so, I was way out of it. And I thought 18-months ago, I would have done that easily" (156-164)[S05] "I'm much improved .... cos when I first came out of hospital ... well I [had] left a truck full of stones round the back which had to be unloaded, chippings. Well I remember coming out of hospital and thinking 'well, I'll do that now, I'll make a start'. Well I couldn't do it. I just felt ... very faint, so I had to stop but I can do that comfortably now. So I've improved a lot since the operation" (178-185)[S05] "[I'm] concerned that it should go off ... We went to an afternoon meeting, seminar with the arrhythmia nurses and other people who had these fitted. ...And in the room of about 30, 40 people only one person had it go off you know ... So for it to go off is obviously unusual and a bit concerning really" (94-99)[S05]			
"Well just carry on with everyday life, and you're busy doing other things and forget about it ... I totally forget about it when I'm doing most things I do, even when I'm walking ... when I cycle around, I cycle fast and I feel 'yeah, I'm ok really' ... (404-407)[N11] "I still feel I'll never get completely used to the idea that I've got this thing really [arrhythmia] ... and this [ICD] is a permanent reminder of it but then it could have been lifesaving though so therefore be grateful" (141-418) [N14]	Acceptance		

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
“So, I think that then really was the underlying thing in my head you know, that running has kept you alive’ ... you got the fitness to get you back up again and you got to accept it and that’s it .. And I must admit I’ve never... never found it difficult to accept really” (157-161)[N03] “... I’m actually fine with it, and it’s [ICD] not changed my life at all ... I’ve not worried at all really about it and I can honestly say that ... that I have not lost any sleep over it” (141-149)[N07] “yes I think about it [ICD] but .. I don’t try and cover it up at all, it’s part of who I am and it just doesn’t bother me. I’ll take anyone’s hand, they’ll say ‘what’s that lump’ and I say feel it, you can touch it. But that doesn’t bother me at all” (68-71 [N19] “... As for the ICD, well I suppose it’s the essential friend, that’s the way I look at it... not sure if it’s a welcome friend but it’s an essential friend” (409-410)[N11] ‘... what I really felt was ‘oh well, they know best, they know best ... obviously if this is what I need [ICD] then I’m going to have it’ (102-104)[N03] “... He wouldn’t have told me I needed an ICD if it wasn’t necessary... so I was quite happy to have it implanted ...” (227-229) [N06] “I’m very confident in the surgeon’s ability and it’s amazing what they’re doing ... So I’ve got no worries about having the battery changed or any further treatment (421-424)[S05] “Oh, I’d give them a ten out of ten, fantastic really were superb ... I have nothing but confidence in the people who looked after me, so I’ve never been in a concerned state” (444-525)[S01] “Reluctance in the sense that you wouldn’t have wanted to have it [ICD] in the first place but an acceptance with an overview of thinking it’s there, it’s going to be an aid obviously .... you don’t want things to go wrong in the first place, so you certainly don’t want to have something inside you that is there because you’d rather it wasn’t there. I’d been living for 20 years after the heart attack, a normal life, I wanted that to continue but the fact this wasn’t going to continue ... it’s coming to terms-the actual coming to terms with didn’t take long ... [what helped you come to terms with it?] Resignation ... just resigned to the fact that it was there” (88-113)[S15] “And I kept saying ‘well, it’s just as well that they found out that I got it, so I can make sure my children and grandchildren are alright. And that was a sort of compensation thing for me. You know, they’d be ok, despite everything” (301-305)[S23]			

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"... What we've got here is an insurance policy and if the pacemaker itself fails then something else is there ... realistically it's an insurance policy" (227-232)[S01] "I have no concerns at all ... since it was sorted, and the euphoria of that probably hasn't gone away, it's still fantastic ... I'm better now than I've been for years .. it was a constant worry, worry, worry and now it isn't and won't be unless something goes wrong and it goes off for no apparent reason" (526-540)[S01] "They tried to explain it to me, if I didn't have it, it was basically a matter of time. Now I've got it fitted and hopefully everything works tickety boo ... this thing will effectively stop my heart accelerating to explosion ... if there was nothing to control it, it could race into a self-destruct mode" (146-152)[S13] "... From a point of view of peace of mind, it's good I got it ... I certainly feel a lot better mentally the fact that it's there. I know it's looking after me, if you like" (155-164)[S13] "... one of those articles I read said it was like having your own paramedic on your back and actually that is very, very true. Because if for whatever reason, my heart does go into some kind of rhythm and I'm accepting that that could happen anytime ... I've got this thing here to bring the rhythm back to normal ... the very fact it is there-it's knowing-it's a protective measure" (479-491)[S15] " well er, it's a good job I got it fitted or I'd be dead .. so I'm pleased in that respect" (93-94)[S05] and "I suppose I'm lucky to have it fitted really aren't I because I would be dead otherwise" (368-369)[S05] "It's sort of having a good friend I suppose, it's nice to know it's there. ..... The fact there is a bully in the cupboard just in case and he's on my side, that's nice to know" (354-360)[S01] "[when asked how he felt after the shock] No different really, in the sense that when things were going very wrong during the operation, whatever happened next was going to be better that this sort of continual worry that something was going to happen" (250-253)[S01] "... When this thing activated, it was like someone hitting me in the chest with a flogging hammer-that's the way I felt ... But I hope the only time I ever have a belt was that time. I wouldn't wish it on my worst enemy to be honest but it did the trick.... Now I know what to expect, yeah ok it's not the most pleasant experience I've ever undergone but now I've had it, I know what to expect and I know at the end of it, it's beneficial to me in some respects . It brings my heart back down to where it should be or puts it back to			

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	**1st Order Theme**	**2nd Order Theme**	**General Dimension**
where it should be and says he hopefully, prolongs life" (101-121)[S13] "Initially going around in my mind was 'what the hell is it going to feel like if it goes off'. Now I've had a belt, I know what's going to happen. ... I know what to expect ... if I feel that belt, I will know something was not quite right and this thing has kicked in and sorted things out for me, hopefully.... I don't particularly want it again if I can avoid it, but now that I've had it, I know what to expect as appose to being in a situation of the unknown. There's nothing worse than not knowing...... Well now it's happened I know what it does-it immobilised me, it knocked me back into the –it really did" (292-309)[S13] "... This device and the medication is looking after me and stop things getting worse but the stem cell trial seems to be able to improve matters, so I'm quite excited about that. It's effectively re-growing the muscle in the heart, they talk about a 5-8% improvement if it's successful and I'm assuming that's the initial improvement so you could probably have it done again couldn't you, and again and again" (190-196)[S05] "It [ICD] hasn't really affected me really. I just carried on as normal and the scar doesn't bother me at all... I think about it all the time but .. very rarely I get upset through thinking about it, I'm just lucky" (63-114)[N19] "... if I had another heart attack I'd be saved" (364)[N06] "Well (ICD), it's just a precaution much as anything else ... just gives you peace of mind I suppose ... put it this way, I wouldn't be doing too much, so it's allowing me to get on with my life .. because if I am out in the garden doing some gardening and (wife) is not here, and something happens, at least if I black out this thing's going to come in and kick start me, which will give me time to get inside and phone for her" (63-68)[N12] "I used to get lots of palpitations ... I went to the GP and she diagnosed that I drank too much coffee ... but what it really was , my condition, my Brugada ... I used to get these flutters and think 'Oh God, what's happening?' and it would get worse, maybe psychologically panicking .. Now I know, I think 'oh it's starting up again' and not think 'oh my God!'... I know what it is; if it got worse the defibrillator would kick in" (620-637)[N14] "... like I say, it's insurance, you've got it in case. Hopefully it doesn't have to be used but if it does it's there and it's got a job to do. Like I say, it's an amazing piece of technology." (651-653) [N08] "... I'm quite ... a positive sort of person. .. I mean when you get this stuck in where it is, I mean you can feel it so you know it's there, but I don't .. I've got it in my head, that I'm probably safer than everybody else (66-70)[N08]			

Appendix VI: Table of themes for patients

Raw Data Item: quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
".. It's constantly there ... I know it's with me now for the rest of my life... I am aware of it... but on the positive side, I'm not going to be taken out, specially not through my heart stopping " (672-679)[N14] "I just think I'm sorted now, now I got that [points to ICD], nothing else can happen can it?" (232-233)[N19]			
"... When I went back for my follow-up ... my daughter came with me because she was going to be tested and my husband was there. And they said are you alright about it [ICD?] But you don't actually want to say how you really feel, cos they [family] are worried enough as it is ... you know they got their own worries, so you got to feel 'oh don't worry, everything's going to be ok'. I didn't want my daughter-my daughter has got it [LQT], so I didn't want her worrying about it. So it was 'oh look at me, I'm doing fine, it's hasn't affected me really if it [ICD] comes to you, you'll be the same" (128-145)[S23] "It [ICD] saved my life ... but it's also changed things (cries) ... I tried to keep it down you know, thinking 'don't worry about it', you can't live your life worrying all the time, but then to say it out loud makes it more real then ... But I don't want to talk to anybody [what about a nurse?] .. no, no, you tend to keep it all in then... I don't want my family to know how upset I am about it, because I think they got enough to deal with, watching me you know" (586-613)[S23] "... everybody copes differently don't they. I was very-quite blasé and all-people were say 'how you coping with this shocking news?' 'Ooh don't worry, I'm alright take it as it comes ... get on with it, that's what everybody got to do'. But inside I was quite scared" (297-301)[S23] "I think we've got a good relationship as a couple ... don't have sex often ... both a bit wary, bit worried ... to tell you the truth .... If anything could happen I suppose (are you thinking of shock?)... I do, but I don't mention it to Meg, cos I don't want to worry ... but I do think about it (shock) (263-278)[N14]	Concealment		

Appendix VI: Table of themes for patients

Partners (Hierarchical Development of the Raw Data, First Order, and Second Order Themes and General Dimensions)

Raw Data Item: Quote, line numbers, participant	**1st Order Theme**	**2nd Order Theme**	**General Dimension**
".. He don't remember nothing but I remember it all ... remember it all ... he was just on the bed ... pumping and pumping ... shocking him, pumping him .... And the doctor said 'you're a very lucky man' he said 'If your wife hadn't phoned that ambulance, you would not be here'... But he can't remember nothing about it... nothing at all. The only thing he remembers is waking up in hospital. Two weeks it was, you know, for him to come round" (12-131) [N06.1] "... I've actually said to her 'you don't know anything about it', she was out, she don't know anything about it. When she woke up she was in hospital and she doesn't know about anything's that's happened. I find that really strange, although it happened to her, the trauma's left with me.. " (601-605) [N19.1] "... my daughter, she turned to her little girl ... 'go and wake Dadu up' ... 'NO!' I said ... 'well he's been up there a while on his own ... and I'm petrified ... cos a lot of people have said 'you have a heart attack, you gone' when I see Sam on that [hospital] bed, there was nothing .. and I don't want my granddaughter to see it' (103-109) [N06.1]	Traumatised by cardiac event		Emotional consequences
"... we were going to bed and he was getting up and he was making heavy breathing .. and I thought 'what's happening, something's happening' .. but it wasn't, he had a blocked nose, that's why he was breathing funny ...I was upstairs cleaning and she [daughter] said 'Mammy you better get down, Daddy's not very well' ... and I thought 'it's a year now, oh no, not again ... here we go again' And that's what's in my mind .... You fear the worst, it's constantly ..." (312-325) [N06.1] "That's always the problem, cos any minor illness, well not minor illness, any illness ... any symptom, you attribute to something going wrong .... before the device had been fitted ... if you were ill, you were ill. But now if you're ill, is there an underlying reason why you're ill? And should I be doing something about it ... I feel responsible and that's my biggest bug bare really. I'm afraid of making the wrong decision. Or not making a decision when I should be making a decision" (269-284)[N17.1] "... 'She's [wife] is under the impression that she doesn't need it [ICD] cos she feels fine now. But like I said to her 'you went 28 years feeling fine', there's nothing to say that it won't happen again and .... I just say 'at least you got this thing and you'll be fine' .... some months I go without even thinking about it [ICD], and then at other times, I think well, especially if she feels unwell, you start thinking of it even more then" (147-149)[N19.1]	Anxiety and Fear of repeat cardiac event	Anxiety and fear	

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
“Sam he say to me ‘oh don’t be silly, don’t be silly, it’s not going to happen again’ ... but it’s on your mind and it is constantly on your mind “’ ‘well is it going to happen again’ ‘what’s going to happen’ ... it’s there ... you’re frightened the heart is going to block again” (235-243) [N06.1] “I have been concerned for a number of years that something might happen. ... so if he stood like this (puts shoulders and head down) then I would ... begin to worry that something was occurring ... so I used to worry and I probably still worry at the moment that something is going to ... Well I suppose I worry that the thing’s not going to work ... I’ve been worried for such a while .. about these funny turns he was having. So .. I think when you’ve been doing that for a few years, it takes a little time to ... probably calm down about it.” (126-190)[S01.1] “...the first six months I was like, I was so scared, every time he felt dizzy, I thought he was going to collapse on me or die. I’d be like a cat, you know, if he said he felt unwell, I could feel my whole nervous system kicking in, adrenalin, and I’d be so anxious” (229-232)[S05.1] “it can’t be cured, it can be controlled with drugs to ensure the heart doesn’t work too hard ... every patient’s different, you know some patients improve, some don’t, some deteriorate quite rapidly, and the prognosis of the disease is very different between people ... so you never know how things are going to pan out” (137-142)[S05.1]			
“... with his running .. he’ll always tell me where he goes, take a mobile phone with him ... but he did go running a couple of months ago and didn’t have anything on him at all .... I wasn’t too pleased when I found out he didn’t have a phone on him, he’d changed the route he’d told me he was going to go ... and it’s just little things like that ... it’s ... It’s always there ... don’t live with it day in, day out, but you’re always conscious that he’s got the defib” (254-261) [N03.1] “... and that does worry me, that if something happens again that somebody won’t be around to-it does help the ICD is there [do you trust the ICD], no, I think the biggest problem is that I tend to look stuff on the net and stuff like .... so you don’t always trust ... I know they have got a very good success rate but still they’re not ...” (113-122)[N19.1] ‘.. it was difficult in the beginning to get the confidence and ... not understanding what it’s there for but what if it goes off, what’ll happen then, what .. what .. you know, how’s he going to feel, when is it going to happen ..’ (224-227)[N03.1] ‘... you’re just conscious that if something does happen .. or what will it be like if it does happen .. what effect with it have on him	**Anxiety and fear relating to ICD and shock**		

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
and stuff like that ...' (266-268)[N03.1] "... yes, because it's [shock] not going to be very nice is it .. and I don't want to hurt him and I don't know where we got this but it says somewhere in those little books, that I may be able to feel it if I'm next to him in bed. Wouldn't quite fancy that myself. And I don't know how I'd react if it went off ... and then I think well you don't need to think about that, cos it hasn't gone off" (427-433)[N14.1] "Given that we've been told that inevitably something is going to happen. She's got a 30% chance of it [shock] happening this year ... So, then you start thinking, well the odds are that something's got to happen eventually, you know. ... you're almost waiting really for something to happen in time. .... I think it has certainly affected us ... made us think about .. how we live our lives and what we do. ... I'm not overly happy about 'wife' being on her own, cos the whole idea of this ICD is that at some stage this it going to kick in" (108-133)[N17.1] "You know we've been told that it's going to be a big wallop across the room and you just want to be there when it happens. ... I try to increase the amount of time I'm with her .... [Who told you wife could be blown across the room?] 'a nurse' ... The idea is-what happens is when this thing kicks, it could blow her across the room or something. ... Well perhaps I got it wrong, but I got the impression that when it does go, it's like a punch in the chest (smacks fist against hand), which in many instances could knock her-knock her down and frighten her- well they said it would be frightening, cos it would almost be like a punch in the chest" (134-154)[N17.1] "... when it actually went off, whether that was because the heart was feeling a bit stressed, I don't know, but when it went off he was doing nothing, which is a bit daunting. To be thinking well, you don't have to do something for your heart to go in the wrong rhythm" (61-65)[S15.1] "I knew it would kick start it back to life. But ... wasn't quite sure what the procedure would be from there on ... the worry was, what happens next after the box went off ... what to do when the box goes off. We had no .. didn't know what to do" (54-73)[S23.1] "And I remember for quite a few months I was worried about it going off 'would it go off when I was next to him? Would it go off when we were in bed? How would I react?" (294-296)[S05.1] "He had two shocks before Christmas ... [how did you cope?] Not very well, I wanted to phone the ambulance, I was scared, afraid"			

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
(57-67)[S05.1] "He had sustained VT again, which led to the device going off. So, it's doing its job, which is a good thing, but I guess also. .. when it happens, it makes me more anxious about 'husband' dying ... thinking, he nearly went then, what if it doesn't work properly sort of thing" (104-108)[S05.1] "... but because 'husband' described quite well how he felt before it went off, certain times he's felt unwell recently, I've thought is it going to go off .... [what do you do?] just be quiet for a while and see what happens, sit down, relax until he feels better again. It's like a dangling sword hanging over you waiting for it" (324-333)[S05.1]			
"Since we started going to the EP, each realisation has perhaps brought us closer together, the fact that his heart is wearing out, that's what they basically told him from the beginning, his heart is wearing out so perhaps each individual step has brought us closer together ... not just the defib ... it brings an end to everything" (171-180)[S13.1] "It's [shock] like a reminder that he has got a serious condition, it's more of a jolt in that way.... So, when it goes off, it makes you more aware of his mortality, that's it's a life threatening condition" (128-133)[S05.1]	Shock of Mortality		
"... the only thing I would query, well not query, is the afterwards. You come home and you're on your own basically aren't you .. I'd just carry on and cope and then if I got a real question, I would ring them and ask them. But I did feel-it's like a cut-off, come home from hospital isn't it, you just got to get on wi-with it .. [what would help?] Perhaps a visit? I don't know" (127-149)[S13.1] "... they [surgeon] put one in then you go, so it's kind of, you know, the consultant said 'right, you can live a normal life now, you're fine, off you go, kind of thing. It was all a bit kind of brusque and dismissive almost" (291-293)[S05.1]	Feeling abandoned/Ill-equipped		
"... he was running along the Taff Trail ... on his own ... nobody around and I .... you talk to people afterwards who live along the Taff Trail or walk along it quite regularly, and they say they do find people just drop dead ... on the trail, and I'm thinking that could have been Tom and I'm thinking you knew of it, so why haven't you contacted us before now', you know. So, I was frustrated and annoyed more than anything" (67-74) [N03.1] "I'm really glad he's got it [ICD] ... the only thing I'm not happy with is the fact that it could ... you know ... it could have happened	Frustration and Anger	Frustration and Anger with the NHS	

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
in those three years when he was being seen by an Electrophysiologist.... If the doctor tells him something, he thinks the doctor knows what he's doing, and a lot of people are like that. And although I'm not saying they didn't know what they were doing ... they weren't on top of the case" (206-221) [N14.1] "... We were quite happy to have it [ICD],... I said 'right ok, how long is this now, just a couple of weeks?' 'On dear me no, not till January'. I said 'excuse me, you've just told me that without this device you know ,, in so many words, he's not going to last?' 'Yes, well you know, we've got a list'. I wasn't happy about it and said 'you know, I don't think this is right. You're telling me that he needs this and he needs this as soon as possible and you're saying three months'.... he's worked in the pit and you know, he's paid in all his money, why shouldn't we have had it straight away, that was my belief anyway" (70-91) [N04.1] "They should have warned us a bit more ... well you know, 'you might feel worse cos of what's happening in your body and this um ... device. ... You know if they had said you might feel quite poorly.... like your appetite and stuff like that might go .. they didn't tell us any of that and the literature doesn't tell you any of that that either.... I would recommend it [ICD] to people, but rather that they know it doesn't work (straight away ... 'cos it was horrendous ... with those noises in the night, you know, we did not have a good night's sleep for about six-months" ((544-569) [N04.1] ".. I'm disgusted 'cos they probably could have found out before his heart got so weak ... We didn't find out till it was chronic heart failure .. We should have found out long before that but we didn't ....it wasn't until he couldn't breathe, they had to rush him in .. I thought I've seen this coming on' .. but I didn't know, I didn't know about it. So it could have been caught a lot earlier, so I mean I'm not happy about that ..." (49-62)[N04.1] "... they didn't come up with .. the diagnosis ... I feel quite strongly ... maybe I'm being hard on the doctors, maybe it was difficult to diagnose ... It was quite worrying. Because I went with him to one appointment .. I can remember saying to the doctor ' .. he's having – what do I do when he does this?'... It was a worrying experience, very worrying, so it was really 'oh, he'll be fine, he'll be fine ... I was told .. it wasn't a problem. You know, 'let him relax, he'll be alright after a while'. ... Looking back on it, I'm probably more angry about it now, I mean it was very concerning every time it happened because it wasn't a very nice experience" (41-102)[S01.1] "I'm cross that he didn't have one earlier actually. You know, a couple of years ago, he should have been having it. But then you know, it's his fault as well .. he was convinced he was stressed by work ... I think perhaps that masked the [symptoms] ... so maybe it's not the doctor's fault" (369-376)[S01.1]			

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"it's a bit fractured I have to say, cardiomyopathy treatment is quite strange ... I would have thought you have a patient, get them on an ICD, stabilise them and then investigate what the causes are and go from there. There's two reasons ,,, it's good to be done early, secondly if it does look like it's genetic ... Husband has two children from his first marriage and they could .. be carriers of those genes .... so it does seem to be a bit haphazard the treatment I find .. I get frustrated, I feel not enough information is given to patients" (162-177)[S05.1] "We've also got a lot of worries about [daughter], to think there's a 50 percent chance that [daughter' could have what [wife] has got. ... well they said the only way to tell is a DNA test, which there is no funding for and I said well I'll pay for a DNA test, and they said you're not able to pay for it. And I thought what type of crazy place are we living in ... it just doesn't make any sense to me ... they got a way of possibly preventing something with [daughter] .. but yet there's no funding for it ... it just doesn't make any sense whatsoever .... and it is annoying cos there is something they can actually do but they don't" (655-680)[N19.1] "I suppose it's like a murder mystery, you want to know where it's come from .. like his mum has died, put down to pneumonia, but could she have been the carrier? .... When I think, if they could just pick out that gene ... then the whole family, not just our family, but the whole family then could be tested and it would be 'yes, you've got it' 'you haven't' type of thing, you know. So, it's that uncertainty and what's in the future type of thing" (664-683) [N03.1]			
"I've tried to explain, 'no, you've got a better bloody chance than we have because you've something to trigger your heart back .... And I don't know how to explain, I can't get through [how does that make you feel?] .. very frustrated. You know, sometimes I just got to go out and take a walk and calm myself ..." (74-86)[N16.1]. "... she's a lot slower than what I am now [post-ICD]. Where I had the problem with arthritis and a bad spine ... it's all changed ... And I say 'come on! You should be jumping over your bloody head, you're six years younger than me" (88-99)[N16.1] "I really do thing that sometimes he's you know, just feeling a wee bit sorry for himself. ....If I had something, to be honest I'd just be glad somebody had saved me. I would have loved my father to have had it [ICD]" (260-265) [N10.1] "I think we're very lucky, very lucky you know ... We've perfectly healthy children, grandchildren. ... When he [Steve] worries, it worries me, 'cos I think that's like a strain ... that why I get him out of it quickly, if it's 4 o'clock in the morning, 2 o'clock, he will lie awake and stress himself out and things get worse .... If we chat for half an hour, he'll be snoring within 5 minutes an... And he'll be like 'oh thanks Mary for that', and I'll be like 'it's the truth Steve ... I've just told you what we actually have'.... I always think the	**Frustration and Anger with the Patient**		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
worst thing that can happen is something happen to one of the children" (277-297) [N10.1] She still has nightmares, we've got to separate the beds ... she's frightened of dying, she thinks she's going to die .. she was violent in bed .. she was sleeping and she was kicking and punching me and I said 'I can't cope with this ... but even though we're separated now, she still keeps me awake most nights .... . and sometimes she'll be crying in her sleep and then she'll wake up heavy breathing. I've got to wake up and sit with her, calm her back down, 'breathe normally, you're alright, nothing's going to happen, you're fine' (45-184)[N16.1] "The only thing I had my hair off in the beginning and it's a bit worrying now ... she won't [apply for] disability. ... Well while she got the ileostomy and it's the pacemaker and defibrillator now and she still won't [apply for] get disability allowance ... I know [people] and they get it, her sister's got an ileostomy, she gets it. She won't appeal cos she's worried about people knowing [about ICD] (285-291)[S23.1].			
"... we don't do as much cos 'husband's always tired ...I get a bit bored. You know, I wish we could do a few more things but I understand. I'm understanding that husband doesn't want to do it cos he's tired. It's his work you know ... and I say perhaps we ought to look at what you do ... and think about doing something else but he can't, he loves it. I think if he stopped doing what he enjoyed, that would be it ... that would take away any kind of purpose in life .... it would just be nice to do more things I guess" (506-525)[S05.1] [How did shock make you feel?] "Cross initially ... you know, flipping heck, that's another 6-months he's not going to be able to-to drive ... I wasn't worried because he was-he was fine" (150-153)[S01.1]	Frustration with the situation		
"... We had those booklets the time before, before we actually had the ICD was fitted ... I still carry it around with me now .. cos if I think of something or I want to show .. th-that's what helpful as well, I was able to ... cos it was in simple English, simple drawings (704-707) [N03.1] "... at the time I thought that it (relationship with partner) possible could change, hugely ... and then when I read up on ICDs and all that, then I reassured myself .." (64-66)[N14.1] "... I've nothing but positive things [about the ICD]. Cos I've read up" (130-131)[N10.1]	Becoming Informed	Problem-Focussed Coping	Coping with the ICD

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"I'm a sort of information gatherer, if something's happening, I'll want to find out everything we can about it, which I found pretty difficult when it came to this ICD" (167-170)[N19.1] "... we do have .. my daughter's a doctor, my son's a dentist .. you know, I think they also .. they are aware of things as well, we can always ask them 'can you find out ...' you know, if we didn't know, they were very helpful" (220-223) [N11.1] "Well I ask a lot of questions ... the nurse was good ... she explained about the box and this and that and you think 'right, ok that's what you do .. but you still worry ... I'm frightened in case I don't do the right thing" (284-305)[N06.1] "...also I read a hell of a lot. I researched the hell out of cardiomyopathy, so read lots of papers, went on the cardiomyopathy site, went to forums, saw how other people were coping. And I realised by reading other people's experiences, this was normal ... the experiences and symptoms they had were what 'husband' had, so it's universal for cardiomyopathy sufferers" (239-243)[S05.1] "... certainly knowing things were normal kind of took away my fear. I think everyone who has this [ICD] is different and you have different relationships but it's kind of understanding they are going to be tired all the time, feel dizzy. I ask 'husband' to describe how it feels ... and you get to know your partner. After eating husband always felt more dizzy, more tired, so these things, you kind of pick up cues from your partner and as I said because I research, it got me a bit more relaxed" (267-275)[S05.1] "My coping is I've got to know everything inside out ... I need to know things" (359-366)[S05.1]			
"... I'm frightened, I don't sleep .. because I'm watching him all the time ..." (90-91)[N06.1] "when she first got home, I was still a bit ... I do actually check her occasionally, you know, prod [her]..." (25-27)[N19.1] "... I like him to go with the phone ... he goes to work every day and in between 10 and 12, he'll phone me ... Well if I don't hear from him, I panic .. I'll worry, I'll phone work and ask them 'is he alright?" (376-380)[N06.1] "... the worse thing is when he's in bed and he goes to move 'urgh' and then you get the noises you know 'oooh' 'aargh' and I panic then. I say 'is there something wrong?" (209-211)[N06.1] " yes [I ring her] to see if she's alright [every] five minutes, 10 minutes ... cos it's a worry. Even when she goes to the toilet ... now	Monitoring Patient		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
and again she's out there changing herself [stoma] and I'll go and say 'are you alright love?" (96-106)[S23.1]			
"For Christmas I bought him a dog-tag (laughs). A heart-shaped dog tag, he'll kill me for it I know ... his name, ICD, and a telephone number ... " (251-253) [N03.1] "I've bought him a jacket, and trousers and I told him ' you're not going (fishing) unless you're warm'. So he's had new waterproofs and I've bought him tidy boots for him to walk .. as long as he takes his phone with him .. it's just that little phone call, just knowing .. puts your mind at ease" (413-424) [N06.1] "I'm not overly happy about [wife] being on her own, cos the whole idea of this thing is that at some stage this is going to kick in ... so I suppose what I try to do is try to increase the amount of time I'm with her, rather than leave her on her own" (132-139)[N17.1] [How do you feel about leaving wife on her own?] "Oh, very, very wary. If I do go up the shed, I got some old cars up there, I like to go and play with, but we got walkie-talkies ... if I go up the shed for anything, even to get a stick of coal, I take the walkie talkie with me, so she can press the buzzer if she wants me like" (88-92) [S23.1]	**Protective Behaviours**		
"... And I was think there was a bit of 'crickey, this is my big, strong boy and he's supposed to be looking after me' and he has always looked after me, very well ... and the tables have turned you know. That was quite hard to come to terms with .. that was- although I would always look after him .. It changed my whole perspective on our relationship" (55-60) [N14.1] ".. We booked a caravan holiday and Tom wanted to cancel it and I said no, and that I would tow the caravan .. Petrified of doing it, but I did it .. and cos I remember saying to him, what if it happened when we were away? You know, how would I get the caravan back. It was six-months of learning for both of us ... you know, I can do things as well as him, and he can do things as well as me, type of thing" (736-742) [N03.1]	**Re-assessing Role identity and control**	**Emotion-Focussed Coping**	
"... we have come a little bit distant at times ... emotionally and physically. Physically more I think, first of all it was fear, not so much now. I know straight afterwards I was very worried about .. triggering it " (267-275)[N19.1]	**Being cautious**		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"... [has ICD affected your relationship?] yes, sex wise I was frightened to-to have sex, in the beginning because I thought all the excitement and everything is going to trigger the ICD off. But the Arrhythmia Nurse put us straight ... She said you're quite safe to have a normal sex life again. Cos Jean wanted sex all the time, and I was-I push her away... We're not back to normal but more sex, I have more of a sex drive than I had at the beginning, I was frightened to do anything" (526-545)[N16.1]			
"I think what has helped is that we've continued to go to the support groups ... the support group is there for that type of thing you know, for people all in the same boat and you've got the partners there as well and you're just generally trying to help each other with that little bit of support .. and 'it's not just m me.... I found them (support groups) very use-.. very, very good, in that it gives you that little bit of extra knowledge ... learning and listening to other people's experiences has given us a bit of .. confidence ..". (146-177)[N03.1] "... because I was always with him all the time, I felt I was constantly baby-sitting or watching ... make sure he was alright and .. you know, when he said he was going back out running and what have you .. it was 'Oh God! Is he going to be ok?' But because I've taken charge making sure he's got his tablets, I feel .. I-I'm in control as well as him, type of thing ... So I'm doing my little bit to make sure he's safe and ok" (240-246) [N03.1]	**Seeking reassurance & control**		
"When he came home from hospital ... I didn't cry in front of him .... my youngest son, he was with us all the time you know ... and he was on the phone all the time ... so I used to tell him how I felt ... I was crying all the time ... because I could see nothing was happening ... it was getting worse .. it was just really traumatic really" (181-190)[N04.1]	**Frustrated Venting**		
"We never talk .. Well, we talk about ... we laughed about it when he first had it done but I think as time's gone by .. it's a year now ... you just don't put it into your life .. We don't 'oh don't get him worked up, he might have a shock'... we don't do any of that" (258-262)[N04.1]	**Denial**		
"... luckily he's got a healthy heart, yes, well it's the electrics that-he had no clogging, his arteries were-didn't have any problems" (72-78)[S01.1]	**Maintaining self-esteem**		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"'Husband's cardiomyopathy, he's coping so well with it ... he does a lot of active outside work and even though he might be slower than he was ... he can still do it, which we've been told is fairly unusual. And we put it down to, he was very very fit before he had the attacks, he used to play a lot of rugby and to his mindset 'I'm not going to be beaten by this'" (181-193)[S05.1]			
"... I don't really tell 'husband' about those [fears of him dying]. You know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful" (116-118)[S05.1] "The defib's wonderful fair play .... There is an element of worry with it. I don't tell the wife to protect her more than anything. She'll say now and again 'you worried ain't you? 'oh yeah, a little bit' but I play it down" (350-357)[S23.1]	Concealment		
"...we don't talk about it [cardiac arrest] now, you know, that's gone and finished. To be honest I don't really think about it now, the fact that she's got this fitted now is a sort ... it just doesn't come into my head and we carry on as normal ..." (50-53)[N08.1] "... she has come on since she's had it fitted, really, really well. She's a different person. If you'd seen her before her op, she was constantly pale, tired and drawn. Basically she looked like death warmed up like but when she had this done, I say even from the first day she home from hospital ... but the difference in her ... she was back to the old [wife]..." (123-129)[N18.1] "I think we're both sort of ... calm ... we deal with things, just get on with it really. ... I think in the early stages of these things, as with anything, you realise you're mortal ... And you somehow have to cope with that ... and then you have to get on with your life because ... that's what you have to do, isn't it ... so, we're both on medication for life" (260-272) [N11.1] "When he had the operation and we know it was in then everybody was relieved. ... it was as when he didn't have it and we found out he had the-the disease ... I was scared, I had sleepless nights, I was really worried, scared, you know checking on his breathing ... I would have nothing negative to say about it [ICD], it's a great thing, it's a great thing, 'cos it's given him a life" (362-370)[N10.1] "We just had a minor concern because his device seemed to be quite raised in his chest ... [but] the fact that it is doing the job that it is meant to do ... and it's keeping him with us ... so anything else is really so secondary that we didn't even think about it" (131-139) [N12.1] "I am happy, I am so pleased that he's got this thing [ICD] ... I mean he could be in the situation that he had something like this	Acceptance		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
[Brugada] and there was nothing they could have done about it, so great!" (509-512) [N14.1]			
"... well it gives me some peace of mind because the day that this thing happened to him I was at work, and I had to suddenly come home from work ... and call the ambulance. And we were grateful that he survived that initial attack and that he has gone to have something ... have the device put in, which is not hindering him in any shape, form or fashion ... it's really not interfering with our lives in many ways .. it's not." (97-103) [N12.1]			
"..... It's a person . .. it's a 24-hour paramedic .. it's there to save his life if it needs to go off' ... we call it CID, that' the only way we can accept it ... it's just an extra member of the family ... he's there as a 24-hour paramedic" (118-135)[N03.1]			
"I thought a lot about you can't change your life to a great extent over something like this and him having had the procedure probably the best thing for him was to walk. Because even if something else got him, it wasn't going to be that [Brugada]" (334-338) [N14.1]			
"My son was asking in the car what you were coming to see us about, and I explained to him about Daddy ... and God love him, he says 'but Mammy if he had a heart attack, that saves his life', and you know ... I said this .. is the basic honest truth" (41-44) [N10.1]			
" ... they (the surgeons) said it might happen again, but if it does then she's got this (ICD) and ... I'm not worried at all ... I just feel confident that if should something happen again, then, you know the device is there to shock the heart back ... " (64-77) [N08.1]			
"... I feel confident now that if anything happens, this is there and you know will put it right until we get to the hospital, and that's what it's there for. Wish I had one!" (303-305) [N08.1]			
"... it's more my peace of mind, cos I am .. I'm frightened, I don't sleep .. because I'm watching all the time .. 'boy' I said 'when you putting that box (ICD) in, you're putting my mind at ease .. I know if something happens to his heart, that will shock him and I know something's happening" (89-94) [N06.1]			
"... if she has a cardiac arrest, it will keep her going again ...." (153-154) [N07.1]			
"I'd be ok about it [husband running a marathon again] ... I think now he's gone the full twelve months and nothing has happened, and .... I think you've got to think of it as well, it's been picked up, he's safer now than when he did his first marathon in which he could have dropped dead on the spot" (351-357) [N03.1]			

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"I was just very, very relieved with he finally got it sorted. I feel safe ... I just feel safer with it ... I feel happier now it's done" (186-196) [N14.1] "And I think there's a sense of security too, that he's still being monitored ... although we're not aware of it in a way ... you know, we have the little device at the side of the bed, the little box. ... And that in some ways gives you a sense of security that somebody is monitoring it, even from a distance" (107-114) [N12.1] "... I'm just glad he's not going to have a cardiac arrest anywhere I'm going with him ... and he's going to be alright ..." (349-351) [N14.1] "Since the box [ICD] has gone in, I've mellowed. I think well that box is there ... to me it's a lifesaver .. That's the way I look at it ... that's the way I look at this box ... it's mine and his life saver. That's how I feel ... well, that in there, that'll give me notification that something is not right with his heart" (430-437) [N06.1] "I've had bad nerves ... my brother .. go back three years ago, he hung himself in my mother's house and I had to cut him down ... so of course, now I panic, I'm terrible ... I panic terrible ... I had my brother then I had Sam who had a big, massive heart attack. So, I had two people dead on me that I couldn't understand so, this box to me, is my lifeline. I know he's got it in there and it's going to show if anything's going to happen" (201-208) [N06.1] "... to me that's the only benefit (reassurance), that's all that matters, it's our insurance policy. There's no other tangible benefits, but I mean what other benefits do you want? That's the only one you want isn't' it, she is no better or worse than she was before, it's just reassurance, that's the only benefit isn't it?" (107-111) [N08.1] "And I'm just very thankful that they did find it and they done it 'cos now ... you know it's more a mental thing that we're going though rather than a physical thing.... You know, I'm not concerned at all about his physical well-being ... because he's got this thing [ICD] now" (69-71) [N14.1] "The feeling that I've been given is that he is much better protected now than he was before, so therefore that's got to be good. So, I think you've got to from the initial being diagnosed then you've got a period of being worried about it all, and then you get through that and hope that everything will be ok" 385-390)[S01.1]			

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"I think we're just looking forward. And I mean none of know what day we're going to die do we? ... I think the ICD is going to be fine, stop the rhythms, you know, get him back if it goes wrong" (257-261)[S15.1] "Very relieved ... obviously when they thought he might need it [the ICD], there must be a good reason ... unless it [ICD] went off, what would we have done? ... Although he's got it, psychologically for him and for me, you're aware there is something in his chest. Well you're just thankful I suppose that it could go off, because it needs to go off" (36-49 [S15.1] [What changed after six months?] "...I got used to it, that's all it was, just got used to the fact he was dizzy and what it meant. It didn't mean he was going to collapse, it was part of his treatment" (237-239) [S05.1] "I've known 'husband' more with the ICD than I've known him without it, so it's get-you kind of get normalised don't you?" (525-527)[S05.1] "I've got used to it now, I don't even notice it's there cos it's part of our life, it's there, I've grown used to it" (282-284) [S05.1] "With the defib fitted, we were flying abroad, we were planning a couple of holidays ... and we got the motor home, so he was driving, we were going places (201-203) [S13.1] "I think the ICD is nothing but positive. You can't get away from what you've got can you? You've got to be thankful you've got a device that can-it's ridiculously incredible!" (322-324)[S15.1] "I think the defib is great really, yes, that really is amazing. To me it's a lifesaver ... so yeah, I think it's excellent" (272-274) [S13.1] "... It's all about living, living with what you got isn't it? You know, living each day ... It's getting off negative thoughts ... just living each day and getting on with it and thanking God for such a device. Because 20-years ago, he probably wouldn't be here. So, it's amazing really" (267-272)[S15.1] "Well it's reassuring if she does pass out, it will kick her back to life" (195-196)[S23.1] " ... 'husband' has described it being punched in the back very hard. I guess one thing is that it works, which in a strange twisted way is kind of good. It was there to do the job and it did the job, so that makes you feel safer in some respects" 321-324)[S05.1]			

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
"He's still here, otherwise he wouldn't be" (114)[S13.1]			
"We are Christians and we do believe ... we believe that it's the Lord that done it [tested him through illness] 'cos we just feel that he was so, so bad that it was only the Lord that could help him. ... I mean obviously he's still got the weak heart, and he's always going to have unless he gets a transplant or the Lord gives him a new heart" (191-196) [N04.1] "... we just take in our stride and thank the Lord that he's still here at 68" (342-344) [N04.1]	Religious coping with Illness		
"I'll be honest with you .. I put that [shocks] to the back of my mind, because ... if I thought about it .. I don't think I would cope ..." (256-257) [N04.1] "... ... When she started working in the shop, her husband put her down ... and then when she got out of that marriage and came with me ... they offered her the Assistant Managers[job] and she was like 'on no I can't. And I say why can't you do it? Go for it, the sky's the limit, you can do anything you want to .... And that's the same in everything, the ICD, I don't want to know the negatives about it, if there is any, ... All I want to know if the positives" (323-331)[N16.1] "The thinking is at the time, we didn't want to know ... too much you know, ... because ... I mean when me and my son went in, we listened to the doctors ... you sort of look at each other and think, they're not saying .. that it's so ..'You can go anytime' she said. You don't want to talk about it but that's how we felt, that they were in so many words were saying to us (409-414) [N04.1] "... the nurses .. they're very good .. but I do think they give them so many books to read .. and books make it for me more worrying, because there's too much information ...don't ask me to say an example cos I've not looked at a book, one of those booklets. They've gone away [books have been put away]... We're getting on with our life. He has been told .. he's to carry on as normal. So, if there is something he shouldn't do or can't do, we would be told" (244-280)[S01.1] [when asked if she thinks about the shock] "I don't think. I'd worry too much" (99)[S13.1]	Cognitive Avoidant coping	Mixed Avoidant Coping	
[To stop worrying] "I'll have a glass of sherry in the night. But I can't have too much in case I got to driver or in case something	Behavioural		

Appendix VII: Table of themes for partners

Raw Data Item: Quote, line numbers, participant	1st Order Theme	2nd Order Theme	General Dimension
happens like ... But I know when her son is home, I might have .... a bottle of sherry a night ... I'm quite alright after drinking a bottle of sherry, I like I don't get 'fall-y' over ... I can't afford to get 'fall-y' over in case something happens" (124-139)[S23.1] "We've refrained from it [sex] for the moment so that was probably about three weeks ago now... I think knowing he had to stop four weeks driving again might stop 'husband' ... We sort of laughed about it ... but that's where its stayed at the moment ... [refrained from sex because of risk of not being allowed to drive not because of shock?] .. yes [driving] ... it's happened, I mean he had one [shock] ... I was quite close to him and I felt it and ... that's fine ... I say it's fine, but it was no big deal and I think it was a worry for 'husband' really, not for me " (298-312)[S01.1]	Avoidant Coping		

Appendix VII: Table of themes for partners

Study Title: Psychological Coping Intervention: A Randomised Control Trial for Implantable Cardioverter Defibrillator Patients

A Study to Compare Booklets – Patient Information Sheet

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have.

What is the purpose of this study?

This study is going to compare two booklets, which help people cope with their implantable cardioverter defibrillator (ICD). We want to see which booklet is most helpful to patients. One of the booklets is the standard treatment – you may receive this booklet or you may receive the other one.

Who is carrying out this research?

Nina Humphreys a researcher from Swansea University is carrying out this research as part of her PhD. The senior research team are Professor Paul Bennett, Dr Rob Lowe, and Dr Jaynie Rance. Nina can be contacted on 01792 205678 ext 4219

Why have I been chosen?

You are able to take part in this study because you will be living with an ICD. I am interested in how you are feeling now. I am interested whether your feelings change over the following 3- to 6-months.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. If you wish to leave, you can ask for your data to be deleted. Your NHS care will not be affected if you do not take part in or later leave my study.

Do I have to decide now?

No, you don't have to decide right now. But you do need to decide before your ICD is implanted.

What are the advantages in taking part in this study?

You may not directly benefit from this study but the information we get from this study may help improve the treatment of people with an ICD.

What are the disadvantages in taking part in this study?

There are no foreseen disadvantages in taking part in this study.

What is involved in taking part in this research?
Sometimes we don't know which booklets patients find most helpful. To find out, we need to compare different booklets. We put people into groups and give each group a different booklet. The results are compared to see if one is better than the other is. To make sure the groups are the same to start with, each patient is put into a group by chance (randomly).

You will be asked to fill in a questionnaire before your ICD is implanted. You will be sent further sets of questionnaires at 3- and 6-months after your ICD implant, which you will need to fill and return to me in an envelope that will be provided. The questionnaires will be used to inform us which booklet was the most helpful.

You will be in the study for about 6-months. We will be recruiting patients for one year.

Will my taking part be kept confidential?
All your identifying information collected will be anonymised and kept confidential, however your Arrhythmia Nurse Specialist/ICD Specialist Nurse will be informed if you wish to participate.

What will the results of the study show us?
The results will tell me which intervention appears to be better at helping patients cope with their ICD.

Complaints Procedure:
Any complaint about the way you have been dealt with during the study or any distress will be addressed. If you would like to make a complaint about any aspect of this study, please contact:

Professor Paul Bennett (Chief Investigator)
Psychology Department
School of Human and Health Sciences
Swansea University
Swansea
SA2 8PP
Tel: 01792 606830.
Email: P.D.Bennett@swan.ac.uk

Details of Insurance
Insurance and indemnity is provided by the Department of Research and Innovation, Swansea University.

Who has reviewed this Study?
The Welsh Office for Research and Development, (Welsh Assembly Government Health Studentship Award) has funded this study through an award made to Professor Paul Bennett, School of Human and Health Sciences, Swansea University. The South West Wales Research Ethics Committee has reviewed the study.

Appendix IX: Sample Participant Consent Form

Participant Identification Number for this Study:

Study Title: Psychological Coping Intervention: A Randomised Control Trial for Implantable Cardioverter Defibrillator Patients

Please Initial

1. I confirm that I have read the Patient Information Sheet (Version 2) dated 24/5/11 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I accept that I will be randomised into a group that will receive one of the booklets. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without medical care being affected. ☐
4. I understand that my ICD- Specialist Nurse/Arrhythmia Nurse Specialist will be informed of my participation in this study. ☐
5. I agree to receive follow-up questionnaires in 3- and 6-months, which are to be completed and returned to the researcher. ☐
6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researcher Nina Humphreys, from Regulatory Authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
7. I agree to take part in the above-named study and I give permission for the researcher to gain access to medical information/notes concerning the ICD and my underlying heart condition. ☐

______________________	___/___/ 2012	______________________
Name of Participant	Date	Signature

______________________	___/___/ 2012	______________________
Name of Person Taking Consent	Date	Signature

Swansea University
Prifysgol Abertawe

Psychological Coping Intervention: A Randomised Control Trial

For

Implantable Cardioverter Defibrillator Patients

Time 1: Before ICD implant
Patient ID =

I would like to thank you so much for your help with this study

This questionnaire is to be filled in <u>before</u> you have your ICD implant

We are very grateful that you are going to fill in this questionnaire for us -

Before you begin, please note the following:

- ***This questionnaire is made up with sets of questions. Please read the instructions on the top of each new set of questions carefully as instructions may differ.***

- ***Please read the column headings carefully as they are different for each new set of questions.***

- ***There are no right or wrong answers. Your first impressions are the only thing that matters.***

Thank you!

Please read the following statements about your ICD (defibrillator) and *circle* the corresponding box that explains best the *level of worry* that you feel. *Don't take too long thinking about each statement.*

I am worried about ...

		Not at all worried	A little bit worried	Somewhat worried	Quite a lot worried	Very worried
1	The ICD firing (giving a shock)	0	1	2	3	4
2	The ICD not working when I need it to	0	1	2	3	4
3	What I should do if my ICD fires	0	1	2	3	4
4	Doing exercise in case it causes the ICD to fire	0	1	2	3	4
5	Doing activities/hobbies that may cause the ICD to fire	0	1	2	3	4
6	My heart condition getting worse if the ICD fires	0	1	2	3	4
7	The amount of time I spend thinking about my heart condition and having to have an ICD	0	1	2	3	4
8	The amount of time I spend thinking about the ICD firing	0	1	2	3	4
9	The ICD battery running out	0	1	2	3	4
10	Working too hard/overdoing things to cause the ICD to fire	0	1	2	3	4
11	Making love in case the ICD fires	0	1	2	3	4
12	Having no warning the ICD will fire	0	1	2	3	4
13	The symptoms/pain associated with my ICD firing	0	1	2	3	4

	Not at all worried	A little bit worried	Somewhat worried	Quite a lot worried	Very worried
Being a burden on my partner/family	0	1	2	3	4
That I can't prevent the ICD from firing	0	1	2	3	4
The future now that I will be having an ICD	0	1	2	3	4
Problems occurring with the ICD eg lead displacement	0	1	2	3	4
Getting too stressed in case my ICD fires	0	1	2	3	4
Not being able to work/take part in activities/hobbies because I will have an ICD	0	1	2	3	4

The section deals with *thoughts* about your forthcoming ICD. Please <u>*circle*</u> the appropriate box that best describes your thoughts. <u>*Don't take too long thinking about each statement.*</u>

		Not at all	Rarely	Sometimes	Often
1	I think about the ICD when I don't mean to	1	2	3	4
2	I avoid letting myself get upset when I think about the ICD, or am reminded of it	1	2	3	4
3	I am trying to remove the ICD from memory	1	2	3	4
4	I have trouble falling asleep or staying asleep, because of pictures or thoughts about the ICD, that come into my mind	1	2	3	4
5	I have waves of strong feelings about the ICD	1	2	3	4
6	I have dreams about the ICD	1	2	3	4
7	I stay away from reminders of the ICD	1	2	3	4
8	I feel as if the implant isn't really going to happen or the ICD isn't real	1	2	3	4
9	I try not to talk about the ICD	1	2	3	4
10	Pictures about the ICD pop into my mind	1	2	3	4
11	Other things keep making me think about the ICD	1	2	3	4
12	I am aware that I still have a lot of feelings about the ICD, but I am not dealing with them	1	2	3	4
13	I try not to think about the ICD	1	2	3	4
14	Any reminder (of the ICD) brings back feelings about the ICD	1	2	3	4
15	My feelings about the ICD are kind of numb	1	2	3	4

We want to understand what it is like for you knowing that you are going to live with a medical device. Please *circle* the most appropriate box to rate the extent to which you agree or disagree with each of the following statements.

Don't take too long thinking about each statement.

		Strongly disagree	Mostly disagree	Neither agree nor disagree	Mostly agree	Strongly agree
1	Thinking about the device makes me depressed	1	2	3	4	5
2	When I think about the device, I avoid doing things I enjoy	1	2	3	4	5
3	I will avoid my usual activities because I will feel disfigured by the device	1	2	3	4	5
4	It is hard for me to function without thinking about the device	1	2	3	4	5
5	The device was my best treatment option	1	2	3	4	5
6	I am confident about my ability to return to work if I want to	1	2	3	4	5
7	I will be safer from harm because of my device	1	2	3	4	5
8	The positive benefits of this device outweigh the negatives	1	2	3	4	5
9	I will continue with my normal sex life	1	2	3	4	5
10	I will receive this device again if need be	1	2	3	4	5
11	I know enough about the device	1	2	3	4	5
12	I will be careful when hugging or kissing my loved ones	1	2	3	4	5

		Strongly disagree	Mostly disagree	Neither agree nor disagree	Mostly agree	Strongly agree
13	I will return to a full life	1	2	3	4	5
14	I feel that others will see me as disfigured by my device	1	2	3	4	5
15	I feel I will be less attractive because of my device	1	2	3	4	5
16	I am knowledgeable about how the device works and what it will do for me	1	2	3	4	5
17	I will not be able to do things for my family the way I used to	1	2	3	4	5
18	I am concerned about resuming my daily physical activities	1	2	3	4	5

This section is about your beliefs *during the past week*. For each of the following statements, please <u>*circle*</u> the answer that best describes what you believe. <u>*Don't take too long thinking about each statement.*</u>

I believe .....

		No, not at all	A little bit	Quite a lot	Definitely
1	I am lucky to be having the ICD	1	2	3	4
2	The ICD will fire when it needs to	1	2	3	4
3	The ICD will protect me if I have an abnormal heart rhythm	1	2	3	4
4	A shock means my heart condition is getting worse	1	2	3	4
5	I am living on borrowed time	1	2	3	4
6	I will feel more in control of my life with an ICD	1	2	3	4
7	I feel reassured having the ICD	1	2	3	4
8	It doesn't bother me that I don't know when a shock might come	1	2	3	4
9	The ICD will be my 'friend' and will become part of my life	1	2	3	4
10	I could have a good work out, and my ICD would protect me	1	2	3	4
11	A shock could damage my heart	1	2	3	4
12	I am confident I will cope with any limitations that living with the ICD may bring	1	2	3	4
13	The ICD will give me a new lease of life	1	2	3	4

This section is about your day-to-day behaviour *over the past week (before being admitted to hospital)*. Please read the following statements. For each statement, please *circle* which box applies to you. *Don't take too long thinking about each statement.*

Some of you may be in hospital when you fill this in but still try to fill in each statement as best you can.

		Totally disagree	Disagree a little	Neither agree Nor disagree	Agree	Completely agree
1	I was an active person	1	2	3	4	5
2	I tended to avoid situations that made my heart beat fast	1	2	3	4	5
3	I approached sex with caution	1	2	3	4	5
4	I did social activities with the same level of enthusiasm as usual	1	2	3	4	5
5	I tended to avoid places that made me anxious so that my heart beat fast	1	2	3	4	5
6	I felt confident to go out and visit most places	1	2	3	4	5
7	I regularly took part in exercise or social activities that increase my heart rate	1	2	3	4	5
8	When doing work around the house, I tended to slow down if my heart began to race	1	2	3	4	5
9	There are places I would liked to have visited but I avoided going	1	2	3	4	5
10	I used up lots of energy when doing exercise or social activities	1	2	3	4	5
11	I tended to go out a lot	1	2	3	4	5
12	I tended to avoid situations that made me anxious	1	2	3	4	5
13	I did household maintenance and chores with vigour	1	2	3	4	5

		Totally disagree	Disagree a little	Neither agree Nor disagree	Agree	Completely agree
14	I tended to stay close to home a lot	1	2	3	4	5
15	I went into most situations quite happily	1	2	3	4	5
16	I tried to avoid places or situations that made me feel stressed	1	2	3	4	5
17	I could be as active each day as I wanted	1	2	3	4	5
18	I approached life with more vigour than usual	1	2	3	4	5
19	I tended to avoid certain situations	1	2	3	4	5
20	I tried to restrict how much energy I used when doing exercise or social activities	1	2	3	4	5
21	I was out and about as much as usual	1	2	3	4	5
22	Every day, I did everything I needed to do	1	2	3	4	5

Listed below are several questions about your thoughts, feelings, and behaviours as they relate to your current condition. Please indicate your answer by *circling* the word(s), which corresponds to your response choice.

1	How much do you want to be involved in decisions regarding your treatment?	Very much	Moderately	Somewhat	Very little
2	How often do you try to talk about your conditions with friends or relatives?	Never	Sometimes	Frequently	All the time
3	In conversations about your condition, how often do you find yourself about thinking about other things?	Never	Sometimes	Frequently	All the time
4	How often do you feel there is really no hope for your full recovery?	All the time	Frequently	Sometimes	Never
5	In the past few days/weeks/months, how much have you learned about your condition from talking with others who know something about it, such as doctors, nurses, etc?	Very little	Some	Quite a bit	Very much
6	How often do you feel that you don't care what happens to you?	Never	Sometimes	Frequently	All the time
7	To what extent do you like talking to your friends and family because you won't have to think about your condition?	Very little	Somewhat	Quite a bit	Very much
8	How much has your condition caused you to think about certain things in your life in a more positive way?	Very little	Some	Quite a bit	Very much

9	When you think about your condition, how often do you try to distract yourself by doing something else?	All the time	Frequently	Sometimes	Never
10	How often do you ask your doctor for advice about what to do concerning your condition?	All the time	Frequently	Sometimes	Never
11	When friends or relatives try to talk to you about your condition, how frequently do you try to change the subject?	Never	Sometimes	Frequently	All the time
12	In the past few months, how much have you learned about your condition from reading books, magazines, or newspapers?	Very much	Quite a bit	Some	Very little
13	How often do you feel like giving in to your condition?	All the time	Frequently	Sometimes	Never
14	To what extent do you try to forget about your condition?	Very little	Some	Quite a bit	Very much
15	How many questions have you asked your doctor about your condition?	None	Some	Many	A lot
16	When you meet someone with your kind of condition, how much do you talk about the details of the condition?	Very little	Some	Quite a bit	Very much
17	How often do you go to the cinema or watch TV in order not to think about your condition?	Never	Sometimes	Frequently	All the time
18	To what extent do you feel there is nothing you can do about your condition?	Very much	Quite a bit	A little	Not at all
19	When close relatives or friends ask you about your condition, how often do you talk to them about it?	All the time	Frequently	Sometimes	Never

Please write down how many minutes you exercise during a typical week using the diary below:

How many minutes do you exercise STRENUOUSLY each day?

Strenuous exercise makes your heart beat very fast such as running, jogging, vigorous swimming or long distance cycling

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
How many minutes?							

How many minutes do you exercise MODERATELY each day?

Moderate exercise makes your heart beat fast such as fast walking, tennis, easy cycling, badminton or easy swimming

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
How many minutes?							

How many minutes do you do exercise MILDLY each day?

Mild exercise causes little or no increase in heartbeat such as yoga, archery, fishing from riverbank, bowling, golf, or easy walking

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
How many minutes?							

This section is about how you view your heart condition. For the following questions along the scale of 0 to 10, please <u>*circle*</u> the number that best corresponds to how you feel *at the moment*.

How much does your heart condition affect your life?

0	1	2	3	4	5	6	7	8	9	10
No affect At all										Severely affects life

How long do you think your heart condition will continue?

0	1	2	3	4	5	6	7	8	9	10
A very short time										Forever

How much control you feel you have over your heart condition?

0	1	2	3	4	5	6	7	8	9	10
Absolutely no control										Extreme amount of control

How much do you think the ICD can help your heart condition?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Extremely helpful

How many abnormal heart rhythms do you experience with your heart condition?

0	1	2	3	4	5	6	7	8	9	10
No arrhythmias										Many arrhythmias

How concerned are you about your heart condition?

0	1	2	3	4	5	6	7	8	9	10
Not at all concerned										Extremely concerned

How well do you feel you understand your heart condition?

0	1	2	3	4	5	6	7	8	9	10
Don't understand it at all										Understand very clearly

How much does your heart condition affect you emotionally (eg does it make your angry, scared, upset, depressed?)

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										Extremely affected emotionally

Please list in rank-order (ie - the first being the most important) the three most important factors that you believe caused your heart condition.

The most important causes for my condition are:

1. ____

2. ____

3. ____

Below are a number of statements that people often use to describe themselves. There are no right or wrong answers; your own impression is the only thing that matters.

Please read each statement and then _circle_ the appropriate number that best corresponds to your views. _Don't take too long thinking about each statement._

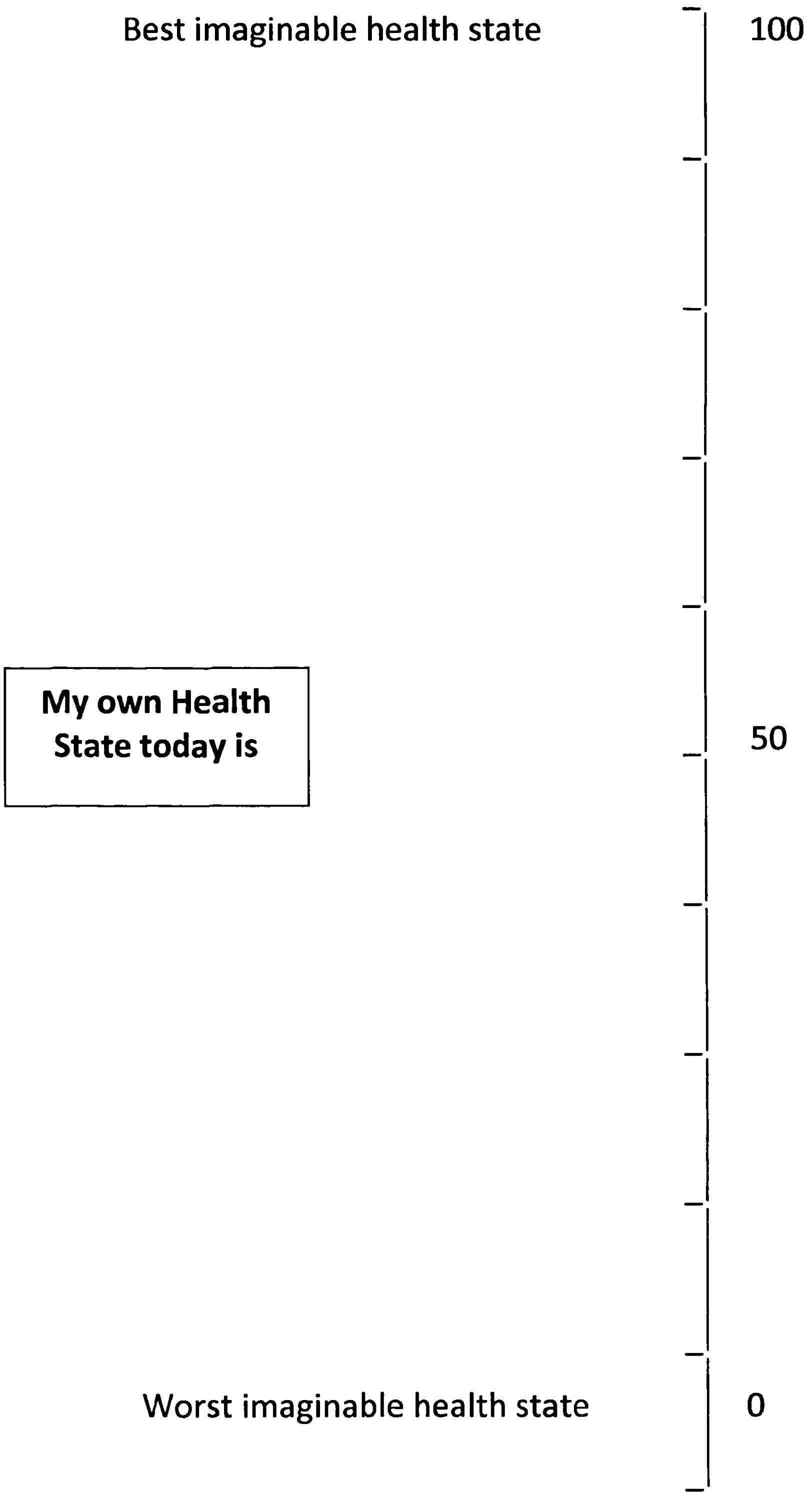
	False	Rather false	Neutral	Rather true	True
I make contact easily when I meet people	0	1	2	3	4
I often make a fuss about unimportant things	0	1	2	3	4
I often talk to strangers	0	1	2	3	4
I often feel unhappy	0	1	2	3	4
I am often irritated	0	1	2	3	4
I often feel inhibited in social interactions	0	1	2	3	4
I take a gloomy view of things	0	1	2	3	4
I find it hard to start a conversation	0	1	2	3	4
I am often in a bad mood	0	1	2	3	4
I am a closed kind of person	0	1	2	3	4
I would rather keep other people at a distance	0	1	2	3	4
I often find myself worrying about something	0	1	2	3	4
I am often down in the dumps	0	1	2	3	4
When socialising, I don't find the right things to talk about	0	1	2	3	4

This section deals with how much emotion you are feeling *right now*. Please *circle* the number along each line that best applies to you. *Don't take too long thinking about each emotion.*

		Not at all	A little	Moderately	Quite a bit	Extremely
1	Tense	1	2	3	4	5
2	Angry	1	2	3	4	5
3	Worn out	1	2	3	4	5
4	Unhappy	1	2	3	4	5
5	Lively	1	2	3	4	5
6	Confused	1	2	3	4	5
7	Peeved	1	2	3	4	5
8	Sad	1	2	3	4	5
9	Active	1	2	3	4	5
10	On edge	1	2	3	4	5
11	Grouchy	1	2	3	4	5
12	Blue	1	2	3	4	5
13	Energetic	1	2	3	4	5
14	Hopeless	1	2	3	4	5
15	Uneasy	1	2	3	4	5
16	Restless	1	2	3	4	5

		Not at all	A little	Moderately	Quite a bit	Extremely
17	Unable to concentrate	1	2	3	4	5
18	Fatigued	1	2	3	4	5
19	Annoyed	1	2	3	4	5
20	Discouraged	1	2	3	4	5
21	Resentful	1	2	3	4	5
22	Nervous	1	2	3	4	5
23	Miserable	1	2	3	4	5
24	Cheerful	1	2	3	4	5
25	Bitter	1	2	3	4	5
26	Exhausted	1	2	3	4	5
27	Anxious	1	2	3	4	5
28	Helpless	1	2	3	4	5
29	Weary	1	2	3	4	5
30	Bewildered	1	2	3	4	5
31	Furious	1	2	3	4	5
32	Full of ‘pep’	1	2	3	4	5
33	Worthless	1	2	3	4	5
34	Forgetful	1	2	3	4	5
35	Vigorous	1	2	3	4	5
36	Uncertain about things	1	2	3	4	5
37	Bushed	1	2	3	4	5

To help people say how good or bad a health state is, we have drawn a scale on which the best state you can imagine is marked by 100 and the worst state you can imagine is marked by 0. We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale to indicate how good or bad your current health is



Please read the following statements. Do not think about each statement for too long. It is best if you can give an immediate answer.

So, think about how you are *currently* feeling and *<u>circle</u>* the appropriate answer.

"I feel tense or 'wound up'"	Most of the time A lot of the time From time to time, occasionally Not at all
"I still enjoy the things I used to enjoy"	Definitely as much Not quite as much Only a little Hardly at all
"I get a sort of frightened feeling as if something awful is about to happen"	Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all
"I can laugh and see the funny side of things"	As much as I always could Not quite so much now Definitely not so much now Not at all

"Worrying thoughts go through my mind"	A great deal of the time A lot of the time From time to time, but not too often Only occasionally
"I feel cheerful"	Not at all Not often Sometimes Most of the time
"I can sit at ease and feel relaxed"	Definitely Usually Not often Not at all
"I feel as if I am slowed down"	Nearly all the time Very often Sometimes Not at all
"I get a sort of frightened feeling like "butterflies in the stomach"	Not at all Occasionally Quite often Very often

"I have lost interest in my appearance"	Definitely I don't take as much care as I should I may not take quite as much care I take just as much care as ever
"I feel restless as I have to be on the move"	Very much indeed Quite a lot Not very much Not at all
"I look forward with enjoyment to things"	As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all
"I get sudden feelings of panic"	Very often indeed Quite often Not very often Not at all
"I can enjoy a good book or radio or TV programme"	Often Sometimes Not often Very seldom

During a **typical 7-day period** how many times on average, did you do the following kinds of exercise for **more than 15 minutes** during the day?

	Before your ICD
Strenuous Exercise (rapid heartbeat) Eg running, jogging, vigorous swimming, vigorous long distance cycling	
Moderate Exercise (fast heartbeat) Eg fast walking, tennis, easy cycling, badminton, easy swimming	
Mild Exercise (little or no increase in heart rate) Eg Yoga, archery, fishing from river bank, bowling, golf, easy walking	(For the example above, you would write 7 in this box)

During a typical 7-day period (a week), on average how often did/do you engage in any regular activity **long enough to work up a sweat** (heart beats rapidly)?

Please ***circle*** one of the answers

Often **Sometimes** **Never/rarely**

Thank you so much for filling in this questionnaire. Please check that you have answered all the questions.

When complete, please place this questionnaire in the envelope with your consent form and form with your address details on.

Please return the envelope to me (Nina) or leave it with a nurse to give to your BHF Specialist Arrhythmia Nurse

Appendix XI: Sample form used to collect demographic and contact details

DEMOGRAPHIC INFORMATION

Please fill in the following:

Full Name:

Address: ______________________________

____

____

____

Postcode: ____________________

Contact Telephone Number:

Date of Birth:

Marital Status: Married/ Divorced/ Single/ Widowed/ Living with Partner/ Civil partnership

Date of proposed Implant:

GP Name :
Address or phone number:

Date:

Dear

Psychological Coping Intervention: a Randomised Control Trial for Implantable Cardioverter Defibrillator (ICD) patients.

This letter is to introduce Nina Humphreys who is a PhD researcher at Swansea University who is going to test the efficacy of a brief intervention to help patients cope with their ICD.

Nina shall soon be testing the efficacy of this intervention by running a randomised control trial with ICD patients from Morriston Hospital and University Hospital of Wales. Therefore, Nina will be coming on to the wards periodically to speak with patients who are waiting for their ICD implant. As part of her study, she will be asking patients to fill in a consent form and a baseline questionnaire.

However, in line with ethics, I would be grateful if you would approach the patients identified by the study criteria (see below) for Nina to make the initial contact with the patient. I would be grateful if you would ask patients if they would be willing to speak to Nina about the study and so allowing Nina permission to speak with them.

Yours sincerely

Mandie Welch
ICD Specialist Nurse

Study Inclusion Criteria:

- Patients aged 18 and over (no upper age limit)
- Patients who are having an ICD fitted for the first time

Study Exclusion Criteria:

- Patients who are having a replacement battery or who are having a replacement ICD due to their ICD having been recalled.
- Patients who are waiting for a heart transplant or coronary artery by-pass.
- Patients with severe psychiatric or psychological health issues
- Patients who cannot read English.

Photo of Nina Humphreys

Appendix XIII: Sample of a participant consent form used for patients in Bristol

University Hospitals Bristol NHS
NHS Foundation Trust

Jenny Tagney
Cardiology Nurse Consultant
Level 7, Bristol Heart Institute
Bristol Royal Infirmary
University Hospitals Bristol NHS Foundation Trust
Bristol BS2 8HW

Tel: 0117 9230000 or 0117 3426571
(secretary)

Patient Information Sheet

Psychological Coping Intervention: A Randomised Control Trial for Implantable Cardioverter Defibrillator Patients

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of this study?

This study is going to compare two booklets, which help people cope with their implantable cardioverter defibrillator (ICD). We want to see which booklet is most helpful to patients. One of the booklets is the standard treatment – you may receive this booklet or you may receive the other one.

Who is carrying out this research?

Nina Humphreys a researcher from Swansea University is carrying out this research as part of her PhD. The senior research team are Professor Paul Bennett, Dr Rob Lowe, and Dr Jaynie Rance. Nina can be contacted on 01792 205678 ext 4219

Why have I been chosen?

You are able to take part in this study because you will be living with an ICD. I am interested in how you are feeling now. I am interested whether your feelings change over the following 3- to 6-months.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. If you wish to leave, you can ask for your data to be deleted. Your NHS care will not be affected if you do not take part in or later leave my study.

Do I have to decide now?

No, you don't have to decide right now. But you do need to decide before your ICD is implanted.

What are the advantages in taking part in this study?
You may not directly benefit from this study but the information we get from this study may help improve the treatment of people with an ICD.

What are the disadvantages in taking part in this study?
There are no foreseen disadvantages in taking part in this study.

What is involved in taking part in this research?
Sometimes we don't know which booklets patients find most helpful. To find out, we need to compare different booklets. We put people into groups and give each group a different booklet. The results are compared to see if one is better than the other is. To make sure the groups are the same to start with, each patient is put into a group by chance (randomly).

You will be asked to fill in a questionnaire before your ICD is implanted. You will be sent further sets of questionnaires at 3- and 6-months after your ICD implant, which you will need to fill and return to me in an envelope that will be provided. The questionnaires will be used to inform us which booklet was the most helpful.

You will be in the study for about 6-months. We will be recruiting patients for one year.

Will my taking part be kept confidential?
All your identifying information collected will be anonymised and kept confidential, however your Arrhythmia Nurse Specialist/ICD Specialist Nurse will be informed if you wish to participate.

What will the results of the study show us?
The results will tell me which intervention appears to be better at helping patients cope with their ICD.

Complaints Procedure:
Any complaint about the way you have been dealt with during the study or any distress will be addressed. If you would like to make a complaint about any aspect of this study, please contact:

Professor Paul Bennett (Chief Investigator)
Psychology Department
School of Human and Health Sciences
Swansea University
Swansea
SA2 8PP
Tel: 01792 606830.
Email: P.D.Bennett@swan.ac.uk

Details of Insurance
Insurance and indemnity is provided by the Department of Research and Innovation, Swansea University.

Who has reviewed this Study?
The Welsh Office for Research and Development, (Welsh Assembly Government Health Studentship Award) has funded this study through an award made to Professor Paul Bennett, School of Human and Health Sciences, Swansea University. The South West Wales Research Ethics Committee has reviewed the study.

01	**1**	**02**	**1**	**03**	**1**	**04**	**1**	**05**	**0**	**06**	**1**
07	1	08	0	09	1	10	0	11	1	12	0
13	1	14	0	15	0	16	0	17	1	18	0
19	0	20	1	21	0	22	0	23	0	24	0
25	1	26	0	27	1	28	0	29	0	30	1
31	0	32	0	33	1	34	0	35	1	36	0
37	1	38	1	39	0	40	1	41	0	42	0
43	1	44	1	45	0	46	1	47	1	48	0
49	0	50	0	51	1	52	1	53	0	54	0
55	0	56	0	57	1	58	1	59	0	60	0
61	1	62	0	63	1	64	0	65	0	66	1
67	0	68	0	69	0	70	0	71	0	72	1
73	1	74	1	75	0	76	0	77	1	78	1
79	0	80	0	81	0	82	1	83	0	84	1
85	0	86	0	87	1	88	1	89	0	90	0
91	0	92	0	93	0	94	1	95	1	96	0
97	0	98	1	99	1	100	1	101	1	102	0
103	0	104	0	105	1	106	0	107	0	108	0
109	0	110	1	111	0	112	0	113	0	114	0
115	0	116	1	117	0	118	0	119	0	120	1
121	0	122	0	123	1	124	1	125	0	126	0
127	0	128	1	129	0	130	0	131	1	132	1
133	0	134	1	135	1	136	1	137	0	138	1
139	0	140	1	141	1	142	1	143	1	144	0
145	1	146	1	147	0	148	1	149	0	150	0
151	0	152	1	153	1	154	1	155	0	156	1
157	1	158	1	159	1	160	1	161	0	162	1
163	1	164	0	165	1	166	1	167	1	168	0
169	1	170	0	171	0	172	0	173	0	174	1
175	1	176	1	177	1	178	0	179	0	180	1
181	0	182	0	183	1	184	1	185	0	186	0

187	0	188	0	189	1	190	0	191	0	192	1
193	0	194	1	195	0	196	0	197	0	198	1
199	1	200	1	201	1	202	1	203	1	204	0
205	0	206	1	207	0	208	1	209	1	210	0
211	1	212	1	213	0	214	0	215	1	216	0
217	0	218	1	219	1	220	0	221	0	222	0
223	0	224	1	225	0	226	0	227	0		

Morriston: 1-12 and 51-62 (9.11.2011); 87-96 (30.3.2012); 102-108 (18.6.2012) 207-210 (5.9.2012)

197-204 (14.9.2012)

UHW: 27-38 (13.9.2011); 71-80 (19.1.2012) 211-218 (18.9.2012)

Bristol: 113-153

Withdrawn

Appendix XV: Sample of a covering letter sent at 3-months

The letter was printed with a Swansea University letterhead

Nina Humphreys
Psychology Department
School of Human & Health Sciences
Swansea University
Singleton Park
Swansea
SA2 8PP

Email Address: 366232@swansea.ac.uk

Date:

Dear

This letter is reminding you that about three months ago you kindly filled in a set of questionnaires for my study. My study is comparing booklets that help people cope with their ICD. Thank you so much for filling in the first questionnaire. At the time, you were told that in three-month's time you would receive a new set of questionnaires to fill in.

Therefore, I would be grateful if you would fill in the set of questionnaires that are enclosed with this letter. This is the second of three sets of questionnaires being used for my study. When you have filled it in, please return it to me in the stamped addressed envelope. If you are unable to fill it in because you are having difficulty, please contact me. My contact details are at the top of this letter.

If you no longer wish to be part of my study, simply do not fill in or return the questionnaires. I will be sending out a reminder letter in a couple of weeks if I do not hear from you. If you no longer wish to be part of the study, simply ignore the reminder and you will not be contacted again. Please be assured that your NHS care will not be affected if you decide to withdraw from my study. If you are happy to continue being a participant in my study, I shall contact you again in another three months with the third and final set of questionnaires.

Thank you so much for all your time and effort that you have given to my study.

Yours sincerely

Nina Humphreys
Researcher

Enc: Psychological questionnaire and pre-paid, addressed envelope

Appendix XVI: Sample of a reminder letter sent to participants after 2-weeks

Nina Humphreys
Vivien Tower 8th Floor
Psychology Department
School of Human and Health Science
Swansea
Singleton Park
Swansea
SA2 8PP

Email Address: 366232@swansea.ac.uk

Date:

Dear

This letter is reminding you that you have kindly filled in some questionnaires for my study to compare booklets that are given to people to cope with their ICD. You should have received a set of questionnaires from me in the post recently. However just in case they never reached you, I am sending you a copy of the questionnaires.

I would be very grateful if you would be able to complete the enclosed questionnaire and return them to me in the stamped addressed envelope as soon as possible. If you are unable to complete them because you are having difficulty please contact me. My contact details are at the top of this letter.

If you no longer wish to be part of my study, please ignore this letter and simply do not complete or return the questionnaires. I assure you that will not be contacted again. Please note that your standard NHS care will not be affected by your decision not to continue taking part in my study.

Thank you so much for all your time and effort that you have given to my study.

Yours sincerely

Nina Humphreys
Researcher

Encs: Questionnaire and pre-paid envelope

Please *circle* the response that matches the choice of your best answer <u>or</u> answer in full as appropriate

Section 1 – Getting on with life: learning to relax CD

Have you listened to the **'Getting on with life: learning to relax CD'**?	Very often/ quite often/ sometimes/ once/ never
If yes, how helpful have you found the CD with becoming relaxed?	Very helpful/ quite helpful/ unsure/ not helpful
If you have not listened to the CD, please can you tell us why?	
Is there anything you found especially helpful about this CD?	
Is there anything you found <u>un</u>helpful about this CD?	

Section 2 – Getting on with life: learning to live with your ICD booklet

Have you read the booklet **'Getting on with life: learning to live with your ICD'**	Yes/ No (if No, go straight to section 3)
How helpful did you find this booklet overall?	Very helpful/ quite helpful/ unsure/ not helpful/
How helpful did you find the section about:	
Common concerns	Very helpful/ quite helpful/ unsure/ not helpful
Keeping active	Very helpful/ quite helpful/ unsure/ not helpful

Please *circle* the response that matches the choice of your best answer <u>or</u> answer in full as appropriate

Getting to sleep at night	Very helpful/ quite helpful/ unsure/ not helpful
Learning to relax	Very helpful/ quite helpful/ unsure/ not helpful
Coping with worries	Very helpful/ quite helpful/ unsure/ not helpful
Planning a shock strategy	Very helpful/ quite helpful/ unsure/ not helpful

In the booklet, **'Getting on with life: learning to live with your ICD'** ...	
... did you use the Exercise diary (at the back)?	▪ No, didn't use it at all or just a few days ▪ for week 1 ▪ for weeks 1 and 2 ▪ for weeks 1, 2 and 3 ▪ for the 4 weeks
... did you use the Activity planner (at the back)?	▪ No, didn't use it at all or just a few days ▪ for week 1 ▪ for weeks 1 and 2 ▪ for weeks 1, 2 and 3 ▪ for the 4 weeks
... how useful have you found the Changing worries chart (at the back)?	Very useful/ quite useful/ unsure/ not at all useful/ I didn't have any worries
How often are you using relaxation skills to get to sleep?	Very often/ quite often/ sometimes/ hardly ever/ never
How often are you using relaxation skills to reduce tension or stress?	Very often/ quite often/ sometimes/ hardly ever/ never
How often are you using meditation to cope with worries?	Very often/ quite often/ sometimes/ hardly ever/ never

Please *circle* the response that matches the choice of your best answer <u>or</u> answer in full as appropriate

How often are you challenging any worries concerning your ICD?	Very often/ quite often/ sometimes/ hardly ever/ never
How often are you using distraction techniques to cope with worries concerning your ICD?	Very often/ quite often/ sometimes/ hardly ever/ never

What have you found especially helpful in the **'Getting on with life: learning to live with your ICD'** booklet?

What have you found especially <u>un</u>helpful in the **'Getting on with life: learning to live with your ICD'** booklet?

Section 3 - Getting on with life: stopping smoking booklet

How helpful did you find the booklet **'Getting on with life: stopping smoking'**?	I am not a smoker/ very helpful/ quite helpful/ unsure/ not helpful

Is there anything you found especially helpful in/about this booklet?

Is there anything you found particularly <u>un</u>helpful in/about this booklet?

Appendix XVII: Sample set of Process measures sent to participants in the intervention group at 3-months

Please *circle* the response that matches the choice of your best answer or answer in full as appropriate

Section 4 – Getting on with life: eating healthily

How helpful did you find the booklet **'Getting on with life: eating healthily**?	very helpful/ quite helpful/ unsure/ not helpful/ did not read it
Is there anything you found especially helpful about/in this booklet?	
Is there anything you found particularly <u>un</u>helpful about/in this booklet?	

Section 5 – Additional information

Do you have any further comments you would like to make concerning the booklets or CD?

Appendix XVIII: Letter sent to Professor Bisson, which reported the outcomes of the independent assessor, who examined the data of the first 30 participants.

Printed on Swansea University headed paper

Nina Humphreys
Psychology Department
School of Human & Health Sciences
Swansea University
Singleton Park
Swansea
SA2 8PP
366232@swansea.ac.uk

Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)
R&D Office
2nd Floor, TB2, Room 1
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW

28th August 2012

Dear Professor Jonathan Bisson

Study Ref:11-CAD-5134: Psychological Coping Intervention – a Randomised Control Trial for Implantable Cardioverter Defibrillator Patients

In our meeting on 22nd July 2011 to discuss the above study, you requested that an independent assessor review the data gathered from our first 30 participants (15 Intervention and 15 Control) at baseline and at 3-months to ensure that the psychological intervention had not been psychologically detrimental to the patient.

Professor Vedhara of Nottingham University has independently assessed the data at baseline and at three-months for the first 30 patients and concurred with our findings that the intervention group has not been negatively affected and that in some areas, their psychological health has improved. Please find enclosed a table of the demographic and clinical history of both groups, graphs depicting changes from baseline to three months for both study groups and a table detailing means at baseline and three months along with the effect sizes (eta squared).

The findings demonstrate encouraging effect sizes found in favour of the intervention group. A medium to large effect size was found for reduced levels of depression (see Hospital Anxiety and Depression Scale), a large effect size for increased positive beliefs about the device (see Beliefs Questionnaire), and a small effect size for improved acceptance of the device (see Florida Patient Acceptance Survey). Please let me know if you would like any more information.

Yours sincerely

Nina Humphreys
PhD student

CC: Professor Paul D Bennett
Dr Peter O'Callaghan
Professor Vedhara

Appendix XIX

Getting on with life: Learning to live with your ICD

Self-management recovery programme for ICD-patients

A step-by-step programme to regaining independent living for ICD patients and facts about common concerns living with an implantable cardioverter defibrillator

Contents

Introduction

You may feel you can't wait to get home after your implant, especially if you have been in hospital for some weeks. Or you may feel a little apprehensive, or a mixture of both. Many people fitted with an ICD experience some uncertainty about the future and how they will cope at home. While in hospital, you received expert care, support and understanding from professionals. But now you are back home, you may be left with a *'what am I supposed to do now?'* kind of feeling.

You may feel that you can't wait to get back to your normal activities, and think you know exactly how to regain your strength and return to normal - and that's great if you do! However, you may feel a little uncertain of how to get back to 'normal living' and that's completely understandable.

Based on research with ICD patients with heart conditions such as heart failure, congenital heart conditions, and heart attacks, this self-help guide aims to dispel a number of common ICD related fears, and to help you gain control of your life. It will help you regain independence and keep your heart as healthy as possible, so you can start living the rest of your life to the full!

We have found there are number of issues to be covered. These are addressed in three leaflets in the Getting on with life series:

- Learning to live with your ICD
- Stopping Smoking
- Eating Healthily.

You may wish to read only one or two of the leaflets - and that's fine.

This leaflet, **'Getting on with life: learning to live with your ICD'** looks at a number of issues. You may wish to read all the leaflet, or just the parts that seem most relevant to you. The issues we cover in this leaflet are:

- **Common concerns**. This section identifies a number of concerns many people have about living with their ICD and puts them into context.

- **Keeping active.** One of the key strategies to a healthy heart and reducing the risk of your ICD firing is to strengthen the heart muscle by keeping active. This is best done in a structured way, neither doing too much nor too little at a time. This section helps you develop an activity plan to help you do this.

- **Coping with sleep problems.** This part of the booklet looks at sleep problems that many people experience and how these can be managed.

- **Learning to relax.** Relaxation is good for a healthy heart and it can reduce the levels of adrenalin that increase risk of your ICD firing at times of stress. The section examines a simple way of learning to physically relax, both as a 'time out' and a relaxation routine that can be used at times of particular stress.

- **Coping with worries.** If you experience unwanted worries or concerns about your ICD that pop into your head - and may even stop you doing things you want to do - this section provides some simple strategies to help you stop being affected by them.

Other two leaflets:

Stopping smoking. Obviously only of benefit to smokers. It's not easy to stop smoking - and it can be even harder to keep not smoking. This section provides a structured approach to stopping smoking and staying stopped.

Eating healthily. This section provides information to allow you to develop or maintain healthy eating habits that are important to your heart health.

Common concerns

Here are some common worries about ICDs, and the facts behind them.

The worries	The facts
My ICD is delicate and may break without my knowing	ICDs have no moving parts and are extremely tough.
I cannot go near electricity as this will interfere with my ICD	Your ICD is in a sealed metal case and is designed not to be influenced by any electrical activity around it
I cannot make love, as the ICD may fire	Lovemaking is safe and is very unlikely to trigger the ICD. Even if it did, any shock would only be felt as a tingle by your partner
My ICD feels to be moving around a bit. I am worried the leads/wires could become dislodged	The feeling that an ICD is moving around is quite common. Your ICD is just settling into your chest. The wires are securely fastened and is it highly unlikely they will become dislodged. Also they come in varying lengths - so if you're very big, you'll have a longer lead than if you're very small. A suitable length lead is fitted in you with enough length to allow you plenty of 'give' for when you stretch
The ICD sticks out so much - much more than I thought it would - maybe something is wrong	The ICD may take up to a year to sink in and how much it sinks depends on the build of your body; if you have little fat, it may show more. Some people use their 'bump' as a 'party piece' and even show off their scar!
I am worried that the battery will run out and I won't be protected by my ICD	The technicians keep a close eye on your ICD's battery life, which is on average about 5 years. The battery will be replaced long before it runs out. The replacement of an ICD battery is a quick, simple procedure. You will likely only be in hospital for a few hours
I am worried about what the shock will feel like. Will it be painful?	This is a common worry to those that haven't experienced a shock. One person said it was like being hit hard in the chest. Another said the feeling was so quick, less than a second. But the common feeling was that they were glad they

	knew what to expect, as not knowing what a shock was like was far worse than experiencing the actual shock itself!
I am worried the wires joining my ICD may not be strong and break	The wires are very robust and unlikely to break. They are fine and flexible and are covered in plastic or silicon rubber so they are very strong.
I must take it easy through the day, as too much activity will tire me and trigger my ICD	It is important to maintain your daily activities. This will help keep your heart healthy and *reduce* the risk of the ICD firing. Your underlying heart condition may dictate how much activity you can do safely. But it is important to be as active as your heart condition will allow. If in doubt about how much activity you should be doing, contact your Arrhythmia Nurse.
I cannot begin to exercise as this is bound to trigger my ICD	It is very important to exercise of some sort. But it is important not to take sudden and excessive exercise. A gradual exercise programme will both improve your heart health and *reduce* the risk of your ICD firing.
When I exercise I must stop when I feel my heart beating fast, in case it triggers an arrhythmia	Exercise is supposed to get your heart beating fast! It is unlikely that you could induce an arrhythmia through any activity, but even if you did develop one, the ICD will take care of it. Remember it is important to *gradually* build up your exercise programme. Some people have their ICD because they have 'slow VT'. These people *might* be able to trigger a shock if their heart rate beats too fast. If you have slow VT speak with your Arrhythmia Nurse to find out how fast the ICD will allow your heart to beat before emitting a shock
I am worried I will pass out when I have a shock from my ICD	Your ICD will not make you pass out. Some people may pass out when they have an arrhythmia. If you pass out, your ICD will safely bring you round again.
I will be really worried if I get a shock from my ICD, because it means my heart condition is getting worse	Not necessarily. You may receive a shock for a number of reasons. Don't forget, the ICD is just doing what it is supposed to do. But if you are worried by a shock, contact your Arrhythmia Nurse
I'm worried a shock will damage my heart	This is an extremely common worry. No, shocks do not damage the heart in any way!

I get frightened when I feel the ICD pacing my heart	Many patients have said that it is not very pleasant when the ICD paces, but they have also said they get used to it, the more times it happens. But if you're worried contact your Arrhythmia Nurse
I used to be so fit, and the ICD has made me feel tired	It is not unusual to feel tired. Feeling tired is not due to your ICD. It may be because you are on beta-blockers. It may be because the ICD is allowing you to do more exercise than you have for some time - which is actually a good sign. Exercising within the limits of your tiredness will be of benefit to your heart. The tiredness will go in time for most patients, depending on their heart condition.
Since my ICD, the arm by my implant is painful and I have restricted movement	This is probably because of the way you are holding your arm - you have been told not to raise your arm above your shoulder and maybe you are restricting its movement. However, if it is painful, contact your Arrhythmia Nurse.
The ICD has made me lose my appetite	Your ICD cannot make you lose your appetite. If you have lost your appetite, it is likely due to your medication. If you have lost your appetite try eating smaller meals with snacks in between - see our Eating healthily leaflet.
Since my ICD, **I find I cannot sleep in bed as it is hard to** breathe	This is not because of the ICD but is could be due to your cardiac condition. Contact your Arrhythmia Nurse so she can arrange for you to see a Nurse who is a Specialist in your particular cardiac condition.
I am worried about going out on my own with my ICD in case something happens to me	You are now better protected than ever before! Some patients felt greatly reassured by having an ICD when going out - having an ICD is like having a 24h paramedic with you!
I don't like working alone now and wait until someone can work alongside me, in case I get an arrhythmia and then a shock	You are no more likely to get an arrhythmia physically working than whilst you are resting. In any case, if you do, then your '24h paramedic' will be working and keep you safe!
I have feelings about my ICD that others with ICDs don't seem to have	Your relationship with your ICD is unique - you may feel it's a friend or you may feel it's a foe! As you learn to live with it, you will develop your own unique set of feelings towards it and eventually you may even forget it's there!

I think I should be grateful that I have an ICD but I don't - in fact I feel quite angry and depressed about it - what's wrong with me?	Nothing in wrong with you. You are not alone with these feelings - many patients feel they should feel gratitude but do not. In fact some patients feel angry or frustrated for a long time after their ICD. If this continues, contact your Arrhythmia Nurse

Here are some common worries reported by partners:

I am worried that I am going to become a full-time carer	**This is a common but often an unfounded fear ... the ICD is there to help your loved one live their life just as normally as they did before**
I don't know what to do - should I stay with my loved-one all day? What am I supposed to do?	This is quite a common feeling for care-givers, especially in the first few weeks after the implant. But you must try to go about your daily activities as normal - the ICD is there to protect your loved one!
I would like to speak to someone about the ICD, but the arrhythmia nurse is really for the patient	You can talk to the arrhythmia nurse about any worries - she is there for both of you and your family. The partner's well being is very important - if you're reassured, then the patient will also feel reassured!

Keeping active

Your heart condition may determine how much and the type of exercise you may do safely. If you are unsure of how much exercise your heart condition will allow you to do, contact your Arrhythmia Nurse.

- *Following a gradual exercise plan will not trigger your ICD. The aim is to keep your heart rate within safe limits. Keeping active will strengthen the heart muscle, or at least not let other muscles deteriorate! Keeping active will also keep you fitter, more mobile and reduce the chance of having a shock in your daily life.*

Apart from very demanding activities such as running or hill climbing you may be able to gradually increase your day to day activity levels back to how you were before your ICD or even above them. If you intend to do highly demanding activities, then you should consult your doctor before doing them.

It may help to bring a bit of structure to this process. One way you can do this is to start by working out how much exercise you can do now, and then to gradually increase this until you are back to normal, or at the level of exercise you wish to achieve or your heart condition will allow.

Getting back to exercise

It's good for your heart and general fitness to get into a habit of taking some exercise each day. But this should be taken gradually. Many new ICD patients are surprised at how easily tired and weak they feel - even those that were very fit and regularly exercised before their implant.

For a first step, go for a walk along a flat bit of pavement or road for around10 minutes and monitor how you feel. It's important to make this first step. If you don't think your heart condition will allow this, try walking around the house or garden as it's important to keep mobile. If you feel OK or even if you feel that you have done too little, make that your limit for today. Then gradually increase your activity each day by a minute or so, *but not too much* - always maintaining that feeling of comfort.

- *The worst case is that you exercise too much one day and then are too tired the next to do any exercise. This will result in a loss of fitness, not a gain. Always work within your limits, but do so consistently.*

Once you are reaching your limits, feeling comfortable with the amount of exercise you are taking but not feeling you could do more, maintain this level for 2-3 days. After this, increase how far you walk by a minute or so, so you feel you are working harder but are not completely out of your comfort zone. Keep this level of exercise for 2-3 days, before increasing your exercise levels again as you get used to this level of exercise. If you start to feel tired, cut down a little and ensure that you remain within your comfort zone on the next day.

Keep this steady increase in exercise going until you are walking comfortably for 20-30 minutes a day in one go. Remember, for a few people, their heart condition may restrict *their ability to do this much exercise, even though they may like to. If you are one of these people, it is important to exercise as much as you realistically feel able - but NOT to push yourself beyond your limits.*

Once you have reached the time limit you want to set, you can increase the pace of your walking if you want. But follow a similar plan - a progressive increase pushing you slightly, but still keeping you within your comfort zone. You could, for example walk more briskly for 30 seconds every five minutes: when this feels comfortable, spend three days walking briskly for 1 minute every five minutes, and so on.

- *Try the talking test as you increase the pace of your walking. During your brisk walking you should be feeling slightly out of breath but still able to talk to someone if they were with you.*

Remember, the amount you increase your exercise should be worked out by how you **feel** - not by the distance or time taken to walk. It is important to work on this gradually, and to take exercise every day. Doing too much one day and then not exercising the next because you have tired yourself out will slow your progress, not speed it up. It may be frustrating, but it will pay off in the long run.

It may help to keep a diary and plan of your progress over the days and weeks, to remind you of how far you have progressed and to plan how far you will walk the next day. There is a diary you can use to do this at the end of the booklet - the Exercise Diary. Note, as with all the diaries in the booklet, there are four copies to allow you to record your progress of the first month after going home. If you find the diary useful, and need further copies you can copy the diary yourself.

But before you do this, it may be worth planning here and now when and how you will exercise. This type of planning is useful, as it prevents you forgetting and finding days slip by and you have forgotten to exercise or have not had enough time due to other things getting in the way.

I will do my exercise:

When (e.g. first thing in the morning after my breakfast)

Where (e.g. to the shops and back)

How (e.g. make sure that I do not plan anything in the day before I do it)

Some key tips to exercise:

- Use the talking test described earlier to make sure you are not pushing yourself too hard.
- Remember to start exercise gradually and to stop exercise gradually. If you are walking briskly, make sure that the first minute or so and the last few minute of the exercise are at a slower pace. This reduces the pressure on the heart.
- Walking can be boring - it may be worth trying out some things to make it less so. Walk with someone you can talk to, walk to a target place (a shop, or to a friend's house), listen to a radio or music while you are walking, and so on.
- Gradually increase your exercise levels following a plan - don't make sudden increases in exercise. It may be tempting, but it may hinder your progress rather than speed it up.

- If you feel anxious your heart rate is increasing too much, or you are out of your comfort zone, slow down *gradually* (don't stop suddenly), use the deep breathing or relaxation exercises we introduce later in the booklet to relax you and reduce your adrenalin levels, then slowly resume your activity.
- Stick to your plan - however, tempted you are, don't do more than you have planned - remember, progression is gradual and will pay off.

Increasing day to day activities

Exercise like walking is a good systematic way of increasing your fitness. It allows you to control how much exercise you do and to plan ahead. But life is not just walking, and it involves many other activities that require some physical effort.

There is no reason why you cannot resume most of the activities you were involved in before your ICD - an you may be able to do a few more. But it is important to follow a similar plan to the exercise programme. You can gradually increase your levels of general activity over the days and weeks following your ICD. As with the walking, do this in a gradual fashion: stretch yourself each day a little, keeping within your comfort zone - not pushing yourself so hard that you are too tired the next day to do anything but take it easy.

It can help to plan ahead what you will do. This will allow you to prioritise what you want to do, and make sure you are doing something that gives you pleasure or satisfaction each day. As with the walking, the aim is to gradually increase your day-to-day activities - to feel you are progressing, but keeping within your comfort zone.

Again, if you want to do plan ahead, there is a plan at the end of the booklet - the Activities Plan. Why not plan to do something interesting, exciting, different like going to the cinema or just washing up, or cleaning the car! The choice is yours ....!

Getting to sleep at night

Many people find it difficult to get to sleep when they get home from hospital - or even have problems sleeping generally. This may be a result of the stress of having the ICD, being away from home, the lack of activity following the operation, and so on.

Getting back into a good sleep pattern is important - if only to prevent the boredom of lying awake at night in your bed! But don't worry if you are not sleeping. It may not be what you want, but it will not affect your health.

Here are a few tips to getting a good night's sleep. None are perfect or the complete answer, but try to find the combination of strategies that suit you:

- Listen to the relaxation tape or use the deep relaxation exercise we provide later in the booklet, if you wake up or before you go to sleep
- Use the meditation exercise from later in the booklet, if you wake up or before you go to sleep
- Wind down during the evening before going to bed - don't do exercise, drink caffeinated drinks in the evenings such as coffee, tea, coke, etc
- Do exercise or keep as busy as possible during the day - regular exercise and activity are strongly associated with good sleeping patterns
- Have a warm bath or a milky drink before going to bed to help you unwind
- Make sure that you do not 'lie in' in the morning - it may be tempting, but it will delay you getting to sleep the following night
- Get into a routine of going to bed at a set time. Don't go to bed too early in an attempt to have more time available to sleep. We are not designed to sleep earlier than we are used to, and the likelihood is you will simply toss and turn and not get to sleep
- If you wake during the night or cannot sleep for 20-30 minutes after going to bed, stop actively trying to get to sleep. Read a book (either in bed or in a comfortable chair) or some other activity that is relaxing and requires concentration until you feel drowsy. Then try again.
- Some people require more pillows to get comfortable after their implant or even change the side of the bed that they usually sleep on. Go ahead and change sides and use as many pillows as you need to make you comfortable.

Learning to relax

Keeping relaxed is good for your heart and health in general. It can also help reduce the stress that can trigger an ICD shock in some people. This section will show you how to spot physical tension that can occur during the day (it's not always obvious), and show you some simple techniques how to reduce the tension.

Spotting tension

Sometimes we are aware we are very tense - when we are angry, upset, and anxious.

However, physical tension may creep up on up unnoticed. Many people get so used to moderate levels of tension that they no longer recognise themselves as being particularly tense.

It can become a habit we are unaware of, and is not associated with particular times of stress.

One simple way to find out if this is true of you is make regular checks on your level of tension through the day. Some of the signs to look for are:

- Shoulders hunched or tense
- Arms crossed or held tightly to the sides
- Tense stomach restricting breathing
- Hands held in fists
- Legs crossed tightly, often with the top foot pointing upwards
- Shallow or rapid breathing
- Facial muscles tight - tight jaw or furrowed forehead
- Standing or walking restlessly

It can be useful to get into a habit of monitoring your tension during the day as you learn relaxation because this gives some indications of the best time to use relaxation techniques.

Becoming relaxed

Relaxation is best done throughout the day - not just when your tension levels are very high. It may feel good at the end of the day to relax with your feet up on a comfy chair, sipping a pleasant drink, but it's not the best way to manage stress. For most of us, tension gradually increases during the day. If we just relax in the evening, the damage has already been done.

Relaxation strategies are designed to help you relax as much as is possible when you feel particularly stressed - angry, anxious, and so on. They are also designed to help you relax at other times of the day when your level of tension is less obvious.

Relaxation can be a time out, but it can also be a skill you can use whenever you feel tense - keeping as relaxed as possible while you go about your daily life. Using relaxation this way takes some practice and a series of steps - from practicing under ideal circumstances to using relaxation at real life stressful times.

Deep muscle relaxation

The first stage of learning relaxation (and using relaxation as a time out) involves a series of exercises that tense and then relax specific muscle groups throughout the body. Ideally hold each exercise for about 5 seconds and repeat each two to three times for each muscle group. The CD with this booklet talks you through the relaxation process. However, if you do not listen to the CD, you can follow the following process, tensing and relaxing each muscle group in turn:

- hands and forearms (making a fist)
- upper arms (touching fingers to shoulder)
- shoulders and lower neck (pulling up shoulders)
- back of neck (touching chin to chest)
- lips (pushing them together)
- forehead (frowning)
- abdomen/chest (holding deep breath)
- abdomen (tensing stomach muscles)
- legs and feet (push heel away, pull toes to point at head: not lifting leg).

You do not need a lot of tension. The most important thing is to focus on relaxing each muscle group following the tension - and not to rush the exercises. Don't stretch or push yourself too far, but while you practice the relaxation, keep yourself aware of how you feel, what the difference is between tension and relaxation, so you can begin to recognise these differences in your day to day life.

Finding time to practice

It is helpful to practice relaxation frequently at first. Ideally, you should set aside 20 minutes each day for two weeks or so until the relaxation process becomes a habit. You may find if you listen to the relaxation instructions on the regularly that you are able to relax increasingly quickly. Also, you may find after a time that you do not need to go through the CD - just using a special word like 'Relax' and thinking about how you relax may be enough to dramatically change how tense or relaxed you feel. This is when the relaxation is at its most useful.

Practice relaxation in very easy conditions - lying on a bed or in a comfortable chair. Make sure you are not going to be disturbed - if necessary take the phone off the hook or get away from noise of anything likely to distract you. The more you practice relaxation, the more useful it becomes. It can take several days before some people begin to feel fully relaxed after the relaxation process, and even longer before they can relax to order.

Using relaxation during the day

As you become used to relaxation, there are two ways you can begin to use your relaxation. Firstly, at regular intervals during the day: say, every half hour. Check your tension levels. Are you as relaxed as is possible given the circumstances you are in? If you feel it would be possible to relax more, try to relax the muscle groups in the order you practised *without* prior tension. Remember, the goal is to relax the excess tension away, not to become so relaxed you cannot operate as you normally would. It may help to take three of four deep, slow breaths to start the relaxation process.

An alternative strategy is becoming aware of situations or feelings associated with tension. These triggers to tension may include:

- ➢ when you are rushing
- ➢ when you feel uptight or upset
- ➢ when you feel angry
- ➢ when you are working to a deadline
- ➢ when you are having many demands made on you

Each situation can act as a trigger to both tension and using relaxation to ease the tension away. Some more examples of choices for cues to break your tension may be as follows:

- Someone who irritates or who annoys you. When you see that person, you are reminded to notice your body and relax. After a while, that person will become a cue to relax.
- If you are frequently up and down from your chair, you could even use this action as a reminder to relax.
- When you are walking, check that you are as relaxed as possible while you do so. Your shoulders, arms and so on are as relaxed as possible.
- Use cues such as the telephone or walking into the kitchen or whenever the door rings.
- When you start back driving, remember to relax fully at traffic lights and when held up. Put on the handbrake, and take time to relax as much as you can before driving off. Make the traffic lights your friend, not your enemy!

Before you get your driving license back, you may have to rely on lifts or may be driven around by your partner. Depending on how they drive, it may be *more important* to learn to relax!

Remember, it takes time and practice to relax fully and appropriately. In the beginning, it may help to practice relaxation quite frequently - even when you may not feel it is necessary - as this gets you into the habit of relaxing to order. This will help when you are trying to use relaxation under more difficult circumstances.

Quick relaxation

One quick way to trigger relaxation during every day activities is by learning to breathe in a relaxed manner. This can trigger the relaxation response. This involves breathing deeply and slowly. Try the following:

- Close your eyes and focus your attention on your breathing. Listen to the sound of your breathing. Take one deep breath and draw it right down into your stomach and let it go. Feel the tension escaping as you breathe out.

- Try to get your stomach to do the work of breathing - not your shoulders and chest. To ensure that you are breathing deeply enough, place your hands flat on your abdomen at the bottom of your rib cage. You should feel a slight movement as you breathe in and out. Continue breathing gently. Don't force it. You don't have to make yourself breathe! Keep your shoulders down and relaxed. If you do not do this naturally, try practicing it regularly until you can.

- You can do this simple breathing routine at any time, in any place, to help you relax. Check up on your breathing from time to time throughout the day until it comes naturally.

As with your exercise, it may be worth planning here and now when and how you will practice your relaxation. This type of planning is useful, as it prevents you forgetting and finding days slip by and you have forgotten to practice or have not had enough time due to other things getting in the way.

I will practice my relaxation:

When (e.g. every lunch time)

Where (e.g. in the bed)

How (e.g. make sure I do not plan to do anything at lunch time, take the phone off the hook)

Coping with worries

It is not unusual to worry about having an ICD. It may feel strange to have it inside you, and it may remind you of any health concerns you may have. Not everyone has worries about their ICD or their health, but if you do, then this section may be useful to you.

This part of the booklet examines two ways to help you cope with worries. Firstly, by checking that any worries you have are not exaggerated and inappropriate, and second by suggesting two strategies by which you can actively rid yourself of them - distracting from worries and learning to live with worries.

Worries in themselves are unpleasant, but an even worse consequence of worries is that they may stop us doing things that may be of benefit to us. In the case of people with an ICD, the experience of worry while exercising may result in them stopping exercise, or doing other physical activities.

- *The most important thing is that your worries do not prevent you from doing things you otherwise would do. Instead, learn to control your worries - and engage fully in life!*

Real life worries

Reading reassuring information can help reduce any worries you have when you are sitting calmly reading a booklet. But what about when worries spring to mind in 'real life' during your day-to-day activities? At this time, they may feel real and frightening. And it is these worries that are the most influential. They may stop us doing things, or spoil the experience of things that we do.

Because inappropriate worries are so common, experts have identified a number of different types of worry that can interfere with our mood and our actions. These include:

- ***Catastrophising***: predicting the worst outcome - "I know I will not be able to cope with the stress of going back to work"
- ***Over generalising:*** *when* things go wrong in one area of life, the belief that it will always happen and in different circumstances - "I opted out of doing things with my family because I felt tired - this is how it's always going to be from now on".
- ***Exaggerating***: giving negative events more importance than they really deserve and positive events less importance - "I felt anxious when I exercised yesterday, and even though I met my goal I, I keep thinking about how anxious I felt, not the success".

It is important to identify when we experience inappropriate worries such as these (and others) and not to be unduly affected by them. There are a number of ways this can be achieved:

- ✓ Challenging the accuracy of the worries/thoughts
- ✓ Distracting from worries
- ✓ Taking time off worries
- ✓ Learning to live with worries

Challenging the accuracy of the worries/thoughts

Many worries spring to mind automatically. They may not be accurate or realistic, but begin to dominate our thoughts. The first approach to reducing worries is to accept that the worries exist, but **not** to accept they are actually true and accurate. Just because they come to mind does not mean they are accurate - in fact there is a strong possibility that most worries are actually inaccurate!

The first response to these worries therefore may be to replace them with more appropriate and accurate thoughts. The thing to remember is that such thoughts are guesses or assumptions that could easily be wrong, they are not truths. Try to remember this and to take a different view on them:

Ask yourself:

About your thoughts

- *What other points of view are there?*
- *What would someone else think here?*
- *Could I be mistaken in the way I am thinking?*
- *Am I thinking straight?*

About reality

- *What are the facts here?*
- *What is the evidence for my worries?*

Try to replace worries with more realistic and positive thoughts when they occur in your day to day life. Sometimes this can be difficult when you are caught up with day to day life, and when the worries seem so real. To help you do this, it may be useful to think through more positive responses to worries when you have a few minutes peace. This can help change your response to the worries you have had, and think through more *realistic* thoughts to replace these worries if they occur in the future.

You can use the table at the end of this booklet (Changing worries) to identify your worries and to develop realistic responses to them.

It is worth spending some time doing this exercise either now or in the future when worries occur. If doing this exercise makes you wonder about issues to do with your ICD, please contact the ICD nurse, who will give you the relevant information.

Distracting from worries

Sometimes it can be difficult to argue worries away. A second line of defence against worries is therefore to use simple distraction techniques to stop them being the focus of our attention. Distraction does not mean just trying not to think about an issue or worry - it means consciously and deliberately focusing on something (anything!) other than the worry. What you think about is not particularly important. The most important thing is that you think about it *immediately* the worry comes to mind and that this distraction becomes the full focus of your attention.

Some distractions that people have used include:

Things you can think:

- ✓ Counting to 50, while imaging the numbers in your head
- ✓ Thinking of a calm or favourite place
- ✓ Thinking of a holiday or other enjoyable times or plans

Things you can do:

- ✓ Talk to someone about anything other than the worry on your mind
- ✓ Absorb yourself in something interesting or fun to do
- ✓ Watch a film or read a book - but be careful to really focus on the plot, not simply do this while actually focusing on your worries
- ✓ Listen to a radio programme.

Different strategies may work for different people and at different times of the day - keeping busy may be more helpful in the day, thinking of a favourite place or listening to the radio may be more helpful at night. The important thing now is to find one or more strategies that work for *you*.

It is worth spending a few minutes now thinking through what may work for you. Your ideas may be as sensible or crazy as you like. The important thing is that it works for you - no one else need know what you are thinking or doing! Jot down some of your ideas in the space below. It's worth thinking of a few strategies you can use - perhaps with separate one for worries during the day and those at night - so you can try them all out and find the one that works best for you.

My distraction strategies in the day will be:

My distraction strategies at night will be:

Once you have thought about your distraction techniques, try to use them every time a worry comes to mind. You may not be successful every time, but keep trying. The more you use them, the easier you will find it to use them, and you will also find that any worrisome thoughts come to mind less frequently.

Taking time off from worries

You can use the realistic responses and distraction at the actual times when you experience worries. But there are also exercises you can do to relax your mind at other times. Here is a simple meditation you can use to help you unwind from the daily pressures, take a time out to really relax your mind. It involves focusing on the present - the physical sensations you are experiencing, and allowing worries to enter but then leave your mind.

You can do this for around 10 minutes and with some practice become fully relaxed and de-stressed. It may help you stop worrying about time while you are doing this exercise if you set a watch or clock alarm to go off after a period of time of your choosing.

If you make it a daily routine, this simple routine can significantly reduce your stress levels.

1. Sit quietly and comfortably in a supportive chair.
2. Either close your eyes or sit so you are looking at something non-distracting like a blank wall.
3. Focus on your self and your surroundings. Become aware of your body, of the physical position of your arms and legs, of your feet and hands. Notice the feel of your body pressing against the chair, of the muscles around your eyes and jaw; notice the feelings of your skin.
4. Become aware of your breathing. Follow a breath as it comes in through your nose, travels through your lungs, moves your belly in and out, and leaves in the opposite direction. Ride the waves of your breathing without attempting to alter it: just notice it and pay attention as it happens.
5. If your mind wanders and you find yourself thinking about your day to day worries, just notice that you have wandered off and bring yourself back in touch with your body. Just notice yourself getting sucked in, and bring yourself back again, gently and without judgment. Your goal here is simply to practice awareness of your bodily sensations. This means that if your mind wanders 100 times, then your job is to gently bring it back to this moment 100 times, starting with the present moment.
6. After a time you chose (5-20 minutes) gradually stretch, focus on things beyond your body, and get back to your normal routine, feeling relaxed and refreshed.

Learning to live with worries

Some aspects of the meditation you have practiced can also be incorporated into your daily life. If we have worries or concerns that concern us they may take the pleasure away from our activities - or even stop us doing them.

One way we have discussed about how to deal with these worries is to 'logic' them away. This approach can be very useful, but sometimes it is very difficult to logic worries away - we cannot think of arguments against them at the time, or we end up just thinking about them more.

An alternative approach involves using a technique called 'mindfulness' to cope with these thoughts. At its simplest, it uses some of the awareness techniques used during the meditation described in the earlier section. That is, it involves being totally aware of all possible sensations you could experience at any one time.

As an example, while walking down the street, you could be aware of

- How are you feeling - how tense are you (n your shoulders, arms, neck, etc), how cold are you, are you walking quickly, how does it feel as your feet hit the ground - is it hard or soft, etc.

- What is happening around you - what can you see, what are the people doing, how hot/cold is it, etc.

This is like an on-going form of distraction - you are so involved and immersed in your experience that although you may be thinking worrisome thoughts, you are aware of them as a part of many many other experiences - and because of this they are not the focus of your attention. And because of *this*, they do not have the emotional impact they would otherwise have.

The aim here is not to actively try to get rid of the thoughts, although with your focus on so many things they may well go. Rather, it is to not fight the thoughts but by not focusing on them, to stop them being the only thing you are concentrating on, and to stop them having any the emotional impact. As with all the other techniques and strategies in this booklet, it is important to practice doing this when you are not experiencing worries, so you can use the skill effectively when you are experiencing them.

Planning a shock strategy!

It is understandable to be worried about an impending shock. But remember that a shock is exactly what the ICD was designed to deliver!

Some patients never receive a shock, and some patients receive more than one. Even though you don't know where or when you will receive a shock, it is helpful to think through what you will do if you do have one. You will then be more equipped to cope with a shock should one happen, a bit like knowing where the fire-exits are and where to assemble to be accounted for should there be a fire.

Patients and partners who knew exactly what they would do if they or their partner had a shock felt much more confident going about their daily business. For example, it could be something simple like finding somewhere to rest, having a cup of tea and phoning someone.

Unless you have been told differently by your Arrhythmia Nurse, try to follow the golden rule ...

"One shock's ok
Two's fine
but three or more, phone 999!"

But the most important thing to remember is to stay calm ... *REMEMBER the ICD is only doing what it is supposed to do!*

Patients have told us that the anticipation of not knowing what a shock was much worse than actually having one!

Always contact your Arrhythmia Nurse Specialist or your ICD Nurse Specialist if you are worried after receiving a shock, if only for reassurance!

Exercise diary - week 1

You can use this diary to plan and record your exercise. You can plan your exercise following the guidance in the booklet by writing your time and route goals in pencil. Then record them in ink to keep a permanent record of the progress you make.

	Time	Route
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise diary - week 2

You can use this diary to plan and record your exercise. You can plan your exercise following the guidance in the booklet by writing your time and route goals in pencil. Then record them in ink to keep a permanent record of the progress you make.

	Time	Route
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise diary - week 3

You can use this diary to plan and record your exercise. You can plan your exercise following the guidance in the booklet by writing your time and route goals in pencil. Then record them in ink to keep a permanent record of the progress you make.

	Time	Route
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise diary - week 4

You can use this diary to plan and record your exercise. You can plan your exercise following the guidance in the booklet by writing your time and route goals in pencil. Then record them in ink to keep a permanent record of the progress you make.

	Time	Route
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Activity planner - week 1

You can use this planner to plan new enjoyable activities that you can take up or restart as you get used to your ICD. It can be useful to complete this on the Sunday before the forthcoming week. You do not need to do a new activity each day, but plan ahead which new (or old) enjoyable activities you will do in the next week.

	Activity
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Activity planner - week 2

You can use this planner to plan new enjoyable activities that you can take up or restart as you get used to your ICD. It can be useful to complete this on the Sunday before the forthcoming week. You do not need to do a new activity each day, but plan ahead which new (or old) enjoyable activities you will do in the next week.

	Activity
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Activity planner - week 3

You can use this planner to plan new enjoyable activities that you can take up or restart as you get used to your ICD. It can be useful to complete this on the Sunday before the forthcoming week. You do not need to do a new activity each day, but plan ahead which new (or old) enjoyable activities you will do in the next week.

	Activity
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Activity planner - week 4

You can use this planner to plan new enjoyable activities that you can take up or restart as you get used to your ICD. It can be useful to complete this on the Sunday before the forthcoming week. You do not need to do a new activity each day, but plan ahead which new (or old) enjoyable activities you will do in the next week.

	Activity
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Changing worries

In this chart, you can write some of the worries you are experiencing, and then counter them using the strategies we discuss in the booklet. Once you have argued against them on paper, remember your argument and use it whenever the thoughts crop up during the day.

My worries	Realistic responses to them

Ring your Arrhythmia Nurse if you have any worries or concerns:

Appendix XIX

Getting on with life: Stopping smoking

Self-management programme for ICD patients to give up smoking

A structured approach to stopping smoking

Contents

Introduction to the programme

NOW you have an ICD, you may feel it's a good time to stop smoking as stopping smoking can only help your heart! This programme is a structured programme developed with experts to help you stop smoking. It is designed to help you plan and choose a quit day, when you will stop smoking completely - hopefully forever.

Each section leads onto the next in the flow of giving up smoking. We suggest that you do this in three stages:

- Stage 1: planning to quit
- Stage 2: your quit day
- Stage 3: staying stopped

The final section, Top Tips, gives some quick ideas to help you quit.

This programme will help you in different ways

- ✓ It will help to identify when and why you smoke cigarettes.
- ✓ How to choose a quit day and make that the day you stop smoking - hopefully forever
- ✓ How to cut down, if you really don't feel you can stop immediately
- ✓ How to cope with the first few days and weeks after you have stopped smoking
- ✓ How to cope with temptation in the long-term

Different sections of the booklet deal with each stage. We recommend you read the entire contents of each stage in the leaflet before you start to work on that stage of the stopping process. In that way, you can prepare fully for what is to come.

But before coming to stage 1, we ask you to consider why you want to stop smoking.

Why should I stop smoking?

It is never too late to stop smoking. Before you even try to stop, it's important to think about what you stand to gain. We all know about the long-term health benefits of giving up smoking, but many people are surprised at how soon some of the benefits kick in - and it's not just your health that will feel better. Here are some of the most common benefits you might experience - in the short and long term.

✓ *Within Hours ...*

Get your breath back! Smokers get more out of breath than non-smokers doing anything that requires intense activity! This is because smoking hampers the body's capacity to carry oxygen around the system. This effect disappears within hours of stopping smoking.

✓ *Within Days ....*

Boost your lungs' natural protection against chest infections and the effects of pollution! Smoking kills microscopic hairs in the lungs that push out pollutants and other bacteria. Without them, smokers are more prone to chest infections or other negative effects of pollution. The hairs grow back quickly and start working properly within days of quitting smoking.

Don't be surprised if you experience a cough in the days after quitting though. This is a sign that the hairs are growing back and pushing out the toxins that have settled in the lungs - perhaps for months or even years!

Boost your body's defence against coughs, colds and other viruses. Smoking reduces the body's ability to fight off infection. This damaging effect can stop within days of stopping smoking.

Rediscover the joy of food! Smoking interferes with the senses of taste and smell, making food less enjoyable. These senses begin to return a few days after stopping smoking.

✓ *Within Months ...*

See how much money you've saved! Smoking is expensive.

Look younger! Smoking can increase the wrinkles in the skin on your face, and makes smokers look older than non-smokers of the same age. Not only can you live longer as a result of stopping smoking, you can look younger as you do! Additionally, the colour of the skin will also improve.

✓ *In the long run ....*

Add years to your life expectancy! The more you smoke, the more you stand to gain! Smoking about 10 cigarettes a day reduces life expectancy by between 1 and 3 years; smoking 20 a day reduces it by between 5 and 7 years; smoking 40 a day reduces it by an average of between 8 and 10 years.

The sooner you stop, the greater the benefits can be! You can reverse the health risks of smoking pretty quickly. Five years of non-smoking substantially reduces risk for smoking-related diseases, and cancers of the lung, throat, stomach, breast and bladder. By ten years, it is almost as if you had never smoked. Quitting even in middle or older age will benefit you and you could avoid most of the later excess risk of death from tobacco.

Add life to years! Enjoying middle- and old-age means not just living longer but being healthy enough to make the most of these years. Stopping smoking will help maintain your health and ensure you keep active and healthy, allowing you to get the most out of this time of your life.

Reasons for stopping smoking

Try to list the five most important reasons for you to give up smoking.
My reasons for wanting to stop smoking now are:

1.

2.

3.

4.

5.

It may be helpful to write down your reasons for quitting on a piece of paper or card and carry it around with you as you stop smoking. It will be a useful reminder of your motivation to quit when the going gets tough. You may want to change the list as time goes by if your reasons for wanting to quit change.

Stage 1: Planning to quit

There's no hiding the fact that for most people quitting smoking can be difficult. You may have tried before - and not succeeded - but that doesn't mean you won't succeed this time.

You can make it easier by planning when and how you are going to stop. The next few sections will help you to understand why you smoke the cigarettes you smoke and help you to prepare for any withdrawal symptoms you may experience when you stop smoking completely, and how to limit the temptation to smoke. This is all a part of the important planning process - helping you to prepare you for the day you stop smoking - hopefully forever.

Understanding why you smoke

You've just worked out why you want to stop - now try to work out why you smoke your cigarettes. Understanding your reasons for smoking is a crucial part of the quitting process.

There are generally two reasons for smoking - dependence on **nicotine** and **habit.**

Nicotine dependence

Nicotine is a powerful and unusual drug - small amounts can pep you up and larger doses calm you down.

This is what causes people to become physically and psychologically dependent on nicotine. People smoke because they feel uncomfortable, irritable or simply have a craving. Smoking relieves this and makes us feel better. Symptoms are worst when the smoker has been prevented from smoking for some time, like in the morning after going through night without a cigarette.

A simple test of how nicotine dependent you are is to think about how you feel in the morning and when you smoke your first cigarette. If you simply cannot do anything in the morning before you have a cigarette you probably have a high level of nicotine dependence. In this case, you could consider using nicotine replacement as a support when stopping smoking.

Habit

Many smokers, even those who are nicotine dependent, frequently smoke out of habit. Habit cigarettes are those routinely smoked - perhaps without even noticing it.

You may light up when you answer the telephone, have a cup of coffee or tea, or when you finish a meal. Sometimes lighting up may be so automatic that you forget you have a cigarette and light another one with the first still burning.

Cutting down your smoking

If you find it difficult to stop at once, you could start to cut down the amount of cigarettes you smoke first. You should aim that the number of cigarettes you smoke is about 12-a day - **but no less**. You'll smoke less than you do now, but not so few that you experience any withdrawal symptoms.

How long you take to get to 12 a day depends on how many cigarettes you smoke and how quickly you want to cut down.

Planning to cut down

1. Decide how long you want to take to cut down the number of cigarettes you smoke to about 12-a day. As a rule, a maximum of 2 weeks is best.
2. Write down the number that you plan to smoke each day until you reach 12-a day. There is a planning diary to help you do this at the back of the leaflet.

Cutting down

1. Think about which cigarettes you will cut out the next day and how you would cope with not smoking them in the evening - so you are prepared to cope with cutting down. Start by cutting out the cigarettes you find the easiest to stop
2. Follow your plan until you get to 12-13 cigarettes a day. This will be your Quit Day, when you stop smoking completely.

How best to avoid the temptation to smoke

There are a number of ways to help avoid the temptation to smoke. They may not all be possible and appropriate for you - pick the suggestion that will work for you.

Try to avoid situations in which you usually smoke

Many cigarettes are smoked out of habit - triggered by routine circumstances.
Do you find yourself smoking in these common habit situations?

- *After a meal*
- *At a work break*
- *While answering the phone*
- *With a cup of coffee or tea*
- *While driving the car*
- *With friends who are smokers*
- *When offered a cigarette by a colleague or friend*
- *The sight of someone else smoking*
- *Watching television*
- *Sitting outside a pub or restaurant with lots of people around who are smoking*

In the days while you cut down or after quitting, you may want to avoid or change some of these danger situations. Or at least make it difficult to smoke in them. How you do this is for you to consider. Write down in the table some ideas that will work for you ....

To help why don't you ....

Try to get support from friends. If you feel comfortable, tell your friends and other people that you come into contact with that you are giving up smoking.

- You won't want your smoker friends to offer you cigarettes.
- Friends can give you support when you are craving a cigarette.
- Ask your friends not to ask you too many times how you are getting on. You don't want to be reminded of cigarettes!
- Knowing you are giving up may help your friends understand why you are avoiding smokers; it's because you feel tempted to smoke, not because you don't like them!
- You may feel more committed once you have told other people you are giving up smoking.
-

Try to:

- *Drink something different instead of your usual coffee or tea - orange juice, water, or whatever. This will break your routine and stop you lighting up automatically.*
- *As you get in the car, chew on a sugar-free gum or sweet. This will interfere with smoking and stop the habit of smoking as you drive.*
- *Move ashtrays around the house or put your cigarettes somewhere that you don't normally put them. Neither will stop you smoking. But they will stop your smoking being automatic. Avoid passing the tobacconist where you usually buy your cigarettes. You may 'just' pop in and buy some without even thinking about it.*
- *Ask your smoker friends not to offer you a cigarette even if they are smoking.*
- *Keep your cigarettes in places that it is a hassle to get them. In the house, for example, keep them in a room as far from where you normally smoke as possible, maybe with an elastic band around them.*
- *If you are in a pub or restaurant try to avoid drinking too much alcohol to avoid the temptation to smoke*

Try to make it difficult to smoke

This can be a very effective preventative measure! Think through some strategies that may help you. Here are some ideas you find useful:

- *Don't carry any cigarettes with you.*
- *Tell your smoker friends and colleagues you are giving up smoking and ask them not to give you a cigarette - however hard you plead!*
- *Do not carry more money than you really need for essentials (bus, taxi, train etc) so that you cannot buy cigarettes.*

Coping with temptation

There will inevitably be times when you are tempted to smoke a cigarette, the thought of that cigarette slowly burning in your mind. But even at this point there are a number of things you can do to reduce your risk of smoking. Try some of these:

- *Deliberately change the focus of your attention. Instead of thinking about how much you want that cigarette, focus your attention on other things - even the bizarre and unusual.*
- *Focus on things happening around you. Concentrate on the conversation you were drifting away from. Pay attention to the television programme that was losing your attention and so on.*
- *Think distracting thoughts - count backwards in sevens from 100, imagining pleasant non-smoking (!) images, and so on.*
- *Try to remember your reasons for giving up smoking. Bring these to the front of your mind and focus on them.*
- *Try to keep yourself busy if you can, so that you won't have time for a cigarette.*

Fiddling hands

Some people find the process of preparing cigarettes (getting them out of the packet, holding them, lighting them, or rolling cigarettes with loose tobacco) to be a way of reducing stress. It gives them something to do with their hands.

It may be useful to have something else to do with your hands at times when you may have fiddled with cigarettes. It doesn't matter what you choose - stress balls, worry beads - anything to fiddle with that can replace your cigarettes.

Stage 2: Your Quit Day

Once you have cut down to 12 cigarettes a day, the time has come to choose a quit day and plan how you will get through it. It may be a difficult day. But it is also a day in which you embark on a New You - an ex-smoker.

Goodbye to the Old You

Celebrate having had your final cigarette in some way. Here are some ideas from other smokers who have stopped smoking to spark your imagination:

- *Bury your last packet of cigarettes deep in your garden.*
- *Give all your last cigarettes and smoking paraphernalia (lighters, ashtrays, etc) to any colleagues and friends who continue to smoke.*

Welcome to the New You

Try not to smoke at all on your Quit Day. Start the day as you intend to continue. Try to make it a special day and plan lots of things that you enjoy to keep you busy and distract from the urge to smoke.

- *Start the day with breakfast in bed - choose your favourite foods and just enjoy yourself. If you always have breakfast in bed, try having a delicious breakfast somewhere you would only go for a treat.*
- *Treat yourself to a day out if you are not at work.*
- *Buy some new clothes or some other treat - you'll be able to afford them with the money you save by not smoking.*
- *Go out for a meal - but be careful not to drink too much alcohol. This may interfere with your motivation to remain a non-smoker.*
- *Go out to a place you enjoy and where you cannot smoke, e.g. cinema.*

If you have a cigarette

If you smoke a cigarette today or on any of the following days, *remember that it is a mistake that can be corrected.* Just because you have smoked one cigarette does not mean that you will inevitably go back to smoking. Learn from your mistake. Think why you smoked that cigarette and how you could avoid a similar mistake in the future.

If you do this, you will gain the confidence that you can remain a non-smoker despite the odd slip, and be prepared for mistakes in the future.

Coping with withdrawal symptoms

The aim of the programme has been to avoid withdrawal symptoms while you cut down smoking. But now is the time you may experience some.

> *Not all smokers experience these effects. In fact, the same person may have more or fewer symptoms on different occasions when they stop smoking. Just because you had severe symptoms on one occasion does not mean that you will have bad ones on another.*

Nicotine dependence

Nicotine is an addictive drug. Over time, the body gets used to a certain level of nicotine. When these levels drop - particularly when people stop smoking - the body has to adapt to lover levels of the drug. The process of adaptation can be unpleasant and result in what are known as withdrawal effects. But this is the body recovering to its normal state so think of them as **signs of recovery.**

As a rule, those who are highly nicotine dependent are most likely to experience withdrawal symptoms. These can be both physical or psychological symptoms.

Physical withdrawal symptoms/signs of recovery can include:

- *Restlessness or tiredness*
- *Disrupted sleep*
- *Shakiness*

Psychological withdrawal symptoms can include:

- *Strong craving for cigarettes. These are usually strongest in the short-term, but it can happen months or even years after stopping smoking.*

How long do withdrawal symptoms last?

These symptoms can be at their worst for about 2 or 3 days, and may continue to a lesser extent for up to two or three weeks.

Coping with withdrawal symptoms

There are a number of ways of combating withdrawal symptoms at this stage.

- *Consider nicotine replacements. If your symptoms are severe, go and see a pharmacist or doctor about their use.*

- *Keep busy. Don't give yourself time to dwell on any symptoms you are experiencing.*
- *Stay away from reminders of cigarettes. Concentrating on cigarettes will also make the withdrawal symptoms feel worse.*
- *Think of your withdrawal symptoms as* ***signs of recovery****. They are a sign of the body recovering its normal state and adapting to having no nicotine in it.*
- *Vitamin C has been reported to help control withdrawal symptoms. Try eating lots of fruit high in levels of vitamin C or fruit juices. But keep your eyes open that you don't drink the high sugar fruit juices. Try to consume the ones without added sugar.*

Congratulations! You are now a non-smoker.
The trick now is to remain a non-smoker over the next few weeks.

Stage 3: Staying a non-smoker

Strategies

For the first few days after your quit day, it can be useful to keep busy and to make your life quite different to your normal routine. This will help you be distracted both from habit cigarettes and from any withdrawal symptoms you may experience. You can use the same strategies you have been using to help you cut down to help you avoid or cope with the temptation to smoke.

Reward your success

Every day that goes by makes you more secure as a non-smoker. Now is the time to pamper yourself and reward yourself for your success. Think about one small reward you can give yourself each day during the first week or two after you have stopped smoking. For example, a cinema ticket, a bunch of flowers for yourself or a romantic gesture to your partner, a nice evening with your partner, a nice book, a warm relaxing bath, a games evening with friends - it doesn't have to be financial!

After each week, you may want to give yourself (or your partner) a bigger reward like a bunch of fresh flowers! You deserve it - and the money you save means that you can reward yourself with something that costs money - without it costing money!

Reward yourself

Think of a few rewards you can give yourself over the next two weeks to help take your mind off any cravings for a cigarette. Try to make this period as much fun as you can.

My daily rewards for success will be:

____
____
____
____
____
____
____

My weekly rewards for success will be:

____
____
____
____

Spotting the benefits

After two weeks of not smoking, think about whether you have noticed any changes after stopping smoking? Are you less out of breath if you suddenly exert yourself? Has your sense of taste improved? Note down any changes you have noticed.

Remember, some uncomfortable symptoms such as coughing may be a sign of improvement as your lungs get rid of the rubbish that has accumulated in them over the years. Rate this as a gain not a loss!

The things I noticed are:

____
____
____
____
____
____
____

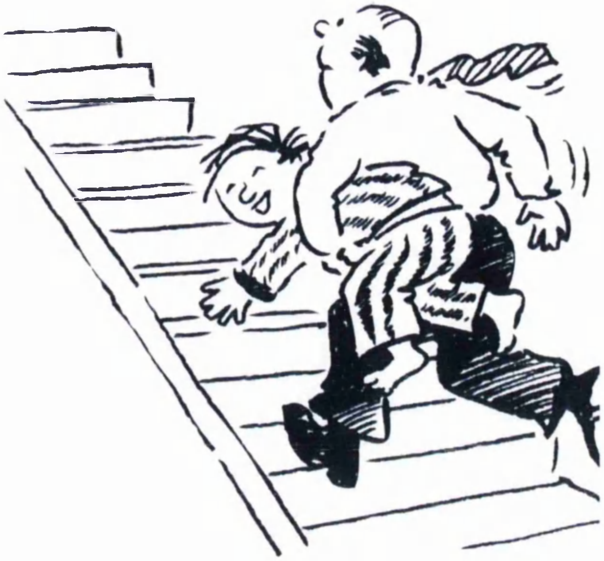
The weeks after stopping

If you have got this far through the stop smoking programme, well done! You are well on the way to being a non-smoker permanently!

The main thing now is to be aware that you may still experience an occasional strong craving for a cigarette - and learn how to cope with it. This is perfectly normal - and each craving will pass relatively quickly. Nevertheless, it is best to be prepared for them, should they occur.

- *Don't be tempted to 'just have one' cigarette - this may put you on the slippery slope into being a smoker again.*
- *Be careful in situations in which you habitually smoked, particularly when you drink alcohol. Many people link a social drink with a social cigarette. If you have been drinking, the chances of keep to 'just one' are really low. For example, in a pub or restaurant garden/terrace, try to sit directly next to non-smokers.*
- *Keep your list of reasons for wanting to stop smoking - just as a reminder should temptation arise in the future.*
- *And once more, the mantra to remember ... if you smoke a cigarette, remember that it is a mistake that can be corrected. Think of it as a mistake - not a disaster - and concentrate on stopping a similar mistake in the future. Think about why you smoked that cigarette and how you could avoid a similar mistake in the future.*

Good luck in your life as a non-smoker!



Top tips to stopping smoking

This section provides some quick tips on quitting. It is a 'taster' for those who are thinking about giving up smoking, but do not want to use the more structured approach. If these strategies work for you, congratulations! If they don't and you are still determined to quit smoking, we recommend you to try the stop smoking programme on page XX and get more support from an NHS smoking cessation nurse as you tackle this potentially difficult process.

Choose a Quit Day

- The best way to quit is to choose a quit day when you will stop altogether.

Coping with Quit Day

- Plan how you are going to cope with your quit day and the days immediately following it. The Tips in this section provide some ideas about how you can go about this.

Celebrate your Quit Day

The day you stop smoking is important and should be marked in some way. On the day you decide to stop smoking, why not:

- ✓ Get your friends around to celebrate your efforts - in a games evening or have a non-smoking party!
- ✓ Don't just celebrate in your head - take someone special (or just yourself!) for a meal, or to the cinema, or whatever interests you.

Once you have reached the end of your first day of being a non-smoker, celebrate! There is still some way to go, but the most important step on any journey is the first one, and you have taken it!

Cutting down

If you really don't feel you can quit immediately, we suggest you cut down to 12-13 cigarettes a day over a period of one or two weeks. Then choose a Quit Day.

Worried about weight?

Some people put on weight when they stop smoking. This is because the nicotine affects the regulation of weight and because many smokers start eating more.
Giving up smoking can take up a lot of your energy and concentration. It can therefore be difficult to go on a strict diet over this period. We suggest that you focus on stopping smoking in the first days. Only try to lose any weight gain when you have gained the confidence in your ability as a non-smoker.

You can, however, take a few simple steps to help your diet.

- If you eat more snacks - try low calorie/low fat nibbles, such as rice cakes, low calorie sweets or gum. Try eating vegetables or fruit snacks. Find something that you enjoy eating, so your replacement gives you some pleasure and is not something you feel you have to eat despite the unpleasant taste.

- Some people have suggested that some fruits high in vitamin C, like oranges, kiwis, may reduce withdrawal symptoms. So, eating them or drinking their juices may have a double bonus.

- If you really do not want to gain any weight, it may be necessary to change your diet and to eat more fruit, vegetables and other low fat foods as you quit smoking.

Do I need nicotine replacements?

Not all people benefit from nicotine replacements. Those who do usually have a high level of nicotine dependence and are likely to suffer withdrawal symptoms as they stop smoking. It is difficult to predict whether you will get withdrawal symptoms - even if you have smoked for a long time.

If you would like to know what the typical withdrawal symptoms are like, please go to "What are withdrawal symptoms" on page 13.

An easy way to find out whether you have a strong dependence on nicotine is to think about when you get up in the morning. If you have a cigarette before you do anything else - have a cup of coffee or tea, get dressed, and so on - then you are probably nicotine dependent. It may be helpful for you to use a nicotine replacement of some kind when you quit smoking.

Kicking the habit

We frequently smoke out of habit, usually as part of our routine behaviour - drinking a cup of coffee, sitting down with a friend in a break at work, watching the television in the evening. How often do we light a cigarette without even thinking about it? Avoid the temptation to smoke on these occasions, at least in the first few days after you have stopped smoking. Try avoiding these situations - go for a walk during your break or have a drink of orange juice, spend time with non-smoking friends and so on. Try to keep busy so that you don't have empty time when you will be longing for a cigarette.

If you cannot avoid situations in which you usually smoke, try to think of some ways in which you can make it difficult to smoke at these times.

Making smoking difficult!

Some people like to carry a packet of cigarettes around with them once they have quit smoking - as a sort of emergency pack or test of willpower. This may suit some people, but most would benefit from setting up their life to make it difficult to smoke. So don't carry cigarettes around with you!

Get rid of ashtrays in the house and you car: avoid walking past the tobacconist where you normally buy your cigarettes.

Think about what strategies you could use to make it difficult to smoke: jot them down the space below:

____

____

____

____

____

Get support

The last thing you need when you are giving up smoking is for someone to offer you a cigarette or be unsympathetic when you are struggling to stay stopped. To prevent this, tell your friends and colleagues that you are going to stop and try to enrol their help. Knowing that they know you are quitting may also act as an incentive to stay stopped!

Reward yourself - have some fun!

Quitting smoking is no fun, but you can make the process more tolerable! Build some treats into your life in the days and weeks following quitting - see it as a reward. In the first week after quitting, you may want a treat quite frequently - maybe once every day or every two days. In the next week or two, think about things you can do every two or three days.

Withdrawal symptoms are a sign of recovery

Withdrawal symptoms can be difficult to cope with but they are a sign that your body is already recovering. Every time you experience a withdrawal symptom, you are actually experiencing your body learning to cope without nicotine and other poisons in it. Tell yourself this when you experience the symptoms. It might not make them go away, but you might feel better about them.

Remember your reasons for quitting

Before you stop smoking, write down why you have decided to quit. What are the most important reasons for you? Jot them down on a small piece of card and carry this with you all the time. When you feel tempted to have a cigarette read the list you have written to remind yourself. It may be useful to re-write the list - perhaps thinking of different issues - every few days to make sure that it is fresh in your mind and relevant to you.

Don't catastrophise

Remember that we all make mistakes. If you have a cigarette (as many people do), try not to catastrophise and think "Now I've smoked this cigarette, I'm back to smoking again - I may as well have another". Instead think of it as a natural mistake - and an opportunity to think how you could avoid making the same mistake in the future. And get back to being a non-smoker.

Avoid the temptation in a pub or restaurant

If you are in a pub garden or restaurant terrace where smoking is allowed, try to sit directly next to friends or people who don't smoke. This makes it harder to get cigarettes off them.

Where to get more information and Support?

The NHS Stop Smoking Helpline have advisors who can advise you what support is available if you feel you are nicotine dependent or if you think you need someone to help you stop smoking. Ring the NHS Stop Smoking Helpline to call to a trained, expert adviser for free on **0800 022 4 332.**

Lines are open: Monday to Friday, 9am to 8pm and Saturday & Sunday, 11am to 5pm

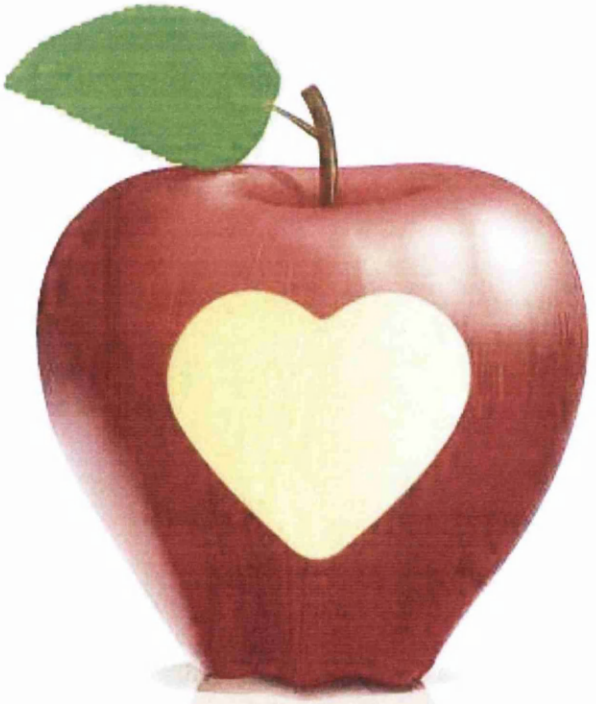
The planning diary

Use the diary to plan how may cigarettes you will smoke each day in the next two weeks, gradually cutting down to 12 per day.

Days	Target number of cigarettes	Days	Target number of cigarettes
Monday		Monday	
Tuesday		Tuesday	
Wednesday		Wednesday	
Thursday		Thursday	
Friday		Friday	
Saturday		Saturday	
Sunday		Sunday	

Getting on with life:
Eating healthily

Eating healthily - self-management programme for ICD patients



Tips to make easy changes for a healthier diet

Contents

Introduction

NOW you have an ICD, you may decide it's a good time to change how you eat, as a better diet can only help your heart!

This is not a manual to tell you how you should be eating from now on! But it is designed to be a gentle reminder of how food affects our bodies and gives easy tips on how to improve what you eat with little or no effort at all!

This issue will help you in several ways

- ✓ You will be reminded of the food groups and their importance
- ✓ You will be reminded of what a unit of alcohol is
- ✓ You will be reminded of how much you should be eating each day
- ✓ You will get tips on easy ways to improve your diet without much effort!

Sometimes it's good to be reminded of the benefits of eating healthily as it's so easy to forget, especially when we lead such hectic lives, and slip into bad habits!

The benefits of healthy eating

We all know that healthy eating is good our health.

First of all, ask yourself what you stand to gain and what you stand to lose by eating a healthier diet. Make a short list. Remind yourself of the health benefits of healthy eating as well as the potential for weight management.

If I change ...	**If I stay as I am ...**
... what do I gain?	... what do I gain?
... what do I lose?	... what do I lose?

Healthy eating can help decrease the risk of making any cardiovascular disease worse, decrease the risk of diabetes, cancer and obesity, helping to prevent the risk of premature death through a poor diet.

Also, keeping your bones and muscles healthy through your diet now might help keep you fitter for longer in later life! But these are long term benefits, and you're probably more interested in the benefits of a healthy diet on your day to day living.

Short-term benefits

We know that healthy eating is good for your heart. But it also has many other benefits.

Healthy eating can help you look and feel better about yourself! And don't forget - these short term benefits can lead to long term effects!

Healthy skin & hair

- A balanced diet that contains the right vitamins and minerals can improve the look of your skin and hair.

Healthy Weight

- Crash dieting is not the way to a healthy weight and it's not much fun either! Healthy eating, alongside physical activity, is one of the best ways to get your body in shape - and get you back into that favourite pair of trousers again!

Improved Immune system

- A good diet with lots of vitamin C and other vitamins and minerals can help improve your immune system. So, if you regularly feel you're getting a cold or spend most of the winter with a red and swollen nose a good diet is one thing you could need. It could put some colour in your cheeks too!

Improved performance

- A healthy diet can boost your energy levels, helping you to give your best at home and work! Research has also shown that a healthy diet can help people to think more clearly.
- It is thought that healthy eating may help you cope better with stress and improve personal relationships. The right foods may even lessen irritability - definitely a plus when you are under stress at work!

Benefits for your family & social life

- A proper meal brings your family or friends closer together.
- Don't forget that preparing meals together can also be great fun!
- You might find that your love life takes on a new zest of life too!

A boost for physical activity

- Healthy eating can give you more energy and stamina to take part in physical activity and sports or even just walking the dog!

Food groups and why we need to eat healthily

This chapter will help you understand the importance of different food groups.

Starchy Foods

Starchy foods include bread, other cereals and potatoes

For example:

- Breakfast cereals, oats, museli
- Bread, chapatti, pitta, naan
- Bread sticks, popcorn
- Potato-boiled, jacket
- Rice, pasta, noodles
- Sweet potato
- Maize, millet and cornmeal
- Beans and lentils

As a general observation, we do not eat enough starchy foods, like bread, cereals, pasta, rice and potatoes to cover our bodies needs.

Whole grain bread, and other whole grain products such as breakfast cereals, pasta, rice, lentils, beans and pulses are important sources of complex carbohydrates, vitamins, minerals and fibre. Diets rich in these whole-grain products tend to be low in fat and saturated fats and are associated with a lower risk of coronary vascular disease.

Fruits and Vegetables

- Fruit and vegetables (which excludes potatoes and nuts) include fresh, frozen, canned, dried and juices.
- According to European recommendations, a healthy diet should include at least 5 portions of fruit and vegetables a day. A portion is equivalent to:
- 2 tablespoons vegetables, raw, cooked, frozen, canned
- 1 dessert bowlful salad
- 1 apple / banana / pear / orange
- ½ large fruit like a grapefruit

- ½ - 1 tablespoon dried fruit
- 1 small glass fruit juice (juice counts only once as a portion)
- 2 plums / satsumas
- 2 tablespoons fruit salad / stewed fruit / canned fruit

Fruits and vegetables are virtually fat-free (exceptions are avocados and olives), relatively low in calories, rich in dietary fibre, vitamins and minerals. They are an important source of anti-oxidants, vitamin C, some B-vitamins and minerals such as potassium and folic acid.

Consuming the recommended 5 (or more) servings of fruit and vegetables a day helps to ensure adequate intakes of vitamins, minerals and other essential nutrients. Fruits and vegetables add minimal calories and maximum volume to the diet, which helps to reduce energy intake and assist in weight control.

Milk and Dairy Products

Milk and dairy foods include:

- Milk
- Cheese
- Yoghurt
- Fromage frais

It does not include butter, cream and eggs!

Milk and dairy products such as cheese, and yoghurt, are all important sources of calcium, protein and B-vitamins. Calcium is essential for healthy, strong bones and can help to prevent osteoporosis later in life. They can also be a good source of vitamin D, which also helps keep bones strong and support the absorption of calcium.

Make healthy choices by opting for semi-skimmed or skimmed products, as they contain less fat!

Meat, Fish and Alternatives

- Meat, fish and alternatives include:

- Beef, pork, bacon, lamb
- Meat products, sausages, beefburgers, ham
- Chicken and turkey
- Fish – fresh, frozen and canned
- Fish fingers and fish cakes
- Eggs, beans, chickpeas and lentils
- Nuts
- Vegetarian alternatives to meat

Meat provides protein and minerals like iron, magnesium, and zinc as well as B-vitamins. It can play an important role in a healthy diet.

However, meat can also be a source of saturated fat. To make a healthy choice, buy lean cuts and cut off any visible fat before eating. If you cannot resist chicken skin once it is cooked, remove it before you cook!

Fish is a great low-fat protein food. Oily fish such as salmon, mackerel, tuna, etc are a fantastic source of healthy long-chain fatty acids. Make sure you eat at least one meal with oily fish a week.

If you are vegetarian, to make sure you are getting all the essential nutrients the body needs, it is important to include a wide range of alternatives to meat, like eggs, beans, chickpeas, lentils, nuts and nut products and other meat alternatives.

Fat and Sugar

Foods containing fat and sugar should be used sparingly. They include:

-
- Butter, margarine, cooking oils
- Cream mayonnaise and salad dressing
- Biscuits, cakes, puddings, ice-cream
- Sweets and chocolates
- Crisps and similar snack foods
- Sweetened drinks
- Chips

Remember that most of the fat we eat in our diet comes from 'hidden' sources, such as pies, pastries, cakes, biscuits, confectionery, chips, crisps, salad dressing etc. Therefore, cutting down on these items will help cut down your fat intake. Removing these items completely from the diet would make eating dull. Instead, try to limit them to a sensible amount.

Foods containing sugar should not be eaten too often, as frequent consumptions can contribute to teeth decay. These foods are best eaten at meal times rather than as a snack between meals.

Fat is actually an essential part of our diet and we do need small amounts to provide the essential fatty acids the body needs and also fat-soluble vitamins. So include small amounts of vegetable spreads and oils in your diet. Fat spreads and cooking products are visible sources of fat. Both should be consumed in moderation.

However, it is not only the amount of fat you eat that is important, but more importantly, it is the type of fat. We especially need to reduce the amount of saturated fatty acids in the diet and change to unsaturated fatty avis instead.

Salt, Fluids and Alcohol

Salt: Eating too much salt in the diet either by adding it during cooking or at the table and by eating too many of the foods that are high in salt may contribute to high blood pressure. High blood pressure is a risk factor for heart disease and stroke.

Although we need some sodium, this is usually easily provided by salt that occurs naturally in foods. Generally, it is recommended that we do not eat more than 6 grams a day.

Fluids and beverages: Fluids are an essential part of our body so a healthy diet should contain lots of water and other beverages. Experts recommend drinking 1.5 litres of water a day. Follow our recommendations below and you'll find that it's not that difficult! The odd glass of red wine is good for your health, but too much alcohol has health risks attached!

Alcohol: The guidelines apply whether you drink alcohol every day, once or twice a week or occasionally. The daily benchmarks for men and women are a guide to how much you can drink without any significant risk to health.

Men:	**between 3 and 4 units a day or less**
Women:	**between 2 and 3 units a day or less**

Remember only the liver can break down alcohol and it takes 1 hour to get rid of each unit.

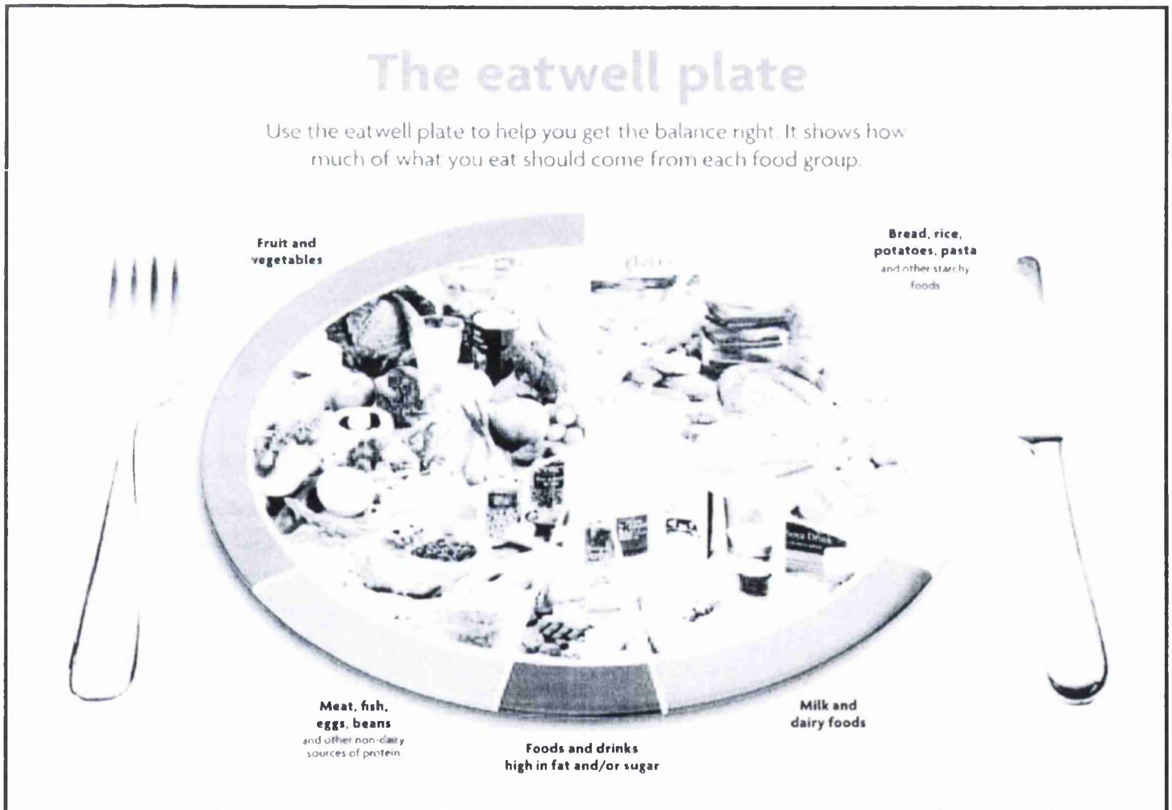
Small amounts of alcohol have been shown to protect the heart, but this benefit is achieved by drinking between 1 and 2 units a day and is only significant for men over 40 and women after the menopause.

What is a unit of alcohol?

1 Unit = ½ pint (300 ml) ordinary strength lager or beer
Small glass of medium strength wine
Single pub measure (25ml) spirits

How much should you eat?

As a general guideline the recommended calorie intake per day is 2000 kcal for women and 2500 kcal for men. That could vary due to physical activity and body sizes. It is very important not to only look at the calorie intake but also very important to have the right balance between the different food sections.



Department of Health in association with the Welsh Assembly Government, the Scottish Government and the Food Standards Agency in Northern Ireland

The general recommendations for a healthy person would be an intake of 25-35% fat, 50-60% carbohydrates and 10-15% proteins. The graph below will show how much of each food section one person should consume each day to meet these recommendations

The balance of good health. Look at how your portions should be balanced. You don't have to get this right at every meal, but try to get it right over a period of a day or a week.

How do I know what changes I need to make to my diet? Fill out a food diary for a few days. For a few days or a week, just write down ***everything*** you eat and drink throughout the day. Keep a food diary like the one below and carry it around with you so you don't forget to write things down. You can use the information on pages 7-10 to find out which food groups your food comes from.

Use the information you get from your food diary to help you work out which areas you might need to work on to increase or decrease your intake. Use the tips on page 14-15 for changes you can make to your diet to increase or decrease problem areas.

Fill in your food diary ...

Day and Time	What I ate or drank	Starchy food	Fruit & vegetables	Milk & Dairy foods	Meat, fish & alternative	Salt, fluids & alcohol

Can you see any obvious changes you could make to your diet? Look at the following two pages for tips on simple dietary changes.

I need to work on areas:

	I'm ok at the moment with …	**I need to increase …**	**I need to decrease …**
Starchy foods			
Fruit and vegetables			
Milk & dairy foods			
Milk, fish & alternatives			
Fat & sugar			
Salt, fluids & alcohol			

Think about how you are going to do this. One way is to shade in the tip(s) (on the following two pages) that you think you could include in your diet.

Starchy Foods	Fruit & Vegetables	Milk & Dairy Foods
For breakfast every day, eat cereals/porridge/toast/toasted muffins	Start each day with a glass of fruit juice	Try making a milk shake with skimmed milk and fresh fruit
Choose wholegrain cereals, such as bran flakes, weetabix	Include a piece of fruit with your breakfast, eg slice of banana on your cereal or half a grapefruit	If you are intolerant to dairy products, use alternatives like soya milk with added calcium
Eat a wide variety of different breads including wholemeal or granary bread	Eat a piece of fruit in place of other snacks at least twice a week	Try semi-skimmed or skimmed milk instead of whole milk
Serve extra bread with main meal, eg rolls, naan bread, pitta bread, chapatti, tortilla	Eat fruit salad for dessert once a week, if possible a fresh one	Drink at least one glass of milk or eat one yoghurt every day
Choose a thick base for a pizza, instead of a thin one	Top your pizza with extra vegetables	Enjoy cheese especially lower fat types as part of a meal
Use brown rice and wholemeal pasta	Try experimenting with different fruits; try a different one every day	Limit full-fat cheese that you may eat to once or twice a week
Replace any sweet and fatty breakfast items such as croissants, with wholemeal bread or toast.	Try a salad as a starter or accompaniment 3 times weekly	Use low-fat yoghurt or fromage frais in recipes instead of cream
Use thick bread for sandwiches with thin spread	Have an extra portion of vegetables with your cooked meal	Try making a dip for sticks of raw vegetables, using low fat plain yoghurt
Have a large portion of rice or pasta with a small serving of sauce	Try making a hearty vegetable soup without adding cream	Have a low-fat yoghurt and/or skimmed milk on breakfast cereal
Have a large baked/jacket or boiled potato instead of chips	Make sure the vegetables on your plate take up at least as much room as the potatoes/pasta/rice	Buy mature cheese - in cooking you need to use less as the taste is stronger
Use breadcrumbs to top 'au gratin' meals instead of grated cheese	Try buying or making a smoothie with fresh fruit	Use yoghurt as a base for home made ice-cream with added soft fruits
Have a least one meal every week based around pulses or beans, eg lentil soup, bean casserole	Replace the chocolate sauce on your ice-cream with pieces of fruit or tinned fruit in natural juice	Have a low-fat cheese sandwich with plenty of salad with it or as dessert
Try bread sticks with a low fat dip as a snack instead of crisps or chocolate	Have extra tomatoes, peppers, onion and mushrooms in your omelette	Use low-fat fromage frais as a topping to fresh or tinned fruit as a dessert once a week

Meat, fish & alternatives	Fat & Sugar	Salt, Fluids, & Alcohol
Buy extra lean cuts of meat	Replace butter with a mono and/or polyunsaturated margarine to reduce your saturated fat intake	Try using fresh herbs like basil, mint, coriander, parsley to flavour foods in place of salt
At least once a week, eat fish of all kinds and try to cook it without adding fat - grill, steam, or oven-bake the fish	Reduce you fat intake by trying a low fat spread	Black pepper and spices like paprika, ginger, cinnamon, garlic all make great substitutes to salt.
Reduce the number of times you eat processed meat products eg pasties, sausages, hamburgers to once a week	Use small quantities of a vegetable oil or margarine eg sunflower or olive oil instead of animal fat (lard)	Try making soups instead of using canned and packet ones as you can use less salt
Swap any fried meat for grilled, roasted or stir-fried	Instead of eating crisps with a drink, chop us crispy vegetables into strips and serve with low fat dips	Make sure that you drink enough fluid - at least 1.5l a day (6-8 glasses) of any drink. Water or fruit juice is best
At least once a week, swap a meal containing meat to a meal containing an alternative eg beans, lentils, soya	Prepare your own coleslaw and potato salad. Use 2 spoonfuls to low-fat yoghurt to 1 of mayonnaise for the dressing	Fill a 1.5 litre bottle with water and try to drink it every day
Try to stick to small portions of meat products by replacing it with extra starchy foods and vegetables	If you feel like something sweet at meal times, try a toasted muffin and jam, scone and jam, or a fruit yoghurt	Cut down your intake of alcohol units by at least 3 units per week
If you currently eat three portions of meat a day, reduce this and increase vegetables, rice, pasta etc	If you have raised cholesterol, try one of the new cholesterol lowering spreads as part of your healthy eating plan	If you try to cut down your alcohol units, start with not drinking on at least two days a week
If you are a vegetarian always eat a variety of beans and pulses and green vegetables every day	Try to avoid frying foods as much as possible and drain your food well on kitchen paper if it has been fried	Replace sugary fizzy drinks with a fruit juice or an ice tea mixed with sparkling mineral water
Remove all visible fat from meat and the skin from chicken, preferably before cooking	Cut thick wedges of potato with skins on, brush with sunflower or olive oil, black pepper and oven-bake	Have a freshly squeezed fruit juice for lots of vitamins at least twice a week
Replace your weekend fry up with a grill up and choose kippers sometimes instead of sausages	Try squeezing a lemon or lime on your salad instead of a high-fat dressing	Try as many different fruit juices as possible
On your bread avoid salami, meat paste, pate and replace with lean products like ham, turkey, tuna	Try baked bagel chips, pretzels or breadsticks instead of crisps	Make alcohol drinks last longer with mixers or water
If you eat fast food restaurants regularly, try to cut this down to once a month	Try to limit your confectionary intake to 4 individual bars a week and enjoy them at the end of a meal	Replace salty crisps with unsalted nuts. They are a good source of protein and essential fats, careful how many you eat
Eat oily fish at least once a week - sardines, mackerel, salmon are great as a bread filling with lots of salad	Try to replace at one biscuit/sweet/pastry a day with a piece of fresh or dry fruit	If you have drunk too much, avoid alcohol for 48 hours to give your body time to recover

Excuse Busters

What's stopping you from changing to a healthier diet?

You need to be motivated to get started on the track to a healthier diet and you'll certainly need to be motivated to stick with it. Finding the motivation and commitment is often the most difficult part of healthier eating. To help, make a short list of things that stop you eating a healthier diet in everyday life.

1.

2.

3.

4.

Have a look at the common ones we have come up with listed below. Have you still got valid reasons not to eat more healthily?

I don't need to eat healthily

It may be that you believe you are already eating a healthy diet or you cannot see any need to eat healthily. Try filling in the food diary and see if there are any changes you can make.

There's no point eating healthily as my heart is already damaged

Then there is more reason to eat healthily! Try to keep your heart as healthy as it is today. Improving your diet, may not 'cure' your heart condition, but it may help you keep your heart from getting worse.

I've lost my appetite and can't face too much food

Instead of three big meals a day, try smaller meals with snacks. Make sure the snacks are healthy though!

I don't have enough time

This is a common complaint. Remember that preparing a healthy meal doesn't need to be time consuming! In fact, many healthy methods of cooking such as stir-frying, are incredibly quick. What's more, many healthy foods need little preparation and no cooking, like salads, fruits and some vegetables! You can save money too by buying deep frozen vegetables.

I don't like healthy food

You are probably already eating a lot of healthy foods and just need to make a few small changes! It could be a case of eating a little more of some foods and a little less of others, or changing the way you cook, like grilling instead of frying. You don't need to suddenly stop eating what you like and eating things you don't like - keep your changes gradual and your diet varied!

If you need to eat more of a type of food that you find boring, try adding herbs and spices. Alternatively, try one of your favourite recipes, adding another vegetable and using less fat or polyunsaturated/monounsaturated fat. Just try it - you might be pleasantly surprised!

Healthy food is expensive

Healthy eating doesn't need to be expensive. You don't need to buy special foods or expensive diet products, you just need to make the right choices. Some fruits and vegetables can be very cheap.

Healthy food is boring

A healthy diet is a varied diet and a great excuse for discovering different tastes from around the world! The Mediterranean diet is the model-example of healthy, good-looking and varied food! And if you find certain foods boring - just look for more exciting alternatives, or spice up your dishes with herbs, spices and exotic vegetables and fruit!

I eat away from home too much to eat healthily

Even in restaurants, you can make healthy choices! Have a salad as a starter, eat fish or chicken and have fruit or sorbet as a dessert. All very tasty and very healthy!

Try to avoid creamy sauces and deep fried food and make sure you don't undo all the good work by drinking too much alcohol!

If there's nothing healthy on the menu, ask the cook what s/he can serve you!

I have tried eating healthily but always fall back into bad habits after a couple of weeks

The best way to succeed to make only a few small changes a week - just keep up the changes you do make.

And remember - reverting to your old ways is not the end of the world - just start again!

My family hates healthy food

Healthy eating shouldn't be a strict regime - make it a fun experience enjoyed together! There are many ways to make healthy food more appealing to children and to partners. Alternatively, you could start by preparing healthy meals for yourself and you may find after a while that curiosity gets the better of your family and they will start wanting to try what you are eating and follow your example.

ANCOVA Tables with Adjusted Means

ICD Concerns Questionnaire:

Table 1: Baseline mean score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=33)	F (df=1, 69)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control (n=32) Intervention (n=26)	F (df=1, 56)	p	Partial Eta^2 (size of effect)
ICD Concerns Questionnaire	Control: 24.88 (16.10) Intervention: 23.39 (14.82)	Control: 18.945 (1.982) Intervention: 18.877 (2.251)	.016	.899	.000	Control 19.190 (2.367) Intervention 17.227 (2.515)	.336	.565	.006

A higher score indicates higher perceived limitations and more ICD-concerns

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Positive ICD Beliefs Questionnaire

Table 2: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	**Baseline Mean Score (S.D.)**	**Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=31)**	**F (df=1, 68)**	**p**	**Partial Eta² (size of effect)**	**Adjusted Means at 6-months (S.E.) Control (n=31) Intervention (n=28)**	**F (df=1, 58)**	**p**	**Partial Eta² (size of effect)**
Positive ICD Beliefs questionnaire	Control: 75.36 (12.56) Intervention: 75.29 (13.92)	Control: 71.212 (1.732) Intervention: 76.572 (1.943)	4.240	.043	.060 (Medium)	Control: 72.612 (1.989) Intervention: 76.694 (2.126)	1.961	.167	.033 (Small-medium)

The level of positive beliefs held about the ICD. A higher score indicate a higher level of positive beliefs

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Brief Illness Perception Questionnaire (IPQ-B)

Table 3: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=38) Intervention (n=31)	F (df=1, 67)	p	Partial Eta² (size of effect)	Adjusted Means at 6-months (S.E.) Control (n=31) Intervention (n=26)	F (df=1, 55)	p	Partial Eta² (size of effect)
Brief Illness Perception Questionnaire – Consequences	Control: 5.68 (3.02) Intervention: 6.97 (2.76)	Control 5.765 (.376) Intervention: 4.708 (.417)	3.458	.067	.050 (Medium)	Control: 5.530 (.382) Intervention: 5.138 (.418)	.471	.496	.009 (Small)
Brief Illness Perception Questionnaire – Timeline	Control: 8.61 (2.64) Intervention: 8.23 (2.99)	Control: 8.927 (.325) Intervention: 9.057 (.359)	.072	.789	.001	Control: 8.928 (.287) Intervention: 9.009 (.313)	.036	.849	.001
Brief Illness Perception Questionnaire – Personal control	Control: 5.13 (2.46) Intervention: 5.87 (2.91)	Control: 6.007 (.456) Intervention: 4.539 (.506)	4.602	.036	.065 (Medium)	Control 5.225 (.433) Intervention 5.385 (.473)	.062	.804	.001
Brief Illness Perception Questionnaire – Treatment control	Control: 1.87 (2.79) Intervention: 1.68 (2.10)	Control: 2.964 (.383) Intervention: 1.431 (.424)	7.215	.009	.99 (Medium-Large)	Control: 2.186 (.347) Intervention: 1.355 (.379)	2.613	.112	.046 (Small-medium)

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=38) Intervention (n=31)	F (df=1, 67)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control (n=31) Intervention (n=26)	F (df=1, 55)	p	Partial Eta^2 (size of effect)
Brief Illness Perception Questionnaire - Identity	Control: 3.32 (3.31) Intervention: 3.81 (3.57)	Control: 1.518 (.391) Intervention: 1.848 (.433)	.320	.574	.005	Control: 2.318 (.484) Intervention: 2.198 (.429)	.027	.869	.001
Brief Illness Perception Questionnaire - Concern	Control: 7.59 (2.80) Intervention: 7.32 (2.76)	Control: 5.882 (.481) Intervention: 5.818 (.526)	.008	.929	.000	Control: 6.101 (.509) Intervention: 5.844 (.547)	.118	.733	.002
Brief Illness Perception Questionnaire – Illness comprehension	Control: 2.19 (2.50) Intervention: 2.81 (2.77)	Control: 2.358 (.418) Intervention: 2.992 (.457)	1.039	.312	.016 (Small)	Control: 2.869 (.479) Intervention: 3.305 (.514)	.383	.539	.007
Brief Illness Perception Questionnaire - Emotional response	Control: 4.81 (3.29) Intervention: 5.27 (3.03)	Control: 4.654 (.458) Intervention: 3.893 (.508)	1.233	.271	.019 (Small)	Control: 4.667 (.508) Intervention: 3.615 (.546)	1.984	.165	.036 (Small-medium)

Consequences: Measures perception of how much the underlying cardiac illness affects patient's lives. A higher score reflects higher negative affect
Timeline: Measures perceived longevity of cardiac illness. A higher score reflects longevity
Personal Control: Perception of control over cardiac illness. A higher score reflects less control
Treatment Control: Measures the extent to which patients believe the ICD can help their cardiac illness. Higher score reflect beliefs that are more negative
Identity: Measures the frequency of abnormal cardiac rhythms. Higher score reflects more rhythms experienced
Concern: Measures patient's level of concern about cardiac illness. Higher scores reflect more concern
Comprehension: Measures the level of patient's understanding about their cardiac illness. Higher scores reflect less understanding
Emotional Response: Level of negative emotion experienced towards the patient's cardiac illness. Higher scores reflect emotion that is more negative

Florida Patient Acceptance Survey (FPAS)

Table 4: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=33)	F (df=1, 70)	p	Partial Eta² (size of effect)	Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention (n=28)	F (df=1, 57)	p	Partial Eta² (size of effect)
Florida Patient Acceptance Survey (FPAS) Total	Control: Intervention:	Control: 71.417 (2.412) Intervention: 73.022 (2.622)	.203	.654	.003	Control: 67.278 (2.685) Intervention: 76.347 (2.826)	5.407	.024	.088 (Medium-large)
FPAS subscale – Return to Life	Control: Intervention:	Control 54.927 (3.605) Intervention: 56.298 (3.920)	.066	.798	.001	Control: 55.445 (4.233) Intervention: 52.007 (4.455)	.311	.580	.006
FPAS subscale – Device-related Distress	Control: Intervention:	Control: 70.179 (3.141) Intervention: 72.970 (3.415)	.362	.550	.005	Control: 66.281 (3.698) Intervention 73.939 (3.891)	2.034	.159	.035 (Small-medium)

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=33)	F (df=1, 70)	p	Partial Eta² (size of effect)	Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention (n=28)	F (df=1, 57)	p	Partial Eta² (size of effect)
FPAS subscale – Positive Appraisal	Control: Intervention:	Control: 78.928 (3.796) Intervention: 79.828 (4.127)	.026	.873	.000	Control: 70.461 (4.658) Intervention: 88.954 (4.901)	7.474	.008	.118 (Medium-large)
FPAS subscale – Body Image Concerns	Control: Intervention:	Control: 80.683 (4.539) Intervention: 79.647 (4.935)	.024	.878	.000	Control: 75.191 (3.763) Intervention: 92.645 (3.959)	10.210	.002	.154 (Large)

Total: Measures the level of patient acceptance towards the ICD. A higher score indicates a higher level of acceptance
Return to Life: Patient's belief that they have returned/will able to return to a full life. A higher score indicates a more positive belief held by patients in their ability to return to a full life
Device-Related Distress: Level of ICD-device related distress. A higher score indicates less distress experienced
Positive Appraisal: Level of positive appraisal towards the ICD. A higher score reflects a higher positive regard towards the ICD
Body Image Concerns: Concerns about the body because of the ICD. A higher score reflects less concern

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

EuroQoL

Table 5: Baseline Mean Score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control: (n=39) Intervention (n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention:(n=28)	F (df=1, 58)	p	Partial Eta^2 (size of effect)
Euro Quality of Life	Control: 59.03 (22.48) Intervention: 59.52 (23.47)	Control: 64.883 (3.081) Intervention: 61.168 (3.349)	.006	.417	.010 (Small)	Control: 63.164 (3.400) Intervention: 61.170 (3.635)	.160	.690	.003

The EuroQoL measures patient's health-related quality of life. A higher score indicates a higher HR-QoL.

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Behaviour Questionnaire (not validated)

Table 6: Baseline Mean Score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=32)	F (df=1, 69)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention (n=28)	F (1, 58)	p	Partial Eta^2 (size of effect)
Behaviour Questionnaire	Control: 78.63 (16.84) Intervention: 73.25 (18.62)	Control: 70.640 (2.715) Intervention: 68.824 (3.041)	.196	.660	.003	Control: 70.812 (2.778) Intervention: 67.894 (2.972)	.508	.479	.009 (Small)

The non-validated Behaviour Questionnaire measures level of typical active everyday behaviour. A higher score indicates a higher level of active daily behaviour

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Appendix XXII

Type-D Personality Questionnaire

Table 7: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=33)	F (df=1, 69)	p	Partial Eta² (size of effect)	Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention:(n=28)	F (df=1, 57)	p	Partial Eta² (size of effect)
Type D personality Scale – Negative Affect	Control: 10.77 (5.67) Intervention: 10.36 (6.27)	Control: 11.689 (.681) Intervention: 10.913 (.741)	.594	.444	.009 (Small)	Control: 12.129 (.842) Intervention: 10.071 (.885)	2.839	.098	.048 (Small-medium)
Type D personality Scale – Social Inhibition	Control: 8.69 (5.09) Intervention: 8.13 (6.00)	Control: 8.549 (.624) Intervention: 9.487 (.689)	1.017	.317	.015 (Small)	Control: 9.084 (.741) Intervention: 8.872 (.780)	.039	.845	.001

Negative Affect: Measures patient's level of negative affect. A higher score indicates a HIGHER level of negative affect
Social Inhibition: Measures degree of social inhibition. A higher score indicates a higher level of social inhibition

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Appendix XXII

Hospital Anxiety and Depression Scale

Table 8: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	**Baseline Mean Score**	**Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=33)**	**F (df=1,68)**	**p**	**Partial Eta² (size of effect)**	**Adjusted Means at 6-months (S.E.) Control: (n=31) Intervention:(n=28)**	**F (df=1,57)**	**p**	**Partial Eta² (size of effect)**
Hospital Anxiety & Depression Scale: ANXIETY	Control: 6.72 (3.59) Intervention: 6.52 (4.08)	Control: 5.760 (.525) Intervention: 5.648 (.571)	.021	.886	.000	Control: 5.828 (.659) Intervention: 5.405 (.694)	.195	.661	.003
Hospital Anxiety & Depression Scale: DEPRESSION	Control: 4.56 (3.59) Intervention: 5.27 (4.08)	Control: 5.194 (4.01) Intervention: 4.468 (.436)	1.468	.226	.021 (Small)	Control: 4.938 (.550) Intervention: 4.604 (.579)	.175	.678	.003

HADS ANXIETY measure levels of current anxiety. A higher level indicates a higher level of anxiety
HADS DEPRESSION measures current levels of depression. A higher score indicates a higher level of depression experienced

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Profile of Moods Questionnaire (Short Form) (POMS-SF)

Table 9: Baseline Mean Score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention:(n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control: (N=31) Intervention:(N=28)	F (df=1, 57)	p	Partial Eta^2 (size of effect)
Profile of Moods Short Form TOTAL	Control: 40.00 (21.97) Intervention: 44.81 (24.06)	Control: 40.779 (3.547) Intervention: 38.543 (3.547)	.181	.672	.003	Control: 43.098 (3.810) Intervention: 38.109 (3.945)	.824	.368	.015 (Small)
Profile of Moods subscale - Depression	Control: 12.54 (5.51) Intervention: 13.94 (7.00)	Control: 13.563 (.898) Intervention: 13.123 (.977)	.109	.742	.002	Control: 14.426 (1.086) Intervention: 12.136 (1.143)	2.099	.153	.036 (Small-medium)
Profile of Moods subscale - Vigour	Control: 15.49 (6.21) Intervention: 12.55 (4.72)	Control: 15.602 (.890) Intervention: 15.441 (.890)	.017	.896	.000	Control: 15.063 (.799) Intervention: 15.251 (.842)	.026	.873	.000
Profile of Moods subscale - Anger	Control: 11.51 (6.05) Intervention: 10.79 (5.80)	Control: 11.484 (.798) Intervention: 11.943 (.868)	.151	.698	.002	Control: 11.552 (.817) Intervention: 10.532 (.860)	.739	.394	.013 (Small)

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention:(n=33)	F (df=1, 70)	p	Partial Eta^2 (size of effect)	Adjusted Means at 6-months (S.E.) Control: (N=31) Intervention:(N=28)	F (df=1, 57)	p	Partial Eta^2 (size of effect)
Profile of Moods subscale - Tension	Control: 12.62 (5.26) Intervention: 12.94 (5.97)	Control: 11.509 (.714) Intervention: 10.882 (.776)	.424	.517	.006	Control: 11.447 (.704) Intervention: 10.933 (.741)	.253	.617	.004
Profile of Moods subscale - Confusion	Control: 8.69 (3.22) Intervention: 9.24 (3.63)	Control: 9.490 (.527) Intervention: 9.360 (.573)	.028	.869	.000	Control: 9.190 (.515) Intervention: 8.433 (.542)	1.023	.316	.018 (Small)
Profile of Moods subscale - Fatigue	Control: 10.95 (5.10) Intervention: 11.94 (5.44)	Control: 10.945 (.791) Intervention: 10.931 (.860)	.001	.979	.000	Control: 11.323 (.833) Intervention: 11.928 (.876)	.251	.616	.004

POMS TOTAL: Measures an overall level of low mood. The higher the score, the lower the mood
POMS Depression: Subscale that measures depression. A higher score indicates a higher depressed mood.
POMS Vigour: Subscale that measures positive mood. A higher score reflects a better mood
POMS Anger: Subscale that measures levels of anger. Higher scores indicate a higher level of anger
POMS Tension: Subscale that measures tension. Higher scores a higher level of tension
POMS Confusion: Subscale that measures levels of confusion. Higher scores reflect a higher level of confusion/uncertainty
POMS Fatigue: Subscale that measures tiredness/fatigue/weariness. Higher scores indicate more fatigue

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Impact of Events Scale (IES)

Table 10: Baseline Mean Score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	**Baseline Mean Score (S.D.)**	**Adjusted Means at 3-months (S.E.) Control (N=39) Intervention (N=32)**	**F (df=1, 69)**	**p**	**Partial Eta^2 (size of effect)**	**Adjusted Means at 6-months (S.E.) Control: (n=32) Intervention:(n=26)**	**F (df=1, 57)**	**p**	**Partial Eta^2 (size of effect)**
Impact of Event Scale - Intrusion	Control: 1.71 (.65) Intervention: 1.83 (.70)	Control: 1.648 (.103) Intervention: 1.660 (.114)	.014	.908	.000	Control: 1.597 (.102) Intervention: 1.499 (.111)	.417	.521	.007
Impact of Event Scale - Avoidance	Control: 1.67 (.572) Intervention: 1.73 (.573)	Control: 1.696 (.093) Intervention 1.543 (.103)	1.207	.276	.017 (Small)	Control: 1.735 (.105) Intervention: 1.560 (.114)	1.273	.264	.022 (Small)

IES Intrusion: Frequency of intrusive thoughts about the ICD. A higher score indicates a higher frequency of intrusive thoughts
IES Avoidance: The frequency of engaging in avoidant behaviours in order to cope with the ICD. A higher score indicates a higher frequency of avoidant behaviours used

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Medical Coping Modes Questionnaire

Table 11: Baseline Mean Score and F, P, Partial Eta² Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	Baseline Mean Score (S.D.)	Adjusted Means at 3-months (S.E.) Control (n=39) Intervention (n=31)	F (df=1, 68)	p	Partial Eta² (size of effect)	Adjusted Means at 6-months (S.E.) Control (n=31) Intervention:(n=26)	F (df=1, 55)	p	Partial Eta² (size of effect)
Medical Coping Modes Questionnaire – Confrontation	Control: 19.03 (3.26) Intervention: 19.13 (3.15)	Control: 19.153 (.496) Intervention: 19.873 (.557)	.932	.338	.014 (Small)	Control: 17.340 (.402) Intervention: 17.941 (.439)	1.020	.317	.019 (Small)
Medical Coping Modes Questionnaire – Avoidance	Control: 11.33 (3.03) Intervention: 12.32 (3.21)	Control: 12.687 (.482) Intervention: 13.039 (.542)	.233	.631	.003	Control: 15.860 (.471) Intervention: 14.821 (.515)	2.171	.146	.039 (Small-medium)
Medical Coping Modes Questionnaire – Acceptance-Resignation	Control: 6.82 (1.68) Intervention: 6.74 (2.24)	Control: 7.285 (.322) Intervention: 7.060 (.322)	.217	.643	.003	Control: 7.312 (.421) Intervention: 7.512 (.460)	.103	.750	.002

Confrontation: Measures a confrontational way of coping. Higher scores reflect more use of confrontation coping
Avoidance: Measures an avoidant way of coping. Higher scores reflect more avoidance used
Acceptance-Resignation: Measures acceptance-resignation way of coping. Higher scores reflect more use of acceptance-resignation

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta² effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Exercise Diary Questionnaire

Table 12: Baseline Mean Score and F, P, Partial Eta^2 Group results from the one-way ANCOVA at 3- and 6-months, including separate analyses, with the covariate for each score being the baseline score

Name of Measure	**Baseline Mean Score (S.D.)**	**Adjusted Means at 3-months (S.E.) Control: (n=25) Intervention:(n=19)**	**F (df=1, 42)**	**p**	**Partial Eta^2 (size of effect)**	**Adjusted Means at 6-months (S.E.) Control: (n=22) Intervention:(n=15)**	**F (df=1, 35)**	**p**	**Partial Eta^2 (size of effect)**
Exercise Measure - Strenuous	Control: 21.21 (61.88) Intervention: 61.58 (135.12)	Control: 27.460 (13.982) Intervention: 28.974 (16.080)	.005	.944	.000	Control: 42.335 (59.270) Intervention: 120.509 (72.230)	.678	.416	.020 (Small)
Exercise Measure- Moderate	Control: 46.36 (85.29) Intervention: 70.00 (116.76)	Control: 72.836 (20.713) Intervention: 71.005 (23.783)	.003	.954	.000	Control: 123.609 (38.329) Intervention: 129.707 (46.506)	.010	.920	.000
Exercise Measure- Mild	Control: 291.12 (1061.53) Intervention: 229.16 (400.44)	Control: 458.921 (170.788) Intervention: 264.788 (195.354)	.399	.531	.013 (Small)	Control: 137.944 (62.147) Intervention: 257.682 (75.298)	1.501	.229	.042 (Small-medium)

Strenuous exercise: Measures number of minutes per week that the participant strenuously exercised. Strenuous exercise is exercise that results in a very fast heart beat.
Moderate exercise: Measures number of minutes per week that the participant engaged in moderate exercise. Moderate exercise results in a fast heart beat.
Mild exercise: Measures number of minutes per week that the participant engaged in mild exercise. Mild exercise results in a little or no increase in heart beat.

S.E. = Standard Error. S.D. = Standard Deviation. The magnitude of the overall effect was explained through the magnitude of the Cohen's partial eta^2 effect size for the F statistic, where .0099 is a small effect, .0588 a medium effect and .1379 is a large effect.

Appendix XXII