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AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN CARING, DEATH ANXIETY AND THE BURNOUT SYNDROME AMONG PALLIATIVE CARE NURSES

BRIAN NYATANGA

SUBMITTED TO THE UNIVERSITY OF SWANSEA IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF NURSING SCIENCE

2011

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ABSTRACT

Introduction

The concept of "Death Anxiety" has been used to denote the apprehension often created by human awareness of the possibility of death and dying. For example, humans are unique in the sense that they must learn to live with and adapt to the awareness of their own ephemeral existence. Similarly, confronting the inevitability of death and its related anxiety is a universal psychological problem faced by most human beings. For nurses working in palliative care, death is an unmistakable reality regardless of experience and understanding. This means that within the process of helping individual patients and their families cope with death and dying these nurses have a central responsibility for providing emotional and social support for the very phenomenon that most threatens their own ephemeral existence. Given the universality of death anxiety, it is academically both interesting and most challenging to investigate how death anxiety might interact with such other variables as burnout and aspects of caring. It is also interesting to note that to date there are no studies that specifically look at possible cause and effect or association between death anxiety, caring and burnout.

Aim

This thesis investigates the relationship between caring, death anxiety and burnout among palliative care nurses with a view to understanding the possible interaction of these three variables.

Methodology

A correlational survey design was used to look for relationships between death anxiety and burnout among palliative care nurses working in hospice, hospital and community settings. A total of 213 nurses completed the 25 item Templer's Revised Death Anxiety Scale, the 22 item Maslach Burnout Inventory, the 5 item Social Support Scale and the 13 item Sources of Pressure Measurement Scales. Spearman's rho correlation was used to establish associations between variables of interest, and multiple regression to determine significant predictor variables of burnout. The Kruskal-Wallis test, tested for significant differences in the mean scores of death anxiety and measures of burnout.

Results

The results show a positive and moderate correlation between death anxiety and burnout. No correlation was found between death anxiety and age/gender. No correlation was found between burnout and age/gender. Social support was negatively correlated with emotional exhaustion (the first stage of burnout) that is, the more social support nurses received, the less emotional exhaustion they felt and the need to depersonalise their care was minimal. Caring shows as a unique statistically significant predictor of emotional exhaustion. The more nurses felt unable to control psychological pain and other symptoms, the more their death anxiety and burnout levels increased. Of the 98 hospice nurses, 91% showed moderate levels of death anxiety, while 8% showed high levels. Of the 78 hospital nurses, 92% showed moderate levels of death anxiety, while 6% showed high levels. Of the 31 nurses from the community, 87% showed moderate levels of death anxiety, while 13% showed high levels. Of the 98 hospice nurses, 35% showed moderate levels of Emotional Exhaustion (EE), while 20% showed high levels. Of the 78 hospital nurses, 30% showed moderate levels of EE, while 22% showed high levels. The 31 nurses from the community, 45% showed moderate levels of EE, while 23% showed high levels.

Discussion

These results are consistent with previous studies particularly from North America. High levels of death anxiety and burnout may interfere with nurses' ability to provide high quality care or engage in reflective practice. Implications of these findings for clinical practice and future research are discussed. These findings are timely for managers, educators and policy makers in devising ways of supporting palliative care nurses if they are to continue caring for dying patients effectively, and without the danger of developing burnout and death anxiety.

Declarations and statements

I hereby declare that this work has not been previously accepted in substance and is not being concurrently submitted in candidature for another degree. This thesis is a result of my own research and acknowledges other sources through references, of which a list is placed at the end. I do hereby give my consent for my thesis, if accepted, to be available for library use by other researchers or interested readers

Brian Nyatanga
15.07.2011

CONTENTS

List of Tables

List of Figures

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ABBREVIATIONS

BO	Burnout
BOS	Burnout syndrome
DA	Death anxiety
DAS	Death anxiety scale
DH	Department of Health
DNA	Deoxyribonucleic acid
DP	Depersonalisation
EE	Emotional exhaustion
EFA	Exploratory factor analysis
EoL	End of life
GAS	General Adaptation Syndrome
HCP	Health care professional
HCI	Holyoake Codependency Index
KMO	Kaiser-Meyer-Olkin measurement
MBI	Maslach Burnout Inventory
MBI-HSS	Maslach Burnout Inventory – Human Services Survey
MR	Multiple regression
MREC	Multi-Centre research ethics committee
NHS	National Health Service
NICE	National institute of clinical excellence
PA	Low personal accomplishment
PC	Palliative care
PCT	Primary care trust
QoL	Quality of Life
RCN	Royal College of Nursing
R & D	Research & Development
RDAS	Revised death anxiety scale
SOP	Sources of pressure
SOCS	Social support
TMT	Terror management theory
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION`

Chapter overview

This chapter begins by setting out the overall plan and structure of the thesis, and explains the contents of each chapter. It end by introducing the overall aim and objectives of the study. This chapter highlights the nature and significance of the research problem and its relevance to palliative nursing. The chapter briefly introduces the notions of death anxiety, burnout and caring, which are central and also variables of interest for this study. The organisation and delivery of palliative care across different settings of the National Health Service within the United Kingdom are discussed.

Overall plan and structure of the thesis

The thesis comprises eleven chapters, with chapter one introducing the overall aim of the thesis. The chapter confirms the nature and significance of the research problem.

Chapter two focuses on the concept of caring, and highlights definitional difficulties of caring, before suggesting a possible definition and model for empathy necessary for caring in palliative nursing. It highlights aspects of caring which are seen as both rewarding and stressful to nurses in general and palliative care in particular.

Palliative care is an environment where death occurs more frequently than in other settings. Therefore, it is of interest to show the impact of such caring on nurses working in this area, in relation to their levels of death anxiety and burnout. The idea of co-dependency is discussed as an extreme type of caring, where carers tend to neglect their own self care in pursuit of caring for others.

Chapter three discusses the burnout syndrome, exploring some of the pertinent philosophical antecedents underpinning its development and impact on caring. It does this by showing how the three components of burnout, that is, emotional exhaustion, depersonalisation and low personal accomplishment, develop, with subsequent psychological adjustments needed to survive. Burnout is viewed as a syndrome which suggests that it is a cumulative process which develops over a period of time. It is important that burnout is detected early therefore, the main focus will be on emotional exhaustion, as it the first phase in the development of burnout.

Such an approach could be an effective way to prevent full blown burnout developing and its associated cost.

This chapter acknowledges that burnout is the result of stress that has carried on unabated. It therefore explores the role of stress in health and shows how it may affect palliative care nurses and the quality of care they give to dying patients. Ways of modifying burnout are briefly discussed with specific focus on social support as one such effective way.

Chapter four explores the concept of death anxiety and its possible impact on human beings in general and palliative care nurses in particular. In exploring death anxiety, this chapter engages with some philosophical arguments underpinning this seemingly elusive phenomenon. The discussion includes a detailed analysis of death, dying and death anxiety from different perspectives and contexts. One context is the perception of death anxiety as terror or threat, which requires more than one person to manage it, and therefore, the Terror Management Theory (TMT) is discussed in order to show how it can be used to alleviate aspects of death anxiety.

Chapter five gives an analysis of empirical literature reviewed on both death anxiety and burnout. This chapter confirms the rationale for this current study, the aims and objectives, the variables of interest which are therefore under investigation. The role of social support in minimising or preventing the development of burnout and death anxiety is discussed.

Chapter six is concerned with the research methodology and procedures employed to carry out this study and demonstrate rigour and ethical soundness. The chapter critically discusses the measurement scales used for data collection and justifies their suitability in terms of validity and reliability to use with this current study. The chapter concludes by discussing in detail multiple regression analysis, performed to determine predictor variables of burnout, however, the test focuses on emotional exhaustion as the dependent variable as it is the first of the three components in the development of burnout.

Chapter seven discusses exploratory factor analyses carried out on the measurement scales used in this study. A detailed discussion is offered on factor analysis carried out on Sources of Pressure Measurement Scale because this scale was newly developed for this study. Issues of validity and reliability are also discussed

Chapter eight reports on results of the study, and presents tables and figures from data analysis. This chapter begins by presenting descriptive statistics and then later inferential statistics to show relationships between variables of interest.

Chapter nine is the discussion of findings in light of existing literature, and considers whether the results are consistent with previous studies. Any new insights from the findings are discussed with managers, educators, fellow researchers and policy makers in mind. This chapter provides strategies for reducing death anxiety and burnout among palliative care nurses.

Chapter ten offers a methodological critique of the whole study's design and procedures employed in undertaking this study in order to show how every effort and sensitivity was taken as far as possible to ensure that this study was methodologically valid and ethically sound. The critique discusses the strengths and limitations of the study to show how these may have implications on generalisability of findings and highlights where caution may be needed when applying the findings.

Finally, chapter eleven is the final chapter and focuses on conclusions reached from the study findings and then draws recommendations for future research and offers strategies for managers, educators and researchers to support nurses.

All sources of evidence consulted in writing of this thesis are acknowledged and a list of full references is placed at the end. Copies of all the measurement scales, ethical approval documents and participant information sheets are included under appendices at the end of the thesis.

Aim and Objectives of the study

The concept of “Death Anxiety" has been used to denote the apprehension often created by human awareness of the possibility of death and dying (Becker 1973; Kastenbaum 1992; Wass and Neimeyer 1995; Kastenbaum 2000; Nyatanga and de Vocht 2006; Kastenbaum 2008). For example, Becker (1973) suggests that humans are unique in the sense that they must learn to live with and adapt to the awareness of their own ephemeral existence. Similarly, Kastenbaum (2008) would suggest that confronting the inevitability of death and its related anxiety is a universal psychological problem faced by most human beings. For health care providers (e.g. palliative care nurses), death is an unmistakable reality regardless of experience and theoretical understanding. This means within the process of helping individual patients and their families cope with death and dying, palliative care nurses have a central responsibility for providing emotional and social support for the very phenomenon (death) that most threatens their own ephemeral existence. Given the universality of death anxiety, it is academically both interesting and most challenging to investigate how death anxiety might interact with such other variables such as the quality of palliative caring and the burnout syndrome. It is also interesting to note that to date there are no studies that specifically look at the possible cause and effect or interaction between death anxiety, palliative caring and burnout.

The aim of this study is to investigate the relationship between caring, death anxiety and burnout among palliative care nurses.

The objectives are to:

- Identify aspects of caring perceived as stressful when caring for dying patients;
- Examine relationship between death anxiety and burnout;
- Examine relationships between social support, burnout and death anxiety;
- Identify significant predictor variables of burnout;
- Identify differences in burnout and death anxiety scores between nurses working in hospices, hospitals and community settings

Personal motivation to undertake study

Working with dying people and reflecting on how they relate to death and dying has partly influenced the focus of this thesis. The way dying people relate to and deal with impending death seems to suggest that it is still difficult to die, even though it is certain that death is the only outcome of our ephemeral existence. Available literature (Neimeyer, 1994; Wass, 2005; Kastenbaum, 2008) suggests that this difficulty is more prevalent in Western societies. There does not seem to be a plausible explanation for this, and therefore, it can be argued that the only explanation possible is through speculation. For example, the fear of death may be to do with the process of dying and not death itself. It is possible that the meaning or impact of death may be what people find difficult to come to terms with. It is also possible that parental attitudes toward death, which often discourage children from attending funerals, means they too grow up not familiar with death and are most likely fearful of it.

Caring for dying patients involves witnessing their death and dying experiences. It involves supporting them emotionally, practically, psychologically and physically. However, it is not yet clear what the impact of repeatedly witnessing these experiences would be on carers like palliative care nurses. It is also not clear how many carers/nurses may already be experiencing adverse effects from caring for dying people, such as burnout, high levels of death anxiety and even co-dependency. The need to understand the impact of caring among palliative care nurses has also partly influenced the focus of the study. The fact that there are no previous studies specifically undertaken to investigate this area makes this study important and timely.

Introduction to the study

This study investigates the relationship between caring, (i.e. the act of providing palliative care), death anxiety and the burnout syndrome among nurses working in palliative care settings in the Mid West region of England, in the United Kingdom.

The study establishes some of the main sources of pressure encountered during the caring process and their impact on nurses' reaction to death and dying experiences in palliative care. Palliative care is a concept practised in settings where terminally-ill patients are cared for, which is governed by a set of principles agreed by the World Health Organisation (WHO 1990) and implemented by different countries world wide. The settings found in the United Kingdom (UK) comprise different environments including hospices, hospitals and the community, as the main ones.

The delivery of care in the community differs significantly from the other two in that nurses visit and provide care in patients' homes, as lone practitioners, away from the close support of the multidisciplinary team structure.

The practice of palliative nursing is capable of providing, among other things, profound stress and satisfaction for health professional carers (Vachon and Benor 2003). First, stress arises partly from the intensity of the emotional involvement when health care professionals invest in their patients' needs. As will be discussed later in this chapter, stress can also have an impact on health and speed up the ageing process.

Caring, which is discussed in detail in chapter two, involves understanding, empathising, and supporting patients with their emotional as well as psychological needs (Smith 1992; Vachon and Benor 2003). Commentators in palliative care including (Noddings 2002; Twycross 2003; Davies 2005; Payne et al 2008) agree that caring can be mentally tiring, emotionally exhausting and physically demanding for nurses. It can be concluded that caring plays a key role in how nurses interact with patients' needs and how much they (nurses) offer emotional support.

Second, satisfaction comes from helping and supporting patients to enjoy an improved quality of life despite their terminal illness. However, there is no evidence to suggest that witnessing death itself provides satisfaction for nurses in general and in palliative care in particular.

Despite the satisfaction palliative nursing may provide, and it is well documented that overall, it is one of the most stressful areas of specialist nursing (Maslach, 1982; Krikorian and Moser, 1985; Mallett, 1988; Smith, 1992; Vachon and Benor, 2003; Sherman, 2004). The range of commentators and spread in the time period (1982 to 2004) suggests that this problem has been in existence for a long time. Health professionals in this field are constantly exposed to issues of loss, some of which are through death of patients, inability to control complex symptoms, and loss of the ability to make decisions. It is therefore inevitable that such nurses may end up being emotionally involved with their patients' needs and problems. When this happens, there is a real danger that their own well-being is threatened, either through developing burnout, being co-dependent or experiencing raised levels of death anxiety.

The literature on stress and burnout suggest that prolonged exposure to such caring demands may result in health professionals feeling emotionally exhausted (Maslach, 1982; Mallett, 1988; Vachon and Benor, 2003; Sherman, 2004). Emotional exhaustion is discussed in detail under burnout in chapter 3, but according to Zellars and Perrewe, (2000), if emotional exhaustion continues unabated, it leads to burnout. When this happens, health professionals may start to distance and depersonalise their intervention from patients' needs. It can be argued that depersonalisation (a psychological defence mechanism) will eventually lead to poor quality of care being provided to dying patients. As a result, patients' death experiences are arguably less individualised and therefore no longer unique to them and their relatives. Indeed, this may not seem a troublesome issue for patients, once deceased, but survivors tend to live with these lasting and negative experiences during their grieving period, and into bereavement. Saunders captures it succinctly when she comments that "how people die remains in the memory of those who live on" (Saunders 1978; p126). This is fundamentally important for each and every nurse to remember when caring for dying patients.

Although health professionals are aware of their patients' poor prognosis, such knowledge may not be adequate to stop them experiencing work related stress. Some health professionals' expectations of themselves may be unrealistic (Vachon 1986; Vachon and Benor 2003) and as a result may end up over-involving themselves.

Although the consequences of over-involvement behaviours could be judged as self-inflicted stress Munley (1985) and Payne (1998) argue that, this is common among hospice nurses, and not likely to abate. Perhaps, this demonstrates the commitment nurses have in caring for other people; a point which is developed later in chapter two. The point though is this, despite any such commitment behaviours, nurses need to be supported through different methods which enable them to continue to provide quality care to dying patients.

Caring in palliative care

Caring seems to be one of the main sources of burnout and increased death anxiety particularly for those looking after dying patients (Mallett, 1988; Payne, et al. 1998; Vachon and Benor, 2003). Nurses in palliative care are at great risk of stress and strain (Mallett 1988). It is acknowledged (Smith, 1992; Munroe, 2004), that caring in palliative care requires both emotional and psychological resilience. Chapter two explores the concept of caring in more detail and discusses aspects associated with most distress for nurses.

It seems possible that caring leads nurses to feel emotionally tired because of the emotional 'investment' they make in patients' needs. Constant exposure to death and to the dying experiences of patients may induce thoughts about their own existential vulnerability and mortality, thus potentially increasing levels of death anxiety among professionals. According to Smith (1992); Vachon (2000) and Munroe (2004), increased levels of death anxiety often impact on the quality of care provided.

Statement of the problem

Health professionals in general and palliative care nurses in particular are continually exposed to death and to the dying experiences of adult patients more often than any other group of professionals. The impact of such exposure on palliative care nurses is not yet clearly understood. The perception of stress (or stressful situations) encountered while caring for dying patients may vary among health professionals. When stress remains unmanaged, it accumulates and eventually develops into a syndrome known as burnout (Maslach and Jackson 1982). Burnout, which is the subject of chapter 3 of this thesis, affects hard-working and highly motivated health professionals, by depleting their strength and resources to cope with demands.

Freudenberger (1983), probably the first to introduce burnout and recently Maslach et al. (2001) and Pines (2002) all describe burnout as a syndrome of physical and emotional exhaustion leading to negative self-concept and negative job attitudes. When this happens, it can be argued that health professionals, once committed, will disengage from their daily work responsibilities and depersonalise their involvement with patients.

It follows from this, that disengaging from their daily work will have negative consequences on the quality of care patients end up receiving. Poor patient care will not only affect the patient, but relatives and close friends as well.

There is evidence (Mallett 1988; Pines 2002) that occupations most susceptible to burnout are the helping professions, of which nursing is one. Helping professions and nursing in particular, are constantly ‘dealing’ with people on a highly emotive level requiring intense cognitive and emotional input. Additionally, helping professions to do with palliative care are also exposed to death and dying episodes while caring for dying patients. Such exposure may ultimately induce high levels of death anxiety, as professionals may be ‘forced’ to review perceptions of their own mortality. One suggestion is that health care professionals may be more susceptible to death anxiety once they experience burnout, as it curtails their ability to be resilient (Cohen 2008). Cohen’s assertion, suggests that, by being repeatedly exposed to death and dying episodes, Palliative care nurses may further increase their susceptibility to death anxiety.

Death anxiety is a sensation of apprehension about threat to our existence (May 1977, Neimeyer 1994; Kastenbaum 2000). It is also regarded as an emotion triggered by multi-faceted concerns and centering on the contemplation of the death of self and the death of others (Nyatanga and de Vocht 2006). This 'centering' is also concerned with witnessing other people's death; a common occurrence for health professionals working in palliative care.

The organisation of care in the UK suggests that caring for dying people by others (professionals or non qualified) is inevitable, therefore what seems crucial is how to ensure supportive measures are in place for all health professionals in order for them to remain resilient and continue caring. In present difficult economic circumstances, most supportive mechanisms are ad hoc, not regular or properly structured. The worst scenario for professionals is when their organisation fails to provide these supportive services. In this case professionals have relied on peers to provide support, which in turn puts more strain on other professionals as they may lack capacity and ability, while dealing with their own practice demands.

Significance of the problem

The impact of caring for dying patients as part of one's job may be threefold:

i. It raises mortality salience (death awareness) and may act as a constant reminder of one's existential vulnerability

ii. It increases emotional exhaustion and depersonalisation (distancing techniques) among health professionals

iii. It affects nurses overall quality of care delivered to dying patients and their families, which may lead to undignified death

Other negative outcomes of burnout are listed by Palmer et al (2001) which include reduced staff performance, reduced staff morale, increased staff sickness and absenteeism, cardiac disturbances, erratic behaviour including alcohol abuse and being more prone to accidents. Literature on death anxiety and burnout suggests that if high levels of either death anxiety or burnout are experienced in individual nurses, this may affect the quality of care delivered to dying patients (Sherman 2004).

The same conclusion was also reported in earlier studies by (Popoff and Funkhauser, 1975; Denton and Wisenbaker, 1977; Stoller 1980). The argument from these findings is that the impact is felt by patients who may not be afforded a unique death that reflects their own individuality. The impact of high levels of death anxiety on nurses manifests as symptoms such as appetite changes, insomnia, alcoholism and depression (Stoller 1980; Tomer 1996; Sherman 2004), which lead to poor job performance and eventually, absenteeism. Some nurses may end up requiring medical and nursing intervention themselves, which adds to the cost of caring on the National Health Service (NHS). This may also affect their own family relationships while depleting staff resources needed to care for dying patients. Further impact on service provision may be as follows:

- According to the CBI (2002) and Christenson (2008), recent surveys in the work place estimate that in the UK 13.4 million working days a year are lost to stress, anxiety and depression, at a cost of £5.7 billion. When considered in true financial costs, this figure rises to £11.5, which includes salaries paid out to absent employees and on additional overtime and temporary staff cover (CBI, 2002);
- It is possible that not only absenteeism costs money, but 'presenteeism' as well, that is, employees who may be at work but not contributing fully because of stress or other ailments;
- An increasing cost of inducting and training new people due to high rates of staff turnover (Palmer, et al. 2001)

The cost of burnout for individuals includes job loss, financial strain, decreased life span, some of which could lead to illness such as obesity, heart attacks, stroke and cancer (Sherman 2004; Epel, et al. 2005; Christenson, 2008). Symptoms presented in those with high levels of death anxiety have also been reported in those presenting with the burnout syndrome (Sherman, 2004), therefore suggesting a possible link between these two phenomena. Burnout is characterised by emotional exhaustion, depersonalisation and low levels of personal accomplishment (Maslach 1982), while death anxiety has been long established as a sensation of apprehension about threat to our existence (May 1977; Tomer 1996; Kastenbaum, 2008).

It can be argued that, such threats become more real when we feel emotionally exhausted, cynical and lack a sense of purpose in life.

When professionals feel anxious about death and are burnt out, the quality of care they provide is likely to deteriorate. Mallett, (1988), reports that the way in which health professionals perceive death and dying significantly impacts on the quality of care provided. The implications for poor quality of care can result in a perception among relatives that patients had a ‘bad’ death and suffered as well. It is the relatives that carry on living with memories of a patient’s death which may continue into their bereavement period and in some cases leading to pathology (Leming and Dickinson, 1998; Twycross 2003; Leming and Dickinson, 2005). When this happens, it can be an additional demand on health care professionals’ already heavy workload. Furthermore, a wider implication is that when funding is redirected to the NHS, it is likely that other public services will suffer financial shortages as a consequence.

Culture and portrayal of death

There are numerous environments where death occurs within the UK, but the common ones include, the National Health Service (NHS) with its hospitals and the community (Field and James, 1993). Outside the NHS are private and independent environments such as, care homes, private hospitals, independent hospices, patient’s home and specialist palliative care units. It is true that death also occurs in other settings such as nursing homes, industrial sites, public roads and airways. Other deaths occur through premeditated actions such as terrorist attacks, criminal murders, and the armed forces’ actions in war times. The extreme would be death through suicide, where individuals make a conscious choice (maybe out of severe suffering and desperation) to end their own lives. This study is primarily interested in chronic illness caused by progressive disease such as cancer, where there is a patient’s journey towards death, and where palliative care is being provided. It is through this type of caring that nurses are exposed to dying and death experiences of different patients.

The way a society views life will dictate how death is perceived. For example if society views life as sacred, everything is done to preserve it, and people will almost always feel sad when a death occurs. This example fits well with the Western world's perception and portrayal of life and death, and this study is being conducted in a society that believes predominantly that life should be preserved. For example, attempts by proponents of assisted dying through euthanasia and assisted suicide have not succeeded in its legalisation in most Western countries except The Netherlands, Switzerland, and Belgium (de Vocht 2008). Instead, more advanced technology is being developed to try and save life or slow the pace of dying. One argument is that nobody has the right to end another person's life even if it is on that other person's request. The UK is well known for its principles of democracy which include freedom of speech and choice, but when it comes to ending one's life, this seems a harder choice to accede to.

There are very few overt discussions about death (Department of Health 2008), therefore death might still be treated or considered a taboo subject despite the increasing volume of literature on death and dying. In other words there may still be substantial ignorance or denial of death within society. Such denial can only make caring for dying patients more challenging in terms of communicating death and dying issues with them (Twycross 1994; Nyatanga 2001; Nyatanga and de Vocht 2006; Nyatanga and de Vocht 2009). The media and other publications play an influential role in shaping death attitudes, which will inevitably influence the perception of death and possible development of death anxiety. The portrayal of death and dying in television programmes like Holby City, Doctors, and Casualty help to form perceptions about death and attitudes towards it. Although it is also true that some of the scenes help to break down barriers and encourage people to talk openly about death, there are however, small pockets of drama television that perpetuate the death-denial attitude while fostering the death fear mentality of the Western societies. If patients possess death-denying attitudes, it can be argued that any discussion regarding death and care options becomes inevitably fraught with communication difficulties.

To this effect, the Department of Health has recently introduced the Advance Care Planning initiative (DH 2008) where professionals initiate discussions with terminally ill people, about their care priorities, and preferred place of death. The 'Dying Matters Initiative' was created out of the End of Life Care Strategy of 2008, to drive through changes and encourage people to talk more openly about death of self.

Health professionals may find tension between their intervention to maximise quality of life and the patient's 'fight' and denial that death is imminent. Where this is the case, it is even harder for patients and their relatives to discuss post-death priorities and rituals. It is in such circumstances that the use of euphemisms is evident, and often true meanings of words are lost or disguised. Where euphemisms are used, there is a danger that communication is no longer straight forward, but filled with innuendo that need deciphering in order to be able to understand the true message and meaning. This often creates communication dilemmas and important messages are lost resulting in poor psychological care being provided. A detailed discussion of euphemisms is given in chapter four. It is within the above context that this study was undertaken.

Summary

Nurses in palliative care settings are exposed to death and dying experiences that can be judged as extremely stressful. However, there is evidence to suggest that palliative nursing can also provide satisfaction to those providing care. Caring for terminally-ill patients is fraught with aspects of caring that can provoke immense emotional reaction among nurses. It can be argued that, being constantly exposed to death and dying experiences acts as an unfortunate reminder of one's own mortality. Therefore, one's existential vulnerability is placed into sharper focus, (Neimeyer 1994; Wass and Neimeyer 1995; Kastenbaum 2000). Often, the outcome of such reminders may induce level of death anxiety among health professionals. Because nurses more than any other group, have sustained contact with dying episodes their resilience is more likely to be affected and their sources of strength tested.

By definition palliative care is based on a multi-disciplinary team approach and nurses tend to rely on other professionals to cooperate in accomplishing their tasks. Establishing and maintaining such relationships can also be a source of stress in caring. There is evidence to suggest that if stress continues unabated, it will develop into burnout (Maslach 2001). It is possible that all these factors can affect nurses' overall perception of their own mortality and induce high levels of death anxiety. High levels of death anxiety can be induced by witnessing others' death. In addition, contemplation of one's own death or that of others may result in high levels of death anxiety.

Continual or repeated exposure to death and to dying episodes of patients may become emotionally exhausting leading to complacency about the uniqueness of each death. Emotional exhaustion is believed to lead to burnout if it continues unabated.

It is now established that when emotional exhaustion sets in, people tend to distance or depersonalise their caring activities as a coping mechanism. In high burnout levels, these two components are raised, thereby diminishing the third component, that is, low personal accomplishment in their work. Nurses who were previously caring and effective professionals may become less so, because of increasing burnout and as a result patient care deteriorates.

This study aims to investigate the relationship between caring, death anxiety and burnout among palliative care nurses.

CHAPTER 2: CONCEPT OF CARING

Chapter Overview

This chapter begins by exploring the concept of caring in general, and palliative care in particular. This exploration will draw on literature from philosophy, psychology and nursing in an attempt to show the breath and depth of this concept thereby demonstrating how elusive it may be to understand. The discussion will then focus on caring offered to terminally ill patients (palliative care) and its impact on nurses providing the care. Palliative care is important in this discussion as its main focus is caring for dying patients, as opposed to curing them. Such an attitude shift from cure to care might be difficult for some nurses who may perceive it as failure on their part. However, on the other hand, caring for dying people may result in greater emotional involvement for health care professionals and such interaction may lead to increased awareness about death and dying. Such awareness might lead also to increased awareness of our existential vulnerability, higher levels of burnout and even co-dependency. As literature discussed in chapter 3 suggests, palliative caring can be a stressful occupation and nurses' ability to provide quality care may be profoundly curtailed.

Caring is discussed as the central tenet that nurses engage in on a daily basis and which brings them closest to dying patients' experiences and associated anxieties. Different types of caring, including empathic care, co-dependency and their ethical and moral aspects are discussed in order to highlight perceived challenges and impact on nurses' well being and perception of their own mortality. Co-dependency is discussed to show an extreme type of caring that people may engage in without recognising the negative impact it has on their tendency towards their self care.

This chapter confirms aspects of caring that are commonly identified as sources of burnout among palliative care nurses. These aspects and the rest of the work undertaken in this chapter are central to this thesis, because caring has to take place first before carers can experience burnout or death anxiety.

Introduction

Caring is, in this broad sense, a basic phenomenon of human life (Noddings 1999), which makes it ontological in nature, that is, an intrinsic part of being human. Ontology involves enquiry into the very nature of things (i.e. nature of humans) and their essential properties. It is from this perspective that the claim that care is fundamental to being human is derived from.

The suggestion here is that everybody (including non-health care professionals), cares as a way of being human. For example, teachers, politicians, the police, homeless, activists and even terrorists, care in their own way. Benner and Wrubel (1989) put it more succinctly when they state:

> "*caring is part of what it is to be a human being. Caring is a basic way of being in the world*" (p. xi; and p368).

In other words human beings may not consciously choose to care, but caring is inherent in them. Therefore, caring is an activity encountered beyond the boundaries of nursing, therefore refuting suggestions by some nurse theorists, for example, Leininger (1984) and Watson (1988), that caring is unique to nursing.

However, when it comes to nurses, in addition to having ontological caring, they also choose to care for others, and this type of caring is what Edwards (2001) refers to as intentional care. The issue of intentionality has several implications for nurses providing care, some of which include, nurses thinking and feeling that despite any hardship, pressure or stress encountered, they will not let the patient down and therefore they will continue to care and ignore any signs of stress or tiredness. Such intentionality may see nurses caring intensively for others to the extent of 'forgetting' to care for themselves and becoming co-dependent in their care giving. It can be argued that caring for others often 'demands' involvement at both the emotional and physical levels of the other person. The impact of such involvement may not yet be clearly understood, although Smith (1992) and Vachon (2003) suggest it leads to compassion fatigue. However, health professionals are motivated to care, even to the extent of 'damaging' their own health and well being (Bakker et al 2000).

Because caring can take place in different settings and both ontologically and intentionally, for purposes of this chapter, the focus will be on caring that takes place within nursing and palliative care settings in particular. The chapter will show the emotional reaction and psychological impact derived from caring particularly by palliative care nurses.

What does not seem to have consensus though is the concept of caring itself and what it is, and the next section will discuss this in more detail. This section will draw from nursing literature on some definitions and will highlight some of the key attributes of caring.

Concept of caring

Evidence from several authors (Roach, 1984; Watson, 1985; Morse, 1990; Leininger, 1991; Boykin & Schoenhofer, 1993), suggests the concept of caring does not have an agreed definition or meaning. Leininger (1981) found that the term caring is often linked as a suffix to nursing without differentiating between nursing and caring. Its use was as if caring was synonymous with nursing. Later in 1991, Leininger attempted to highlight the centrality of caring in her work. For example, Leininger (1991) saw caring as actions and activities directed towards assisting, supporting or enabling another individual or group with anticipated needs to ameliorate or improve a human condition or to face death. Leininger makes the claim that caring is a universal trait vital for human survival. This assertion is not only a deviation from her earlier claim that caring is unique to nurses but seems consistent with Heidegger's idea of *Dasein, (*discussed briefly in chapter 4, and in more detail below) which claims that caring is ontological, that is, part of being human, and therefore helps refute the suggestion that caring is a prerogative of nursing. From this, caring may not be that different from other behaviours, for example, altruism.

Another view of caring was offered by Noddings who sees caring as an intentional act. According to Noddings (2002) caring starts with learning what it is like to be cared for. Then gradually, learning both to care for and by extension, to care about others (Noddings 2002). Noddings goes further to argue that this caring 'about' others is almost certainly the foundation of our sense of justice. She believes that caring 'about' or a sense of justice, must be seen as instrumental in establishing conditions under which caring 'for' can flourish.

This seems to be central to the care theory (Noddings 2002) that when we care, others ought to benefit and not be disadvantaged. According to Noddings, those who care about others in the justice sense must keep in mind that the objective is to ensure that caring actually occurs. Caring 'about' is empty if it does not culminate in caring relations (Noddings 2002). In order to establish such relations, Noddings asserts that carers should step out of their frame of reference into the others', in order to fully understand the other person's situation and world view. This assertion, although welcome, highlights its own areas for debate which will be discussed later in this chapter. Noddings is arguing for empathic understanding which seems essential for person centred and holistic care necessary when caring for dying people (WHO 2002). This assertion has the strongest appeal to palliative caring and may be the answer to the question of "what constitutes good care in palliative nursing".

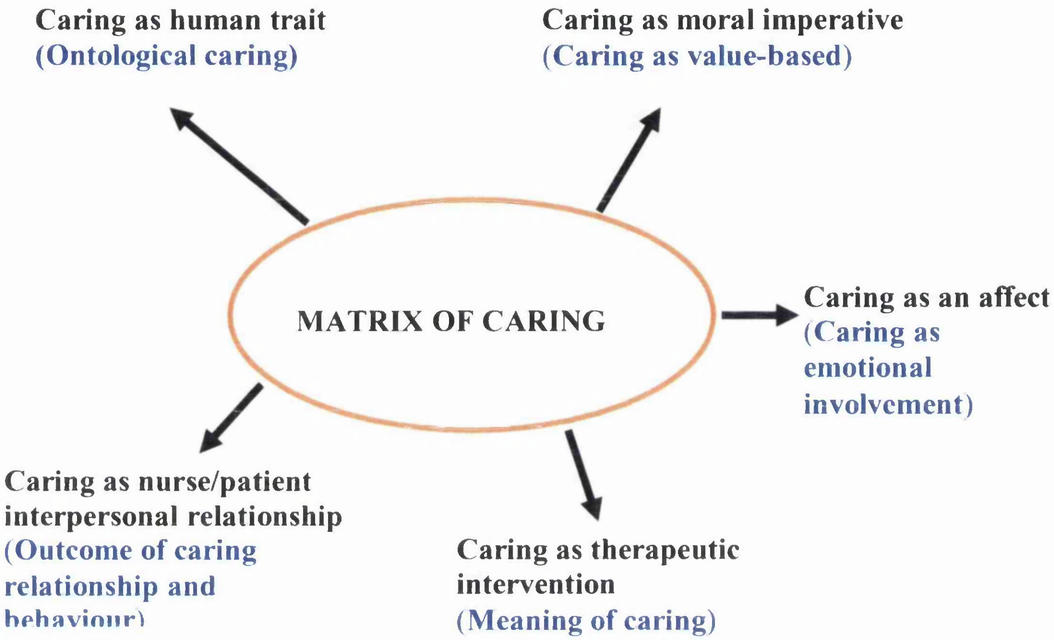
Working and caring for dying patients (or palliative nursing) requires compassion, which in turn comes from empathy and interest in peoples' needs or distress (Rogers 1962; Smith 1992; Noddings 2002; Vachon, 2004). On the other hand, exposure to other peoples' distress can be distressing for caregivers, and this is part of what empathic caring is about.

Morse et al (1990) claim, after looking at 35 different definitions of caring by nurse theorists, that there are five possible ways of understanding caring:

1. Caring as a human trait, where caring is seen as part of human nature and essential to human existence. This is also seen as a motivator of nursing actions;
2. Caring as a moral imperative or ideal where caring is seen as a 'fundamental value', that is, actions committed to maintaining the individual's dignity and integrity;
3. Caring as an affect which suggests caring is seen as involving the emotional side and empathising with patients, with a view to protecting and supporting them;
4. Caring as an interpersonal relationship, in which caring is seen as an interactional relationship between nurse and patient. This includes the nature of feelings and behaviours within the relationship;
5. Caring as a therapeutic intervention, that is, caring is seen as an intervention to help the patient feel better. Interventions can be active listening, "being there", addressing physical needs, educating patients and offering psychological support.

Although, Morse et al's five ways of caring seem quite generic and not specific to professional nursing, some (e.g. 3 and 4) do relate to caring encountered in palliative nursing. These five ways shown in Figure 1 do not seem to offer a clear definition that is consistent and which leads to a better understanding of caring in palliative care settings. It is not implausible to suggest that Morse was simply mapping out the range of caring aspects covered by the numerous definitions that she investigated and not attempting to offer a definition at the end of this process. It can be argued, that if the above premise is acceptable, then Morse was in a subtle way, illustrating the elusiveness of a clear definition of caring.

Figure 1: Matrix of Caring



What the above five ways in figure 1 suggest is a matrix of caring. However, some discrepancies exist, which also suggest differences in how the concept of caring is viewed. Some of the statements offer meanings of caring and not necessarily a concept as such (e.g. caring as therapeutic relationship).

In the matrix, one way (caring as a nurse-patient interpersonal relationship) confirms caring as an outcome of congruence in feelings, understanding and behaviours between nurse and patient. On the other hand caring that is ontological (caring as human trait) is now being justified as nursing. The argument from Heidegger's perspective is that we do not choose to care, but we find ourselves caring as part of what it is to be human beings. In other words, being human suggests we do not have a choice about caring unlike nurses who make a conscious decision (intentional) to care for another person.

The point to emerge from this brief analysis is a lack of consensus on what caring is or ought to be. It must be pointed out that because of the different attributes and permutations of caring, it may not be possible or even desirable to reach a consensus on such a concept. It is therefore plausible, as a way of summary, to suggest that caring shown in the matrix, highlights multi-dimensional facets that embrace the different approaches to caring. However, such caring is not completely specific to the empathic caring witnessed in palliative nursing (Twycross 2004; Vachon 2003; Smith 1992). In search of a more succinct understanding of caring, the discussion now looks at the epistemological basis of caring and different types of caring which will lead on to an appropriate model of empathic caring witnessed in palliative nursing.

Epistemology of caring

Epistemology seeks to uncover the basis of knowledge that palliative caring is based on. But more important for this chapter is the knowledge of how palliative caring is practised, and whether such practice may have an adverse effect on perceptions of death anxiety and feelings of burnout among palliative care nurses. There are several views about the knowledge base and practice of caring. Caring is encountered in two key dimensions; ontologically and intentionally.

Ontological care can be understood from Martin Heidegger's postulates, (that is, his assumptions that such care exists, is true and can form a basis for discussion (Heidegger, (1962), and especially when he writes; " *dasein* (the quality of being there), when understood ontologically is care" p84 and 237. In this context, *dasein* is Heidegger's term for "being", and can be taken literally to mean 'being there'. What Heidegger is pointing to is that, as human beings, we inevitably find ourselves in the midst of things; we are 'thrown' into the world, and as a result we have no option but to deal with them (things) in order to cope with the situation we find ourselves in. In this way, being in the world is essentially caring, and this is ontological care (Heidegger 1962). This view is succinctly described as follows:

"Dasein is always occupied with the entities it encounters in the world... The point is not that Dasein is always caring and concerned, or that failures of sympathy are impossible or to be discouraged; it is rather that, as Being-in-the-world, Dasein must deal with that world. The world and everything in it is something that cannot fail to matter to it" (Heidegger 1962; p237).

A closer scrutiny of Heidegger's view reveals two main aspects of caring:

i. negative - possibility of failure in caring and
ii. positive - determination to deal with situations as part of caring.

The negative aspect is the claim that care is not synonymous with intentional care when he asserts that, the point is not that '*Dasein*' is always caring and concerned. In other words we can care, but the way we care can also inflict pain and discomfort. For example, the intention might be to relieve another person's physical pain, and this can be done by injecting an analgesic drug, the process of which often causes pain as well. In other words, while we care enough to alleviate the pain, the way we achieve this (injecting) inflicts pain/discomfort to the patient. It is possible to consider such processes as negative, thereby highlighting caring as not being concerned about the plight of the other person. However, this negative approach is often inevitable in order to achieve the positive or success points of caring, like pain relief.

A positive aspect comes from Heidegger's view that by virtue of our inevitably being situated within the world, being surrounded by people, objects, by having needs, feelings and desires, we are compelled to 'deal' with the world and the situations within which we find ourselves. It is in this sense that the world inevitably matters to us. This 'mattering' need not be the result of our conscious deliberation. Within situations we make choices, some reflective and some less so. Thus our actions reveal what matters to us, whether or not these acts result from conscious or reflective choices. It is this feature of what it is to be a human being (in Heidegger's terms; of human Being- in-the-world), that Heidegger describes as '***sorge***', the term meaning to care. The implication for *sorge* is that the outcome ought to bring about a better solution (eg freedom from anguish) than where the person was when caring started.

This outcome is arguably similar to that pursued by palliative care nurses while they care for dying patients. However, palliative care nurses may achieve this through a holistic approach to care which involves emotional investment in patients' needs.

Finally, the key point according to Heidegger is that ontological care is an inescapable part of what it is to be human, and humans are situated in a world with things that matter to them. It is plausible to suggest that palliative care nurses view dying patients as 'mattering' to them and therefore choose to provide care for them. However, in addition to ontological care, nurses in this case make a conscious choice to care, and according to Edwards (2001) this is intentional care.

Intentional Care

Intentional care stems from deliberate acts of care on the part of human beings (Edwards 2001). This type of care is usually driven by beliefs, desires, thoughts and perhaps emotions about that particular aspect of care. One such desire might be better quality of life for all patients. Intentional care is based on well thought out deliberate actions to care for somebody (care for) or something/somebody (care about).

It seems clear that there is a distinction between ontological and intentional caring - although some nurse theorists and commentators seem to encourage a conflation of the two positions (whether intentionally or unwittingly) thereby 'misleading' readers to the subtleties of the differences of these two positions. In practice, nurses who choose to care for dying patients tend to make a conscious decision to do so (hence, intentional care). The argument might be that some may not have expected what they encountered in terms of the level of emotional experiences and exposure to other people's death and dying episodes. Caring for dying patients is often labour intensive and emotionally exhausting (Smith 1992, Maslach and Schaufeli 2001, Vachon and Benor 2003). The impact from such exposure and experiences might be a development of anxiety about death and emotional exhaustion leading to burnout, which this current study is investigating.

According to Bakker, et al (2005), one persuasive explanation of why nurses engage in such caring is the idea of reciprocity. Reciprocity is where nurses choose to work with dying patients, provide high quality care in the belief that they too may suffer a terminal illness someday. When this happens, other people will be available to reciprocate by providing high quality care to them which is equal or better than that they provided to their patients. Although it is sensible and logical to suggest that nurses may over-identify with dying patients, the overriding reason for their actions is to provide high quality care and enhance quality of life for others. Although Bakker et al's (2005) assertion seems plausible, the possibility of this reciprocity happening remains spurious and therefore the link between the two positions always debatable.

Health care professionals may care for a majority of patients and families whose sole perspective is coming to terms with death. Health professionals would view effective pain and symptom management as rewarding and achieving a dignified death (WHO 2002), as points of success.

Summary of key points

The discussion so far demonstrates the difference in perceptions and perspectives about caring which has resulted in a lack of consensus of what caring is or ought to be. It is possible where complex aspects like caring exist that consensus may not be achieved or even necessary. The discussion has clearly shown that caring is ontological and applies to all human beings. In addition to being ontological, some people like nurses in this case, also engage in intentional care which is based on choices they make to care for others. Intentional caring therefore, involves two parts: the carer and the cared for.

The idea of carer and cared for

There are potential limitations in some assertions given about caring. For example, one assertion by Noddings (2002) advocates that the people caring for someone should step out of their frame of reference into the other's, for the care to be effective. This requirement seems unnecessary if not impossible. One's frame of reference cannot simply be put aside or as Edwards (2001) puts it, jettisoned, while caring, because that reference is what guides us to understand the other's frame of reference. We view the world through a set of concepts (concept of a person, concept of pain, concept of life) and so on.

What seems possible from Noddings' claim is considering the other's point of view, but with our own frame of reference still intact, and this gives clarity to our understanding of the other person's situation. Using our frame of reference is an important part of caring in palliative nursing, as it helps bring about a clearer understanding of patients' needs. Edwards concurs and sees this as considering the plight of the cared for (Edwards 2001). In considering one's plight, it may be argued that carers often need to have the ability to imaginatively understand and view the other person's world as if they were that person. Other commentators (Benner and Wrubel 1989, Davies 2005) call this way of understanding, empathy. Both Noddings and Edwards in effect concur with Rogers's 1964 definition of empathy: *The ability to experience another person's world as if it were one's own* *without ever losing the "as if" quality* (Rogers, 1964; p226). Rogers went further and pointed out that even imagining that we could wholly enter into another's pain was disrespectful of their uniqueness. This can only emphasis the important of remembering the '*as if*' in all our attempts to help, care and support other people at the end of life.

What can be gained from the above discussion is an understanding of caring as it ought to be applied to palliative nursing, and at the same time place empathic caring at the centre of that caring.

Empathic caring in palliative nursing

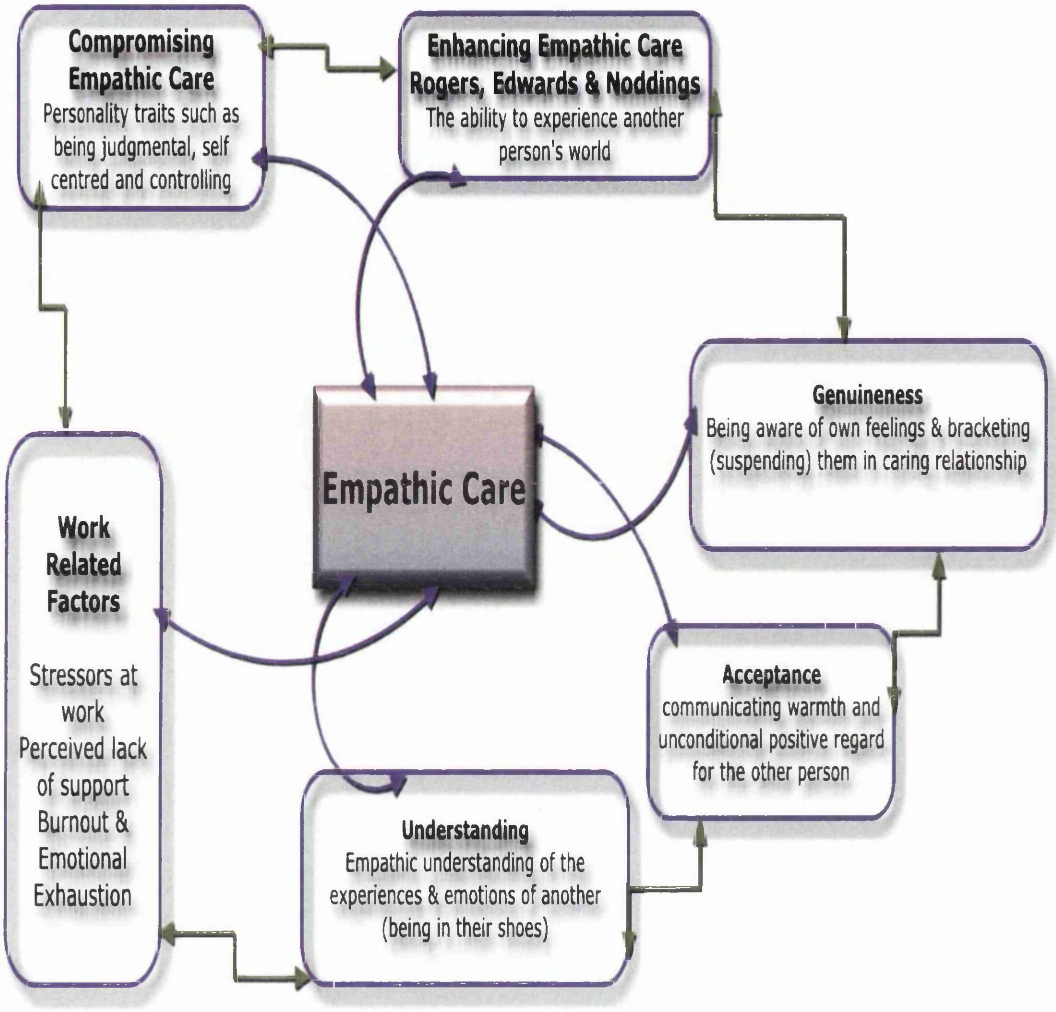
Empathy is necessary in order to understand another human being at both emotional and psychological levels. In palliative care, Davies (2005) makes the point that, empathy is crucial in helping dying patients to adjust to their dying. It is possible that such caring, which involves a range of human attributes, like those highlighted in figure 2, e.g. genuineness, is one of the reasons that palliative nursing is emotionally exhausting (Vachon and Benor 2003, Munroe 2004 and Davies 2005). As shown in figure 2, empathic care is an interaction of different human attributes to do with personality traits, genuineness, understanding and accepting the other person without condition.

Noddings (2002), Edwards (2001) and Rogers' (1964) ideas all give rise to the possibility of empathic care and these are presented in figure 2. Briefly, the motivation for empathic care is believed to be a product of both biological and psychological influences.

- Biological evidence suggests that the brain structures required for a primitive affective involvement with other humans have been present since early human evolution. It can be argued therefore that empathy could have contributed to aspects of human social existence. It is well documented that throughout history, humans have always been exposed to danger (MacLean 1985), and because of the enormity or perceived enormity of the threat, the only way forward was not for one individual, but a group of individuals to come together and unite against the danger. Therefore, such evidence may have led Davies (2005) to conclude that, the tendency to help others in distress may be part of our biological inheritance. The idea of uniting against a common danger or threat has resonance with terror management theory (discussed in chapter 4) in that human beings tend to 'pool' resources together to fight against a common terror or threat.

- Psychological evidence (Davies, 2005) points to a need by human beings (even those starting wars) to live harmoniously together, cooperating and helping each other. This may be a strange characterisation of 'war mongers' and how they show empathy, but at the root of their actions, may be the same desire like every decent human being, to do one's best for others. This approach is considered part of being empathetic, and according to Davies (2005), motivates people to care for one another.

Figure 2: Empathic care in palliative caring



The idea of empathic care suggests that there may be positive and negative experiences that will be encountered. Working with and caring for dying patients requires compassion, which is based mainly in empathy and unconditional interest in other peoples' needs or distress (Rogers 1964; Smith 1992; Noddings 2002; Vachon, 2003). Negative care may arise from having too much interest in other peoples' distress, in which caregivers end up being distressed themselves (Vachon 2003).

The extreme of such care may manifest itself as co-dependency (Jun et al 1999) which is characterised by excessive care for others' needs while neglecting one's own.

The concept of co-dependency

Different people tend to display various tendencies towards caring expressed through their feelings and overt behaviours. In most cases the degree of caring behaviours will fall within a 'normal' range from minimal to optimum care provided. However, there are people who tend to care in an excessive way and often end up neglecting their own self care. Such caring often results in the carer becoming co-dependent on the person they are providing care for (Prest et al 1998), hence the concept of co-dependency.

Originally, co-dependency stems from Alcoholics Anonymous (Gomberg 1989) where partners/spouses of alcoholics cared for them excessively and in so doing sacrificed and neglected their own needs in order to continuously provide care and keep life progressing (Prest et al 1998).

Nowadays, and according to Jun et al (1999), co-dependency is defined more broadly to include a tendency to behave in an overly passive or excessively care-taking way that negatively impacts on one's relationship with others and quality of life. In other words, nurses may exhibit behaviours that are only focussed on caring for others regardless of consequences on themselves, thus limiting their caring responsibility. Co-dependency also involves placing one's own needs at a lower priority than those of others, while being excessively preoccupied with the needs of others (Gomberg 1989; Prest et all 1998).

Despite claims that co-dependency is a disorder (Cermak (1986), it should be pointed out that there is no consensus on whether it should be treated as a personality disorder. Most psychiatric disorders are recorded in the DSM IV- TR manual (Gomberg 1989), and the absence of co-dependency in this manual suggests it is not classified as such, although it overlaps with 'dependent personality' characteristics. Prest et al (1998) have argued that co-dependency in non-clinical populations can be a positive trait in that it can contribute to successful family function. Although Prest et al (1998) make a valid contribution here, questions arise as to whether the person who ends up being co-dependent would find such positive traits beneficial for them as well. It is clear from the literature that co-dependency refers strictly to those caring behaviours and feelings that are excessive and often leading to unhealthy consequences on the person providing the care.

From the above, it can be concluded that co-dependency can be viewed as representing a continuum of caring behaviours ranging from positive to extreme self-sacrificing excessive caring behaviours with negative impact on the co-dependent person. Carers at the negative end of the continuum have difficulty acknowledging their own feelings and needs, and as a result will always neglect their self care. Based on this premise, it can be argued that co-dependent people may be prone to developing emotional, physical and psychological negative ailments. The evidence so far suggests that such people may have an impulsive tendency to care for others without paying attention to their own needs (Gomberg 1986; Prest et al 1998). As a result, it is plausible to suggest that co-dependent people may eventually find themselves experiencing both physical and emotional exhaustion. Emotional exhaustion, which is discussed in detail in chapter 3, is a well established initial phase in the development of burnout (Maslch and Jackson (1982).

There is little published evidence on the relationship between co-dependency and burnout, and the one Japanese study so far (discussed in more detail in chapter 3) sheds some light on a possible link between these two notions. Because the evidence is scarce, it is not clear whether nurses who care for dying patients may end up with co-dependency characteristics. However, although the evidence is still scarce, there are suggestions outlining how co-dependency may present in terms of feelings and overt behaviours. For example, co-dependent people may have difficulty identifying what they are feeling. They may minimise or even deny how they are feeling. They may even perceive themselves as completely unselfish and only dedicated to the well being of others. The extent of such dedication suggests that they may be incapable of relaxing and instead receive/accept care from others.

Their behavioural side can manifest in various ways, including misplaced loyalty, arrogance, notions of grandiosity, people pleasing and as an extreme behaviour, even accepting sex when what they really need is love. According to Gomberg (1986; Cermak 1986; Prest 1998), co-dependent people can be prone to depression, physical illness or job burnout. They almost always feel guilty if they take time for their own self-care, and these sentiments are in line with Dear and

Roberts' (2002) conclusion that co-dependent people have a "*...tendency to put other people's needs ahead of their own" p159.*

Finally, co-dependency may in nurses, translate as lacking empathy and compassion when caring for dying patients. This lack of empathy and compassion is also experienced by those presenting with burnout (Sherman 2004; Maslach 2001) fuelling suggestions that there may be a relationship between co-dependency and burnout, although it is not yet clear what the nature of the relationship may be.

Organisation of Caring in palliative care settings

In essence caring is strictly about an appreciation of the other person's perspective in order to determine their needs. Such needs identification should also consider cultural, religious and other differences so that needs identified match needs being experienced by the other person. The importance of doing it this way is that once needs are identified, a specific tailored and negotiated response can be devised into an achievable care plan. Such practice reflects palliative care which works in conjunction with patients' needs and those of their relatives.

The practice of palliative care is now viewed as a concept (World Health Organisation 2002; Twycross 2003), which suggests that it can take place in different settings including a patient's home, the community setting (Dunne et al 2005), hospitals and hospices. What is common in these settings is the presence of patients dying from life threatening illness.

Contrary to the view that patients want or prefer to die at home (The National Council for Palliative Care (NCPC) 2003), a large proportion continues to die in hospitals (Field and James 1993; Davies, et al. 2006). Davies et al's study showed that a small proportion of patients die in hospices and in their own homes. Nursing homes accounted for the smallest number of all deaths. What is of note is that Davies et al's figures show an huge increase of deaths in hospices from Field and James' (1993) reported findings (see Table 1). Another increase since 1993 is reflected in more deaths at home, which is also in line with some patients' preferences to die in their own homes. The idea of patients dying at home is a fundamental principle for the End of Life (EOL) strategy (DH 2008) across the UK. Table 1 shows the percentage deaths in each setting over two periods. Although fewer people now die in hospitals than they did in 1993, overall more deaths still occur in hospitals. The figures in blue in table 1 are based on a study by (NCPC) (2003) and show the preferred place of death by patients. The point to emerge so far is that palliative care takes place in different settings, and any study, including the current one, on palliative care nurses should include all the key or major care settings like hospital, hospice and community settings. It is true that the quality of palliative care may differ with each setting and this requires further investigation in order to understand the nature and degree of burnout and death anxiety experienced in these settings.

Table 1: Preferred and actual place of death

Place of death **Preferred place of death**

	Hospital	**Hospice**	**Own Home**	**Nursing Home**
Field & James 1993	54%	4%	23%	13%
NCPC 2003	11%	24%	56%	?
Davies et al 2006	44%	20%	30%	8%

Hospitals have many advantages in terms of caring; they have caring facilities under one roof, that is, staff expertise, multidisciplinary diversity, nursing equipment like oxygen, hoists and readily available medicines for patients' treatment and pharmacist input on site. However, one of the drawbacks of caring for dying patients within hospitals is the existence of competing caring philosophies. On one hand, the hospital is there to cure patients whose goal is to regain full independence in order to return to society. On the other hand, the hospital is caring for dying patients whose goal may not always be regaining full independence but perhaps achieving a dignified death. The main focus of care is improving the quality of the remaining life (World Health Organisation 2002). One other key difference is that hospitals focus their care mainly on the patient (personhood), whereas when providing palliative care, the focus extends to include the patient's family (familyhood) as the unit of care (WHO 2002, Twycross 1994, Lloyd-Williams and Field 2002; Munroe 2004).

The needs of these two patient groups found in the hospital are significantly different as reflected in the intended outcomes of their care. Tension appears when both groups are being cared for on the same ward environment and by the same nurse. As discussed earlier, caring involves emotionally grasping a patient's plight in order to help and support them effectively. While this may be achievable for the patient, it is not always clear what emotional 'cost' impact this has on the nurse providing this intensive care with competing philosophies.

For the nurse, there is the need and ability to 'fluctuate' emotionally between patients' predicaments throughout the time one is in contact with them. The emotional 'toll' or emotional labour as Smith (1992) and Vachon and Benor (2003) call it, tends to 'drain' the ability for nurses to be resilient. Without support for the nurse, such emotional involvement may lead to emotional exhaustion and possible burnout. The concept of burnout and its three dimensions are discussed in detail in chapter 3.

Care within Hospice settings

During medieval times, the word hospice was used to denote a place where travellers could find rest and shelter on their journey (Saunders 1978). These places were run and maintained by religious orders, and even now some hospices have remnants of religion within their care. In the 19th and 20th centuries the Irish Sisters of Charity began to use the word hospice to refer to homes for dying patients (Saunders 1978). In time, hospices started to offer nursing and medical care for very ill and dying patients. This type of care has now developed and diversified world wide. Simultaneously, Kubler-Ross (1970) was emphasizing that choice and control about dying should be given to patients . Such suggestions would have created dissonance in nurses' minds as they were challenged to change their caring practices and involve patients more in their own care.

Hospice care philosophy is based on the notion that achieving the highest quality of life (QoL) for dying patients is the ultimate goal (WHO 1990). The main emphasis in achieving QoL is on controlling patient's pain and other distressing symptoms. Care is extended to the patient's family unit, as they too have psychological and emotional needs (WHO 2002). The overall aim of the philosophy is to return to a more human, family-oriented care that improves quality of the remaining life of the patient (Lattanzi-Licht and Connor 1995). Because hospices are by nature small places where only a few patients at a time can access care, the long range goal is to develop the hospice philosophy and its principles, see WHO, (1990), into the fabric of the entire UK National Health Service (NHS) and those of other participating countries. Hospice care is in essence a philosophy, and not a facility, that can and should be applied in diverse ways and environments.

To hold such a view enables the philosophy to be applied, not only to cancer patients, but to other patients suffering from life limiting and chronic illness like heart failure, motor neurone disease and dementia, just to name a few. Nurses working in hospices are now caring for a range of other conditions collectively known as long term conditions, and not only cancer, and therefore the challenges of achieving high quality of life for all are equally greater.

It can be seen that hospice care requires dedication and commitment by its staff for the care to be successful. Values that underpin this care emphasise individual worth, advocacy and not prescriptive paternalism (Lattanzi-Licht and Connor 1995). Lattanzi-Licht and Connor (1995) claim that nurses working in such caring environments tend to 'give of themselves' more than those working in curative units. One of the goals of nursing dying patients is achieving a dignified death (WHO 2002, Twycross 1997). It is possible to have different perceptions of a dignified death when considered from a nurse's and relative's perspective. It can be argued that when nurses care for such patients, they tend to 'go the extra mile' to ensure that the patient's every need, and in some cases, every want and desire is satisfied. Such acts require patience, tolerance, sensitivity and the ability to be resilient. It is also claimed (Street 1992) that nurses and other professionals tend to be unnecessarily nice to dying patients, in some cases to the detriment of their own well being.

It is from such intense involvement that caring could be argued to be a source of stress which may lead to burnout. Chapter 3 discusses how burnout develops with stress as a starting point (Maslach 2001)

Challenges of achieving outcomes of caring

There are three main settings where palliative care takes place within the UK; that is, hospices, hospitals and community. However, there are other settings like nursing homes where some palliative care takes place. In such places palliative care knowledge and skills are provided by visiting specialists both nursing and medical. Given all these different settings, there seem to be two main outcomes of caring:

- First, within the general nursing set up, the aim is to return patients to a degree of independence and back into society, and
- Second, in the palliative care environment, the aim is to ensure quality of life for dying patients followed by a dignified individualised death.

When considering outcomes of caring, there appears to be the patient's perspective and that of the professionals providing the care. Morse, et al (1990) tend to focus outcomes on the patient's perspective; that is the patient's subjective experience of caring, and their physical response to care. It may seem straight forward to suggest that in order to ensure the subjective experience of the patient is achieved the patient must be involved in the planning of that care. It is more difficult to achieve the second outcome of patient's physical (physiologic) response, since it is clear that caring can not arrest pathology. (Gadow 1985) and Leininger (1985) note that caring is a necessary but insufficient condition for cure. However, the question that arises from Leininger's assertion is whether cure can be truly possible without caring. Caring aims to alter the patient's response to illness. This may not involve physical treatment (cure) but an increased awareness and perception of the illness and possible prognosis. Caring provides information for patients to understand their circumstances. Caring can effectively reduce psychological and emotional distress like anxiety, which in turn will ensure the patient is more relaxed and calm while receiving treatment. One can argue that this state of patient equanimity is a pre-requisite to effective treatment (cure), and therefore ensures that caring is an important element of cure. Finally, the next outcome of caring has its focus on the nurses themselves as they provide care for patients.

According to Pinch (1996), one of the outcomes or moral traps of caring is burnout. Pinch sees the demands placed on nurses to care, and given the unremitting nature of this ideology in practice, as leading to burnout. Continual focus by nurses on meeting 'patients' needs without re-energising themselves and without respite from caring eventually wears them out leading to emotional exhaustion and depersonalisation (Maslach, et al. 2001). Nurses working in palliative care settings come across emotive experiences and continued exposure to these may have negative and damaging outcomes on their mental ability to be resilient. (Castledine 2007) argues that in order for nurses to care effectively they need to posses two main qualities:

(i) Equanimity - evenness of mind or temper.

(ii) Imperturbability - calmness, composure and presence of mind under all circumstances.

What is of interest to this current study, is a further claim from Castledine (2007), that these two qualities are often absent in nurses working under stressful situations. It is therefore important to identify which aspects of caring are perceived as stressful by nurses working in palliative care. It can be argued that working under stressful situations may affect judgements and result in poor quality of care being delivered to dying patients and their families. As will be discussed in chapter 3, stressful situations, if unabated, often lead to emotional exhaustion, the first stage in the development of burnout. The challenge for nurse managers, researchers, educators, policy makers and employers is how best to ensure that nurses are well supported emotionally and physically so that they can continue to provide sensitive care to all dying patients all the time.

Summary

The concept of caring seems elusive to define in a way that achieves universal agreement or consensus. Evidence from the literature suggests there are two main types of caring, ontological and intentional. Ontological caring is inherently present in all human beings as a trait of what it means to being in the world (Heidegger 1962). On the other hand intentional caring is in addition to ontological where individuals make conscious choices about caring for or about someone or something. This chapter has critically discussed the different views on the concept of caring as espoused by other commentators. A lack of a definitional consensus about caring raises two possible suggestions:

- The concept of caring is complex and therefore elusive in terms of what it means;
- It may not be possible or necessary to have a consensus on such a subjective concept.

What seems clear from this discussion is that, through caring, health care professionals' engage and interact with dying patients' emotional needs, a possible source of burnout and death anxiety.

There are benefits and as well as negative aspects to caring for people providing the care. Benefits include patients' enjoying an enhanced quality of life and for dying patients being afforded a dignified death. The negatives may be excessive caring where carers neglect their own well being, a concept discussed above as co-dependency. Eventually, nurses may feel disillusioned, working under stress which, if it remains unabated, may lead to the burnout syndrome. As already discussed in this chapter co-dependency has been described as a plausible explanation of these catalogue of events, where carers themselves care excessively and even relegate their own needs to a low priority. Genuine caring requires or 'demands' the presence of empathic care with its different facets as articulated in figure 2. Empathic care has the ability to increase understanding of patients' needs while carers remain non-judgemental. It is from empathic care that palliative care nurses maintain a certain level of sensitivity and emotional 'grasping' of patients' needs all the time.

It is also important to highlight that co-dependency may interfere with empathic potential of carers therefore crucial that further understanding of manifestations of co-dependency is sought.

In caring for dying patients, palliative care nurses have interactions with patients' relatives, fellow professionals and the employing organization. Arguably, palliative care more than all other health care settings involves team work and the dynamics of team working and the interactions involved may be in themselves stressful (Bayliss 2008). These interactions and the actual "hands on" caring can lead to stress and eventually the burnout syndrome. The next chapter focuses on this syndrome and how it may develop among those caring for others.

CHAPTER 3: CONCEPT OF THE BURNOUT SYNDROME

Chapter Overview

Although this chapter focuses on the burnout syndrome, discussion of the role of stress is important as a way of showing how unresolved stress eventually leads to burnout. This chapter will discuss in detail the three dimensions of burnout including the sequence in which they develop. The epistemology of burnout is critically discussed followed by a discussion of burnout among palliative care nurses. The impact of burnout and its relationship to variables of death anxiety and caring will be examined.

Introduction

The burnout syndrome is reported to be an outcome of a cumulative stressful process (Maslach et al 2001) where demands outweigh resources. The experience of burnout syndrome would appear to affect health care professionals' performance in providing quality care for dying patients (Maslach et al 2001; Vachon 2003; Cohen 2007). According to Cohen (2007) burnout is itself a syndrome which develops after prolonged unresolved job related stress. According to this view, such stress in turn contributes to poor health and weakens the immune system.

There has been marked increase since the 1990s in research on job related stress and burnout, (Dewe, et al. 2000; Payne 2001; Teasdale, et al. 2001; Edwards, et al. 2006). This increase may suggest a parallel rise in work-related stress among professionals, and that the impact is more evident now than ever before. Research into occupational stress has focused on two main areas:

i) Seeking to investigate sources of stress in the work place (Maslach and Jackson 1982; Sutherland and Cooper 1990; Summers et al. 1995);

ii) Examining effects of stress on individuals' well-being through measuring performance, effectiveness and absenteeism (Sutherland and Cooper 1990; Bhagat, et al. 1995).

Despite such increased scrutiny and interest in work-related stress, conceptual and definitional problems on stress still exist. To add to this impasse, stress researchers have tended to use different meanings of stress interchangeably, thereby not always making clear which meaning they have chosen for stress. However, a lack of consensus or clarity has neither prevented research activity nor dissemination of research findings on burnout.

The role of stress in burnout

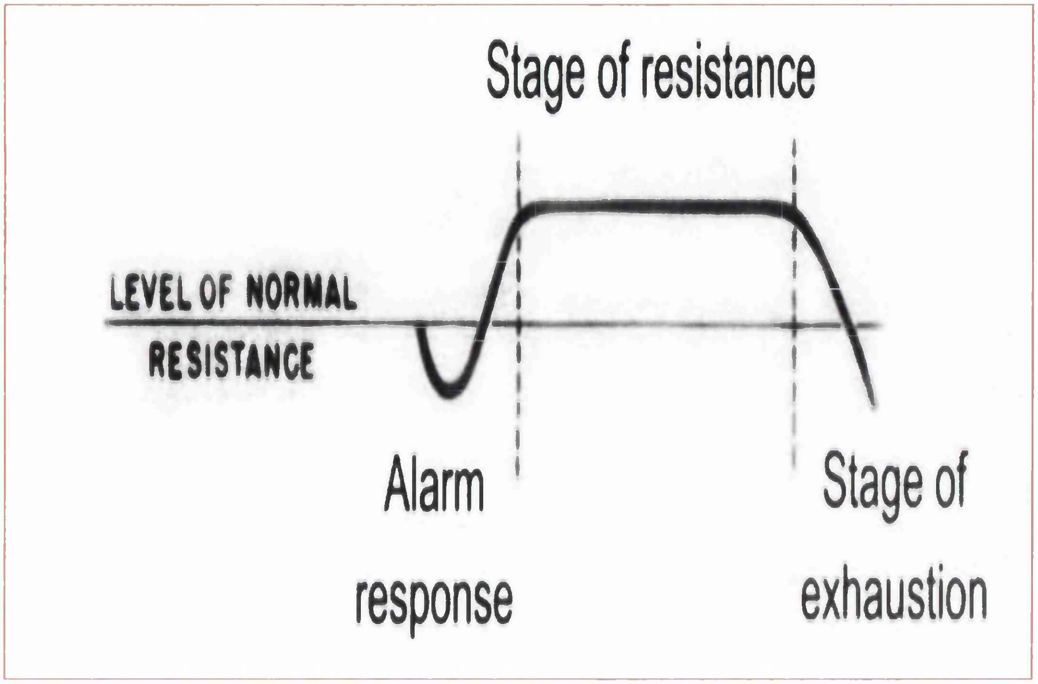
The term stress has been used for decades and in different contexts. For example, stress has been used with reference to metals in mechanical engineering. It is in this field, particularly the construction of bridges to support vehicles exerting weight (stress) as they move across them, that the concept of stress was first applied. When the concept is applied to human beings it is perceived differently, in that, unlike metals, people vary and will experience pressure (stressors or demands in life) and react according to individual adaptive patterns and personality factors. The point to emphasise is that, unlike metals, people have psychological attributes such as personality factors, previous experience, meaning and motivation that influence different perceptions of stress. Factors like age, gender, ethnicity, and education level may influence possible reaction to stress.

In health care services, caring environments like nursing provide the largest sources of stress (Vachon and Benor 2003). It can be argued that carers may be stressed if there is work overload, both quantitatively and qualitatively, and difficult dynamics with colleagues or not feeling in control of their practice. According to Maslach, et al. (2001), Payne (2001), Vachon and Benor 2003), if the stress continues unabated, emotional exhaustion (EE) may occur. If the stress situation continues unresolved, Maslach et al (2001) claim that a three-phase development sequence takes place. That is, emotional exhaustion first after which two further phases, depersonalisation and low personal accomplishment, tend to develop. Most commentators including Maslach et al (2001) claim that at this third phase, the burnout syndrome is evident.

The depletion of coping resources which results from unresolved stress has a physiological process (Seyle 1936), which leads to a syndrome coined by Seyle as the General Adaptation Syndrome (GAS) as illustrated in Figure 3. The end point of this process is exhaustion, which, as explained above, is the first phase in the development of the burnout syndrome.

Seyle (1936) outlined a sequential response of three definable stages affecting all bodily systems when exposed to stress. The first stage known as Alarm (stimulus) reaction, is similar to the fight or flight response described by Cannon (1935) which prepares the body for extreme action. This is followed by an adaptation or resistance phase, which is marked by reduced capacity by the organism to deal with subsequent demands. This in turn leaves the organism vulnerable to further stressor attack. In clinical practice, it is important to intervene early (for example with antibiotics against infections) and help the organism fight the threat. If the stressor persists, the organism runs out of resources, body energy and immunity, and the final stage of exhaustion is reached. At this point, Seyle claims that symptoms of the initial alarm reaction may return, before leading to burnout and ultimately death. Only severe stress levels lead to exhaustion, as humans tend to respond and adapt to most non-severe stressors. Physiologically, blood sugar levels decrease as adrenaline reserves become depleted, leading to reduced stress tolerance (Cohen 2007). There is also progressive mental and physical exhaustion, illness and eventual collapse of the body. In other words, continual levels of stress damage the immune system leaving the individual prone to disease. The final stage of exhaustion, in work related stress, would be the first stage in the development of the burnout syndrome (Maslach and Jackson 1981; Maslach, et al. 2001)

Figure 3: Stages of the General Adaptation Syndrome



According to Maslach et al (2001), Payne (2001) and Vachon and Benor (2003), emotional exhaustion occurs first, and if this state continues unresolved, then de-personalisation or cynicism follows, which greatly affects carers' performance and eventually the care and support they give to patients. After this stage individual carers may perceive themselves as no longer competent to achieve set goals, hence lack of both personal accomplishment and job satisfaction is evident (Maslach 1982; Maslach, et al. 2001). The ideas of emotional exhaustion, depersonalization and low personal accomplishment are discussed in more detail below under the concept of burnout.

Another link with burnout can be hypothesized using Cohen's evidence above, that stress can increase the body's susceptibility to certain diseases. If we accept that stress is the main starting point for burnout, it is plausible to suggest that burnout can make the body more prone to disease. In the context of this study, it is also plausible to suggest that burnout is a clear indication that individuals' resources, immune system and mental ability have been depleted, leaving the individual more susceptible to pathology.

The concept of burnout

Burnout is viewed as a syndrome that results from a cumulative effect of unresolved stress, which in turn contributes to poor health and weakened immune system (Cohen 2007). The philosopher Albert Camus once said that,

"Without work, all life goes rotten, but *when work is soulless, life stifles and dies* (Camus 1913 – 1960*).*

Camus could have been referring to the consequences of the burnout syndrome at work. The question of the nature of burnout remains almost unanswered after more than three decades of research and related debates. The modern concept of burnout can be traced to the work of Freudenberger (1974), and Maslach (1982), which suggest a relationship between work demands and one's inner resources to respond. While Freudenberger and Maslach were working quite independently, they both provide the initial conception of the burnout syndrome. They independently show that burnout can be a fairly usual occurrence in many aspects of human life. What then follows is the scientific desire to operationalise the burnout syndrome so that it can be measured appropriately. Thus, research undertaken in the United States on burnout, (Greene 1961; Maslach 1976; Maslach and Jackson 1981; Zellars and Perrewe 2000) and later around the world (Smith 1992; Vachon 2000; Adali and Priami, 2002) continue to show that burnout is a complex construct which is based on subjective relationships people make with their work and general environment.

Kacmaz (2005) suggests that burnout can lead to social and medical problems, including frustration, disappointment, anxiety, apathy, psychological fatigue, headaches, sleep disorders, and a desire to quit a job. Therefore there is an element of detachment and distancing from the people being cared for, which can only lead to quality of care being negatively affected. Many areas of applied psychology (e.g. health psychology) have joined the research and debate on burnout syndrome. Burnout comprises three dimensions, and these are distinguished and measured using the Maslach Burnout Inventory (MBI) (Maslach and Jackson 1982). These dimensions are to do with:

- emotional exhaustion (EE),
- depersonalization (DP) or cynicism and
- perceived low personal accomplishment (PA) or inefficacy)

Emotional Exhaustion in burnout

Maslach et al (2001) assert that emotional exhaustion is the central and most obvious manifestation of the burnout syndrome. Emotional exhaustion seems to be a widely reported dimension in most research studies. In most cases when study participants describe themselves as experiencing burnout within the job, they are often referring to the emotional exhaustion experience (Maslach et al 2001; Vachon and Benor 2003). The focus and emphasis on exhaustion should not be taken to suggest, as Shirom (2003) once argued, that the other two: depersonalization; and lack of personal accomplishment, are incidental. However, having said that, the fact that emotional exhaustion is a necessary condition for burnout does not mean it is also a sufficient condition. The following explanation tries to show the link between emotional exhaustion and the other two components. On its own, exhaustion would not be able to influence critical aspects of the relationship people have with their work and environment (Zellars and Perrewe 2000). Zellars and Perrewe, (2000) explain that exhaustion is not something that is simply experienced, rather it prompts the individual to adopt actions or behaviours that distance one (emotionally and cognitively) from the stress inducing situation. This may be a way of coping with the work demands. Emotional exhaustion is characterized by lack of energy (Zellars and Perrewe 2000) possibly as a result of intensive emotional interactions with patients.

This exhaustion, also known as compassion fatigue may co-exist with feelings of frustration and tension (Cordes and Doughtery 1993). The implication from this may suggest that people may not continue to give of themselves emotionally to their patients as they have in the past. Professionals caring for and supporting patients with complex psychosocial and emotional needs may end up being emotionally exhausted themselves. This may be the point where health professionals adopt psychological ways of protecting themselves, one of which is depersonalisation, from their patients.

Depersonalisation (cynicism) in burnout

This dimension is characterized by an attempt by individuals like nurses to put distance between themselves and their work by actively sidelining or ignoring aspects that make these individuals unique and effective. This depersonalisation may be a psychological coping mechanism of making the demands seem impersonal as a way of managing them. For example a nurse caring for a dying patient may start to avoid a patient's questions about his impending death by changing the topic, because she cannot prevent death or prolong the patient's life. Maslach and Leiter (1996) state that depersonalisation occurs when carers develop negative cynical attitudes and feelings about their patients. Distancing or depersonalization is an immediate reaction following exhaustion as a protective mechanism against further exhaustion. In most burnout research across organisations and occupations a strong association and developmental sequence from exhaustion to depersonalisation is consistently found (Maslach and Leiter 1996; Zellars and Perrewe 2000; Maslach, et al. 2001). Toon et al (2005) confirmed a similar sequential development following a review and two longitudinal tests of the dimensions of burnout.

Low personal accomplishment in burnout

This dimension is probably the most complex of the three. In some instances, it appears to be a function, to some degree, of either exhaustion or cynicism and at times, of a combination of these two. Byrne (1994) and Lee & Ashforth (1996) claim that any work environment with chronic, overwhelming demands that result in exhaustion and cynicism is likely to erode one's sense of effectiveness.

It can be argued that when feeling this way, it is almost always difficult to have a sense of accomplishment. Furthermore, it becomes plausible to suggest that, in this state of mind, individuals may not continue to care for patients towards whom they are now indifferent. According to Leiter (1993), lack of accomplishment tends to develop in parallel with exhaustion and depersonalization. However, a key distinction is that lack of accomplishment tends to arise out of a lack of relevant internal resources, whereas exhaustion and depersonalization arise from work overload and social conflict. To recap the main points from the discussion so far; there is a sequential development of the three dimensions of burnout (Toon, et al. 2005). It is hypothesized that exhaustion is experienced first, followed by cynicism/depersonalization, which subsequently leads to a perception of lack of personal accomplishment. Having said that, Maslach, et al (2001) later state that the sequential link to the perceived lack of accomplishment is less clear, but instead suggest a simultaneous development of this last dimension with depersonalization.

However, following two longitudinal tests on burnout dimensions, Toon et al (2005) reported that there was a sequential development, and that lack of personal accomplishment (PA) was the last to develop. This sequence seems logical as PA is only distorted after one feels emotionally exhausted and has engaged in depersonalisation as a coping mechanism. If this state continues unabated then the individual is psychologically 'forced' to abandon future goals. Psychological abandonment of goals may suggest an inability to perceive options to accomplish these goals; hence a lack of personal accomplishment is experienced (Maslach and Jackson 1982; Maslach et al 2001; Toon et al 2005).

Epistemology of burnout

The epistemological basis of burnout tries to understand how it develops and the evidence base for it. With any construct like burnout, questions are often asked about its uniqueness and whether it is distinctly different from other established constructs like anxiety, depression or stress for example. Earlier studies including Leiter and Durup (1993) found burnout to be related to anxiety and depression; however it was later confirmed empirically in several studies including (Glass and McKnight 1996; Bakker, et al. 2000) using the Maslach Burnout Inventory (MBI) and various measures for depression, to be distinct from depression and anxiety.

Burnout was established as directly related to specific work contexts whereas depression tends to pervade every aspect of a person's life, and hence it has a broader context. This pervasion suggests a psychological impact (weakening) of the person's resolve, which therefore becomes more susceptible to ailments like stress and burnout. From this distinction, it is also plausible to suggest that people with a high tendency to depression are also more susceptible to burnout. Findings from other studies (for example Adali and Priami 2002) and that used the Maslach's inventory concur with earlier reports that burnout is more job-related and situation-specific than general depression. Further distinction comes from Schaufeli et al (2000) who analysed different conceptualizations of burnout and reported five common elements of the phenomenon:

- Predominance of dysphoric symptoms such as emotional exhaustion and fatigue;
- Emphasis on mental and behavioural symptoms more than physical ones;
- Symptoms are work-related;
- Symptoms manifest themselves in 'normal' persons who did not suffer psychopathology before;
- Decreased effectiveness and work performance are present due to negative attitudes and behaviour toward work

Development of burnout in professional groups

Development of burnout in professional groups has been the subject of theorisation, with scant research to test the assumptions. One possible explanation is the inherent difficulty of undertaking longitudinal research studies; therefore the only evidence has come from cross-sectional, correlational survey studies. However, some theories on burnout development have been proposed, and one such theory is that the best and most idealistic workers experience higher levels and incidence of burnout (Maslach, et al. 2001). The assumption is thus: dedicated workers end up doing too much work in support of their ideals and aspirations. Eventually, such commitment leads to exhaustion and later depersonalization, when all their efforts have not yielded the required goals or outcomes.

The extreme of such caring may also lead to co-dependency which is characterised by excessive caring for others while neglecting one's own needs (Dear and Roberts 2002). A study by Jun et al (1999) reported a relationship between burnout and co-dependency among Japanese nurses. The study used a sample of 1370 nurses and 1247 women office workers and concluded that:

- Many nurses scored higher on burnout than office workers;
- Co-dependency scores were not different between the two groups;
- Those nurses who presented with high co-dependency scores where also nearing the burnout state.

Interestingly, such a relationship between co-dependency and burnout was not only found among nursing staff but also in office workers. Co-dependency has three measurable aspects, and Dear (2002) performed a test-retest reliability over a three week interval on the 13-item Holyoake Co-dependency Index (HCI), and confirmed its reliability. The three factors measured by the HCI are external focus, self-sacrifice and reactivity. Reactivity is to do with a sense of being overwhelmed by another person's problematic behaviour (Dear 2002) but still wanting to care for them.

Results from Jun's et al (1999) study, conclude that co-dependency was positively correlated with high scores of burnout.

What is not clear and therefore can not be concluded is whether co-dependency may contribute to the development of burnout or vice versa. However, these questions are beyond the remit of this current study, but should be addressed in future research studies, and include males as well in the sample.

Another theory postulates that burnout is the end result of long exposure to chronic job stressors (Maslach 1993; Jenkins and Elliott 2004). Following on from this theory, it can be argued that burnout is a 'condition' that develops later in one's work rather than at the beginning of one's career. Obviously, work load demands and other organisational influences, like culture towards work, resources and staff development are contributory factors. Most literature suggests that burnout is directly related to work overload (Maslach and Jackson 1982; Maslach and Schaufeli 1993). Although this suggestion is widely accepted, there is however, an argument that work under-load for example, being engaged in tedious, non-challenging and monotonous tasks may also lead to elements of burnout. However, this does not suggest work-under load would lead to full burnout, but possibly strain and boredom. It is also plausible to argue that the state of being unemployed without social or financial support can be even more stressful than any work-related stress.

Burnout and health

It appears that the emotional exhaustion component of burnout is more predictive of stress-related health problems, both physical and mental, when compared to the other two components. However, the link between burnout and mental health is more complex and Maslach, et al (2001) claim that burnout is linked to the personality dimension of neuroticism. Neuroticism is also thought to lead to job-related neurasthenia (a condition marked by chronic mental and physical fatigue and depression). The assumption is that burnout precipitates negative feelings (in terms of mental health) like anxiety, reduced perception of self-esteem and depression.

This assumption emphasises two important points;

i. A possible link between burnout and anxiety, and other psychological attributes like personality. However, a detailed discussion on neutroticism and possible relationship between personality and burnout is beyond the scope of this thesis.

ii. A curtailment of one's ability to cope with chronic stress in order to ensure positive mental health. This point suggests that, in addition to internal individual resources, external intervention like social support could modify and minimize the impact of stress.

However, it is not always clear what the individual's mental health status was before experiencing burnout. The argument is that people who are mentally healthy (strong) are better able to cope with chronic stress and therefore less likely to experience burnout. One study by Jenkins and Elliott (2004) concluded that people who were psychologically healthier in adolescence and early adulthood were more likely to remain in emotionally demanding jobs, while showing greater involvement and satisfaction with their work.

In addition to health, burnout is also a social phenomenon. There is evidence (Hare et al. 1988; Maslach, et al. 2001) that burnout has a negative impact on professionals' private and social life due to increased mental and physical fatigue and possible depression. Although detailed exploration of this point is beyond the scope of this thesis, the important point though, is that, it is possible such impact on social life will eventually affect the professional's life and compromise the quality of work produced.

The implications for these conclusions are far reaching. For example, the level of performance among health professionals may be affected. Performance is often judged by one's input into a job and whether the desired outcomes have been achieved. Professionals who are burnt out have reduced productivity and effectiveness in their work (Maslach et al 2001). The extreme outcome of burnout is that professionals are not able to function at all, and may become absent from work.

Wider implications for burnout include some of the following:

- With reduced productivity, comes reduced quality of care;
- Absenteeism creates heavy patient caseload for other staff;
- Possible qualitative and quantitative work overload (Zellars and Perrewe 2000; Pines 2002) for other staff.

Professionals experiencing burnout have reduced cognitive functioning and an inability to recall experiences (Zellars and Perrewe 2000), making efforts like reflective practice difficult to attain, since reflection is based on a recall of past experiences. Prolonged exhaustion often leads to individuals' inability to function and provide effective care, which in turn leads to feelings of incompetence or in burnout language, low personal accomplishment, and may lead to absenteeism.

Finally, although commentators like Palmer et al (1994); Johns (2000), and Rolfe and Freshwater (2001), advocate the use and benefits of reflective practice as a learning and development tool for nurses, it must be recognized that not everyone will benefit, particularly those unable to recall critical incidents. Given this position, it is logical to introduce other ways of supporting staff, and social support is one such method.

Role of social support in burnout

The term social support has been used widely to refer to the mechanism by which interpersonal relationship 'buffers' one against stressful events, or stressors) (Cohen et al 1984; Mor-Barak 1988; Bakker et al 2000). Social support has been defined in most literature, for example, (Shumaker and Bronwell 1984; Wortman and Dunkel-Schetter 1987; Ringdal et al. 2007) as the assistance and protection given to others, especially individuals. Here assistance can be tangible as in financial aid, or intangible as in giving empathy and moral support. According to Cobb (1976) and Ringdal et al (2007), protection is the ability to shield people from adverse effects of life events.

The premise is that social support acts as a modifying mechanism which ameliorates the impact of occupational stress thereby preventing burnout. Social support has the ability to 'buffer' the effects of stressful situations on physical and mental health, hence it is often referred to as the buffering hypothesis (Mor-Barak 1988). The hypothesis states that, psychosocial stress will have deleterious effects on the health and well-being of those with little or no social support, while these effects will be lessened or eliminated for those with strong social support.

Both Mor-Barak (1988) and Bakker et al (2000) contend that in some cases, social support can eliminate the presence of occupational stress. As already discussed in this chapter, if stress continues unabated, it develops into the burnout syndrome in most work environments.

An additional consideration is that, to provide social support there needs to be a relationship between the provider and the receiver. In our case the receiver is the palliative care nurse and the provider is someone from the employing organization, like line manager, supervisor, mentor/coach or others with similar responsibility. The provider should understand the organization's values, culture and priorities in terms of staff support and development needs. Such knowledge is crucial for signposting and planning future action plans with the receiver. The nature of the relationship is important if social support is to be effective, that is, if it is going to have a positive effect on an individual's overall health (Langford, et al. 1997).

It is now increasingly acknowledged that burnout is also influenced by organizational contexts, which include job-related situations. The point to emphasise is that work-related situations take place within boundaries and guidelines of an organization. Organizations, like hospitals and hospices in the UK, have their own culture of working, based on values and philosophy which drive the work. The organizational context is also shaped and influenced by social (based on societal needs and expectations) cultural and economic drivers. Recently, the UK has witnessed organizational changes, restructuring, mergers and increased partnership working and creation of networks within the NHS.

These changes are likely to create a new set of dynamics between individuals and among different professions. Although such reorganisations are seen as increasing organizational effectiveness, the impact on employees seems to be underestimated, as the level of social support is not reviewed accordingly. Rousseau (1762) argues that this is a direct change in the psychological contract – the belief in what the employer is obliged to provide based on perceived promises of reciprocal exchange.

For example, the dynamic of expectations change without agreement; the employer may expect more effort, time, flexibility, while the employee expects job security, career opportunities, more social support and a work-life balance. Rousseau (1712-1778) argues in *Du Contract Social* (The Social Contract), 1762, that one outcome of violating the contract is burnout as this erodes the notion of reciprocity, which is crucial in maintaining well-being.

Burnout and Palliative Care Nurses

It is well documented that seeing patients improve and regain independence is one of the most rewarding aspects of care for health care professionals (Holland and Neimeyer 2005). In palliative care nursing, this intrinsic reward is not always achieved as most patients end up dying and not improving. Contact with terminally ill patients may be synonymous with death and a perception of failure on medical/nursing interventions. Furthermore, continual care for dying patients and grieving families might lead palliative care nurses to examine their own death anxieties and concerns (Neimeyer 2000). Caring, as was discussed in chapter 2, involves emotional involvement with patients' needs, and may eventually lead nurses to be emotionally exhausted unless some buffering mechanism is introduced.

This involvement and emotional investment is intensified in environments where dying and death episodes are especially prevalent. Vachon and Benor (2003) claim that palliative care nurses frequently 'suffer' with the patient they are caring for. Their claim suggests that suffering is contagious, a conclusion also reached by Bakker et al (2005) when he reported that nurses who worked alongside those who were already burnt-out in intensive care units, ended up experiencing burnout themselves. Detailed discussion of Bakker's findings is given below.

The claim of suffering with patients may be better understood if we accept that palliative care work involves emotional caring (labour) for nurses. The emotional labour of dealing with and ameliorating patients' negative feelings and their own suffering becomes the trigger for stress and eventually, burnout. The assumption is that, in so doing the nurses have to 'give themselves' emotionally, and over a period of time they too will reach a stage of compassion fatigue (Gil-Monte and Peiro 1998; Munroe 2004) and may 'transfer' patients' suffering onto themselves. When this happens, it is possible that they might seek ways to protect themselves, and one such way is the psychological process of depersonalization (Maslach 1993; Maslach, et al. 2001). Depersonalization was discussed in detail earlier in this chapter, and often evokes cynicism towards patients and everything else that requires sensitive care and attention.

Burnout as emotional contagion

The study by Bakker et al (2005), reported that burnout is contagious; that is, it may 'cross over' or transfer from one nurse to another. Contagion is found at two levels, emotional and psychological, both of which are related to the emotional exhaustion aspect of burnout (Bakker et al 2005).

- Emotional contagion is the automatic tendency to mimic and synchronize facial expressions, postures, vocalisations and movements with those of another person. The emphasis Bakker et al make is that this process is at the non-conscious emotional level. However, this suggestion does not and should not be seen as a rejection of the opposite happening, that is, psychological contagion;
- Psychological contagion is where people can engage in a conscious cognitive process and 'turn into' and experience the emotions of others as if it were their own. It is like being "in someone's shoes"; therefore, it can be argued that it is a form of empathy.

Other contributors to burnout among palliative care nurses are based around expectations nurses bring to work. Some expectations may be regarded as idealistic (achieving total pain free status for all patients) or unrealistic (curing cancer patients) and both are seen as risk factors for the development of burnout where these are not achieved. Such expectations may lead nurses to work harder and even do too much additional work to try and achieve these goals. In the event that these expectations are not met, Semmer (I996) claims that emotional exhaustion may result. This is followed by depersonalization, cynicism and a reduced sense of competence, thus leading eventually to the Burnout Syndrome.

Sources of burnout are well documented (Zellars and Perrewe, 2000; Pines 2002; Vachon and Benor, 2003) and below, the most common of them are discussed. It must be emphasized that the introduction of social support may help moderate the impact of these sources on palliative care nurses.

- Work overload, which can be divided into quantitative and qualitative overload (Zellars and Perrewe 2000), is characterised by nurses being over stretched to provide the type of care they believe is best. It occurs when one is expected to do more than time permits (Pines 2002). In other words, it is having too many demands without sufficient time and resources adequately to meet these.

- Palliative care nurses are finding that their job, once a source of pride in providing plenty of caring time for patients (Saunders 1978; Pines 2002; Vachon and Benor 2003), is increasingly changing with less and less time to interact with patients. The changes are due to financial constraints, staff shortages and therefore nurses are no longer able to find the time to provide sensitive palliative care in which they once took pride (Vachon and Benor 2003);

- Some of this type of work suggests qualitative role overload, which may include having to do work that is too difficult or without proper training. Palliative care nurses now have extra duties, for example, being on call, travelling to visit patients in their homes, record keeping, managing caseloads and professional leadership expectations (NICE 2004). Although some of these duties have always existed, the main difference now is that they are being performed with reduced resources and inadequate training (Vachon and Benor 2003);

- The second common aspect is to do with dynamics of health care teams, which may create conflict for most palliative care nurses (Vachon 2000). Although the conflict is associated with teams, it appears the underlying factor is lack of understanding of each other's roles. It is also possible that conflict is due to ethnocentric tendencies by in-groups (Carpenter and Hewstone 1996; Foreman and Nyatanga 1999; Nyatanga 2002) where group identity is at stake. Bene and Foxall (1991) believe that a lack of support from team members can lead to stress;
- Effective support itself offers confidence and options to resolve difficult situations. Support may encourage the other person to consult freely and generate ideas in order to arrive at the most beneficial solution for all.

However, according to Payne (2001), dealing with death and dying experiences, inadequate preparation and workload are slightly more problematic than perceived conflict with doctors and other nurses. Lack of support and uncertainty concerning treatment were also seen as contributing factors. It is concluded that dealing with all the different factors may contribute to conflict, exhaustion and depersonalization. When this happens and remains unresolved, it may lead to the burnout syndrome.

Summary

The concept of burnout is viewed as a syndrome that results from a cumulative effect of unresolved stressors. Stressors lead to stress which in turn contributes to poor health and weaker immune system (Cohen 2007). If stress remains unresolved it eventually develops into burnout; a much more chronic condition, which requires more intensive intervention if its impact is to be reversed. Burnout has three main dimensions, emotional exhaustion (EE), depersonalization (cynicism) (DP) and low personal accomplishment (PA). All three factors could have detrimental effects on the quality of palliative care provision. The general understanding is that development of these dimensions is sequential in nature. It is now accepted that during work-related stress, emotional exhaustion tends to develop first, when the individual's coping resources are inadequate or no longer effective. It is also generally accepted that the development of depersonalisation is the next phase of the body's psychological ploy in its attempt to arrest further emotional exhaustion. Therefore depersonalization can be regarded as a psychological defensive mechanism, and often interpreted as distancing oneself from patients. The final dimension to develop is lack of personal accomplishment, which affects perception of competence in a job. However, there are also suggestions (Shirom 2003) that depersonalisation and low personal accomplishment develop simultaneously, but there is no consensus on this claim. Therefore, in the absence of clear evidence or consensus, the prevailing understanding that DP develops before PA seems logical to work with for now.

It is not yet clear whether development of burnout may lead to co-dependency or raised levels of death anxiety, but there is support (Neimeyer, 2000; Holland and Neimeyer, 2005) for claiming that continually caring for terminally ill patients may lead nurses to experience death anxieties and a review of their mortality. It can be argued that the process of caring for palliative care patients may be the source of stress, burnout and death anxiety among carers. Given this claim, caring becomes central and therefore, perceived as a stressor by health care professionals. However, it remains unclear which aspects of caring are likely to lead to the development of burnout and death anxiety. There is also a need to test statistically test to see whether caring is a significant predictor of burnout.

The role of employing organizations in minimizing or preventing burnout is crucial. The tension has always been how to balance the cost of providing effective social support for staff and funding essential caring services for patients. Admittedly, research to date has not clearly explained how social support reduces or prevents burnout from developing. This is an important gap in the literature which requires further investigation through research. To compound this, social support itself has various components and can be provided from different sources, either socially or professionally in a structured way, that can be individually focused or in groups.

The organisation provides an environment in which to work, the culture and remunerations, which all need to be supportive to staff and their perception of being valued. This chapter has already highlighted and exposed important information which confirms that caring for dying patients demands specialist approach and sensitivity in caring, which might have its on emotional toll on the nurses.

Palliative care nurses are constantly exposed to death and dying experiences of their patients. The impact of such exposure needs further understanding including how it may interact with such other experiences like death anxiety, which may suggest that nurses are being reminded of their existential vulnerability. There is no clear consensus from previous studies on the impact of caring on health professionals' levels of death anxiety.

The previous chapter explored the concept of caring and how it may be a source of burnout. The impact of caring on nurses' perception of their own mortality was also discussed. Such perception and the possible link with death anxiety is the subject of the next chapter. Palliative care nurses regularly witness patients' experiences of death and dying. The question therefore is whether such exposure may lead to nurses feeling and experiencing high levels of death anxiety.

CHAPTER 4: CONCEPT OF DEATH ANXIETY

Chapter overview

This chapter starts by discussing the epistemology of death anxiety, highlighting its philosophical base and its various definitions. A brief discussion on the meaning of death is provided drawing on, amongst others, sociological and psychological perspectives. This exploration discusses the significance of death and how its imminence may provoke death anxiety. This chapter offers a definition of death anxiety as it is understood and used for this thesis. This definition is perhaps more comprehensive than many existing ones and tries to incorporate most facets thought to provoke death anxiety. The concept of death anxiety is discussed in relation to palliative care nurses and show how they may deal with it in order to minimise its impact.

Introduction

In health care provision and palliative care in particular, many educators, researchers and practitioners alike teach and research about death anxiety (Neimeyer 1994; Langs 2004; Earle, et al. 2009). They teach how to ameliorate it and in some cases conduct research on it, and yet there is no consensus on what death anxiety is or what it means. It is true to suggest that any variable which is difficult to define is likely to present difficulties with its measurement. A lack of definitional consensus may suggest complexity of death anxiety as it manifests from both life and death. It appears logical therefore that, in order to appreciate death anxiety, an understanding of life (existence) and death (non-existence) is a crucial starting point.

Death anxiety is thought to have its origins in existence (Kierkegaard 1947), hence it is considered existential or ontological in nature. The fact that people exist (have a life) is in itself sufficient reason to induce within them death anxiety. Heidegger (1962) suggests that the way we live our life is essentially geared at preventing death, therefore experiencing death anxiety is an inevitable consequence of what it is to be human. Heidegger (1962) suggests that death anxiety is also thought to be induced by the thought of our own death or the witnessing of another's.

In essence, the presence and awareness of death seems to be the main source of death anxiety and, as Kierkegaard (1947) argued, people's death anxiety is concerned with the real possibility of their state of nothingness or non-existence. Although Kierkergaard's (1947) point seems to reflect the reality for most people, it does not seem logical to have a specific reaction (anxiety) from something (non-existence) that has not yet been experienced (Williams 2005).

According to the ideal of rationality, such anxiety can be argued to be irrational because when death occurs (non-existence) Epicureans suggest that we are not conscious enough to experience it. The point from the Epicureans is that, it is not possible and therefore does not make logical sense to fear something like death when we have not experienced it personally. If we accept the irrationality of such fear, the question should then be, what exactly do we fear, if it is not death? It is plausible to suggest that the fear may be to do with the process leading to death, past experiences of witnessing death and what death means to the person dying and those significant others. The fear may also be to do with the unpredictability and indiscriminate nature of death which can, at any point in time interrupt life. Because nobody really knows what happens beyond death, according Parkes (1978) and recently supported by Twycross (2003), people who fear death may also associate it with fear of the unknown.

It is has to be pointed out that it is possible that when one person witnesses another's death, and if the experience is perceived to be painful or distressing, it is likely to lead them to a fear of their own death. This is important when considering nurses working in palliative care who witness patients' death frequently. However, other writers challenge this seemingly negative view of death. For example, in his writings, Plato wrote in The Apology;

"No one knows whether death may not be the greatest of all blessings for man, yet men fear it as if they knew that it is the greatest of evils. And surely it is the most blameworthy ignorance to believe that one knows what one does not know" **(Plato 427-347BC).**

Here, Plato was refuting the assertion that the presence or thought of death results in people being anxious about it, and therefore experiencing death anxiety.

The emphasis Plato makes is that 'men' fear death as if they know it is one of the evils. The point in question is again, on the rationality of such fear, since one has not actually experienced death to be able to make such an informed judgment. To make such judgment in this context would be informed by a level of awareness of death, its meaning and impact on the dying person or significant others. Other commentators including Lecrutius (1951), Nagel (1970), Nyatanga (2005), and Williams (2005) have argued that the rationality can be explained if it is based on the fact that people know what death means (that is, loss of life, non-being and fear of judgement) and that is what most people may be anxious about.

In essence such anxiety is provoked by awareness of one's own impending death, witnessing another's, or in the case of carers, the thought of death per se. Heidegger (1962) argued that any death anxiety felt or expressed is based mainly on the way individuals process and perceive the threat (death), hence the anxiety is subjective. He argues that it is a state of mind for some in that:

> "*in fearing as such, what we have thus characterized as threatening is freed and allowed to matter to us*" (Heidegger 1962, p180).

Although Heidegger makes an important point, it has to be stated again that it is possible that when one person witnesses another's death, and if the experience is perceived to be painful or distressing, it is likely to lead them to a fear of their own death.

Epistemology of death anxiety

There are numerous commentators on the philosophy of death anxiety, for example, Heidegger (1962) 'the impossibility of further possibility', Kierkegaard (1947) 'the dread of non-being', Jaspers (1951) ' the fragility of being' and Tillich (1952) 'ontological anxiety'.

Ontology may be defined as the "science of being", (Westen 1996), the study of the form of things and their associations. According to Weston (1996), Appignanesi (2006), Heidegger uses the concept of Dasein (literally meaning "to be there" in the world) to explore the ontology of human existence.

According to Tillich (1952) and Heidegger (1962), the fact that we live (being) is sufficient to create anxiety about how we preserve this state of our dynamic and creative self. The tension is often between the state of our 'being', and constant threat from the possibility of our non-being (Kierkegaard 1947; Heidegger 1962). This tension is what is considered by both past and current writers (Kierkegaard 1947; Tillich 1952; Neimeyer 1994; Park 2001; Kastenbaum 2008), as ontological anxiety. In essence, non-being is death, and if every living being experiences ontological anxiety, it is logical to view ontological anxiety as death anxiety. Kierkegaard (1947) argued that, where there is an imminent threat to life (the possibility of non-being), the feeling of death anxiety is equally raised or brought to the forefront of our existence. The threat of non-being is therefore synonymous with fear of our own nothingness, and this can be explained as cognitive processing of what it is like to be nothing.

Ontological anxiety is provoked when there is a threat on our being which is capable of turning us into non-being or extinction. According to Park (2001), there are different sources for this anxiety with the most pertinent caused by a permanent inner state of 'being'; that is utterly and constantly threatened; leading to insecurity. It is this insecurity that according to Heidegger (1962) manifests as death anxiety.

Heidegger (1962) claims death is within us and although its physicality destroys, the idea of death saves us and somehow prompts us to 'shift' into a higher mode of existence. The higher mode of existence suggests that at this point people become more consciously aware of the importance of life and the possibility of death. At this higher level, Heidegger (1962) argues that people move from forgetfulness of their being to a state of mindfulness. In other words, people become more consciously aware of their own existence. It can be argued that mindfulness can be an outcome of our realization that we will not always be here alive, thus making us more alert to our time on earth. The state of forgetfulness may suggest that the thought of our existence is 'pushed' to the unconscious as we pursue other pleasant thoughts and life activities.

Although the shift in mental states can be useful in understanding how the mind deals with the threat of death, it also suggests that death is inevitably brought to the forefront of our consciousness, which in itself may result in increased levels of death anxiety. Solomon et al (2004) cite Kierkegaard (1944-1957) as summing up living in the context of death as follows:

"although knowing that one is alive is tremendously uplifting, we are also perpetually troubled by the concurrent realization that all living things, ourselves included, ultimately die" (Solomon et al 2004: p16).

This concurrent realization could be argued to be a basis for death anxiety. However, this may not necessarily be true for those who believe that there is a life after death. The question though, is whether to believe in, without real evidence, the possibility of such a life.

In spite of increased literature and discussion about death and using different perspectives, (for example, Martin Heidegger (1889-1976), Jean Paul Sartre (1905-1980), Simone de Beauvoir (1908-1986), Friedrich Nietzsche (1844-1900), Gabriel Marcel (1889-1973), Albert Camus (1913-1960) and Edmund Husserl (1858-1938), death itself remains a taboo in most Western countries (Kastenbaum 1986; Neimeyer and Brunt 1995; Nyatanga and de Vocht 2006; Kastenbaum 2008).

A taboo would be regarded as something not openly talked about, therefore suggestive of a deep-seated anxiety about that phenomenon or object itself. The fact that death itself is one certainty in life and yet it remains the greatest cause of anxiety makes it complex to comprehend, therefore mystical. Generally, many people still find it difficult to talk openly about death in general, let alone their own death.

Even philosophers have not achieved consensus on what is death and how it could induce so much anxiety in many people. One of the causes of death anxiety was identified as the 'unknown' nature of what lies beyond death (Parkes 1978; WHO 2002) . The fact that death is guaranteed and yet unpredictable in its timing, making it indiscriminate, may offer a possible explanation as a cause of death anxiety. The fact that human knowledge and science have, up to now, failed to control or stop death completely, means that death remains ill-understood. When we fail to understand a phenomenon like death, it is often likely that the propensity is to construct our own image of it. In this case, the image constructed and held by many people tends to be largely negative or destructive, therefore inducing anxiety. It should be mentioned however, that there is a difference between anxiety about dying and anxiety about death, and this study is primarily concerned with the latter.

Defining death anxiety

It is well documented that there are definitional problems regarding death anxiety (Neimeyer and Brunt 1995) but research studies continue to be undertaken on this topic without any clear consensus of what it is. This problem is further compounded by the lack of differentiation between anxiety associated with "dying" and "death anxiety". However, although seeking differentiation is helpful for understanding, there is possible overlap between these two anxieties which needs to be noted. In addition, the interchangeable and sometimes careless use of the terms 'anxiety' and 'fear' has contributed to the current confusion and definitional difficulties of death anxiety. May's (1950) seminal work which was later revised (May 1977) argues that the key distinction is that anxiety is the perception and creation of an element of uncertainty, whereas fear is a perception of an actual danger. May is postulating that, for anxiety to arise, our inner state feels insecure and provokes the sympathetic nervous system to produce a reaction (anxiety).

It is logical from this observation to suggest that anxiety develops first and if the cause of it continues unabated, it may lead to fear, which is deeply held within the individual.

It seems the distinction between these two terms is not compellingly persuasive on conceptual or practical grounds. However, Neimeyer and Brunt (1995), claim that a distinction between fear and anxiety has often been made through construction of instruments developed to assess these two concepts. For example, a questionnaire measuring death anxiety might ask about reactions to more abstract factors like, apprehension about the state of non-being that death might represent. Questionnaires measuring fear of death tend to focus on pain of dying (both physical and existential), and on individual reactions to death. Other writers have tried to offer definitional clarity on death anxiety; for example Templer (1970) , who developed the first questionnaire to measure death anxiety in North America, and Thorson and Powell (1988) argue that death anxiety is best understood through its characteristics, which are multi-dimensional concerns such as denial of death, fear of death of self and others, avoidance of death, and a reluctance to interact with dying persons. Whilst this is useful in offering characteristics of death anxiety, it still fails to state what death anxiety itself is. It also fails to discuss whether death anxiety is best defined as an emotion or a mood.

Lonetto and Templer (1986) have defined death anxiety as an “unpleasant” emotional feeling upon the contemplation of one’s own death. This definition is restrictive as death anxiety can also be provoked by witnessing or thinking of other people’s death. However, one important distinction which can be inferred from this definition is that, death anxiety is viewed as an emotion as opposed to a mood.

Tomer (1994) views death anxiety as anxiety caused by anticipation of the state in which one is dead. This definition excludes related aspects such as fear of dying or death of significant others. Exclusion of death of significant others as provoking death anxiety, makes this definition, like that of Lonetto and Templer (1986) limited, in that witnessing or contemplating other people’s death can equally provoke death anxiety.

From a psychoanalytical perspective, Bowlby (1981) would describe death anxiety as a response to internal processes or external forces having its roots in castration and separation anxiety. This view, however, is countered by a more behaviourist perspective that death anxiety is in fact a learned response of experiential origin, for example Frankl (1963) argues the point in his classic book, '*Man's Search for Meaning*'. In view of the existential view and discussion earlier, viewing death anxiety as a learned response creates tension with Heidegger's (1962) notion that our mere existence is itself enough to provoke death anxiety, which is, existential death anxiety. Tension is thought to arise from the state of our being and constant threat from the possibility of our non-being (Heidegger 1962). DePaola, et al. 2003), argue that death anxiety is a result of our thought processes about the anticipation of physical alterations, and an awareness of finite time between birth and death.

The above discourse demonstrates the complexity of defining death anxiety and a continued lack of definitional consensus. However, this discourse also highlights key facets that encapsulate the notion of death anxiety as a destructive phenomenon, which results in the annihilation of life. According to Sherman (2004) the perception of death as a destructive phenomenon, has arguably created a predominantly negative interpretation and this is what seems to provoke most death anxiety.

For Kierkegaard (1947) and Heidegger (1962), death anxiety might ultimately be the fear of the possibility of not having any further existential possibilities. Although this sums up death anxiety well, it does not however, offer a clear definition. Therefore, for the purposes of this study, death anxiety will be defined as:

> ***"A disturbing emotion triggered by multi-faceted concerns centering on contemplation of death of self and death of others".***

It must be emphasised that this definition argues that contemplation of the death of others is but one of the triggers of death anxiety.

Death anxiety in everyday life and death

According to Langs (1997) death anxiety is prompted by any traumatic event, that our mind registers as life threatening. For example, a diagnosis of cancer is usually perceived as life threatening, therefore capable of producing feelings of death anxiety. This type of anxiety is based on a perceived threat to our continued existence, and Langs (2003) labels it existential death anxiety. Out of all the different types of death anxieties, existential death anxiety (Kiekergaard 1947) is experienced in everyday life, and therefore is of prime significance.

Existential death anxiety (Kiekergaard (1947) is probably the most powerful of anxieties and well entrenched in human existence. It is activated with a definitive, conscious awareness and anticipation of the inevitability of an individual's demise (Langs 2004).

The individual's ability to anticipate the future and its possibilities is threatened by the possibility of non-existence. In philosophical terms, Honderich 2005: p634) claims that:

"Existential anxiety is embraced in ideas of ontological anxiety"

However, there seems to be tension between humans' recognition of existential death anxiety and the way in which it is managed. According to Langs (2004) humans defend against existential death anxiety through denial, often effected through a wide range of mental mechanisms and physical actions. While limited use of denial tends to be adaptive, its use is often excessive which may prove emotionally costly long term (Langs 2004). Denial comes from the unconscious, providing mechanisms that enable individuals to avoid meeting or facing uncomfortable reality. However, although the use of unconscious thought may be helpful for many people, nurses working in palliative care have death pushed back to the conscious regularly by witnessing deaths of their patients.

All these theories on death anxiety seem to contain some influence from two theorists, that is, Freud and Becker. First, Freud (1856-1939) and specifically his works published in 1953 and 1961, well after his death, recognised that people sometimes expressed fears of death. These thanatophobic expressions (as Freud suggested) were a disguise of deeper sources of anxiety, and not death and qualified his reservations by writing,

> "Our death is indeed unimaginable, and whenever we make the attempt to imagine it we only survive as spectators….. at the bottom nobody believes in his own death, or to put the same thing in a different way, in the unconscious every one is convinced of his own immortality" (Freud 1953) p126.

According to Freud, the unconscious mind does not deal with the passage of time, and does not register that this life will one day come to an end. He also argues, like many other writers, that one cannot fear death because one has never died. This assertion would be true only on rational/logical basis, because the reality is people continue to fear death. However, the fact that such fear cannot be explained should not invalidate it. Freud's explanation of fear of death is that such fear is focused on unresolved childhood conflicts, which are too painful to acknowledge and discuss openly. It seems Freud was basically reducing fear of death to some neurotic underpinning, and this remained so until Becker's (1973) existential theory.

Becker (1973) postulated that, not only is death anxiety real, it is most people's profound source of concern. Becker (1973) claimed that most people's daily behaviour consists of attempts to deny death and thereby keep death anxiety in check. One example today is the reluctance to talk openly about death as if silence would remove death's reality. However, it would be difficult to deny the reality of death or reduce one's death anxiety, if one is constantly exposed to reminders of their own existential vulnerability and mortality (Psysczynski, et al. 1999).

It can be argued that such mortality salience may be provoked through repeatedly caring for dying patients. For example, palliative care nurses are being exposed to other people's dying experiences repeatedly through their jobs.

Becker argued that it was the function of society to put in place mechanisms that would strengthen individual defences against death anxiety. Becker's (1973) recommendation would suggest the need for groups and communities to 'deal' with death anxiety. This would further suggest that, death anxiety, even though it may be experienced by one person, it would be too enormous for that person to deal with it alone. This would place death anxiety as some kind of terror (Solomon 2008) that requires groups or communities to manage it. This assertion was instrumental in the need for terror management theory popularized by Greenberg et al (2004).

Terror management theory (TMT) was introduced in the late 20th century and is thought to be a way human beings manage death anxiety. As intelligent human beings, (which is what separates us from other animals) we are self-aware and know that we are alive. Being alive enables us to reflect on the past, think about the future and therefore participate and function in the present

In everyday life, death anxiety can be seen as terror since it threatens one's life, and requires or forces people to act in order to preserve life. One of the ways is through establishing close relationships, such as love, partnerships and marriage (Greenberg et al 2004). According to Mukulincer et al (2004) "Most close relationships tend to offer communion, belongingness, affiliation, attachment, togetherness and intimacy, which are all subordinate components of the fundamental need for self-preservation" (p288).

These components often serve as protective shields against the terror of death awareness (Mukulincer et al 2004). It is plausible to suggest that individuals feel inadequate facing threats alone, hence the need for pairs, families, friendships, groups and large communities. It is common for family members living apart to come together in times of threats, serious illness or crisis.

In the event of life threatening illness, there are institutions like hospitals and hospices with fully trained medical and nursing staff to offer treatment in order to preserve life. Unlike families, health professionals are not related, but come together to support each other while caring for dying patients. By offering support to each other, they are also managing the terror of death anxiety, which may be intensified by being frequently exposed to death and dying episodes of patients.

Death anxiety in formal health care settings

Understanding different perspectives of death anxiety, possible sources and variables that can modify it may all help in minimising its impact on health care professionals. The reluctance of Western societies openly to discuss death, despite an increasing literature on the topic, (Neimeyer and Brunt 1995; Kastenbaum 2008; DH 2008), makes caring for dying patients arduous. As highlighted in chapter 1, many people still die in hospitals, which may suggest death is being hidden from society, sanitized and is the responsibility of health professionals. It can be argued that lack of exposure to death and dying episodes by families leads to inexperience in interacting and managing death. Such inexperience, coupled with the misrepresentation of death by the popular media, has resulted in increased fear of death and development of assumptions and permutations about the possibility of an afterlife existence. It is logical to suggest that most people would, as a result of the above portrayal, hold negative connotations of death, thus creating death anxiety. For health professionals, the challenge is to care and support patients and families who hold such views about death. As was discussed in chapter 2, caring involves emotional investment in patients' world view; and developing an effective interaction with them.

Effective interaction may involve using language that tries to soften and ameliorate the impact of death on the patient and families. One such interaction is the increased use of euphemisms, which are in themselves a futile attempt to keep death anxiety in check (Becker 1973; Neimeyer and Brunt 1995). This method is common for both professionals and patients/families as they engage in ritualistic reassurances that are in themselves obviously false but mask the impulse to panic or run away from it all. Generally some people will often use euphemisms to hide or minimise death anxiety (Neimeyer and Brunt 1995). This psychological indulgence in euphemisms is important for them as a way of 'buffering' or softening the impact of death anxiety.

In other words, it makes discussion around death more palatable, since death is not always openly talked about.

The practice of using euphemisms for death is likely to have originated with the magical belief that to speak the word "death" was to invite death; where to "draw Death's attention" is the ultimate bad fortune—a common theory holds that death is a taboo subject in most English-speaking cultures for precisely this reason. It may be said that one is not dying, but *fading away quickly* because *the end is near.* People who have died are referred to as having *passed away* or resting or *departed. Deceased* is a euphemism for dead and sometimes the *deceased* is said to have *gone to a better place*, but this is used primarily among the religious with a concept of Heaven. The media and in particular newspaper obituaries seem a rich vein for such death euphemisms, which arguably do little to help people talk openly about death.

Health care professionals' tendency to use euphemisms as a defence mechanism against death anxiety is most likely to begin with their cultural and religious socialization. For most people, dependence on parents and society as role models may have a lot to do with eventual in-authenticity and self deception inherent in euphemisms. In essence, euphemisms serve to soften the impact of death on family, friends, community and society and also to reduce associated death anxiety. Second, euphemisms encourage portrayal of positive perception within a death, while focusing on the 'good' aspects of the person who has died.

Just like the fear of the possibility of having no further existence, euphemisms express a pervasive fear of the unknown, and the six main categories of euphemisms listed below in table 2, go some way towards illustrating the widespread use of euphemisms. This also shows how deeply entrenched these are in many peoples' ways of thinking about death, therefore it may prove difficult for Western societies to change attitudes and openly discuss death.

Table 2: **Common Euphemisms**

Journey Euphemisms	**Rest Euphemisms**	**Loss Euphemisms**
The departed Cross the great divide Go to meet ones maker Go to the happy hunting ground Joining the angels Joining one's ancestors A big send-off	Gone to eternal rest Resting in peace Go to one's rest Now in Heaven Everlasting sleep Everlasting peace	No longer with us Will be sadly missed Society has lost---- The greatest With fond memories- Reported missing Unaccounted for Off the record
Reward Euphemisms	**Joy Euphemisms**	**End Euphemisms**
No more suffering No more pain Freedom of the soul Relieved of suffering Called to rest	Peaceful In the arms of the father United with God In heaven In Paradise Singing with the angels	The late ----- No more Deceased Time or number was up Presumed dead Debt we all must pay Pull the plug

Source: http://www.bored.com/deathslang/ accessed 19th August 2006 & 19 August 2009

In addition, fear of death or the possibility of it brings about pseudo-humbleness expressed through euphemisms. For health professionals like nurses in palliative care, open discussion about death would make caring honest in terms of what treatment can be realistically offered and when death is likely to occur.

Death anxiety and palliative care nurses

Palliative care nurses regularly witness patients' death and dying experiences, which may act as reminders of the fragility of life, and unpredictability of death. As a result, nurses may experience a sense of existential vulnerability and Psyszczynski et al (1999) and Kastenbaum (2000) have labelled it mortality salience. Mortality salience is born out of death awareness which can be intensified by constant reminders of death, thereby continually challenging the instinct of human beings to preserve life.

It can be argued that, palliative care nurses, by nature of their work, are continually reminded of their mortality. For example, the diagnosis of cancer for patients they care for, and the associated suffering with the disease treatments and side effects, may result in mortality salience among nurses (Lawton 2000). Nurses therefore need to develop ways to defend themselves from such threats, one of which is death anxiety. According to Psysczynski (1999), on one hand, death anxiety is a psychological defence mechanism developed to preserve one's self-esteem, while buffering the impact of mortality salience. On the other hand, death anxiety can be uncomfortable leading to poor cognitive functioning (Psyszczynski 1999; Kastenbaum 2000; Lawton, 2000). For palliative care nurses, it can be argued that, any cognitive impairment will compromise their well-being and the quality of care they provide to patients.

If death anxiety is viewed as terror (Psyszczynski 1999), it will require more than one nurse to manage it, therefore, there is a need for nurses to work in unison. There is evidence from Lawton, (2000); Kastenbaum, (2000); Psyszczynski (1999) and Sani et al (2009) that individuals use groups to buffer their mortality salience anxieties, and palliative care nurses would be no different. It is therefore important that multi professional teams found in palliative care are effective and offer support to each team member.

The discussion so far suggests that death anxiety among palliative care nurses can be managed by preserving self-esteem, which along with other psychological attributes like personality hardiness, internal locus of control, self-efficacy and confidence, (Lawton 2000) act as buffers against death anxiety. Care environments like hospices are keen to offer social support to their staff which WHO (2002) claim helps to enhance self–esteem. Health professionals are also given support through continual professional development (CPD), which helps to keep them up to date with current treatment options for symptoms. The nature and quality of social support received by palliative care nurses from employing organizations helps them remain resilient in the face of demands from caring for dying patients. The idea and role of social support and its buffering effect were discussed in more detail in chapter 3.

Summary

The concept of death anxiety is complex and eludes clear definition, which makes it difficult to measure. The difficulty in measuring it is further compounded by the lack of differentiation between anxiety associated with "dying" and that of "death", and between anxiety and fear. The definition offered thus far for this thesis, goes a way to elucidate this concept and capture all the dimensions that make up the concept of death anxiety. There are numerous permutations of what constitutes death anxiety. This chapter has explored some of the different definitions from philosophy, psychology and psycho-analytic perspectives. The diversity of perspectives suggests that death anxiety remains complex. Knowledge of one's possibility of being dead (a state of non-being or nothingness) often triggers different reactions; some of which are geared to prevent death or prolong life. On a psychological level, contemplation of the possibility of one's death may result in both cognitive and emotional reactions, of which death anxiety is one of the most potent and common.

Death anxiety is an emotion which can be triggered by thoughts of death of self or others or witnessing actual death. Death anxiety can be viewed as terror which requires groups and communities to manage as it may be too overwhelming for one individual. The suggestion in this chapter was the use of terror management theory to help manage death anxiety effectively. Nurses in palliative care settings are constantly being reminded of death by being exposed to dying experiences of patients, and therefore raising their mortality salience. It is not yet clear whether high levels of death anxiety might lead nurses to become more susceptible to job related stress as well, which eventually develops into the burnout syndrome. Burnout was the subject of discussion in the previous chapter which explored the main dimension of this syndrome.

CHAPTER 5: LITERATURE REVIEW OF EMPIRICAL STUDIES

Chapter overview

This chapter is a critical review of some empirical studies related to death anxiety, burnout syndrome and caring. There is a paucity of British studies on both burnout and death anxiety therefore, some of the key studies reviewed are based on research carried out in North American in the main. Studies that specifically explored the relationship between death anxiety and burnout among health professionals and the interaction these two variables may have with caring are reviewed. Finally, studies that explore both death anxiety and burnout among hospice, community and hospital nurses will also be reviewed. In this review, the use of dated literature sources serves to show the paucity of recent literature on the topic. Use of dated sources may seem unorthodox, but highlights the gravity of the problem, and that the issues are still as pertinent now as they were then. It therefore, gives justification for the need to undertake this current study. At the end of this chapter, the aim, rationale for undertaking this study and the theoretical framework are confirmed.

Search strategy

The search strategy aimed to be comprehensive and relevant for this study. A detailed explanation of each search source is given below to show why it was selected for this study.

Academic Search Complete	This is a multi-disciplinary full text database containing full text for nearly 4,500 journals, including more than 3,600 peer-reviewed titles. I could have just used this alone as it is so comprehensive
BNI – British Nursing Index	Covers all British nursing and midwifery titles, plus other major English language journals. This was included to cover all options available and also being British was an attraction for my study
CINAHL Plus with Full Text	This is deemed the world's most comprehensive source of full text for nursing and allied health journals and e-books. The site provided full text articles and papers, which made it handy for my searches
Cochrane Library	This is a high quality independent evidence database of systematic reviews and clinical trials. Here my interest was more on reviews rather than clinical trials because the study topic would not be ideal for clinical trials.
Google Scholar http://scholar.google.co.uk	Search engine from Google covering academic sources. Some articles freely available. Where access was not free, I had to look for the full articles through my work Athens password and also the university library using the A-Z Journals list for the journal titles.
Intute www.intute.ac.uk	These are quality evaluated websites, with sections on health and life sciences and social sciences.
Medline/Pubmed	Citations and abstracts from health related journals. Pubmed is the public face of Medline so combines the two approaches nicely in one search.
MyiLibrary	Offers a collection of many e-books, and growing all the time. This was quicker and cheaper to access than hard copies
NHS Evidence www.evidence.nhs.uk	This is a new platform for the National Library for Health. Access to NHS guidelines, evidence and a wealth of information for those working in health and social care, such as the nurses in this study.
PsycINFO, PsycARTICLES and PsycBOOKS	From the American Psychological Association (APA), PsycINFO contains citations and summaries of scholarly journal articles, book chapters, books and dissertations, all in psychology and related disciplines. This was considered important to search as concepts such as death anxiety, depersonalisation and buffering theory have psychological undertones. PsycARTICLES contains full text from the top 66 APA journals. PsycBOOKS contains full text e-books and chapters from the APA.
Science Direct	Includes access to full text journals in Health Sciences, and Nursing. This was seen as useful in order to have a broader look at health and nursing issues
Social Care Online	UK's most complete range of information and research on all aspects of social care. Considering social support in the prevention of burnout, this was seen as most appropriate source of evidence
Others	Relevant journals, unpublished thesis, conference papers/abstracts delivered by other researchers and academics were accessed

Key words: Caring, Death Anxiety, Burnout, Occupational Stress, Palliative Care Nurses, End of Life Care, Social Support, Buffering theory, Palliative Nursing, Emotional Exhaustion, Ontology, Existential Death Anxiety, Death and Dying.

Introduction

Many studies have been undertaken, albeit mainly in North America on aspects of death anxiety and the burnout syndrome (Bene and Foxall 1991; Crandall and Perrewe 1995; Maslach and Leiter 1996; Maslach, et al. 2001; Vachon and Benor 2003) and fewer undertaken in the United Kingdom (UK), including one by Payne et al (1998). There may be two reasons for this lack of research towards death anxiety in the UK;

> **i.** neither death anxiety nor burnout syndrome are perceived as highly critical elements in caring and;
> **ii.** There has been little concern and expertise, hitherto, to understand the impact that caring for dying patients may have on levels of death anxiety and burnout syndrome among palliative care health professionals like nurses.

The Burnout Syndrome can be experienced in most nursing populations, that is, from generalist to specialist settings, of which hospices and palliative care units are examples. The burnout syndrome may develop through direct contact with patients (Vachon 2000), or more subtly through "contagious" means (Bakker, et al. 2005). Developing burnout by contagious means was discussed in more detail in chapter three, but briefly, it suggests that other people and palliative care nurses in particular, may 'catch it' by working alongside those who are already burnt out.

Studies on Burnout

Recent studies on burnout have tended to reflect the pace of change, that is, increased pressure on professional carers to meet targets within the health care service, as a source of job-related stress on nurses. Stress that continues unmanaged often leads to the Burnout Syndrome (Vachon 2000; Maslach, et al. 2001). Emphasis on holistic and individualised patient care (Llewellyn and Fielding 1987; Twycross 1994; Fawcett, et al. 2001) has encouraged nurses to explore patients' inner perspectives; gaining a deeper understanding of patients' aspirations, and their emotional, social and psychological needs.

During episodes of dying and death, such involvement becomes more intense and often comes with an emotional cost for most nurses (Tyler and Ellison 1994; Vachon and Benor 2003), or what Smith (1992), calls emotional labour of caring, which often results in compassion fatigue. Compassion fatigue is what Maslach and others call the extreme of emotional exhaustion, and as already highlighted in chapter 3, is one of the fundamental components of the Burnout Syndrome (Maslach and Leiter, 1996; Maslach, et al. 2001).

Burnout among generalist nursing populations

Nurses in general are considered particularly susceptible to the Burnout Syndrome (Vachon 1978; Demerouti, et al. 2000). One possible explanation is that caring, as explained in chapter 2, involves carers engaging with patients at an emotional level, which in turn is exhausting and draining for the carers. Research studies undertaken on burnout have also focussed on stress which is viewed as a precursor to the development of the Burnout Syndrome.

Burnout is reported to develop in different health care settings, but other settings seem to be more stressful than others. For example, Vachon found that nurses working in emergency rooms were prone to more stress than in other clinical areas (Vachon 1986). It can be argued that, one of the main sources of stress was the fact that nurses in emergency rooms were only caring for patients short term, and after a death they did not have time or psychological space to 'deal with' or process their own reactions. This type of working led to emotional exhaustion, which in turn leads to burnout. It can be argued that this picture may be true of all those who work in emergency services like the ambulance paramedic personnel and fire services.

A year later, Vachon undertook another study (Vachon 1987), but this time focussing on care settings of oncology, palliative care and critical care settings, and examined the stressors perceived by nurses working in these areas.

She reported three main categories of stressors that led to burnout:

- Characteristics of the illness of the patient;
- Dealing with patient and family stressors;
- Work environment and work overload

Although these two studies focussed on different issues, the latter study is more informative as it identified three categories of stressors encountered by health care professionals. However, only highlighting categories of stressors does not clearly identify types of stressors encountered, and therefore may hinder provision of tailor-made support for nurses.

The culture of the work environment is an important factor where professionals feel valued and have less role ambiguity. It is documented that other aspects of caring like work overload and poor work environment contribute greater stressors for nurses (Vachon 1987; Maslach, et al. 2001; Vachon and Benor 2003).

One study by Adali and Priami (2002) used the Maslach Burnout Inventory to compare levels of burnout among a sample of 233 nurses working in intensive care unit (ITU), medical wards and accident & emergency (A&E). At the centre of this study was the need to determine factors that contributed to the development of burnout. Nurses working in A&E were found to have significantly higher levels of emotional exhaustion compared to nurses in the other two settings. As discussed in detail in chapter 3, Emotional Exhaustion (EE) is one of the three key characteristics of the Burnout Syndrome (Maslach 1982; Maslach, et al. 2001) and often leads to a deterioration of the caring relationship between nurses and patients, nurses and other health professionals, and nurses and families/relatives.

However, this study does not elaborate on the actual source of emotional exhaustion while caring in such a setting. In A & E, death is often sudden and traumatic in case of serious road traffic accidents or shootings/stabbings. The pace of care is faster than in palliative care settings, as patients always present with acute symptoms. The goals of nursing would be to save lives, and return patients to independence.

These goals are sharply contrasted with those of improving the quality of life for those dying in palliative care settings. The process of dying tends to be longer, which arguably suggests that palliative care nurses would be exposed to dying experiences for much longer periods. This may place intense emotional demands on their coping resources, like resilience (Munroe 2004); In addition, it is important to consider whether role attitudes to death and dying might play on the overall reaction of nurses when caring for dying patients. Determinants of attitudes encompass not only cultural, societal, philosophical and religious beliefs to giving meaning to death, but also personal and cognitive frameworks from which individual attitudes toward death and dying are formulated and interpreted (Rhooda, et al. 1999).

The fact that these frameworks are prone to subtle changes across the adult life span (Neimeyer and Moore 1989), demonstrates how different attitudes can be held by the same person about the same thing but at differing times of life. It also demonstrates the complexity of attitudes. One explanation offered by Wass and Neimeyer (1995) is that because attitudes are not crystallised they are prone to fluctuate depending on the situation at the time, hence they are often referred to as situation-dependent.

Burnout among palliative and hospice nurses

Research has shown that professionals caring for dying or bereaved individuals are particularly at risk of developing burnout (Foxall, et al. 1990; Bakker, et al. 2005; Ekstedt and Fagerberg 2005; Holland and Neimeyer 2005). The way health care provision for dying patients is organised in the UK, suggests that hospices can care only for dying patients and their families. The intensity of caring solely for dying patients and their families can be emotionally overwhelming for carers. Vachon and Beno (2003), claim that carers truly suffer together with the patient which often results in compassion fatigue.

The suggestion here is that the experience of suffering is contagious to the nurse witnessing it. The idea of someone's distress being passed on to others is fascinating and was discussed earlier in chapter three with reference to burnout (Bakker, et al. 2000; Bakker, et al. 2005). In a 'dying' environment like hospice/palliative care unit, the challenge is how to 'strike a balance' between helping others to die well and retaining health professionals' resilience and emotional well-being. Although it can be argued that the hospice environment can provide both stressful and rewarding aspects of care, a strong argument has to be the focus of care provision which only has one inevitable outcome, that is, death of the patient.

Many studies including a few listed in table 3 below, reported on burnout experienced by nurses working in hospices or other palliative care settings. The assertion made earlier that burnout has been an enduring issue in health care for so long is reflected in the timeframes of studies in table 3. Gray-Toft and Anderson (1986) found that stress and burnout in hospices was a result of location of hospices within hospital grounds, leading to a poor relationship between hospital and hospice administrations. It can be seen that having hospices in hospital grounds may create tension in terms of space allocation and difference in the philosophy of care since the intended outcomes of care for these two establishments are not always similar. For example, hospices aim mainly to achieve a dignified death for patients, whilst hospitals main aim is to return patients to full independence. However, Gray-Toft and Anderson's conclusion does not reflect the UK setup, since hospices are mostly independent and situated in their own grounds. Therefore this is not an area of interest for this study.

A study by Krikorian and Moser (Krikorian and Moser 1985) and also Munley (1985) reported that there were two major stressors;

- **i.** Those relating to patients and families' experiences of dying. These include witnessing rapid physical deterioration of the patient, and nurses feeling rejected when their care was refused by families of dying patients. Psychological aspects included nurses witnessing patients' and families' denial of the illness and its poor prognosis;
- **ii.** Organisational structure and culture within work environments, as highlighted by Gray-Toft and Anderson above. To be specific, the work environment led to nurses' frustration with bureaucracy, increased paperwork and excessive record keeping. It can be argued that, although these may be indirectly related to caring for dying patients, they could still induce stress and eventually burnout.

Nurses in palliative care work within similar structures and organisations; therefore it would be an area of interest for this study.

Larson (1985) commented on the more intrinsic aspects of the nurse by concluding that certain thoughts and feelings of the nurse could contribute to distress. The same sentiments were reported by Munley (1985), when he concluded that nurses felt burdened by a sense of responsibility for the quality of life patients ultimately experience. Some nurses felt guilty because they could not do any more for dying patients. In such situations, it is possible to distance oneself from patients and as a result the quality of care provided would also suffer (Vachon and Benor 2003). Some nurses even felt guilty for being alive themselves in the face of patients' impending death. To this end, Larson coined the term "helpers' secrets" to denote these troublesome thoughts of hospice nurses. Such thoughts are arguably followed by an emotional reaction, like a sense of rejection, sadness and depersonalisation. Depersonalisation is a psychological component of burnout (Maslach 2001) and therefore warrants closer scrutiny in this current study.

Demerouti et al (2000) found a relationship between job demands and feelings of exhaustion among nurses. They also concluded that a lack of resources to carry out their work resulted in disengagement by nurses. When this happens, care provided is often less effective. In a similar study four years later, Jenkins and Elliott (2004), as shown in table 3, reported two main issues:

i. Lack of adequate staffing levels as a source of burnout. This meant extra workload was experienced by other staff members as they covered for those who were burnt out could not carry on working;

ii. dealing with difficult (awkward physical posture) or demanding patients was most stressful for nurses.

However, it was not clear whether it was those patients who were physically threatening who caused stress, or those who were demanding more care from nurses or both. It is possible that professionals may 'label' a patient demanding when in fact they have not been able to understand the patient's needs. Such perceptions have resulted in patients being referred to as 'difficult' (Steinmetz and Tabenkin 2001). However, according to Steinmetz and Tabenkin's findings, the more experienced doctors are the less they are likely to perceive patients as difficult, because they have developed greater understanding of diverse patient behaviours.

This finding can be applied to nurses and this study will examine whether experience plays a role in minimising the development of burnout. Another point of interest for this study is the understanding of specific aspects of caring that may lead nurses to develop burnout and or death anxiety.

The study by Bakker et al (2005), as shown in table 3, reported that burnout is contagious; that is, it may ‘cross over’ or transfer from one nurse to another. Contagion is found at two levels, emotional and psychological, both of which are related to the emotional exhaustion aspect of burnout (Bakker et al 2005):

- Emotional contagion is the automatic tendency to mimic and synchronize facial expressions, postures, vocalisations and movements with those of another person. The emphasis Bakker et al make is that this process is at the non-conscious emotional level. However, this suggestion does not and should not be seen as a rejection of the opposite happening, that is, psychological contagion;

- Psychological contagion is where people can engage in a conscious cognitive process and ‘turn into’ and experience the emotions of others as if it were their own. It is like being “in someone’s shoes”; therefore, it can be argued that it is a form of sympathy.

There is therefore a need to be aware of the wider impact of burnout that is, ‘spreading’ to those who are not yet experiencing it (burnout).

Table 3: **Studies relating to burnout and palliative care/hospice nurses**

Study	Design used	Sample size	Key findings
Gray-Toft and Anderson (1986)	Survey using self-report questionnaires	17	Stress from: - workload - Physicians - Isolation from other units
Krikorian and Moser (1985)	Survey using self-report questionnaires	117	Stress from: - Patient/family needs - Working conditions
Larson (1985)	Survey using self-report questionnaires	200	- Self-doubt, guilty - Thoughts & feelings - "Helpers secrets"
Munley (1985)	Survey using interviews	Not given	Stressors: - Patient/family - Work environment - "Inner experiences"
Demerouti et al (2000)	Survey using self-report questionnaires	109 nurses	- Job demands caused exhaustion among nurses - Lack of job resources caused disengagement among nurses
Jenkins & Elliott (2004)	Survey using self-report questionnaires	93	- Lack of adequate staff resulted in Burnout among trained nurses - Difficult patient or situations was stressful for care assistants
Bakker et al (2005)	Survey using questionnaires	1849	- Burnout experienced can be passed on (contagious) to other nurses working in the same environment

Summary of studies on burnout

Most studies on burnout were undertaken across health care environments including palliative care mental health. Studies focused their enquiries on sources of burnout, like job-related stress, and the impact of these on care provision. Some of the common occupational stressors were work overload, that is, work demands being greater than resources available to deal with them. While this explanation refers to quantitative work over-load, there is also qualitative work over load. For example, the nature of communication between health professionals, autonomy exercised in decision making and the culture found within employing organizations all contribute to the development of the Burnout Syndrome (Maslach 2001). The study by Larson focused on carers' cognitive and affective processes while caring for dying patients. Some of the feelings expressed by nurses included inadequacy and guilt, because they had outlived their patients. Larson concluded that most nurses had such 'carers secrets' most of the time as they interacted with dying patients. This study demonstrates how someone else's distress or misfortune can emotionally affect those witnessing it. Similar conclusions were also reported by Bakker et al (2005) who concluded that burnout was contagious, suggesting that it can be 'transmitted' to others working alongside those already experiencing burnout. This has implication for the rest of the workforce; therefore, it is imperative that effective intervention is provided in order to minimize the possibility of burnout developing in the first place. Finally, the sources of burnout seem to be similar when viewed across a span of time as reflected in the literature reviewed for this thesis.

Literature on burnout suggest that stressors include – work overload (qualitative and quantitative), role stress, difficult interpersonal relations, and personal achievement (Crandall and Perrewé 1995). In addition to these stressors, ineffective organisational structure and culture may impact negatively on the home/work interface of its workers.

If these stressors remain unresolved, they may impact on caring, and most likely increase levels of death anxiety among carers (Sutherland and Cooper 1990).

The next section focuses on studies on death anxiety, with its concept, impact and meaning having already been discussed and defined in chapter 4. In the same chapter, a new working definition of death anxiety for this thesis was offered as:

a disturbing emotion triggered by multi-faceted concerns and centering on the contemplation of the death of self and the death of others.

The context of death anxiety

Death anxiety was taken to include measures of the extent to which one experiences angst in reference to death. The theoretical distinction between constructs related to death angst, such as death anxiety and fear of death is debatable (Neimeyer and Brunt 1995), and clear separation of how they are operationalised has not been definitively demonstrated. However, May (1950) and later in a revised version (May 1977), argued vehemently that there was a fine distinction between anxiety and fear. The main point to reiterate on the distinction between anxiety and fear (as already discussed earlier in chapter 4) is that, death anxiety affects the fundamental element of the individual, creating a sense of insecurity from the resulting uncertainty (May 1977). On the other hand fear is experienced where there is direct danger from a threat which is also imminent. Within the literature including Neimeyer and Brunt (1995) and Alvarado et al (1995), some studies use both terms, but of interest for this study is the feeling of the emotion of death anxiety and its impact on professionals and the quality of care they provide.

Studies on death anxiety and nurses

Some studies reported on death anxiety and nurses' experiences (Table 4), whilst others reported on death anxiety and impact of death education on nurses. It appears studies on death education were aimed at finding mechanisms to manage or deal with death anxiety and not understand the relationship between nurses' experience of caring for dying patients and the levels of death anxiety.

These studies were excluded from this review as they did not specify whether the education in question was specific to death (death education) or was to do with higher education of diplomas and degrees. This lack of clarity meant that, it was not possible to conclude whether or not level of education moderated levels of death anxiety.

Stoller (1980) and Thompson (1985) reported that experiences with death and dying did not result in a decrease in death anxiety among nurses. Chen, et al (2006) studied nursing students and reported that experienced students reported significantly higher levels of death anxiety than the less experienced students. Indeed Chen concurs with earlier conclusions by Stoller and Thompson, that experience with death and dying does not necessarily reduce one's death anxiety. These findings are contrary to an earlier study by Denton and Wisenbaker (1977) which reported that as experiences with death occurred, death anxiety diminished. This assertion seems to be based on a general assumption that experience of death and dying moderates death anxiety levels.

The opposite is possibly true as well, where peoples' experiences of death might not be pleasant, or where the experience reminds those witnessing it of their own existential vulnerability.

Two points emerge from Denton and Wisenbaker's assertion;

- First, people in the 1960s were probably more familiar with death than most people in late 1980s when the second study was undertaken. The 1960s saw death occur in family homes and children were also present, and therefore were exposed to death at a much earlier age in their life;

- Second, from the 1980s onwards, death was being removed from family homes to institutions like hospitals where professionals (but strangers to dying patients) looked after the dying (Clarke 1996; Walter 1997; Nyatanga 2001). The fact that there is a discrepancy between two studies in two periods gives ample justification, and a rationale to undertake this current study.

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It must be acknowledged that the recently published End of Life Care Strategy by the UK government, encourages a reversal of the above argument, in that patients are encouraged to be cared for in their own homes and be supported well to die there if that is their preferred place of death (DH 2008) However, clarity or definition of 'home' is not offered, therefore patients may end up being cared for in nursing or residential homes, their own homes or that of a relative.

In a study by Reisetter and Thomas (1986), it was concluded that as death anxiety levels increased the quality of nursing care was reported to be poor. What this inverse relationship suggests is that if the levels of death anxiety were to decrease, it could be argued that the quality of nursing care would improve. This argument would be supported by evidence from other researchers, for example, Payne et al (1998), who focused on the levels of death anxiety between hospice and emergency nurses (see Table 4). The study by Payne et al was the only British based study found, and therefore makes the current study timely. Using a cross-sectional study design with a sample of 43 nurses (23 hospice, 20 emergency), from a district general hospital and local hospice, they reported that hospice nurses had lower death anxiety levels than the emergency nurses. Hospice nurses were more able to recall both good and difficult situations involving patient care. However, the sample size from this study was too small to generalize results.

However, of interest was that 20% of the emergency nurses, unlike the hospice staff, were unable to discuss problems with colleagues as they could not recall incidents. Implications for these nurses are far reaching regarding the type of support they are offered and the use of reflective practice. The emphasis in reflective practice is the ability to recall incidents or situations that occurred and then goes through an analytical process in order to learn and develop from the experience.

The conclusion that can be drawn from Payne et al's findings is that reflective practice may not always benefit those nurses experiencing high levels of death anxiety, since they are unable to recall situations they encountered while caring. Recall of situations requires cognitive ability which tends to be impaired by high levels of death anxiety.

Table 4: Studies relating to death anxiety among nurses

Study	**Study design**	**Sample Size**	**Measurement scale**	**Key findings**
Payne et al (1998)	Cross sectional survey	43	Death attitude profile revised and interviews	Hospice nurses had less DA than Emergency nurses
Sherman (1997)	Survey (questionnaires)	220	Templer 1970	DA significantly correlated with willingness to care for AIDS patients and spirituality
Reisetter & Thomas (1986)	Survey (questionnaire)	210	Templer 1970	Inverse relationship between death anxiety and quality of care
Thompson (1985)	Survey (questionnaire)	52	Guttman's	Experience with death does not decrease death anxiety
Stoller (1980)	Survey (questionnaire)	62	Lester's	Experience with death did not decrease DA.
Denton & Wisenbaker (1977)	Survey (questionnaire)	76	Templer's 1970	Death anxiety decreased with more experiences of death
Chen et all 2006	Survey (questionnaire)	152	Multi-dimensional fear of death scale	Death anxiety increased in more experienced student nurses than less experienced

Other studies by Rigdon and Epting (1985); Thompson and Powell (1988) on gender and death anxiety found that females tend to report more death anxiety than males (as shown in Table 5 below). In a separate study by Marks (1986), however, no gender difference was found. The fact that men are generally less expressive with their emotions was not commented on in the studies that found more death anxiety in females than males.

What might be the difference is the way the two genders express their feelings, and in this case it seems women are more vocal and expressive than their male counterparts.

It therefore does not necessarily suggest women experience more death anxiety than men. It is logical to suggest that women are more expressive than men about their emotions. It is plausible to suggest that both men and women may experience the same level of anxiety but express it differently. The potential difference in gender and experience and expression of death anxiety is of interest to this study.

Other variables studied alongside death anxiety included attitude towards the older patients (Eakes 1985), as shown in Table 5. Eakes reported a negative attitude towards elderly patients correlated with high death anxiety levels. Eakes's study is important in that the majority of adult palliative care patients in the UK are considered elderly. It is widely recognised that negative attitudes toward older patients affect the quality of care they receive (Burnside 1976; Kennedy 2005).

DePaola et al (2003) confirmed Eakes's earlier findings when he reported that white and black Americans with high levels of death anxiety showed negative attitudes towards the elderly. DePaola further reported that white Americans presented with higher levels of death anxiety than their black counterparts. The difference here may be highlighting cultural variations, ethnicity, ways of upbringing, religious commitment and the timing of exposing children to death and dying experiences, whether be it of family members, pets or other dying objects. Exploring the relationship between aspects such as ethnicity/cultural variations and death anxiety would be of interest for this current study.

Rose and O'Sullivan (2002) explored relationships between belief in life after death and death anxiety, and found no relationship. Although this finding is important, it, however, does not give in-depth insight into this relationship since, according to Aday (1984) a belief in an afterlife should be considered in conjunction with the level of religious involvement. In the study by Aday (1984), findings concluded that belief in life after death was a function of high religious involvement. High attendance at church was positively correlated with belief in an afterlife. Alvarado, et al (1995) also found that strong religious conviction was associated with less death anxiety.

What is clearly lacking is research on the association between death anxiety and non religious samples. The argument seems to be that people with a belief in an afterlife appear to exhibit low death anxiety levels, as they view this life as a transitional platform to another better one.

The other argument is that, since there is up to now, a lack of evidence of life after death, religion may be used as a buffer against death anxiety by anticipating an eternal life. The idea of buffering was analysed in depth in chapter 3. The key argument from the analysis was that buffering is viewed as a psychological coping mechanism used by most people in different situations including those facing death.

A recent literature review revealed two studies by Russac et al (2007) which reported the same findings that death anxiety peaked in both men and women during their 20s and declined significantly thereafter. However women were reported to peak again during their early 50s. The first study used the Collett-Lester Fear (1986) of death scale with 304 participants, and the second study used Templer's (1970) death anxiety scale with 113 participants. As discussed earlier in chapter 4, death fear and death anxiety are slightly different entities, and may explain the difference in these results, as what was measured by the two scales would also be different. However, the relationship between age and death anxiety is of interest for this current study, mainly because as age increases so do other co-morbidities and multiple losses. In a study by DePaola et al (1992) which they repeated in 1994, they reported similar findings that older adults showed lower levels of death anxiety than younger people. It is plausible to suggest that the younger people may feel more anxious as they still believe they have not yet achieved any of their goals in life.

It is also possible that, at a younger age, they would not have witnessed any deaths themselves, therefore the thought of their own would be anxiety provoking that the older adults.

Table 5: Studies relating to death anxiety (DA) and a variable

Study by;	**Study design**	**Sample size**	**Variable**	**Measurement scale**	**Key findings**
Rigdon & Epting 1985	Survey questionnaire	Not given	Gender	Templer 1970	Females reported more DA than males
Eakes 1985	Survey questionnaire	159	Attitude towards older patients	Templer 1970 Palmore's facts aging quiz	high DA revealed negative attitude to elderly
Thorson & Powell 1988	Survey questionnaire	Not given	Gender	Templer's RDAS	Females reported more DA than males
Marks 1986	Survey questionnaire	1374	Race and Gender	Not Indicated	No race or gender differences were found
Depaola et al 2003	Survey questionnaire	197	Attitude toward the elderly; role of gender and ethnicity	MFODS. Multi dimensional fear of death scale	High DA associated with negative attitudes. Whites showed more DA than Black
Aday 1984	Survey questionnaires	181	Belief in life after death	Templer 1970	High church attendance associated with low death anxiety
Servaty et al 1996	Survey questionnaires	129	Empathy	Mehrabian and Epstein empathy scale. Templer 1970	High levels of empathy positively associated with death anxiety
Galt & Hayslip 1998	Survey questionnaires	83	Age differences	Templer 1970 Collett-Lester	Adults showed high overt DA, Younger ones showed higher covert DA
Rose and O'Sullivan 2002	Survey questionnaire	111	Belief in life after death	Templer 1970. Osarchuk and Tatz Belief	No relationship found
Russac et al 2007	Survey questionnaire	304	Age differences	Collett_Lester 1994	Young adults in their 20s (both sexes) showed high DA . Only women in their early 50s showed high DA
Russac et al 2007	Survey questionnaire	113	Age differences	Templer 1970	Young adults in their 20s (both sexes) showed high DA. Only women in their early 50s showed high DA.

However, another explanation can be found in Fortner and Neimeyer's (1999) study, which reported higher levels of death anxiety among older adults who also had distressing psychological and physical problems. This may suggest that psychological and physical problems might have intensified the levels of death anxiety, as increasing age alone was not reported to have this impact.

Two studies in table 6 explored the association between stress and death anxiety (Sinha & Nigan 1993) and death anxiety and burnout (Mallett, 1988). The Sinha and Nigan (1993) study concluded that stress was a good indicator of death anxiety presumably in both men and women. But what is meant by stress and good in this study remains unclear. The study by Mallett (1988), on the other hand, explored the association between death anxiety and burnout with other variables. These two variables are also of interest for this current study, therefore further analysis of Mallet's was deemed important.

Table 6: Studies relating to death anxiety, burnout and another variable

Study	Research design	Sample Size	Variables	Measurement scale	Key findings
Mallett 1988	Correlation	376	Death anxiety, Burnout, & Social support	MBI & Templer 's scale 1970	Positive association between Death Anxiety and Burnout
Sinha & Nigan 1993		50 males in study 1 100 women study 2	Stress	Thakur DAS	Stress was good indicator of Death anxiety

Mallet's study compared occupational stress, levels of burnout, death anxiety and social support among hospice and critical care nurses. Unlike Mallet's categorisation that hospice nurses are the same as critical care nurses, in the UK, hospices and intensive care nurses are different in terms of their philosophy of care. Hospices and their associated care focus mainly on achieving a dignified death and best quality of life possible (World Health Organisation 2002), whereas, intensive care is primarily to prolong life and eventually return the patient to full independence (Twycross 1994, and 2003).

This study therefore seeks to understand the levels of burnout and death anxiety among nurses working in different settings of hospital, hospice and community.

Analysis of Mallett's study

Mallett's (1988) study used four measurement instruments to obtain data on occupational stress, burnout, death anxiety and social support from a national sample of 376 nurses in the two settings. Table 7 gives a summary:

Table 7: Summary of methodology used in the Mallett's study

Variable	Instrument	Type of measure	How it measured items
Occupational stress	Stressful situation scale	5-point Likert scale	Not stressful = 1, to extremely stressful = 5
Burnout	Modified Maslach & Jackson MBI	22-item scale	3 sub-scale EE, DP, PA
Death anxiety	Collett-Lester fear of death scale	36-item likert scale	Measures 4 concerns using 6-point Likert scale. Strong agreement = +3 to strong disagreement = -3
Social support	Sarason, Levine et al	27-item social support Questionnaire	6-point Likert scale. Very satisfied = 6 to very dissatisfied = 1

According to Mallett, the sample was representative of the continental regions of the USA. It therefore follows that the findings from Mallett's study could not be generalised beyond these continental regions (Bryman 2004; Burns and Grove 2005). However, this study is being used as a basis for this current study, but investigating different variables, with a different type of sample.

Results from Mallett's study

The results from Mallett's study are shown in table eight. From the results, hospice nurses seem to work under more favourable conditions than critical care nurses. They worked fewer hours per week, had been in their jobs longer and they were older than the critical care nurses. Staying in a job for long periods may suggest, among other explanations, job satisfaction for employees.

Table 8: Summary of descriptive data in Mallett's study

	Critical care Nurses	**Hospice Nurses**
Response rate	167 (56%)	209 (70%)
Mean age	34.8 (SD = 7.9)	40.2 (SD = 9.1)
Mean years experience	11 (SD = 7.9)	14.3 (SD= 9.2)
Hours worked per week	38.9 (SD = 8.8)	34.3 (SD = 9.0)
Nurses married	64.1%	71.33%
Nurses single	18.6%	9.1%

The inclusion of marital status may have been based on the understanding that marriage is a useful source of social support (Barrera 1986; Ringdal, et al. 2007). What Mallett does not say is whether the single nurses lived alone or were living with a partner or family. In terms of those who were married it is not clear whether they were in happy stable relationships as this would suggest positive social support (Ringdal et al 2007). The idea of a 'good' marriage or close relationship is that it provides social support (Smeija, et al. 2006) which will act as a buffer against death anxiety (Greenberg, et al. 2004), and burnout.

In Mallett's study, death anxiety correlated positively but weakly with burnout (Table 9). Similarly, when using the EE and DP components of burnout, they correlated positively with death anxiety although weakly. PA showed non significant correlation with death anxiety.

Table 9: Correlation between burnout and death anxiety

Variables	**Death anxiety**	**Direction and strength of correlation**
Burnout	(r .17)	Positive but weak
Emotional Exhaustion	(r .20)	Positive but weak
DePersonalisation	(r .21)	Positive but weak
Personal Accomplishment	(r - .01)	No significant correlation

Social support and health care professionals

There seems to be an association between social support and stressful events. However there is a lack of consistency in the nature of this association. Social support has the ability to 'buffer' stressful situations on physical and mental health, hence it is often referred to as the buffering hypothesis (Mor-Barak 1988). Mor-Barak contends that in some cases, social support can eliminate the presence of occupational stress. It is well documented that occupational stress is a precursor to the burnout syndrome (Maslach, 2001; Vachon 2003), and therefore social support may be the mechanism to prevent development to the burnout syndrome. .

A few studies including Constable and Russell (1986) reported that lack of social support in hospital nurses resulted in burnout. Table 10 includes findings from this study and others on relationships between social support and stress/burnout. As can be seen from these studies, the samples do not include palliative care nurses This omission creates a valid gap for this current study to address.

Table 10: Studies relating to social support and health professionals.

Study	Study design	Sample size	Professional group	Key findings
Constable & Russell 1986	Survey questionnaires	310	Hospital nurses	Lack of social support was a predictor of Burnout
Jenkins & Ostchega 1986	Survey questionnaires	152	Oncology nurses	Social support negatively correlated with Burnout
Kaufman & Beehr 1986	Survey questionnaires	102	Hospital nurses	Lack of Social support at work increased nurses stress levels
Llewelyn & Fielding 1987	Focus groups	40	General nurses	Utilised staff support meetings to deal with stress
Grassi et al 2000	Questionnaires	1341	Patients in primary care	Social support help reduce psychological distress
Fujita & Kanaoka 2003	Questionnaires	1634	Mental health carers	Perceived social support improved mental health of subjects

Llewelyn and Fielding's study (1987) was most interesting in that the researchers encouraged nurses to develop their own support mechanisms. As a result, nurses formed regular group support meetings. These meetings were used as a platform to share distress, frustrations and any emotional aftermath from their caring roles. Other studies found negative correlations between social support and burnout (see Jenkins and Ostchega 1986). Although social support is of interest, previous studies have been inconsistent about its association with burnout. Researchers have failed to demonstrate how social support prevents the development of burnout.

However, it would appear that where social support has been effective, it included both emotional and physical input. The duration, type, quality and frequency of social support are all important aspects to make it effective.

Summary of methods used in the studies

The studies that sought to establish a relationship between death anxiety and other variables employed sectional survey methods and used Templer's (1970) Death Anxiety Scale (DAS). For example, the study by Alvarado et al, seeking to understand the relationship between DA and religious belief employed the DAS together with the religious inventory (Alvarado, et al. 1995).

Studies that compared DA between two groups of professionals employed a combination of methods, that is, a survey followed by structured interviews using convenience samples, for example, the study by Payne and others (Payne, et al. 1998). Combining methods ensures rich data are obtained and a deeper understanding of the subject of study assured.

The use of Templer's death anxiety scale in these studies seems justified and popular, as the scale was reported to be one of the most widely used measures of death anxiety with high validity and reliability reported. Most importantly, the scale was preferred because it did not refer to death as a negative destructive force. Instead the scale only elicited the individual's emotional response to the contemplation of their own death.

The average sample size from all the reviewed studies was 210 participants. As a rule of thumb, (Bryman 2004), the bigger the sample the more representative it is going to be and therefore more confidence in generalization of findings. In this case 210 participants form an acceptable sample size (Cohen, et al. 1999; Bryman 2004; Munroe 2005) to detect statistically significant results.

Participants included in the studies ranged from older adults, undergraduate students from nursing and psychology programmes to general trained nurses.

Most of the studies employed a convenience sampling strategy as most of the researchers in North America used students studying on their university courses.

All but one of the reviewed studies failed to mention ethical approval or considerations for their studies. Ethical principles are universal and should be observed regardless of the country in which studies are undertaken. However, it is also possible that these studies observed the ethical principles, but researchers failed to mention this in their published papers for a number of reasons, one common one being limited words imposed by journal editors.

In a few American studies, student participants were guaranteed extra module credits if they took part in the study, and the ethical consideration for such incentive was not discussed. While external incentives may have a place in research studies, the contribution and commitment of the participants can be questionable and arguably less genuine.

Justification for current study

It is clear from this literature review that, although a lot of studies have been undertaken on death anxiety and burnout, the most recent study was by Mallett in 1988 as part of her doctoral studies. It is rather an academic antithesis to refer to studies conducted in 1988 as most recent. However, such realisation can only serve as a timely reminder of the dearth of recent studies on the topic and valid justification for undertaking this study.

Implication of Mallett's study on current study

There seems to be a minor but important discrepancy in Mallett's study, in that she measured death anxiety, which has been shown to be an emotion (May 1977) using a scale that measures death fear, which is regarded as a mood (May 1977). The discrepancy is that what was being measured by the fear of death scale was specific to fear of death which focuses on a perceived threat, and not necessarily death anxiety as described earlier in chapter 4, which focuses on feelings of uncertainty (May 1977). The two terms were shown to have a fine distinction between them, and it is important that this distinction is observed and reflected when measuring these concepts.

It seems a lot of studies including Mallet's, have been undertaken, on patients, older adults and undergraduate students, and no evidence to date to suggest any studies undertaken specifically on palliative care nurses caring for dying patients. This is a clear gap in the literature which the current study will address.

Findings on social support have not been consistent, However, it is generally accepted that social support has the ability to moderate or buffer the impact of stress on psychological and physical health, thereby minimising on the development of burnout (Cohen and McKay 1984; Cohen 1988). Although there may be general acceptance, there is still lack of consensus on its conceptual and operational definitions (LaRocco, et al. 1980), hence it is not clear how the buffering actually works. As already discussed in chapter 3, there are different aspects to social support, including physical and psychological which can play a key role in preventing burnout. The use of social support seems central in any stressful environment like caring, if the deleterious effects of stress on health are to be lessened or prevented.

Previous studies have focussed at hospices and acute hospital care settings for their investigations. In the UK, palliative care today takes place in the community and specialist units in addition to hospices and hospitals. It is therefore important to include these settings in the current investigation so that a broader understanding of caring for dying patients and its impact on nurses' death anxiety can be achieved.

We also know that patients' needs have changed since these studies in the 1980s. Today's patients are exposed to more information about cancer, and other life-limiting diseases including treatment options. It is therefore plausible to suggest that patients today are more informed and inquisitive about their illness, and inevitably have increased expectation of the nurses to provide the answers. While such expectation is welcome in terms of improving nurse-patient relationship, it may also increase expectations on nurses to be more knowledgeable about diseases and prognosis. Nurses' workload pressures have also increased leading to emotional exhaustion. The discussion in chapter 3, confirmed that emotional exhaustion as the first sign of the Burnout Syndrome (Maslach et al 2001). With increased workload pressure, nurses may begin to protect themselves psychologically by depersonalising their contact with patients.

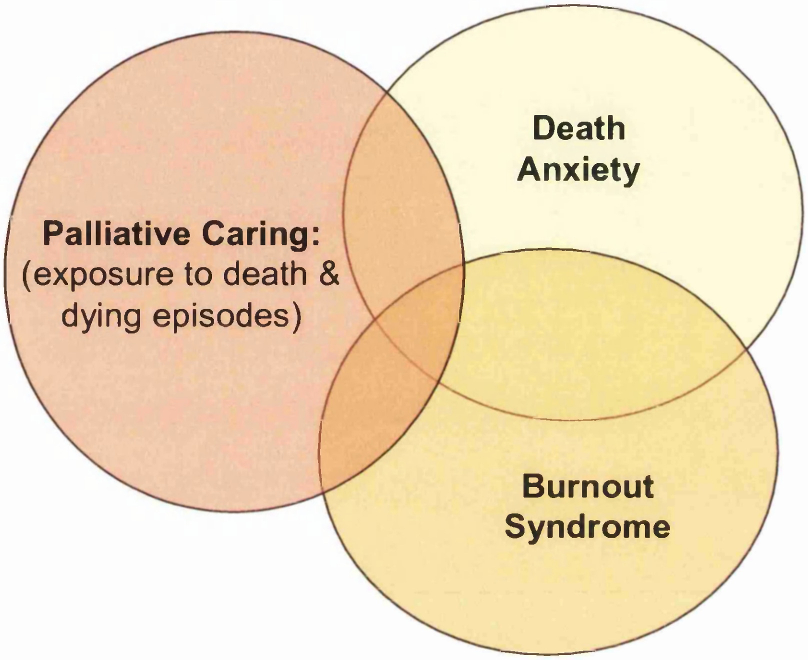
Depersonalisation follows after emotional exhaustion and is one of the three dimensions of the burnout syndrome. It is therefore important for this study to investigate any possible association between burnout and caring. Caring exposes nurses to death and dying episodes, which could induce the development of death anxiety. It is by axiom crucial that this study also examines possible association between death anxiety and burnout.

Although previous studies have investigated death anxiety and burnout among health professionals, there is no specific discussion about caring as a potential source for the development of both death anxiety and burnout. This is a major omission which this study will address. Chapter 2 highlighted what and how aspects of caring may be responsible for inducing death anxiety and burnout. This study presents a real opportunity to investigate and identify specific aspects of caring that are seen as sources of pressure for health professionals. In this case caring is made up of different dimensions as shown on the measurement scale (appendix 1).

We now understand the staged development of burnout as outlined earlier in chapter 3, but the question that remains is whether there is a relationship between the burnout syndrome and levels of death anxiety among palliative care nurses. It is not yet clear whether the development of burnout contributes to the development of death anxiety or vice versa. One possible argument is that when people develop high levels of death anxiety, they may not be able to process and cope with work demands. This weakness may leave them susceptible to stress, which will eventually lead to burnout.

From this summation, it is clear that there are three variables of interest to consider, and these are represented in Figure 4 below.

Figure 4: Variables of interest for current study



In this figure, caring is seen as the source of pressure on nurses and without intervention (for example using preceptorship or social support), nurses may experience either burnout or death anxiety, or both.

The link between the burnout syndrome and death anxiety was brought into sharper focus by findings from a study by Sherman (2004). In this study, Sherman reported that people presenting with burnout experienced psycho-emotional symptoms that were similar to those of people presenting with high levels of death anxiety. This link raises the question of a possible relationship between death anxiety and the burnout syndrome.

Up until now, no study has yet examined this tripartite relationship; that is, caring, death anxiety and the burnout syndrome. Levels of death anxiety and burnout can determine and influence the quality of care nurses provide to dying patients (Vachon 2000).

Role of social support in preventing death anxiety and burnout

There is evidence from the literature review that variables like age, gender and ethnicity can moderate death anxiety and burnout, while on the other hand social support can be manipulated to either prevent or minimise the development of death anxiety and burnout (Hammer 1983; Gottlieb 1985). It is therefore important for this current study that such variables are considered with particular emphasis on their interaction with social support, which can be provided in varying degrees. Social support is not a fixed entity, therefore can be adjusted to suit the psycho-emotional imperatives faced by palliative care nurses. According to Grassi et al (2000), social support can minimise and prevent death anxiety and burnout from developing. Caring is viewed as a potential stressor for palliative care nurses, whereas social support is seen as a buffering mechanism against burnout and death anxiety and therefore a moderating variable which helps to protect nurses' mental well being. It can be argued that, with such protection, caring can be enhanced.

Interacting variables like social support may be capable of moderating death anxiety and burnout. In the event that social support offered is not effective, the result may be that death anxiety and burnout will increase. The cost and health implications of burnout and death anxiety are far reaching, as highlighted in chapter 1, and hence it is important to have an effective supportive mechanism in place.

Implications for current study

As already discussed in detail earlier, the study by Mallett (Mallett 1988), was the only one found which investigated two of the variables of interest to this current study. Mallett investigated the relationship between death anxiety and burnout in hospice and critical care nurses in North America. The study used a national sample of 376 hospice and critical care nurses. The findings indicated that critical care nurses reported more burnout and also experienced higher death anxiety levels than hospice nurses.

This thesis builds on Mallett's (1988) study, by adding caring and social support as variables of interest. It seems important to investigate the extent to which caring can be associated with death anxiety and burnout. It can be argued that the capacity to care is the most important attribute in palliative nursing as well as other branches of nursing. It is also important that health professions understand the psycho-emotional aspects of death and dying as this creates the association with the three variables in this thesis (i.e. caring, death anxiety and burnout). For palliative nursing, caring will carry greater importance because it is no longer confined to hospices but can occur in various other settings within the new NHS, where dying patients are cared for. This further implies that the psycho-emotional aspects of death and dying require serious attention particularly in the provision of social support within the different NHS settings.

Summary

To many researchers and palliative care nurses, caring for dying patients has the potential to be both stressful and rewarding. The reward may come from helping and supporting dying patients to achieve a dignified death free from pain and suffering. Stress may result from actually witnessing death episodes, uncontrollable pain and the 'emotional turmoil' of close relatives. Witnessing patients' death episodes may also remind health professionals of their own vulnerability which may raise their levels of death anxiety.

It has been suggested that both death anxiety and burnout can be moderated by different variables including age, gender, and social support.

Literature review suggests that discrepancies still exist on the impact of social support on death anxiety and burnout among nurses. Although social support is believed to have a buffering effect, it is not yet clear how this happens.

The ultimate goal of caring should be minimising death anxiety and burnout among health professionals. By ensuring that death anxiety and burnout are minimised or prevented, this will mean, **i.** health professionals can continue to deliver high quality care, and **ii.** patients can be afforded a unique and dignified death. The cost of burnout is too high, for example absenteeism, which may indicate poor health and quality of life for health professionals. It is important that the mental and physical well being of all palliative care nurses is preserved so that they can continue to provide high quality care for dying patients and their families.

Given the evidence and gaps inherent in the literature, the aim of this study was to investigate the relationship between caring, death anxiety and burnout among palliative care nurses.

The objectives of the study were to:

- Identify aspects of caring perceived as stressful when caring for dying patients;
- Examine the relationship between death anxiety and burnout;
- Examine the relationships between social support, burnout and death anxiety;
- Identify significant predictor variables of burnout;
- Identify differences in burnout and death anxiety scores between nurses working in hospices, hospitals and community settings.

CHAPTER 6: METHODS

Chapter overview

This chapter describes research design, sampling strategy and study setting. Measurement scales used for data collection are discussed and issues of validity and reliability are analysed. Variables of interest, that is, death anxiety, burnout and caring, are discussed and their relationships analysed. This chapter explains the research process undertaken for this study from accessing participants, piloting of questionnaires over three phases to data collection in 2005 and its analysis. Ethical considerations and processes leading to ethical approval are discussed.

Finally, multiple regression analysis, using the method enter technique, is used to identify predictor variables of burnout. However, before multiple regression can be performed several assumptions need to be satisfied, and this chapter gives a detailed discussion of how these assumptions were checked. In total, four predictor variables are included and judgements made on their predictive value on emotional exhaustion.

Research Design

This study used a correlational survey research design to explore the relationship between death anxiety, burnout and caring among palliative care nurses (Bryman 2004; Burns and Grove 2005; Bryman 2008). The survey is cross-sectional in that data were collected at one point in time. The design allows for examination of scores of death anxiety and burnout, the direction and strength of relationships between the variables under investigation. The correlational research design used in this study seeks to determine the relationships or associations between the variables, death anxiety, burnout and caring. Therefore, there is no intention from this study to draw conclusions of cause and effect when extrapolating findings.

Aim of the study

The study investigates the relationship between caring, death anxiety and burnout among palliative care nurses. The objectives of the study were to:

- Identify aspects of caring perceived as stressful when caring for dying patients
- Examine the relationship between death anxiety and burnout
- Examine the relationships between social support, burnout and death anxiety
- Identify significant predictor variables of burnout
- Identify differences in burnout and death anxiety scores between nurses working in hospices, hospitals and community settings

The Sample

All 350 palliative care nurses identified were invited by letter to participate in the study. The participants were identified as follows:

Hospices N = 165
Hospitals N = 120
Community N = 65

From these, a total of 213 (60.86%) responded by returning completed questionnaires. More details on the breakdown of respondents are given in the results chapter. It is hard to find consensus on what is acceptable response rate. For example, Bryman and Cramer (2001) would consider the response rate for this study acceptable for generalisability, whereas, Mangione (1995) argued that response rate between 50-60% is barely acceptable. On the other hand, Passmore, et al (2002) argue that generalisability is impossible with a response rate below 70%. Although, these arguments are valid, the point to make is that, the exploratory nature of this current study meant the response rate was not seen as a major issue and therefore was acceptable at 61%.

Nurses in this sample comprise a convenience sample (Bryman and Cramer 2001), since the researcher selected them to volunteer in the study. Although Bryman and Cramer (2001), Bryman (2008) claim that use of convenience samples limits generalisability, as this is an initial exploratory study, this was not seen as problematic. In addition, Bryman and Cramer (2001) argue that factors like low and declining response rates with probability samples, mean that the difference in the relative representativeness between the samples may not be as great as first thought. They add that where random samples are used, non-response rates may greatly affect their random qualities.

All nurses in the sample were working in the Mid West region of England in one of the three settings, that is, hospice, hospital and the community. To be included in the study, nurses needed to have worked in palliative care for a minimum of three months. The reason for stipulating three months is that this period of time would allow the nurses some contact with, and experience of, caring for dying patients. For ethical reasons, nurses who had recently experienced a death of a close relative or friend were discouraged from participating in the study. This action was intended to minimise harm on such nurses, since the study would ask them about aspects of death and dying.

It is well documented (Woof and Nyatanga 1998; Jeffrey 2003, Twycross 2003; Doyle, et al 2005) that most sensitive conversations with dying patients take place, or at least start, during intimate and personal caring procedures like bathing, meal times, toileting, wound dressing, personal hygiene care and night time drug rounds, and these tasks are in the main performed by nurses. Similarly, post death activities, such as performing last offices, informing relatives of the death and supporting bereaved relatives are to a large extent the remit of nurses. Allied Health Professionals (AHP) including physiotherapists and dieticians focus on rehabilitative aspects of care, and are in contact with patients for much shorter periods of time when compared to nurses. Because of minimal involvement, and a different focus of their role, they were not included in the study. Doctors were also excluded from the study as their contact with dying patients is at specific targeted times, normally distressing ones, and therefore may need a separate study to examine their issues.

Access to respondents

Once approval had been received from the Research and Development (R & D) departments across the NHS Trusts and hospices, a contact person was confirmed at each site. Each contact person identified potential participants within their organisation. They also helped to preserve anonymity of all respondents since there was no direct contact between them and myself as the researcher. The research pack (comprising four self rating scales, participant information sheet, covering letter and self-addressed stamped envelope) was therefore sent to contact persons for onward distribution to the participants. By including a self addressed stamped envelope, it meant the respondents would send their completed questionnaires direct to me and not the contact persons. In hospices, care directors acted as the contact person as they also met weekly with the nurses. In hospitals and the community, contact persons differed in scope of their roles and it was therefore important that they all had the same message and information about the study. Contact persons included team leaders, lead nurses, nurse consultants, line managers, and directors of nursing. Information giving meetings were arranged where the study and role of the contact persons were explained. These meetings also enabled any points of clarification to be raised and addressed. In total, six meetings were held in different venues across the West Midlands between 3.00 and 4.30pm. All travel expenses for contact persons were reimbursed by the employing organisation as agreed by their R&D departments when they approved the study. After meetings, contact persons went home on my suggestion and did not return to their offices. This, I believed would give them extra time and space to think about my study and hopefully have an increased understanding of what was required of them, or telephone me to clarify further questions.

All contact persons were asked to keep a record of who had received a research pack so that they could send reminders to non-responders. Two reminder letters were sent out through contact persons, and by so doing, it is believed respondents were assured of anonymity. It can be argued that this process was one of the key factors for the high response rate for this study.

Reminders

Non-responders were sent two reminders at separate times, that is, at six and eight week periods. The first reminder letter (appendix 6) was sent out six weeks after the distribution of research packs. These generated a handful of responses, and two weeks after the first reminder letters, a second reminder letter was sent out, to those respondents who still had not responded. A few more responses were received and it was decided to proceed with data analysis.

It can be argued that data yielded from reminders may have been biased and therefore considered not valid because the respondents may have felt pressurised to return the questionnaires and may not have answered the questions truthfully, as they felt rushed. However, in this study, this possibility would not have affected the validity of the data as only a few extra questionnaires were received as a result of the reminders. Therefore the issues of validity and generalisability were not perceived as threatened to invalidate the findings from this study

Research Instruments

On searching for appropriate research instruments, it was evident that for the subject matter of this study, there were no recently validated measurement scales to use. It was therefore decided to use measurement scales validated in the 1980s. Thus the Revised Death Anxiety Scale (RDAS) by Thorson and Powell (1988) (appendix 1) and the Maslach Burnout Inventory (MBI) by (Maslach and Jackson 1982) (appendix 2) were used with their permission to measure death anxiety and burnout respectively. Because of changes in social and health care contexts since these scales were validated, their suitability to use with this current study was assessed through factor analysis.

The results confirm that the two scales are still suitable. A detailed discussion on factor analysis and the results is given in chapter seven. Issues of reliability and validity of these scales is discussed later in this chapter.

In addition two other scales were developed specifically for use with this study. First, the Sources of Pressure Scale (SOP) to collect data on what nurses perceived as stressful when caring for dying patients. Second, the Social Support Scale (SOCS) which was adapted from Borrill's (1996) scale measured level of support nurses received from their managers. Copies of both scales are in section A of appendix 1. Both scales were factor analysed and results reported in detail in chapter 7.

Selecting the Revised Death Anxiety Scale

Although other measurement scales like the Death Attitude Repertory Test (Neimeyer 1994), and Collet-Lester's Fear of Death Scale (Lester 1994) may provide more appropriate means of measuring complex individual framework of orientations towards death fear, this study was concerned with death anxiety, therefore, the revised death anxiety scale (RDAS), shown by Thorson and Powell, (1988 and 1994) to be more robust was preferred. The scale has a seven factor structure as shown in Table 11, in measurement of death anxiety (Thorson and Powell, 1988 and 1994), which was also confirmed for this study through factor analysis. However, table 11 shows the original factor structure of the RDAS when it was developed by Thorson and Powell. In addition, the RDAS, like most psychological scales has the virtue of convenience of administration with large samples and provide a means of assessing differences between and within groups.

Table 11: **7 Factor Structure of Revised Death Anxiety Scale**

1.	Fear of uncertainty and missing out on things
2.	Fear of the pain associated with death
3.	Concern over the disposition of one's body
4.	Fear of helplessness and loss of control
5.	Afterlife concerns
6.	Fear of decomposition
7.	Concerns over leaving instructions on how things should be done after one's death
Source: Thorson and Powell (1988)	

Thorson and Powell (1988) suggested that the original death anxiety scale developed by Templer (1970) had lacked internal consistency and Nehrke (1973) suggested that the same scale only measured a single general death anxiety construct. Nehrke (1974) added one item of his own construction to the scale which was tested with several studies. Thorson and Powell, (1984) factor analysed Nehrke's modifications and revised them further over five major studies.

The revisions strengthened and improved on internal consistency by removing ambiguous items and by changing from true/false responses to a Likert scale format. In general Likert scales are concerned with unidimensionality, ensuring that all items measure the same thing. However, Lonetto and Templer, (1986) subsequently showed that in fact the scale had a diverse factor structure. Indeed on publication of his death anxiety scale, Templer had proposed it as theoretically unidimensional, but it was in fact, according to (Neimeyer and Brunt, 1995) empirically multidimensional measure.

Scores on the RDAS Likert scale range from 1, least levels of death anxiety to 5, highest level of death anxiety. This allows a minimum score of 25 and a maximum score of 125. Low levels of death anxiety are those at ≤ 39, and moderate levels range between, 40 – 80, whilst high levels are those at ≥ 81

Reliability of Revised Death Anxiety Scale

The RDAS was tested by a number of researchers including Neimeyer and Brunt (1984), Thorson and Powell (1988) and Neimeyer and Brunt (1995) with several large and diverse samples and factor analyses of the data showed that internal consistency had also increased, with Cronbach Alpha reliability of .80, (n= 599) as smallest sample. In their conclusion, Neimeyer and Brunt (1984) claimed that the RDAS had increased sensitivity over its predecessor, Templer's Death Anxiety Scale, and therefore deserved greater use.

The RDAS was tested for this study for internal reliability and had a Cronbach Alpha of .85, (n= 205). According to (Bryman and Cramer 2001), this is an acceptable level, and therefore in selecting it, one can be confident that this measurement scale is internally reliable and measuring items from the same conceptual domain (Bowling 2005).

The Revised Death Anxiety Scale is a 25-item self-administered scale (appendix 1), 17 of which are positively phrased and the remaining 8 items are negatively phrased. The negatively phrased items were reverse-scored prior to data analysis. Respondents were asked to select one response for each statement that closely reflected their view about that item statement. Responses are based on a Likert scale which ranges from strongly disagree (1) to strongly agree (5). The fact that the lowest score is 1 suggests that every respondent and people in general, may have some residual degree of death anxiety, minimum 25. Although Thorson and Powell do not offer an explanation of this, it is possible to explain it from an ontological perspective described in more detail earlier in chapter 4, which suggests that every human being has an underlying inherent level of ontological death anxiety. Heidegger (1962) maintains that being human comes with ontological death anxiety as humans constantly endeavour to protect themselves from life threatening situations. Similar argument was made by Greenberg et al (2004) and went further to suggest that human beings perceive ontological anxiety as too overwhelming to deal with it alone, therefore, they form partnerships, some loving and intimate and others based on friendship in order to confront the threat in numbers as opposed to individually.

The mid point of the Likert scale used for this study has neither agree nor disagree, which according to Oppenheim (1992) can encourage respondents to be undecided and opt for the neutral point. Therefore, removing the neutral point may prove helpful (Oppenheim 1992) in countering this behaviours. It can be argued that the removal of this neutral point may deny those participants, who truly neither agree nor disagree, an option. Having considered the arguments, for this study, it would have been preferable to remove the mid point and 'force' respondents to either agree or disagree with the statements. However, the fact that eight items on this scale are negatively phrased helps to minimise the tendency for response sets and acquiescence in particular by respondents (Webb, Campbell et al. 1996).

The RDAS is user-friendly and takes between 10 to 15 minutes to complete, which was seen as positive in view of the participants' busy workloads. In fact, during pilot phases, it was confirmed that, completing all the scales for this study took on average 30 minutes. This short completion time might have helped to generate an increased overall response rate of 60.8% for this study.

The Maslach Burnout Inventory - Human services survey (MBI-HSS)

Maslach Burnout Inventory (MBI) has now been developed into three separate questionnaires, that is, Human Services, General and Education surveys. These comprise questionnaires specifically designed for those working in the human services, such as Health Care Professionals (HCP), and those employed in education, with the general type designed for all other occupations. For this study, the MBI Human Services Survey (appendix 2) was used to collect data on burnout. A slight modification to the MBI was necessary by changing the word 'recipients' to 'patients' to reflect the specific client group the respondents were caring for. However, this modification did not affect the internal reliability of the scale, which was estimated at Cronbach's alpha of .70, (n=204)

This 22 item inventory measures three main dimensions that comprise burnout syndrome, namely: emotional exhaustion, with nine items; depersonalisation, with five items; and low personal accomplishment, with eight items (Maslach and Jackson 1982). A detailed breakdown and discussion of these three dimensions was given in chapter 3 of this thesis. Although initial research on developing the burnout inventory was based on data from Canada and the USA, more studies have been conducted in many other countries world-wide. For example, the Greek study by Adali and Priami (2002) used the MBI (HSS) for its data collection.

The MBI-HSS has now been translated into various languages, and psychometric studies of the MBI-HSS in these different countries continue to validate the three-dimensional structure of the burnout syndrome. In addition, factor analysis on the inventory was undertaken and confirmed its suitability for use with this study.

Each of the three dimensions of burnout is measured by a separate sub-scale, which is assessed using a six-point response format (Maslach and Jackson 1982). The Emotional Exhaustion sub-scale assesses feelings of being emotionally overextended and exhausted by one's work. The Depersonalisation sub-scale measures lack of feeling and impersonal response toward patients, care or instruction from others. Maslach and Jackson (1982) claim that there is a correlation between emotional exhaustion and depersonalisation, in that development of depersonalisation is only possible where there is evidence of emotional exhaustion.

The low personal accomplishment sub-scale measures feelings of competence and successful achievement in one's work with patients. All sub-scales measure the frequency with which each respondent experiences feelings related to emotional exhaustion, depersonalisation and low personal accomplishment. Because burnout is conceptualised as a continuous variable (Maslach 2001), it ranges from low, moderate to high degrees of feelings experienced. It is therefore not viewed as a dichotomous variable which is either present or absent. Interpretation of the scores is that, high degree of burnout is reflected in high scores on EE and DP, and low scores of PA. Table 12 below gives a breakdown of normative scores relating to the three dimensions of burnout.

Table 12: Normative scores for MBI Human Services Scale

Sub-scale	**Low (lower third)**	**Average (middle third)**	**High (upper third)**
EE	≤18	19-26	≥27
DP	≤ 5	6-9	≥ 10
PA	≥ 40	39-34	≤ 33

Reliability and validity

According to Maslach and Jackson (1982) internal consistency was estimated by Cronbach's coefficient alpha (*n*=1 316) and the reliability coefficient of the three subscales are given as follows:

Emotional Exhaustion = .90;
Depersonalisation = .79;
Low Personal Accomplishment = .71.

Data on test retest reliability of the MBI –HSS was reported on five samples, but using different time periods ranging from four weeks to twelve months. Maslach and Jackson (1982) give detailed explanation and reliability coefficients from all five samples, and show that, although these coefficients range from low to moderately high, all were significant at .001 level.

Validity was demonstrated in different ways including, external validation of personal experience and discriminant validity (Maslach and Jackson 1982). External validation was demonstrated when a number of observers provided anonymous behavioural judgement on co-worker colleagues who had completed the inventory. (MBI-HSS). Co-workers who were judged to be emotionally drained and fatigued by their job were the ones who scored high on emotional exhaustion and depersonalisation on the MBI-HSS.

Further validity of the MBI-HSS was confirmed by distinguishing the inventory from other psychological constructs like depression that might be presumed to be confounded with burnout. However, Maslach and Jackson compared scores from MBI-HSS and General Job Satisfaction scale (n=91), and confirmed that the two were different constructs.

However, it can be argued that scores on MBI-HSS may be distorted by a social desirability response set, because many of the items on the scale describe feelings that are contrary to professional health care ideals. To test this possible distortion, Maslach and Jackson, used a sample of 40 graduate students to complete the MBI-HSS and Social Desirability Scale (SD) and reported that burnout is not influenced by social desirability response set.

A distinction was also made by Leiter and Durup (1994) between burnout and depression. Depression is confirmed as a clinical syndrome which pervades every aspect of a person's life, whereas burnout is an emotional crisis in one's relationship with work that involves human services (Leiter and Durup 1994).

Administration of the MBI-HSS takes about 5 to 10 minutes to complete. It is self-administered, and Malsach and Jackson (1982) recommend this is done in private without knowing what other respondents have indicated in their questions. In this current study, privacy was guaranteed by sending the instrument to respondents individually. However, there was no control over those respondents who might have shared information before completing the questionnaire.

There is confidence in using this inventory as its validity was confirmed and reliability established as demonstrated above. Factor analysis also confirmed its factor structure and suitability for use with this study.

Source of Pressure Measurement Scale

The scale was developed for this study to measure stressful aspects of caring commonly encountered while caring for dying patients. These aspects were viewed as sources of pressure (SOP), hence the name of the scale. The SOP scale (appendix 1) is made up of three factors, that is, clinical, workload and perceived control.

i. **Clinical**; to do with supporting patients and their relatives during the emotional times of the dying process;
ii. **Workload;** to do with increasing job demands but without enough resources to do the job;
iii. **Perceived Control**; to do with nurses perception of their ability to control patients' psychological and physical symptoms, and also feeling excluded from clinical decision making processes.

These three factors were confirmed through principal component factor analysis of all the 13 items. A detailed explanation of the process and extraction of the factors is given in chapter 7. The internal reliability was estimated at Cronbach's Alpha of .830, which according to Bryman (2008), and Pallant (2007) is an acceptable level.

This Sources of Pressure measurement scale has a total of 13 statements, based on a 6-point Likert scale ranging from 1 – very strongly agree to 6 – very strongly disagree. The scale has no neutral point. A neutral point was omitted deliberately in order to reduce the possibility of acquiescence by respondents (Bryman 2004)While omitting a neutral point in such a scale denies those respondents who truly neither agree nor disagree an option, it was however deemed favourable in order to minimise the acquiescence response set option.

The scale is self-administered and can be completed in 5 minutes (see appendix 1 questions 8 -20 in section A) .

Social Support Measurement Scale

For this study, the scale was adapted from Borrill et al's (1996) measurement scale, (Borrill, et al. 1996)to elicit the level of support managers offered to nurses. It comprises 5 items on a Likert scale format (appendix 1). Social support was treated as an interacting variable, which is capable of buffering against burnout. The scale was part of a number of scales used by Borrill and colleagues to ascertain the mental health of the workforce in the NHS Trusts, by determining levels of social support available from peers, managers and employers. The main focus of the scale was on level of managerial support employees received from line managers. Internal reliability was estimated at Cronbach's Alpha, = .94, which is deemed highly reliable (Bryman and Cramer 2001). This scale was deemed suitable for use with this study, as it elicited information on how nurses perceived level of support from managers as a possible mechanism for ameliorating high levels of death anxiety and burnout.

In this study managers were seen as crucial as they are part of the management structure that should provide social support to employees.

Managers were viewed as having direct contact with nurses and therefore would be able to understand nurses' needs and offer social support appropriately. Respondents were asked to select the most appropriate response for them. A copy of the scale is in (appendix 1, questions 21 to 25 in section A).

Differences in death anxiety and burnout among palliative care nurses

Further analysis was made to establish any significant differences in death anxiety and burnout mean scores among palliative care nurses working the three settings of hospice, hospital and community. The World Health Organisation (2002), NICE (2004) and DH (2008) show evidence to suggest that hospices provide high quality palliative care and also look after their staff better than in other settings. Although settings such as these care for dying patients, the culture and delivery of care is different. These differences were discussed in detail earlier in chapter 2.

Patterns of work and level of support for carers also differ, hence the interest to see if these differences are also reflected in the findings of this study. Therefore, any significant differences in mean scores on burnout and death anxiety among palliative care nurses working in hospices, hospitals and community was established using the Kruskal–Wallis test. Since the data were not normally distributed (see table 37), Kruskal-Wallis test was the most appropriate non-parametric test to use (Field 2005; Pallant 2007; Bryman 2008) to establish any significant differences among the three groups of nurses. Results from this test are presented in chapter 8.

Biographical data

Biographical questions to do with age, gender and ethnic orientation were asked at the beginning of Section A of the revised death anxiety scale. There were seven other biographical questions. For example, know how long nurses had been working continuously in palliative care with dying patients. It was also important to elicit how long ago each participant had last witnessed a death of a patient in their care. Witnessing a death might either increase or decrease feelings of death anxiety and therefore may influence response to the death anxiety questionnaire.

It can be argued that the impact of witnessing a death may depend on factors like, whether the death was perceived as dignified, pain free, unexpected, where it happened and surviving relatives' reaction and behaviour post death.

Ethics

Ethical approval for this study was sought through the Multi-Centre Research Ethics Committee (MREC) to enable data collection to be at numerous sites within the West Midlands region. The Ethics committee made a few suggestions which were incorporated into the study. For example, excluding the consent form as it would undermine anonymity of participants. Following approval by MREC (appendix 3), the study was also approved by all the Research and Development (R&D) departments within the NHS acute Trusts and Primary Care Trusts (PCT) hospitals and community. Further approval was gained from six hospices, which also used their own internal ethics committee to decide on what type of research is permissible on their staff. This was in addition to the approval obtained through MREC. Different trusts and hospices used varying procedures for ethical approval, and as a result some took longer, while others were fairly quick in arriving at a decision. This discrepancy meant delays in proceeding with the study, and therefore became a limitation.

Finally, special consideration was given to the emotiveness of the topic of death anxiety being studied. At the bottom of the revised death anxiety scale, contact telephone numbers of credible national counselling services were provided (see end of appendix 1). This information was for respondents to access if they felt the need after completing the questionnaires. It must be emphasised here that although the services are national they offer support to individuals at regional level too through their satellite offices.

Ethical procedures

Following ethical approval from the MREC in the West Midlands, all Research and & Development departments and hospices in the area were contacted for permission to access their palliative care staff. A contact person was identified in each setting and close working links were quickly established with them. The contact person provided information about total numbers of palliative care nurses working in their organisation. A series of meetings was arranged with all contact persons, the aims of which were to explain the purpose of the study, and the role of the contact person.
Issues of confidentiality and anonymity of respondents were discussed. The distribution of research packs was also discussed and clarified including reminders.

At the end of each meeting the number of questionnaires to be distributed to each contact person was ascertained. Each research pack included a covering letter (appendix 4), participant information sheet (appendix 5), four measurement scales (appendix 1) and a self-addressed stamped envelope to return completed questionnaires direct to the researcher. This was welcomed by the contact people as they did not have to collect the questionnaires afterwards.

Process for Piloting of measurement scales

There were three pilots undertaken with three different groups, that is, university lecturers, lecturer practitioners and nurses working in three palliative care settings of hospital, hospice and community. For pilots one and two, lecturers were asked to feedback on theoretical issues and construction of questionnaire items. The third pilot used a relatively large number as it took into account the proportions of nurses found in the three settings. More detail is provided below under appropriate headings.

The overall aim of piloting is to improve the content validity of the measurement scales (Oppenhiem 1992; Gillham 2000; Bryman 2008), and also the clarity of questions and format. It also tests the whole approach to administration of all questionnaires to be used. Piloting helped to test the whole process of mailing out the measurement scales with a view to standardising the process for the main study. It also helped to gauge how long it would take respondents to complete the questionnaires.

1st Pilot

The first pilot was conducted with 15 lecturers, working in similar roles as myself, in a University setting, teaching mainly on cancer and palliative care courses. Lecturers were asked, in addition to completing the scales, to comment on question construction, use of words (terminology) and clarity of statements. Their suggestions were acted upon and amendments made before sending the scales out on the 2nd pilot

2nd Pilot

The second pilot was conducted with 10 lecturer practitioners, who by the nature of their roles, worked in both clinical and university settings. In addition to timing how long it took to complete the scales, they were asked to list aspects of caring for dying patients they encountered most while in clinical practice. The most occurring aspects were used to formulate additional items to the Sources of Pressure Scale. For example, communicating with other health care professionals, and doing your job without administrative support were additions. All changes were made before the 3rd pilot

3rd Pilot

The third and final pilot was conducted with a total of 50 nurses from the three palliative care settings listed below. These nurses were similar in most respects to the respondents in the main study but they were working in a different region of the country. Focussing on these nurses was important as it offered a simulation "mock-up" exercise for the actual study.

The number of nurses in this pilot was proportional to the total numbers found in the three different settings. These were broken down as follows:

Hospice based nurses = 25
Hospital based nurses = 15
Community based nurses = 10

In addition to completing the scales, respondents were asked, as in the 2nd pilot, to list what they found most stressful while caring for dying patients. They were also asked to list what support structures (eg staff meetings, managerial support, mentorship or clinical supervision) they had at work and who was providing and financing it. The frequency and length of support was also elicited, which suggested there was not a uniform support structure even in the same region.

A few additional comments were written by squeezing them at the bottom of the questionnaire. This prompted the addition of a box for “any other comments” at the bottom of the final version of the questionnaire.

Data collection

Each participant received a research pack from the contact person within their organisation to complete the self rate questionnaires anonymously and return them direct to the researcher. This procedure was felt to maximise participant anonymity and therefore increase response rate.

The whole population of 350 palliative care nurses were targeted for this study.
A total of 350 packs were sent out and 213 were returned. This provided a 60.86% response rate, which is deemed acceptable for this study (Bryman 2004; Parahoo, 2006; Creswell 2010).

Data gathered for questions 1, 3, 4, 5 and 6 in section A were regarded and treated as nominal level. Data from questions 2, 6 and 7 were regarded as interval level, and data from the Likert scales from both sections A and B, were treated as ordinal level (Bryman and Cramer 2001). Bryman (2004) has highlighted that although strictly speaking multiple scales like the Likert produce ordinal data, many social researchers argue that they can also be treated as if they produce interval variables. In this study all data from the Likert scales was treated as ordinal level in accordance with the strict conventional and conservative school of thought as originally espoused by Stevens 1946 and supported by Oppenhiem (1992), and Jaimeson (2004). Arguments by Stevens (1946); Knapp (1990); Bryman (2008) favour the use of Spearman rho (p) when analysing data which is ordinal level and not normally distributed, both of which are found in this study.

Data collected on the MBI-HSS were treated as ordinal data and therefore as discussed above, subjected to Spearman rho (p) test.

Biographical data provided a mixture of categorical and continuous data.

Exploratory Factor Analysis

This technique was confirmed by Gorsuch (1983) and later supported by Field (2005), Pallant (2007) and Tabachnick and Fidell (2007) to reduce a larger set of variables to a couple or so of central factors which underlay a set of items. Ideally, exploratory factor analysis (EFA) is used where new scales are being developed in order to eliminate items that do not 'factor' in the same direction as those of interest (Field 2005), and Bowling (2009). However, in this case it was carried out to access suitability of such older scales for current use, in view of the time lapse since their development in the 80s and also changing social and care contexts.

In assessing suitability, the point was to see, as expected by Gorsuch (1983), Field (2005 and Pallant (2007), whether EFA achieves similar underlying dimensions (structures) of a large set of variables as those uncovered when the scale was first developed. (Darlington, Weinberg et al. 1973; Gorsuch 1983).

Exploratory factor analysis is important to perform where there are a lot of variables, but certain conditions should be met, that is, sample size, level of data and strength of the correlation relationship among the variables or items (Pallant 2007; Tabachnick and Fidell 2007).

A detailed discussion on how factor analysis was carried out for all the measurement scales used to collect data in this study is given in chapter 7.

Statistical data analysis

Data were analysed using the Statistical Package for Social Scientists (SPSS) version 15, to understand relationships between variables of interest. Data collected revealed that there were predominantly white female respondents, and therefore it was deemed statistically irrelevant to perform tests to determine significant differences between groups.

The scores for death anxiety, burnout and, and each of the three components of burnout (i.e. EE, DP, & PA) were totalled. Preliminary analyses were performed to ensure no violation of the assumptions of normality of variables. Therefore the Kolmogorov-Smirnorv test of normality (Bryman and Cramer 2001; Field 2005) was conducted. All the variables tested that is; (age = .004, time working in same post = .000, time since witnessing a death = <.000, death anxiety = <.001, burnout (total score) = <.000, EE = <.003, DP = <.000, PA =.003), Caring = < .000) revealed that they were not normally distributed (Bryman and Cramer 2001; Pallant 2007). Full details are presented in table 13 below. Testing for normality helps to determine the appropriate statistical test to use for analysis, and in this case use of non-parametric tests as opposed to parametric tests were more appropriate, since the variables were not normally distributed (Bryman 2004; Polit and Beck 2008).

In order to determine the association between age (which was treated as continuous/interval data) and death anxiety (treated as ordinal data), Spearman's rho test was used. To determine the association between age and burnout, age and each of the three components of burnout, Spearman's rho was also used.

Finally, Spearman's rho was used to determine the relationship between death anxiety and burnout, death anxiety and each of the three components of burnout, that is; emotional exhaustion, depersonalisation and lack of personal accomplishment.

In order to allow for multiple testing with three or more groups, it is normally advisable to use the Bonferoni correction technique (Bryman and Cramer 2001). However, Bonferoni was in this case too conservative for the volume of tests, therefore the significance level was set at 1% (p=0.01) rather than the traditional 5% (p=0.05).

Table 13: Kolmogorov-Sminorv Tests of Normality of variables

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
gender	.538	207	.000	.271	207	.000
age	.078	205	.004	.990	205	.155
time in post in years	.094	207	.000	.955	207	.000
time since witnessing in weeks	.330	204	.000	.484	204	.000
total_DA_Score	.088	205	.001	.969	205	.000
TotalEE	.080	207	.003	.983	207	.012
TotalDP	.204	206	.000	.598	206	.000
TotalPA	.079	205	.003	.975	205	.001
TotalBO	.106	204	.000	.945	204	.000
Caring	.124	207	.000	.888	207	.000

a. Lilliefors Significance Correction

Organisation of data

Before analysis all data were given a value label and coded. It was important to allocate a figure for missing values, and in some questions 9 was used, whereas in others 99 or 999 was used. For example, question 1 in section A, (see appendix 1) had a missing value as 9, since the coding was 1 for male and 2 for female. For question 2, it was safe to use 999, as it was very unlikely that anyone would be as old as 999 years. For section B, the missing value used for all questions was 9, since the highest coding value was 5.

There is considerable evidence from other fields of study (Benner, 1984; Woolery 1990, Hampton 1994; Benner et al 1996), that a minimum of ten years' experience equates to mastery phase in most activities to do with knowledge and skills acquisition. The complex nature of palliative care means that most nurses would have encountered a range of deaths and dying episodes in the first 10 years but not expected to have developed intuitive abilities in caring or assume mastery of their roles. This assertion is also in line with Benner et al's (1996) idea of a minimum of 10 years before practitioners can function as an expert nurse.

In order to distinguish the level of experience, the sample was split into two groups to determine, one with less than 10 years experience of working in palliative care and the other with over 10 years.

One of the objectives of this study was to determine any predictor variables of burnout. It was therefore appropriate to perform multiple regression analysis, and the following section gives a detailed account of the procedures undertaken for testing assumptions for multiple regression and outcomes.

Multiple Regression analysis to determine predictor variables

Multiple regression has a variety of purposes that can help answer research questions and or as is the intention of this study, to show relationships among variables. By showing relationships among variables, multiple regression does not imply that the relationships are causal (Tabachnick and Fidell (2007). In this study, multiple regression was used to identify predictors of emotional exhaustion (EE) as the criterion variable among palliative care nurses. Throughout most of the literature (Field 2005; Munroe 2005; 2009; Tabachnick and Fidell 2007; Field 2009) the terms predictor and independent variable tend to be used interchangeably. Similarly, the terms criterion and dependent are also used interchangeably. For purposes of this study, predictor and dependent variables will be used. As already discussed in chapter 3, emotional exhaustion is the first phase in the development of burnout, therefore it was important to treat it as the dependent variable and determine its predictor variables. Establishing predictor variables of emotional exhaustion enables early intervention to prevent it developing into the burnout syndrome.

Multiple regression was therefore used to show how much of the variance in the dependent variable, Emotional Exhaustion (EE), could be explained by the predictor variables, that is, Death anxiety, Age, Time in post and Caring (Pallant 2007; Tabachnick and Fidell, 2007). It was important to include caring as an independent variable, because one of the objectives of this study was to determine whether caring itself is a significant predictor of burnout.

The standard regression analysis method was used for this study. This method is commonly preferred in social sciences research (Tabachnick and Fidell 2007) and all predictor variables are entered into the equation simultaneously. Through this regression analysis, it would be possible to show how much variance in emotional exhaustion, the predictor variables were able to explain as a group and also as separate individual predictors. But, first it was important to examine whether some assumptions for performing multiple regression were violated or not, and the next section reports on these tests.

Testing assumptions for multiple regression

Multiple regression makes a number of assumptions about the data set but is sensitive if these assumptions are violated (Tabachnick and Fidell 2007; Pallant 2007). It was therefore important to analyse the data, checking all the assumptions before multiple regression could be performed. It was equally important to run an initial regression test before checking the assumptions, so that this could be used as a baseline for future comparisons in case transformed variables are used or outliers were removed. Below, is a detailed discussion summarising these assumptions, and a decision trail to justify some of the choices made in multiple regression analysing for this current study.

Assumptions on sample size

Although there is no consensus on the actual sample size to be used for multiple regression (Pallant 2007), and research on this is ongoing, however, Stevens (1996) originally recommended that "15 subjects per predictor variable be used" p72. However, Tabachnick and Fidell (2007) give a formula for calculating sample sizes required for multiple regression testing. They suggest "$N > 50 + 8m$, (where m is the number of independent variables), when using the model as a whole" p123. Using this formula with the four predictor variables for this study, the sample size should be 82 cases. For testing individual predictors independently, they suggest using $N \geq 104 + m$ (where m is the number of predictors). Using this formula, with four predictors, the sample size should be 108. This current study has a total of 213 cases and therefore exceeds the minimum sample size requirement to perform multiple regression.

Tabachnick and Fidell (2007) recommend using the largest size to ensure the regression is powerful enough to detect a medium sized relationship (with an alpha level of 0.5 (p.123) between the independent and dependent variables. However, it is recognised that in later analyses, this number will drop due to missing data, but remains well above the minimum number of cases needed.

Assumptions of no multicollinearity between predictors

Predictor variables showed correlation coefficient of below r=.9 (Pallant 2007, p149). None of the predictors variables correlated above r=.410 (age and time in post). The Tolerance values for each variable exceeded .10 and the variance inflation factor (VIF) value (which is the inverse of the tolerance value) were all below 10 (Pallant, 2007, p.156. Therefore, it is safe to assume that multicollinearity is not present in either model (Tabachnick and Fidell 2007), and therefore not violated for purposes of performing multiple regression analysis.

To explore whether the relationship between age and EE was confounded by time in post a partial correlation was conducted (between age and EE whilst controlling for Time in Post). This partial correlation did not reveal a significant relationship (r=.023, p=n.s). A re-run of the test with outliers removed did not reveal a significant relationship either (r =.013, p=n.s).

Assumption for normal distribution of variables

In order to determine normality of distribution of variables, the Shapiro-Wilk test was preferred because it is more conservative (although slightly) than the Kolmogorov Sminorv test (Field 2005 p527). Table 14 below shows the Shapiro-Wilk tests of normality statistic values for all the variables. .

Table 14: Test of Normality using Shapiro-Wilk test

Prior to transformations

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
time in post in years	.087	201	.001	.957	201	.000
age	.080	201	.003	.989	201	.140
total_DA_Score	.088	201	.001	.968	201	.000
Total EE	.086	201	.001	.979	201	.004
Caring	.111	201	.000	.906	201	.000

a Lilliefors Significance Correction

All of the variables chosen for the regression have significant results for the Shapiro-Wilk test, except for age. This suggests that all of the variables' distributions significantly deviate from normality, except age. This required further analysis.
Field (2009), suggests that these tests of normality should only be used as a guide, as obtaining significant results with these tests are common when dealing with large samples (Field 2009, p.144). As such, these tests can tell us if our distribution deviates from normality, but not whether they will bias our statistical analysis. Field therefore recommends interpreting visual plots and making an "informed decision" (Field 2009 p.144)

In addition to the above tests, and before examining the plots, it is important to also determine the level of skewness and kurtosis in the variables (Field 2009).

If these values fall between ± 1 then there is no severe deviation from normality. If however, values exceed ± 1 then there is a potential problem with the distribution. In this analysis, Time in post, emotional exhaustion (EE) and Total DA score appear to have slight positive skew (values less than +1, but greater than 0). Caring appears to have greater positive skew (value greater than +1). There is also evidence that Caring and Death Anxiety are Leptokurtic (values greater than +1). Leptokurtic suggests the distribution of values are relatively thin and therefore look quite pointed and high (Field 2005).

Looking at the histograms, boxplots and Normal Q-Q Plots for each variable, some conclusions could be drawn. Investigation of plots suggests that:

a. Total DA Score –there is slight deviation from normality and potential outliers (cases 92 and 139). Normal Q-Q plot reveals slight deviation from normality – mainly owing to the two extreme scores.
b. Caring – there is deviation from normality greater than that of Total DA Score – with outliers (2 cases in particular: 144 and 91). Normal Q-Q plot reveals slight deviation from normality, again mainly owing to the two extreme values.
c. Time In Post – there is slight deviation from normality. Inspection of Normal Q-Q plot reveals only slight deviation from normality.

The fact that there were slight deviations from normality, Field (2009) suggests that further analysis is required. It was therefore considered important to run square root and logarithm transformations on the non-normally distributed variables (Tabachnick and Fidell 2007). The idea was to check what impact the transformations would have on their distribution with the dependent variable. Table 15 below shows the tests of normality after Square root transformation.

Table 15: Tests of normality after Square Root transformation:

Tests of Normality

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
SqrtTotalEE	.065	201	.040	.989	201	.117
SqrtCaring	.087	201	.001	.955	201	.000
sqrtDAScore	.082	201	.002	.985	201	.028
SqrtAge	.075	201	.008	.987	201	.070
SqrtTimeInPost	.070	201	.018	.979	201	.004

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Table 16 shows the results of the tests of normality after Logarithm transformations. The histogram in figure 5 shows that square root transformation corrects the distribution of emotional exhaustion (EE) variable (see figure 5 part B after square root transformation).

Table 16: Tests of normality after Log Transformation

Tests of Normality

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
LogTotalEE	.116	201	.000	.927	201	.000
LogCaring	.099	201	.000	.968	201	.000
LogDAScore	.073	201	.011	.991	201	.262
LogAge	.078	201	.004	.979	201	.004
logTimeInPost	.114	201	.000	.935	201	.000

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Figure 5: Histogram and Normal QQ Plots before and after transformation

Square root transformation corrects the distribution of EE:

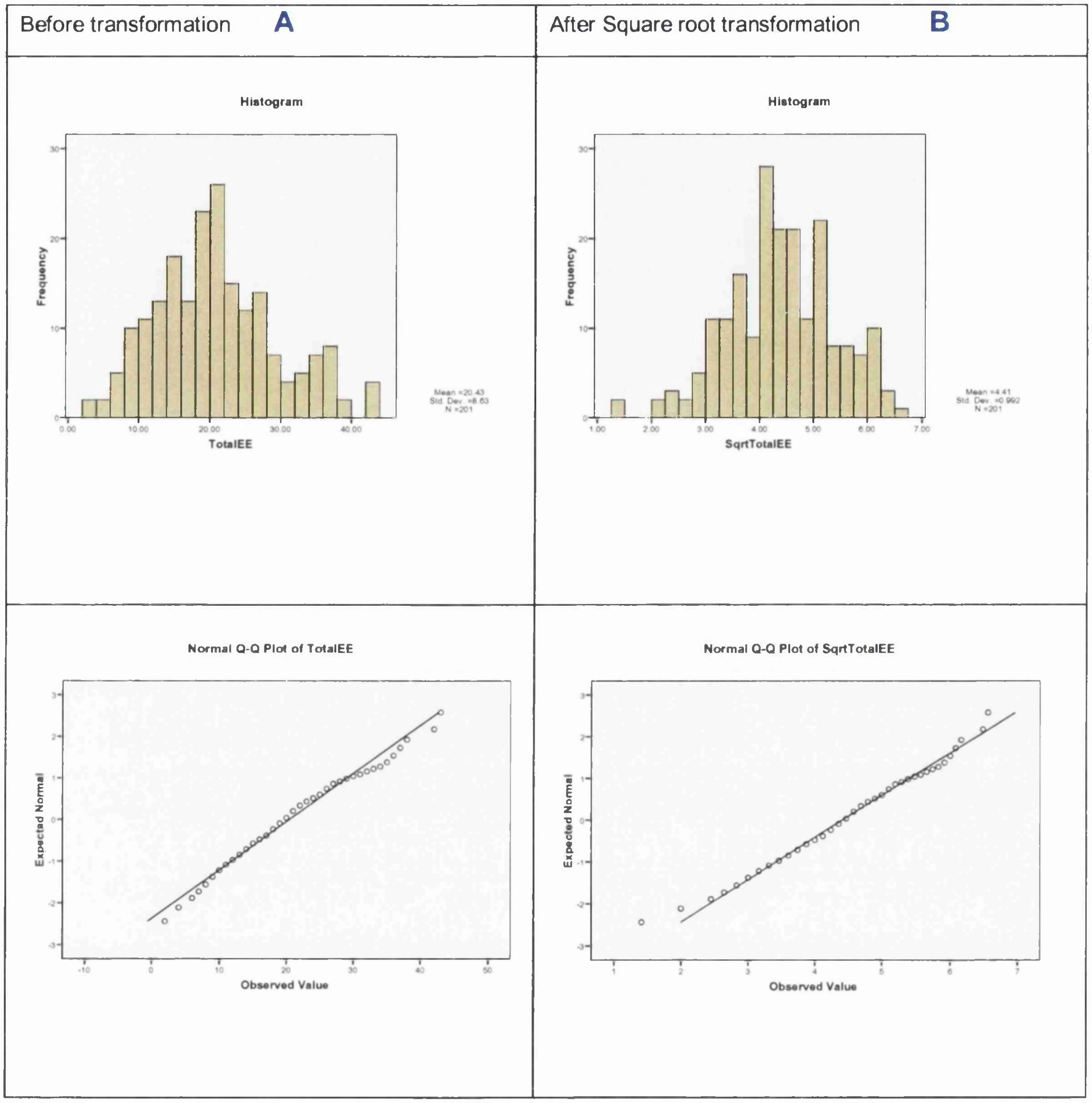
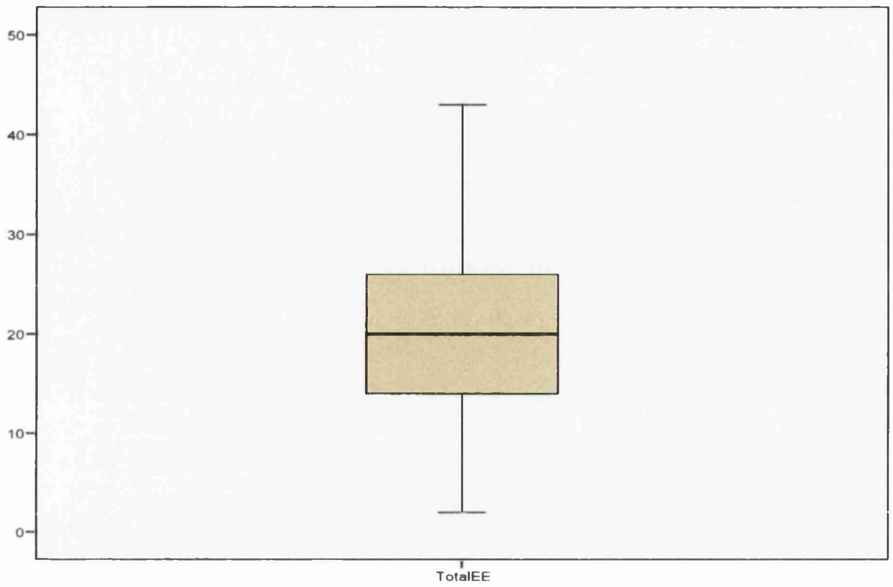
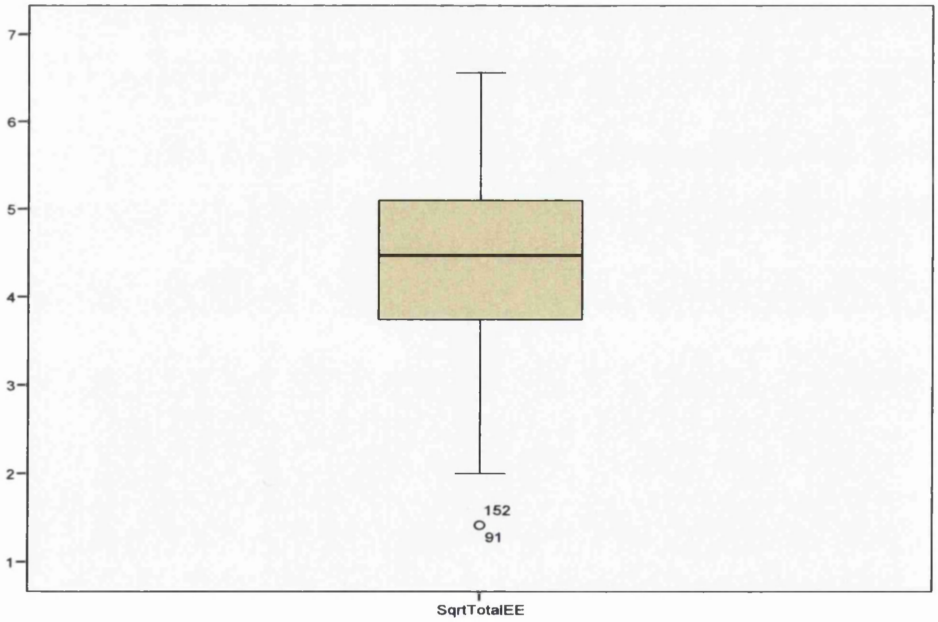


Figure 6: Box plots with outliers present and removed

Outliers removed



Outliers present



Using results from the tests of normality after transformation of variables, the following conclusions could be made:

1. Log transformation appears to make the deviation from normality worse for the Emotional Exhaustion (EE) variable – as the deviation from normality for this variable was small to begin-with (W=.979, df=201, p<.005). Both skew and kurtosis values were within +1 and -1 range
2. According to Field (2009); Tabachnick and Fidell (2007) this result suggests that a transformation may not be necessary. Field (2009) recommends that for samples of 200 or more which this current study has, it is more important to look at the shape of the distribution and the values of skew and kurtosis, rather than calculate their significance (p. 139). This is because with larger samples, there is a tendency for significant values to arise from even small deviations from normality.

3. For the Caring variable, Square root transformation does not make the distribution normal and does not eliminate the problem of outliers (W=.945, df=204, p<.001). Following the log transformation the Shapiro-Wilk statistics (W=.965, df=204, p<.001) still suggests the distribution of this variable is not normal. The log transformation reduces both skew and kurtosis more than the square root transformation. However, the problem of outliers is not eliminated.
4. For the Time in Post variable, both the square root and the log transformations still resulted in significant results for the Shapiro-Wilk test (sqrt: W=.978, df=204, p<.005 and log: W=.936, df=204, p<.001). Again – the deviation from normality was only small to begin-with – suggesting that the impact of this deviation from normality may not have a strong impact on future analyses (Tabachnick and Fidell 2007; Field 2009).
5. For the Death Anxiety variable, the square root transformation improved the distribution but was still not normally distributed (*W*=.985, df=204, p<.05. The log transformation resulted in the Shapiro-Wilk test returning a non-significant result (*W*=.991, df=204, p=n.s).

Decision on future analysis

Considering the impact of the transformations on the variables, a decision had to be made on whether to use transformed or untransformed variables for future analyses.

For most of the variables the gains from the transformations as already discussed above, are small and outliers are not completely eliminated. Also, the deviations from normality appeared to be small in the first place. Therefore, it was decided to use untransformed data for multiple regression for this study, but Pallant (2007) advises to then look for extreme outliers and remove them, because multiple regression can be very sensitive to outliers (p149).

Removing outliers has its own potential checks needed including any impact they could have on the model. For example, removing outliers may mean that the model will be good at predicting moderate scores but not extreme ones. For this study, outliers, although extreme, may be beneficial in highlighting characteristics of emotional exhaustion that would otherwise not be known in the normal course of the analysis. On the other hand, they (outliers) can be problematic if they are not representative of the population and therefore distort statistical tests (Munroe 2005). Below I offer an argument for removing univariate outliers in this study.

According to Tabachnick & Fidell (2007), univariate outliers are usually those cases with standardised residuals greater than ±3.29. However, in large samples it is expected that there will be a few values greater than this. One other point to consider is put forward by Munroe (2005) who exposes the problem that outliers have a tendency to inflate the deviations found in the standardised residuals. However, since Tabachnick and Fidell's approach offers an objective method of identifying outliers, it was preferred for this analysis. The standardised residuals were inspected for any univariate outliers with values exceeding ±3.29.

Cases with standardised residuals greater than ±3.29 were identified in the following variables: Total DA score (case 92) and Caring (cases 144, 176 and 91). It was therefore decided, as Munroe (2005) and Field (2005) recommend, to run two analyses, one with outliers in and the other with outliers removed and compare normality of scores. Below are tables 17 and 18 showing normality tests, one with outliers and the other with outliers removed respectively.

Table 17: Tests of normality with outliers

Tests of Normality

All cases:

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	Df	Sig.	Statistic	df	Sig.
Age	.080	201	.003	.989	201	.140
TotalEE	.086	201	.001	.979	201	.004
total_DA_Score	.088	201	.001	.968	201	.000
Caring	.111	201	.000	.906	201	.000

Removing the outliers results in the Shapiro-Wilk test returning a non-significant result for the variable "DA Score" (W=.987, df=198, p=<n.s). The test was still significant for the "Caring" variable, W=.981,df=198, p<.001 and "Total EE" variable, W=.978,df=198, p<.005, but the distribution had been improved a little.

Table 18: Test of normality with outliers removed:

Tests of Normality

All Cases

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	Df	Sig.	Statistic	df	Sig.
age	.081	198	.003	.989	198	.133
TotalEE	.085	198	.001	.978	198	.003
total_DA_Score	.089	198	.001	.987	198	.061
Caring	.088	198	.001	.981	198	.009

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Skewness and Kurtosis tests

A similar comparison was made with skewness and kurtosis, one with outliers (see Table 19) and the other with outliers removed (Table 20). As already reiterated above, if these values fall between ± 1, then there is no severe deviation from normality.

Values that exceed ± 1 are found in Table 19, which suggests a potential problem with the distribution. However, in Table 20, the same values are now below ± 1, which suggests that with outliers removed there is no potential problem with the distribution (Field 2005), and therefore no severe deviation from normality.

Table 19: Skewness and Kurtosis tests with outliers

Descriptives

		Statistic	Std. Error
age	Mean	44.54	.534
	5% Trimmed Mean	44.53	
	Skewness	.013	.172
	Kurtosis	-.458	.341
total_DA_Score	Mean	64.9104	.81641
	5% Trimmed Mean	64.4961	
	Skewness	.715	.172
	Kurtosis	1.598	.341
TotalEE	Mean	20.4279	.60871
	5% Trimmed Mean	20.2255	
	Skewness	**.414**	.172
	Kurtosis	**-.166**	.341
Caring	Mean	34.7114	.59853
	5% Trimmed Mean	34.2700	
	Skewness	1.552	.172
	Kurtosis	7.562	.341

Table 20: Skewness and Kurtosis tests with outliers removed

Descriptives

		Statistic	Std. Error
age	Mean	44.49	.540
	5% Trimmed Mean	44.47	
	Skewness	.026	.173
	Kurtosis	-.454	.344
time in post in years	Mean	10.13	.428
	5% Trimmed Mean	9.88	
	Skewness	**.511**	.173
	Kurtosis	**-.530**	.344
TotalEE	Mean	20.5505	.61019
	5% Trimmed Mean	20.3283	
	Skewness	.436	.173
	Kurtosis	-.200	.344
total_DA_Score	Mean	64.7525	.77990
	5% Trimmed Mean	64.5079	
	Skewness	.325	.173
	Kurtosis	-.071	.344
Caring	Mean	34.2677	.52068
	5% Trimmed Mean	34.0859	
	Skewness	.328	.173
	Kurtosis	.849	.344

Continuing with potential univariate outliers removed from dataset

As discussed above, the assumption of univariate normality was violated when tested with outliers included. However, although the degree of deviation from normality is small, the fact that skewness and leptokurtic values were found when testing with outliers, suggests that there is likely to be significant bias introduced into the analysis (Field 2005; p 162-3) as they affect the value of the regression coefficient. For this reason, it was decided to remove univariate outliers for multiple regression analysis for this study.

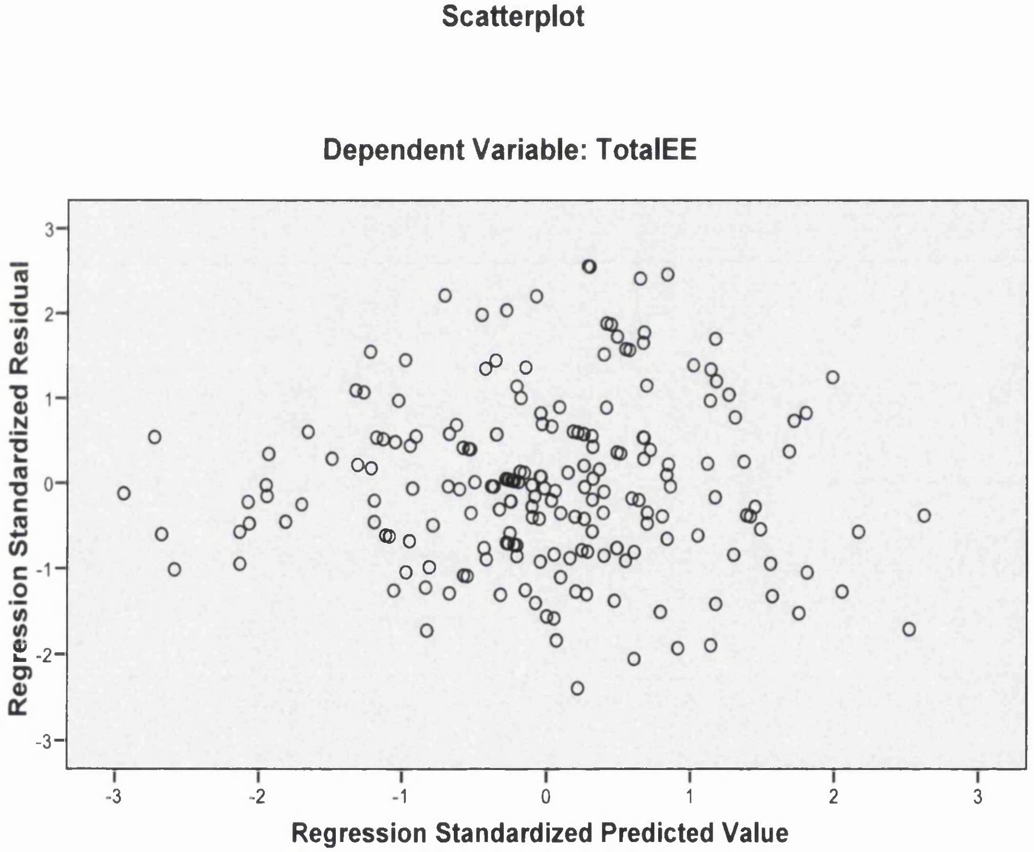
Multivariate outliers

For multivariate outliers, the Mahalanobis Distance and Cook's Distance values were inspected and compared with critical values appropriate for the number of predictor variables to be tested (Barnett and Lewis, 1978; Pallant 2007). Using four predictors that were entered into the model (Age, Time in Post, Total DA Score and Caring score), the critical value would be 18.47 (with an alpha level of .001) (Pallant 2007). From the work of Barnett and Lewis (1978) it is clear that in large datasets some outliers are expected. For instance, they give an example where in a sample n= 500 using 5 predictors, values of 25 would be a cause of concern. The point to make is that in this study, using a large sample size of 207, outliers are expected, but what is more important is to establish the degree of their influence on the model.

Inspecting the results of this model revealed no cases with values greater than this (the largest Mahal. Distance value was 14.57 (case 139). Also, examining Cook's Distance values revealed no indications that any one case was exerting undue influence on the model. According to Pallant (2007); Field (2009) if a Cook's Distance value is greater than 1 then the case could be exerting influence on the model and its removal should be seriously considered. If the Cook' Distance value is less than 1, then the case need not be deleted (Field, 2009, p.217). The largest Cook's distance value was 0.03, indicating that no cases need to be removed from the dataset.

Therefore, there do not appear to be any multivariate outliers in this dataset.
Tabachnick and Fidell (2007) recommend that, the residuals created by the model must be checked for evidence of normality, linearity, homoscedasticity and independence. Checks for these were carried out using the standardised residual scatterplot (Figure 7), normal probability P-Plot (Figure 8) and histogram of standardised residuals (Figure 9).

Figure 7: Scatterplot of Standardised Residuals



Tabachnick and Fidell (2007) suggest that scatterplots should be inspected for evidence of pattern formation (i.e. curves and funnelling), which could suggest a violation of the linearity and homoscedasticity assumptions.

Figure 8: Normal Probability P-Plot of Regression Standardised Residuals

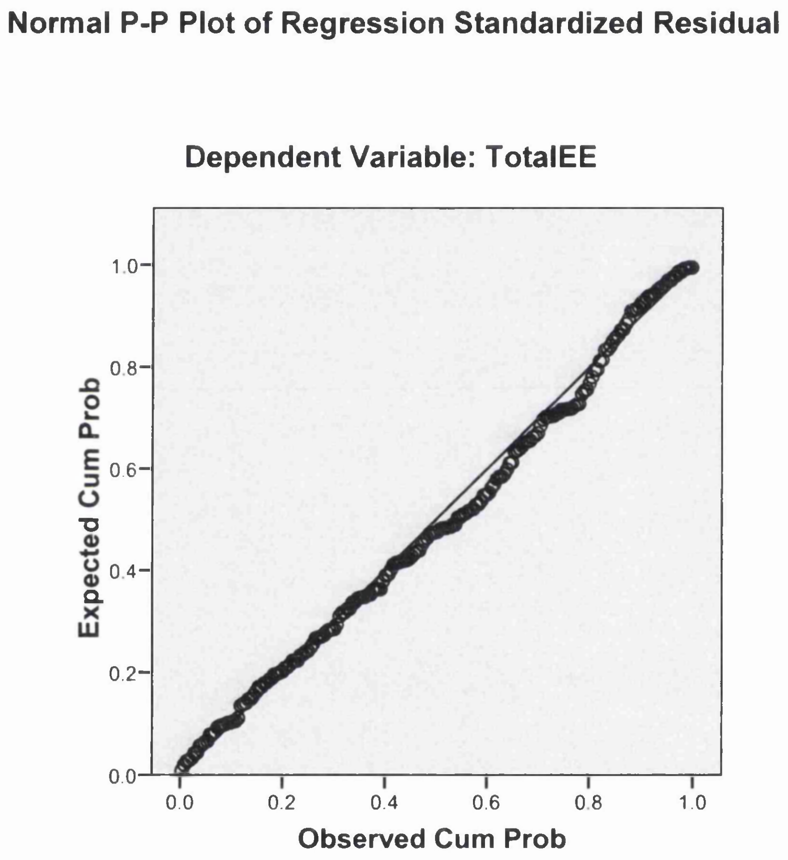
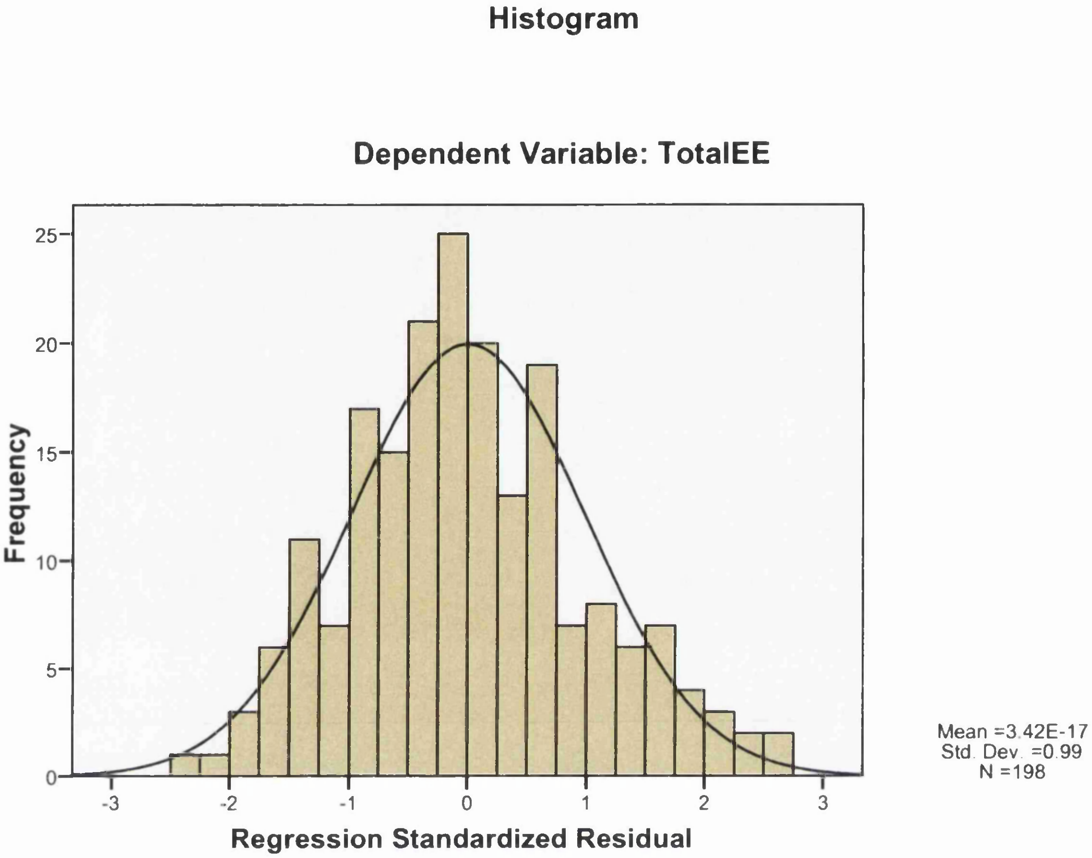


Figure 9: Histogram of standardised residuals.



To check these assumptions an examination of the histogram and P-plot was necessary, and the following conclusions were made.

- When looking at the scatter plot of the standardized residuals of the 4 predictor model there is possibly evidence of slight funnelling, although there does not appear to be a violation of the linearity assumption.

- When looking at the histogram of the standardized residuals there appears to be a normal distribution and the Shapiro-Wilk test returned a non-significant result (*W*=.987, df=198, p=n.s) (Table 21) – suggesting that there are no serious violations of the assumptions.

Table 21: Tests of Normality – Shapiro-Wilk

Tests of Normality

	Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Statistic	Df	Sig.	Statistic	df	Sig.
Standardized Residual	.056	198	.200(*)	.987	198	.066

* This is a lower bound of the true significance.
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Therefore, the assumption of linearity appears to have been met. The above findings suggest that there is a violation of the assumption of homoscedasticity, resulting in a non-normal distribution of error in the model. Although this deviation appears to be small, the model may be weakened and may not fully capture the relationship between the variables.

The Assumption of homogeneity of variance

As there were no dichotomous variables included in the regression, this assumption does not need to be checked (Pallant 2007; Field 2009), therefore the Levene's test of homogeneity was not performed. However, although gender was a possible dichotomous variable to test, this was resisted, for reasons already alluded to in the methods chapter, because the number of males in the sample was very small, therefore not seen as meaningful, therefore, not relevant.

Independence of errors

Independence of errors checks that the errors of prediction are independent of one another (Field 2009). The Durbin-Watson statistic, as recommended by Tabachnick and Fidell (2007); Field (2009) was testable by looking at the residual analysis. Tabachnick and Fidell (2007) suggest that values below 1 or above 3 are a cause for concern. For the assumption to have been met, the value should be as close to 2 as possible.

For the 4 predictor model the Durbin-Watson statistic was 1.873 and the conclusion from this test suggests that the assumption of the Independence of errors has been met, that is, they are uncorrelated.

Conclusion on assumption checking

Although regression analysis assumes that predictors are measured without error, Tabachnick and Fidell (2007) warn that this assumption may be impossible to achieve in social and behavioural sciences research. Therefore, the best advice they give is to choose the most reliable predictors possible. It became important to exclude variables that were non-significantly correlated with emotional exhaustion (EE). Using the 4 predictor model, the analysis confirmed that caring is a highly significant predictor of emotional exhaustion. These results are explained in more detail in chapter 8, under Table 32. However, what could not be established is which aspect of the three variables of caring was the highest and statistically significant predictor of emotional exhaustion.

Neither square root nor log transformations significantly improved the distribution of the variables. This suggests that it would be inappropriate to run parametric tests on the data (Bryman 2004; Field 2005). For this reason it was decided that non-parametric correlations would be conducted between the three components of Caring (i.e. Clinical, Workload, and Perceived Control) and Emotional Exhaustion. Table 22 below shows the results of the Spearman's rho correlations between emotional exhaustion and the caring variables mentioned here.

Table 22: Correlations between Emotional Exhaustion and the Caring variables

Correlations

			Caring Clinical Total	Workload Total	Perceived Control Total	Total EE
Spearman's rho	Caring Clinical Total	Correlation Coefficient	1.000	.394(**)	.366(**)	.227(**)
		Sig. (2-tailed)	.	.000	.000	.001
		N	209	209	209	203
	Workload Total	Correlation Coefficient	.394(**)	1.000	.399(**)	.368(**)
		Sig. (2-tailed)	.000	.	.000	.000
		N	209	209	209	203
	Perceived Control Total	Correlation Coefficient	.366(**)	.399(**)	1.000	.291(**)
		Sig. (2-tailed)	.000	.000	.	.000
		N	209	209	209	203
		Sig. (2-tailed)	.024	.042	.010	.000
		N	202	202	202	202

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Therefore looking at the Spearman's rho correlation results, the following conclusions are drawn:

Emotional exhaustion (EE)

- Shows a positive and moderate relationship with clinical aspects of caring (r = .227)
- Shows a positive and moderate relationship with workload (r = .368)

- Shows a positive and moderate relationship with perceived control among palliative care nurses (r = .291). All values were significant at 0.01 level.

However, caution must be exercised when reading the results from small size data having now separated caring into its three variables, as Field 2005; Pallant 2007, argue, using small size data might distort the actual results.

Finally, after preparing the data for multiple regression, four independent variables (age, time in post, death anxiety and caring) were entered into the regression equation to determine which one of them predicts most the variance in the dependent variable emotional exhaustion.

Table 23: Multiple regression for predictor variables of emotional exhaustion

Model Summary(b)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.378(a)	.143	.125	8.02981	1.873

a Predictors: (Constant), Caring, age, total_DA_Score, time in post in years
b Dependent Variable: TotalEE

Using the 4 predictor model, multiple regression analysis confirmed that caring is a highly significant predictor of emotional exhaustion. These results are shown and explained in more detail in chapter 8 - The Results chapter .

The multiple regression model, including the age, time in post, total death anxiety score and caring as predictors, and emotional exhaustion score as outcome variable, resulted in an R^2 value of .143, suggesting the model explains 14.3% of the variance in Emotional Exhaustion scores. This model is highly significant (F(4, 193)=8.060, p<.001), warranting examination of the contribution of the individual predictors. However, according to Tabachnick and Fidell (2007) when there is a small sample in the study, using the R square value may provide an over estimation of the true values, therefore Tabachnick and Fidell (2007) recommend using the Adjusted R Square value.

In which case, although this current study's sample size is not considered small, it was thought prudent to be cautious and use the Adjusted R Square scores. Therefore, using the same four predictor model and emotional exhaustion as the dependent variable, the Adjusted R Square value is more conservative at .125, suggesting the model explains 12.5% of the variance in emotional exhaustion scores.

Examining the individual predictors in the model reveals that Age (β=.005, $t_{(193)}$=.062, p=.951), time in post (β=.067, $t_{(193)}$=.908, p=.365), and total death anxiety score (β=.066, $t_{(193)}$=.925, p=.356) were not significant predictors of emotional exhaustion. However, the Caring variable was identified as a significant predictor of emotional exhaustion (β=.354, $t_{(193)}$=4.896, p<.001).

Examining the part correlations (semi-partial correlations) explains these findings further, as Field (2005) suggests that these values represent the amount of unique variance in the outcome variable explained by each predictor, after controlling for the effect of all other predictors on the outcome variable (p.194) (See table 24 below). These values can then be squared and multiplied by a hundred, to obtain the percentage of unique variance the predictor explains of the outcome variable.

Table 24: Part (semi-partial correlations) for each of the predictor variables in the regression model.

Variable	Part correlation	Squared part correlation	Percentage of uniquely explained variance
Age	.004	0.000016	0.002
Time in post	.061	0.003721	0.37
Total Death Anxiety score	.062	0.003844	0.38
Caring	.326	0.106276	10.63

Thus, Age is found to explain only 0.002% of the variance in emotional exhaustion, time in post only 0.37% and total death anxiety score only 0.38%., whereas the Caring uniquely explains 10.63% of the variance in emotional exhaustion.

DeLimitations

All research studies have delimitations, and this one is no exception.

- Data for the study were obtained only through self-report and on one point in time.
- Being part of doctoral qualification, the study was conducted within a prescribed time frame and with a specific focus
- The study only accessed nurses in practice and did not therefore contact those who were already off sick through burnout. This is an area for further research
- The sample was predominantly white female nurses therefore it was not possible to determine any differences between ethnic groups and gender. However, this picture seems a true reflection of current breakdown of the workforce in palliative nursing.

It must be noted that, the limitations from the current study are discussed fully in the discussion chapter.

Summary

This chapter has described procedures and processes undertaken to maximise the rigour of this current study which includes application of ethical principles. The sensitivity around the topic of death and dying was acknowledged in the procedure and helpful contact numbers were included at the end of questionnaires in case respondents felt the need to seek counselling support afterwards. In addition, respondents had an option to write down their thoughts and feelings about the subject matter, by using the "any other comments" spaces provided on the questionnaires. A detailed critique of the measurement instruments revealed that they had sufficient validity and reliability to use with this study, hence their selection here.

Considering that the measurement scales were developed in the 80s and the social and care contexts have since changed, they were factor analysed and results confirmed that they were still suitable for use 30 years on with this study.

The high response rate in this study indicates the value that respondents placed on the importance of this study, despite the low morale prevailing in the workplace at the time of data collection. However, it is evident that around 39% did not respond, and therefore their views were not ascertained, which arguably are different from those who responded.

This chapter has demonstrated a thorough assumption checking for multiple regression test to establish predictor variables for emotional exhaustion, which eventually leads to burnout. This chapter discussed how the Kruskal-Wallis test was preferred and used to establish any significant differences in death anxiety and burnout scores among nurses working in three different palliative care settings.

Finally, this study provided a platform for palliative care nurses to comment on available facilities and resources in the care of dying patients. This study enabled nurses to express their opinions based on their experiences of caring for dying patients and the impact this has on their own well-being and their ability to continue to provide high quality care.

The next chapter discusses how a new measurement scales was developed and factor analysed so that it can be used to measure aspects of caring. Other existing measurement scales used for this current study were retested for internal consistence and to confirm their factor structure

CHAPTER 7: FACTOR ANALYSIS OF MEASUREMENT SCALES

Chapter Overview

This chapter discusses in more detail the statistical analyses performed for this study, which were only briefly introduced in the methodology chapter. This chapter discusses three exploratory factor analyses (EFA) carried out on the measurement scales used to collect data in this study. These are:

- The Sources of Pressure Measurement Scale.
- The Maslach Burnout Inventory and
- The Revised Death Anxiety Scale,

Exploratory Factor Analysis

This technique can be used to reduce a larger set of variables to two or three of the central factors which underlie a set of items (Gorsuch 1983). Ideally, exploratory factor analysis is used where new scales are being developed in order to eliminate items that do not factor in the same direction as those of interest (Field 2005). Exploratory factor analysis (EFA) achieves this by uncovering the underlying dimensions (structures) of a large set of variables (Darlington, et al. 1973; Gorsuch 1983). It is important to perform exploratory factor analysis where there are a lot of variables, but certain conditions should be met, that is, sample size, level of data and strength of the correlation relationship among the variables or items (Pallant 2007; Tabachnick and Fidell 2007).

Factor analysis of the Sources of Pressure Measurement Scale

This scale was developed for this study and therefore more detailed explanation on the process will be given. However, it must be emphasised that this scale should be treated as a pilot that will require further work to develop more items, refine current ones and test with larger sample sizes. The current 13 items from the Sources of Pressure measurement scale were useful and small enough as an initial starting point in developing the scale, but further work is needed to develop the robustness of this scale to promote its use beyond this current study.

Suitability of the data set for factor analysis was checked by considering the value of the Kaiser-Meyer-Olkin Measurement of Sampling Adequacy (KMO) and whether the Bartlett's Test of Sphericity (BTS) was significant. According to Field (2005) and Pallant (2007), KMO should be .6 or above and the BTS should be .05 or smaller. For this measurement scale, table 25 shows the KMO value was .820 which is much higher than the recommended and BTS significant at (p.000) therefore confirming that factor analysis is appropriate for this measurement scale.

Table 25 : KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.820
Bartlett's Test of Sphericity	Approx. Chi-Square	776.619
	Df	78
	Sig.	.000

For exploratory factor analysis of the Sources of Pressure measurement scale, principal component analysis (PCA), using SPSS Version 15, was used. The three factor outcome that emerged from the analysis of the 13 items (Table 26) accounted for 56.2% of the total variance was subjected to rotation method, direct oblimin with Kaiser normalisation (Field 2005; Pallant 2007). The oblimin method was preferred on the assumption that the factors may correlate (Field 2005) and therefore not be seen as unrelated.

Extraction of factors

To consider the number of factors (components) to extract from the data set, the Kaiser criterion was used to determine factors with an eigenvalue of one or more. Kaiser criterion or the eigenvalue rule (Field 2005) is used to guide which factors, should be retained for further scrutiny. In order to determine which factors should be retained, that is, with eigenvalue of one and more, the Total Variance Explained scores (see Table 26) was used for analysis. Scanning down the initial eigenvalues column, only the first three components recorded eigenvalues above 1, that is, 4.394, 1.801 and 1.101.

These three components explain a total of 56.25 per cent of the variance. On further scrutiny, there are two other components (4 and 5) with eigenvalues close to one (.892 and .822) which may suggest that with further refinement or omission of item variables within the scale, their values may increase, resulting in more factors being extracted. As already explained above, further development of the scale will need to be undertaken following this study.

Table 26: Factor extraction showing components with eigenvalues above one

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings(a)
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	4.394	33.803	33.803	4.394	33.803	33.803	3.590
2	1.801	13.851	47.654	1.801	13.851	47.654	2.845
3	1.101	8.471	56.125	1.101	8.471	56.125	2.195
4	.892	6.858	62.984				
5	.822	6.324	69.308				
6	.758	5.833	75.141				
7	.650	4.998	80.139				
8	.597	4.590	84.729				
9	.473	3.642	88.371				
10	.444	3.416	91.787				
11	.434	3.338	95.125				
12	.387	2.976	98.101				
13	.247	1.899	100.000				

Extraction Method: Principal Component Analysis.

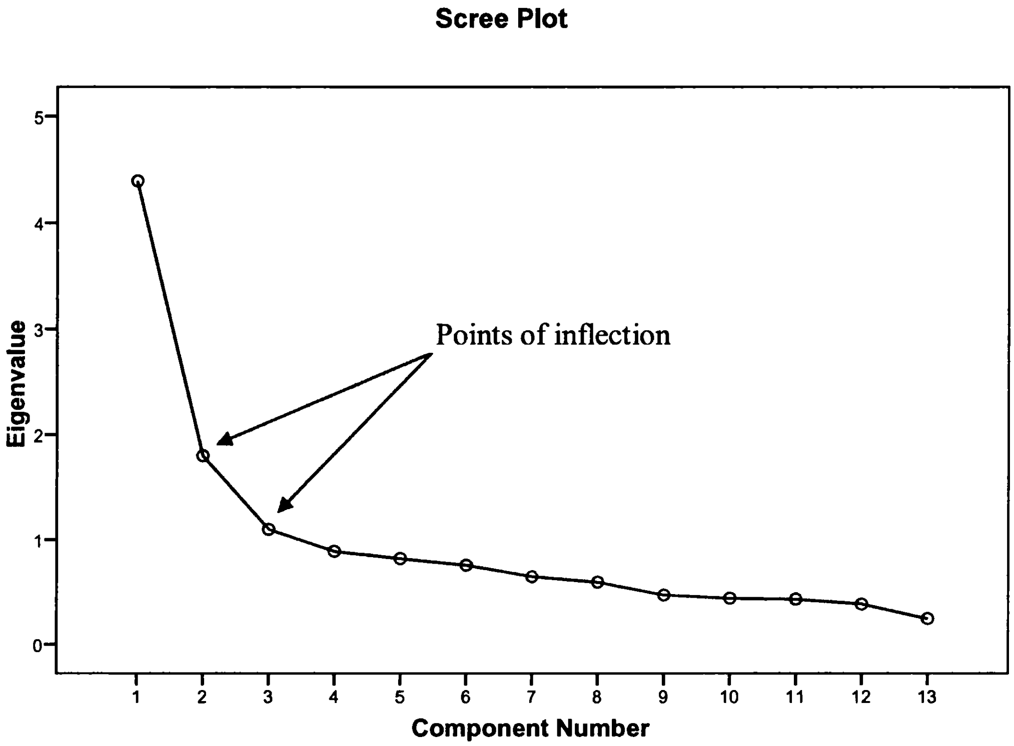
a When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

The Kaiser criterion has been criticised for a tendency to extract too many components (Pallant 2007), and for this study, it may not have been as accurate as it should be since the sample size was 213, which is below the recommended minimum of 250 (Field 2005; Tabachnick and Fidell 2007). Working with such a sample size of 213 to extract factors, it would not be advisable to rely entirely on the Kaiser criterion. Therefore, it was important for this study also to use Catell's scree test to confirm the number of components that can be retained.

In the scree test, the cut off point is at the point which the shape of the curve changes (Catell 1966) to horizontal, also called the elbow (Pallant 2007) or point of inflection (Field 2005). Inspecting the scree plot in figure 10, it reveals a break or change in the curve to horizontal after the third component. This confirms, as did the Kaiser criterion, that there are three factors that can be extracted from this data set. Using Catell's scree test, it was decided with confidence to retain all three components as factors for the Sources of Pressure measurement scale.

Figure 10: Catell's Scree Plot

Catell's Scree Plot Test for components of the Sources of Pressure Measurement Scale



Below, Table 27 shows a structure matrix of the components (factors) extracted and the item loading in each of the factors.

Factor 1 consisted of six items (7,8,4,2,,10,11) referred to as 'clinical' aspects of caring. Factor 2 consisted of four items (13,9,12,6) referred to as 'workload' issues encountered while caring for dying patients. Factor 3 consisted of 4 items (3,1,5,6) referred to as 'perceived control' over symptom management in dying patients.

The Sources of Pressure Measurement Scale was developed for this study to measure caring, and factor analysis was important to extract the components, but more refinement is needed if it is to be used beyond this study.

Although, Table 27 shows that three factors have emerged, it also shows that some variables, (those highlighted in blue) load onto more than one factor, which suggests shared variance therefore, a relationship between the factors. This overlap tends to complicate interpretation, although the highlighted variables are too small compared to the other variables on the same factor to influence factor selection. A clearer picture can be obtained by examining the pattern matrix (Table 28), which tends to suppress small variables loading across more than one factor. Graham et al (2003) recommend reporting both pattern and structure matrix as a way of double-checking the emerging factors, and to that end , Table 28 has been created to show both pattern and structure matrices.

Structure showing three components of Sources of Pressure Scale (N = 213)

Table 27: Three Factor Structure of Sources of Pressure Scale

Structure Matrix of the three components

Sources of Pressure Items	**Factors** **1**	**2**	**3**
	Clinical	**Workload**	**Perceived Control**
Source Of Pressure 7 Having to support relatives while viewing the body of the dead patient	.793		
Source Of Pressure 8 Having to witness a difficult death of a patient	.771		
Source Of Pressure 4 Having to support relatives by the bedside as patient dies	.767		.338
Source Of Pressure 2 Having to break bad news to relatives	.737		
Source Of Pressure 10 Having to support young children related to the dying patient	.613	.393	
Source Of Pressure 11 Having to perform last offices	.582		
Source Of Pressure 13 Being expected to do your job well without administrative/secretarial support		.832	
Source Of Pressure 9 Being asked to do your job without adequate resources	.323	.776	.378
Source Of Pressure 12 Having too much workload to deal with	.399	.743	
Source Of Pressure 6 Feeling excluded from decision making process about patient care		.620	.562
Source Of Pressure 5 Inability to control patient's psychological symptoms			.730
Source Of Pressure 1 Inability to control patient's physical pain	.379	.339	.702
Source Of Pressure 3 Lacking clarity of your role		.327	.589

Extraction Method: Principal Component Analysis.

Rotation Method: Oblimin with Kaiser Normalization.

a. three components extracted

It is clear from Table 28 that the pattern matrix contains precise factor loadings and the structure matrix shows the relationship between factors. What can be concluded from both matrices, is that three factors have emerged from the data set. However, the fact that a few variables load across more than one factor suggests not only a relationship between factors, but a need to refine existing variables or increase the number of variables to encourage stronger factors to emerge.

Table 28 includes a list of communalities, which help to explain the variance in each of the variables. According to Pallant (2007) low variables (e.g. less than .3) may suggest that the variable does not fit well with the other variables in the factors. In table 28, all variables are above .3, although two of them, Source of Pressure (SOP) 8 and 5 are just above the .3 value, which is the recommended minimum, therefore acceptable for this current study. If items were below .3, then Field (2005) and Pallant (2007) would recommend their removal as this would increase the total variance explained, and ensure that the remaining items fit better with other variables in the factor.

Pattern and structure matrix for Principal Component Analysis with Oblimin Rotation of three factor solution of Sources of Pressure scale items (N= 213)

Table 28 : Pattern and structure matrix for Sources of Pressure Scale

	Pattern Coefficient			Structure Coefficient			Communalities
	1	2	3	1	2	3	
SOP7	.792			.793			.568
SOP4	.756			.771		.338	.559
SOP8	.751			.767			.384
SOP2	.709			.737			.642
SOP11	.603			.613			.565
SOP10	.548			.582	.393		.567
SOP13		.835			.832		.642
SOP12		.729		.399	.776		.600
SOP9		.702		.323	.743	.378	.640
SOP6		.536	.437		.620	.562	.432
SOP5			.733			.730	.382
SOP1			.632	.379	.339	.702	.622
SOP3			.551		.327	.589	.695

Extraction Method: Principal Component Analysis.

Rotation Method: Oblimin with Kaiser Normalization.

a Rotation converged in 10 iterations.

Finally, the component correlation matrix below, (Table 29) shows the strength of the relationship between the three factors. The low nature of the correlation matrix suggests that the factors are separate therefore, independent of each other (Pallant 2007), which suggests that they can be extracted with confidence.

Table 29: Strength of relationship between variables

Component Correlation Matrix

Component	1	2	3
1	1.000	.268	.177
2	.268	1.000	.282
3	.177	.282	1.000

Extraction Method: Principal Component Analysis.

Rotation Method: Oblimin with Kaiser Normalization.

Reliability and validity of three-factor scale

It was important to establish the internal consistency of this scale in measuring sources of pressure in caring for dying patients. Cronbach Alpha α reliability coefficient, which is also, according to Field (2005); Tabachnick and Fidell (2007) and Cresswell (2009), the most common measure of a scale's reliability, was estimated at .83, N=13 (Table 30) and this result confirms that the scale consistently measures sources of pressure (Field 2005 and Pallant 2007), therefore is reliable.

Cronbach alpha of .830, can be considered as a moderate to strong indicator of a scale's reliability. By suggesting that it can be considered moderate to strong, it acknowledges disagreements among different authors on what the cut off point is, for example; Pallant (2007) and De Vellis, (2003) suggest .value of 7, whereas Field (2005), Grayson (2004) and Kline (1999) suggest values between .7 and .8 Tabachnick and Fidell (2007) suggest .9 while Bryman (2004) claims .8 is generally the accepted rule of thumb.

Although, Cronbach alpha values are sensitive to the number of items in the scale, ideally, the value should depend on what is being measured, for example, psychological constructs which are in themselves diverse, can have lower (below .7) Cronbach alpha value as acceptable (Field 2005). Given these differences on the cut off point, a Cronbach alpha value obtained for the Sources of Pressure Scale can be confidently accepted as a high indicator of reliability.

Table 30: Reliability Statistics of the Sources of Pressure Measurement Scale

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.803	.830	13

Factor Analysis of the Maslach Burnout Inventory

As discussed earlier, the MBI is an existing validated scale, and was factor analysed for this study to confirm the factor structure and reliability. The 22 items of the Maslach Burnout Inventory (MBI) were subjected to principal component analysis (PCA) using SPSS Version 15. Prior to performing PCA, suitability of data for factor analysis was assessed. The Kaiser-Meyer-Oklin value was .796 higher than the recommended value of .6 (Kaiser 1974; Field 2005). The Bartlett test of sphericity reached statistical significance, supporting the factorability of the correlation matrix.

Principal component analysis showed that there were three components with eigenvalues greater than one. These values account for the 46.005% of the variance. An inspection of the scree plot confirmed a clear change in the curve to horizontal after the third component. The three factors also confirmed the extraction made by the original authors Maslach and Jackson (1982), who developed the inventory.

Factor 1 consisted of nine items that referred to emotional exhaustion (EE). Factor 2 consisted of eight items which referred to depersonalisation aspects (DP). Factor 3 consisted of five items which referred to low personal accomplishment (PA). This factor structure confirms the original structure as developed by Maslach and Jackson (1982).

Reliability of the Maslach Burnout Inventory

Cronbach alpha coefficient of .746 was recorded for the Maslach Burnout Inventory used in this study. This was deemed moderate indicator of reliability sufficient to be confident to use the inventory with this current study.

Factor analysis of the Revised Death Anxiety Scale

The revised death anxiety scale (RDAS) is an existing validated tool which was used for this study. Factor analysis was performed to determine factor structure for use with this study. The 25 items of the RDAS were subjected to principal component analysis (PCA) using SPSS version 15. Prior to performing PCA, suitability of data for factor analysis was assessed. The Kaiser-Meyer-Oklin (KMO) value was .841 exceeding the recommended value of .6 (Kaiser 1974; Field 2005).

The Bartlett test of sphericity reached statistical significance, supporting the factorability of the correlation matrix.

Principal component analysis revealed seven components with eigenvalues greater than one. These values account for the 59.224% of the variance. Inspection of the scree plot confirmed a clear change in the curve to horizontal after the seventh component. The seven factors also confirmed the extraction made by the original authors, Thorson and Powell (1984), and reported earlier in chapter 6, who developed the RDAS.

Factor 1 consisted of 14 items that referred to 'Fear of uncertainty and missing out on things'. Factor 2 consisted of seven items which referred to 'Fear of the pain associated with death'. Factor 3 consisted of five items which referred to 'Concern over the disposition of one's body'. Factor 4 consisted of 5 items which referred to 'Fear of helplessness and loss of control'. Factor 5 consisted of four items which referred to 'Afterlife concerns'. Factor 6 also consisted of four items which referred to 'Fear of decomposition' and finally Factor 7 consisted of three items which referred to 'Concerns over leaving instructions on how things should be done after one's death'. This factor structure confirms the original structure as developed by Thorson and Powell (1984).

Reliability of the Revised Death Anxiety Scale

Reliability of this scale was reported in the methods chapter as .85, (n= 205). According to (Bryman and Cramer 2001), this is an acceptable level, and therefore in selecting it for use with this study, one can be confident that this measurement scale is internally reliable and measuring items from the same conceptual domain (Bowling 2005).

Summary

The measurement scales used for data collection for this study seem reliable judging by the Cronbach alpha values reported above. The factor structure obtained here for all the scales support original factor structures as reported by the developers of the scales in the 1980s. The Sources of Pressure Scale (SOP), which was developed for this study, confirmed it had three factors extracted from the 13 items comprising the scale. Despite disagreements on the cut-off point for reliability value, the SOP Scale showed a moderate to high degree of reliability at Cronbach alpha .830. It is from this value that data collected using this scale can be treated as reliable, and therefore utilised with confidence.

CHAPTER 8: RESULTS

Chapter Overview

This study investigated the relationship between caring, death anxiety and burnout among nurses working in palliative care. The objectives were to:

- Identify aspects of caring perceived as stressful when caring for dying patients;
- Examine relationship between death anxiety and burnout;
- Examine relationships between social support, burnout and death anxiety;
- Identify significant predictor variables of burnout;
- Identify differences in burnout and death anxiety scores between nurses working in hospices, hospitals and community settings

The purpose of this chapter is to present the results only. Although an extended discussion of the implications of these results is important, this will be the focus for the discussion chapter. This chapter begins by describing characteristics of the sample before reporting on results of inferential analyses to do with testing for relationships between variables and differences between groups. Total mean scores of death anxiety and burnout are presented together with the range (minimum and maximum) scores found among nurses working in three different palliative care settings. Descriptive statistics are used to show the number of nurses with low, moderate and high levels of death anxiety and emotional exhaustion and depersonalisation. With regard to the development of burnout, emotional exhaustion appears to occur first followed by depersonalisation and the final phase is low personal accomplishment which signals the burnout syndrome. Therefore, it was considered important to determine levels of both of these variables (Tables 32, 33 and 34 respectively). Reasons for analysing it this way have already been outlined in the methods chapter. A further influence on the decision to focus on emotional exhaustion and depersonalisation is that Maslach and Jackson (1982) only give cut off points for low, moderate and high levels of the components of burnout and not the burnout syndrome itself. Palliative care nurses who participated in this current study worked in hospices, hospitals and the community, and the levels of emotional exhaustion and depersonalisation were tested across these three clinical practice settings.

Levels of death anxiety are based on the combined total scores of death anxiety, but for burnout, the scores of its three components are used. Results from multiple regression tests are discussed. Emotional exhaustion was entered into the regression analysis as the dependent variable and the predictors or independent variables included are death anxiety, age, time in post (experience) and caring.

Characteristics of the sample

There were a total of 213 respondents with six classified as missing data, giving a response rate of 60.85%. Of the 213 respondents, six did not complete their gender group. From the 207 completed gender responses, 14 (6.8%) were male and 193 (93.2%) were female. These figures are not surprising as they reflect the picture found in general nursing and palliative care in particular, where according to the RCN (2006) survey more than 80% of nurses are female.

The age of the respondents ranged from a minimum age of 24 to a maximum of 62 years old. Of the 213 respondents, 98 (46%) worked in hospices, 78 (36.6%) worked in hospitals, 31 (14.6%) worked in the community and six (2.8%) did not specify which setting they were working in.

Ethnic break down of respondents

Of the 213 respondents, 200 (96.6%) were white, six (2.8%) did not state their ethnicity and the remaining seven were divided among the other groups as follows:

Asian 1 = 0.5%.
Black 3 = 1.4%
Mixed 2 = 1.0%
Other 1 = 0.5%

These figures reflect the ethnic picture of nurses currently working in health care environments within the UK where palliative care nurses are predominantly white and female (RCN, 2006).

Level of death anxiety among palliative care nurses

The following section presents descriptive statistics on levels of burnout (specifically emotional exhaustion, depersonalisation and low personal accomplishment) and death anxiety found among palliative care nurses. The levels show the degree by which nurses were suffering with both death anxiety and burnout. Table 31 shows levels of death anxiety among nurses from the three palliative care settings. Most nurses showed moderate levels of death anxiety, with 88 (91.7%) nurses from the hospice, 72 (92.3%) nurses from the hospitals and 27 (87%) nurses from the community. Less than 10 nurses from each of the three settings showed high levels of death anxiety from across the three settings (Table 31).

Table 31: Levels of death anxiety among nurses in three locations

	Death Anxiety levels			Total
Location	Low level DA (less than or equal to 39)	Moderate level DA (40-80)	High level DA (equal to or greater than 81)	
Hospice	0	88 91.7%	8 8.3%	96
Hospital	1 1.3%	72 92.3%	5 6.4%	78
Community	0	27 87%	4 13%	31
Total	1	187	17	205

Key: DA = death anxiety

Levels of burnout among palliative care nurses

Burnout was considered using its three components for reasons already explained in chapter 6, (Table 32), that is, emotional exhaustion (EE), Table 32, depersonalisation (DP), Table 33 and low personal accomplishment (PA), Table 34, among nurses working in the three palliative care settings as already discussed. In Table 32, of the 97 nurses working in hospices, 43 (44.3%) showed low levels of emotional exhaustion, whilst 35 (36.1%) showed moderate levels and 19 (19.6%) showed high levels.

Only seven (2.2%) nurses in the community setting showed high levels of emotional exhaustion, 14 (45.2%) showing moderate/average levels and 10 nurses with low levels. Of the 78 hospital nurses, 17 (21.8%) showed high levels of emotional exhaustion, 23 (29.5%) showed moderate levels whilst 38 (48.7%) showed low levels.

Table 32: Emotional Exhaustion levels among nurses in three locations

	EE levels			
Location	Low EE (less than or equal to 18)	Average EE (19-26)	High EE (equal to or greater than 27)	Total
Hospice	43 (44.3%)	35 (36.1%)	19 (19.6%)	97
Hospital	38 (48.7%)	23 (29.5%)	17 (21.8%)	78
Community	10 (32.2%)	14 (45.2%)	7 (22.6%)	31
Total	91	72	43	206

Key: EE = emotional exhaustion

For depersonalisation, 11 (10.6%) nurses from the hospice, six (4.7%) nurses from the hospital and three (0.9%) nurses from the community showed high levels of DP. There were large numbers of nurses across the three settings who showed low levels of DP as shown in table 33. As already explained in chapter 3 on p .... depersonalisation is the next phase to develop after emotional exhaustion. What this suggests is that nurses were experiencing feelings of depersonalisation well before they presented with high levels of emotional exhaustion. Therefore, the phased development of these components as described by Maslach and Jackson (1982) can be understood differently.

Table 33: Levels of Depersonalisation among nurses in three locations

Location	Depersonalisation levels Low DP (less than or equal to 5)	Average DP (6-9)	High DP (equal to or greater than 10)	Total
Hospice	68 (70.1%)	18 (18.6%)	11 (11.3%)	97
Hospital	59 (75.6%)	13 (16.7%)	6 (7.7%)	78
Community	24 (80%)	3 (10%)	3 (10.%)	30
Total	151	34	20	205

Key: DP = depersonalisation

For low personal accomplishment, it is important to reiterate that these measurements are scored in the opposite direction from those of emotional exhaustion and depersonalisation , therefore, when nurses show high levels of emotional exhaustion and depersonalisation, they are showing high levels of low personal accomplishment , (see table 34). This means they are feeling less competent in achieving their caring goals.

Table 34: Levels of low personal accomplishment among nurses in three locations

Location	Low personal accomplishment levels Low PA (equal to or more than 40)	Average (39-34)	High PA (less than or equal to 33)	Total
Hospice	26 (27.1%)	29 (30.2%)	41 (42.7%)	96
Hospital	30 (38.5%)	26 (33.3%)	22 (28.2%)	78
Community	17 (56.7%)	7 (23.3%)	6 (20%)	30
Total	73	62	69	204

Key: PA = low personal accomplishment

The table below shows the total mean scores for burnout and death anxiety among all palliative care nurses. Here scores of the burnout syndrome are shown, as opposed to just its early stages of development, that is, emotional exhaustion and depersonalisation.

Table 35: Total mean scores of burnout and death anxiety

Total scores		**Total Burnout**	**Total Death anxiety**
Total	Mean	60.67	64.81
	N	199	201
	Std. Deviation	12.51	10.91
	Minimum	30.00	36.00
	Maximum	126.00	100.00

Key: BO = burnout; DA = Death Anxiety

Table 35 shows the total mean scores of burnout (60.67, SD= 12.51, n=199) and death anxiety (64.81, SD= 10.91 n=201) for the total sample of nurses. Minimum and maximum scores for both burnout (30/126) and death anxiety (36/100) are also provided

Below, Table 36 shows mean scores and maximum and minimum scores for burnout and death anxiety among palliative care nurses working in the three palliative care settings of hospice, hospital and community. The community setting shows the highest mean score for burnout (64.07, SD= 16.31) whilst the hospice nurses show the least mean scores (58.97, SD=11.09). For death anxiety, the hospital setting shows highest mean scores (65.65, SD= 10.34), whilst the community setting shows least mean scores (62.42, SD= 12.86).

Table 36: Total mean scores of burnout and death anxiety in the three palliative care settings

Report

Location		Total BO	Total DA
Hospice	Mean	58.97	64.90
	N	93	93
	Std. Deviation	11.09	10.67
	Minimum	30.00	46.00
	Maximum	96.00	100.00
Hospital	Mean	61.44	65.65
	N	77	77
	Std. Deviation	12.33	10.34
	Minimum	36.00	36.00
	Maximum	97.00	93.00
Community	Mean	64.07	62.42
	N	29	31
	Std. Deviation	16.31	12.86
	Minimum	42.00	41.00
	Maximum	126.00	92.00

Key: BO = burnout; DA = death anxiety

Before further tests could be carried out, it was important to check assumptions of normality of the data, and table 37 below presents the Shapiro-Wilk test showing the results.

Table 37: Assumption of normality across the three settings

Tests of Normality

		Kolmogorov-Smirnov(a)			Shapiro-Wilk		
	Location	Statistic	df	Sig.	Statistic	df	Sig.
Total DA Score	Hospice	.094	91	.045	.971	91	.039
	Hospital	.095	77	.085	.980	77	.267
	Community	.208	29	.002	.931	29	.058
Total BO score	Hospice	.106	91	.013	.973	91	.056
	Hospital	.118	77	.010	.965	77	.031
	Community	.148	29	.105	.833	29	.000

a Lilliefors Significance Correction

For both death anxiety (hospital and community) and burnout (hospice) there are groups with distributions which differ significantly from normal distribution. Therefore non-parametric tests were chosen to analyse these data (Pallant 2007; Field 2009). Differences between the three locations were therefore examined using Kruskal-Wallis, a non-parametric test of difference (as an alternative equivalent to the ANOVA which is more appropriate for parametric data), was preferred. Kruskal-Wallis test was therefore used for establishing any significant differences between the three locations of hospice, hospital and community where palliative care nurses care for terminally ill patients. The first table (table 38) shows mean scores in death anxiety among the three groups of palliative care nurses and that hospital nurses showed the highest mean scores (107.45), whilst the community showed the least mean scores (86.00).

Table 38: Significant differences in death anxiety mean scores

Ranks

	Location	N	Mean Rank
Total_DA_Score	Hospice	93	100.66
	Hospital	77	107.45
	Community	31	86.00
	Total	201	

A chi-square goodness of fit test indicates there was no significant difference in the levels of death anxiety identified in the current sample across the three settings, that is, X^2 (2, n=201) = 3.02, $p < .22$

Table 39 shows total mean scores of burnout among the three groups of palliative care nurses and that hospice nurses have the lowest mean scores (93.97), whilst the community nurses show the highest scores (109.88).

Table 39: Significant differences in Burnout mean scores

Ranks

	Location	N	Mean Rank
Total BO	Hospice	93	93.97
	Hospital	77	103.56
	Community	29	109.88
	Total	199	

Kruskal-Wallis output (Burnout)

A chi-square goodness of fit test indicates there was no significant difference in the levels of burnout identified in the current sample across the three settings, that is, X^2 (2, n=199) =2.17, $p < .34$.

Table 40 below shows the correlation between death anxiety, the three components of burnout, that is, emotional exhaustion (EE), depersonalization (DP) and low personal accomplishment (PA).

Relationship between death anxiety and components of burnout

Using table 40, the correlation coefficient between death anxiety and emotional exhaustion is .211 which is significant at 0.01 level. This result shows that there is a positive and weak relationship between death anxiety and emotional exhaustion. The next part of the result shows that the correlation coefficient between death anxiety and depersonalisation (DP) is .204. This suggests a positive and weak relationship which is significant at 0.01 level.

Table 40: Correlation between death anxiety and components of burnout

Correlations

			Total_DA Score	**Total EE**	**Total DP**	**Total PA**	
Spearman's rho	**Total DA_Score**	Correlation Coefficient	1.000	.211(**)	.204(**)	-.140(*)	
		Sig. (2-tailed)	.	.002	.003	.047	
		N	205	204	203	202	

* Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed).
Key: DA = death anxiety, EE = emotional exhaustion, DP = depersonalisation, PA = low personal accomplishment

The third component, low of personal accomplishment (PA) shows a correlation coefficient with death anxiety of -.140. This suggests a negative and non-significant relationship between these two variables. Given the fact that PA is scored in the opposed direction to emotional exhaustion and depersonalisation, (explained in detail earlier in chapter 6), these results are not unexpected and therefore make sense. As death anxiety increases nurses' feelings and perceptions of nurses own competence would decrease

Nature of the relationship between death anxiety and age

Table 41 presents the correlation coefficient for death anxiety, age and the components of burnout. None of the correlations are significant.

Table 41: Correlation between death anxiety, measures of burnout and age

			Age	**Total DA Score**	**Total EE**	**Total DP**	**Total PA**	**Total BO**
Spearman's rho	age	Correlation Coefficient	1.000	.059	.006	-.071	-.038	-.018
		Sig. (2-tailed)	.	.401	.936	.314	.591	.804
		N	205	203	204	203	202	201

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

*** Correlation is significant at 0.001 level (2 tailed)

Key: DA = death anxiety, BO = burnout, EE = Emotional exhaustion, DP = depersonalisation, PA = low personal accomplishment

Sources of Pressure and time in post

For this analysis, the sample was split into those respondents with less than 10 years experience and those with more than 10 years service in palliative nursing. Table 42 shows statements of sources of pressure (SOP1 to SOP13) and their correlation with death anxiety and the components of burnout.

Table 42: Relationship between sources of pressure, death anxiety, and measures of burnout

Correlation with Spearman's rho showing correlation coefficients:-

		Less than 10 years experience				More than 10 years			
	Element of caring	**Total DA Score**	**Total EE**	**Total DP**	**Total PA**	**Total DA**	**Total EE**	**Total DP**	**Total PA**
SOP1	Inability to control patient's physical pain	.092 n-113	.224* n-115	.048 n-115	-.096 n-115	.208* n-92	.144 n-91	.234* n-90	-.086 n-89
SOP2	Having to break bad news to relatives	.301 n-113	.094 n-115	.057 n-115	-.003 n-115	.231* n-92	.373** n-91	.305** n-90	-.118 n-89
S0P3	Lacking clarity of your own role	.033 n-113	.236* n-115	-.006 n-115	-.100 n-115	.082 n-92	.246* n-91	.145 n-90	-.012 n-89
SOP4	Having to support relatives by the bedside as the patient dies	.178 n112	.336** n-114	.143 n-114	-.206* n-114	.186 n-96	.455** n-91	.359** n-90	-..228* n-89
SOP5	Inability to control patient's psychological symptoms	.261* n-113	.234* n-115	.204* n-115	-.056 n-115	.262* n-92	.325** n-91	.418** n-90	-.216* n-89
SOP6	Feeling excluded from clinical decision making process about patient care	.162 n-113	.214* n-115	.207 n-115	-.021 n-115	.266** n-92	.221* n-92	.165 n-90	-.008 n-89
SOP7	Having to support relatives while viewing the body of the dead patient	.217* n-111	.185 n-113	.159 n-113	-.233* n-113	.302** n-90	.408** n-89	.332** n-88	-.159 n-87
SOP8	Having to witness a difficult death of a patient	.303** n-111	.052 n-113	.141 n-113	-.031 n-113	.290** n-92	.412** n-91	.244* n-90	-.092 n-89
SOP9	Being asked to do your job without adequate resources to complete it	.284* n-113	.187* n-115	-.007 n-115	.169 n-115	.370** n-92	.391** n-91	.329** n-90	-.140 n-89
SOP10	Having to support young children related to the dying patient	.202 n-111	.001 n-113	-.031 n-113	.118 n-113	.146 n-91	.343** n-90	.219* n-89	-.210* n-89
SOP11	Having to perform last offices	.160 n-107	-.263** n-108	-.200* n-108	.317** n-108	.050 n-89	-.039 n-88	-.121 n-87	.156 n-87
SOP12	Having too much work load to deal with	.232* n-113	.450** n-115	.107 n-115	-.022 n-115	.268** n-92	.368** n-91	.110 n-90	.014 n-89

SOP13	Being expected to do your job well without administrative/secretarial support	.280** n-112	.264** n-114	.130 n-114	-.173 n-114	.292** n-92	.370** n-91	.190 n-90	-.165 n-89

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).
Key: DA = death anxiety, EE = Emotional exhaustion, DP = depersonalisation, PA = low personal accomplishment. SOP = Source of pressure

First, six of the 13 sources of pressure statements show positive but weak to moderate correlation with death anxiety among palliative care nurses with less than ten years experience. The strongest correlation of these can be found in the statement which relates to witnessing a difficult death of a patient ($r = .303, p<0.01$) and death anxiety. The association is that the more nurses witness difficult deaths, the more their levels of death anxiety increase. Inability to control patients' psychological pain was positively and moderately correlated with emotional exhaustion and depersonalisation among nurses with more that 10 years experience.

For those nurses with over 10 years experience, nine of the 13 statements showed weak to moderate correlations with death anxiety. The strongest of these can be found for the statement, 'being asked to do your job without adequate resources to complete it' ($r = .370, p < 0.01$) with death anxiety. The remaining four statements, although showing a positive correlation, show no statistical significance, and are therefore not viewed as meaningful for this study.

Sources of Pressure, measures of burnout and years experience

For nurses with less than 10 years experience, eight of the 13 sources of pressure statements show weak to moderate correlations with emotional exhaustion. There was a weak to moderate correlation with depersonalisation for two of the 13 statements. The remainder of the statements show no significant correlations with both emotional exhaustion and depersonalisation. When experience was correlated with low personal accomplishment (PA), all but three statements showed a negative and non-significant relationship. The three statements that were positive, had non-significant correlation with experience.

For nurses with over 10 years' experience, eleven of the 13 statements showed moderate positive correlation with emotional exhaustion. The strongest of these relationships can be found for the statement, 'having to support patients by the bedside as the patient dies' ($r = .455$, $p < 0.05$) with emotional exhaustion. When correlated with DP, 8 statements on experience show weak to moderate correlation with depersonalisation.

The strongest of these relationships can be found for the statement about 'the inability to control patient's psychological symptoms' and depersonalisation ($r = .418$, $p<0.05$). When correlated with PA, all but two statements show negative and weak correlation with experience.

Multiple Regression Analysis

The following section evaluates each of the independent variables' contribution to the prediction of the dependent variable (Emotional Exhaustion) using multiple regression analysis

Using the 4 predictor model, multiple regression analysis confirmed that caring is a highly significant predictor of emotional exhaustion. The multiple regression model (Table 43) included age, time in post, total death anxiety score and caring as predictor variables, and emotional exhaustion as outcome variable, resulted in an adjusted R^2 value of .125, suggesting the model explains 12.5% of the variance in Emotional Exhaustion scores. This model is highly significant $F(4, 193)=8.060$, $p<.001$), warranting examination of the contribution of the individual predictors.

Table 43: Multiple regression for predictor variables of emotional exhaustion

Model Summary(b)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.378(a)	.143	.125	8.02981	1.873

a Predictors: (Constant), Caring, age, total_DA_Score, time in post in years
b Dependent Variable: TotalEE

Examining the individual predictors in the model reveals that Age (β=.005, $t_{(193)}$=.062, p=.951), time in post (β=.067, $t_{(193)}$=.908, p=.365), and total death anxiety score (β=.066, $t_{(193)}$=.925, p=.356) were not significant predictors of emotional exhaustion. However, the Caring variable (which is the sum of the sources of pressure variables) was identified as a significant predictor of emotional exhaustion (β=.354, $t_{(193)}$=4.896, p<.001).

Examining the part correlations (semi-partial correlations) explains these findings further, as Field (2005) suggests that these values represent the amount of unique variance in the outcome variable explained by each predictor, after controlling for the effect of all other predictors on the outcome variable see table 44 below).
These values can then be squared and multiplied by a hundred, to obtain the percentage of unique variance the predictor explains of the outcome variable.

Table 44: Part (semi-partial correlations) for each of the predictor variables in the regression model.

Variable	Part correlation	Squared part correlation	Percentage of uniquely explained variance
Age	.004	0.000016	0.002
Time in post	.061	0.003721	0.37
Total Death Anxiety score	.062	0.003844	0.38
Caring	.326	0.106276	10.63

Thus, Age is found to explain only 0.002% of the variance in emotional exhaustion, time in post only 0.37% and total death anxiety score only 0.38%., whereas the Caring uniquely explains 10.63% of the variance in emotional exhaustion.

Correlation between social support, death anxiety and measures of burnout

Another area of interest was the level of social support nurses received from their employing organisation. The next table shows correlation between social support and death anxiety and the three components of burnout. Respondents were asked the following question:

In your current job, to what extent can you count on your manager(s) to:?

Table 45: Correlation between social support, death anxiety and measures of burnout

Correlation with:- Less or equal to 10 years More than 10 years

	Spearman's rho	**Total DA score**	**Total EE**	**Total DP**	**Total PA**	**Total DA**	**Total EE**	**Total DP**	**Total PA**
SOCS1	Listen to you when you want to talk about problems at work	.108 n=113	-.480** n=115	- .581** n=115	.031 n=115	.098 n=92	- .404** n=91	- .559** n=90	.259* n=89
SOCS2	Back you up at work	.111 n=113	-.520** N=115	- .494** n=115	.002 n=115	.012 n=92	- .482** n=91	- .465** n=90	.200* n=89
SOCS3	Help you with difficult tasks at work	.126 n=112	-.495** n=113	- .545** n=113	.060 n=113	.032 n=92	- .591** n=91	- .542** n=90	.305** n=89
SOCS4	Help you in a crisis situation at work, even though they would have to go out of their way to do so	.109 n=113	-.306* n=115	-.240 n=115	.034 n=115	.103 n=92	-.358* n=91	-.372* n=90	.284** n=89
SOCS5	Protect you from outside criticism - such as other Health care professionals, patients and relatives	.159 n=113	-.602** n=115	- .579** n=115	.068 n=115	.105 n=92	-.312* n=91	-.336* n=90	.286** n=89

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Key: DA = death anxiety, EE = Emotional exhaustion, DP = depersonalisation, PA = lack of personal accomplishment

SOC = Social support

Table 45 shows the two groups of nurses; one with up to 10 years experience and the other with more than 10 years working experience Of caring for dying patients. There were no significant correlations found in both groups between social support and levels of death anxiety. However, there were negative and moderate strength correlations between elements of social support and emotional exhaustion and depersonalisation regardless of length of their experience working in palliative care. The negative correlation suggests that the more social support that was received by nurses, the less they felt emotionally exhausted and a low sense of depersonalisation.

Qualitative data from additional comments

This study yielded qualitative data from additional comments made by respondents. Their comments were insightful and important in order to add context to their feelings and perceptions of caring for dying patients. However, these comments could not be statistically measured. The idea of including comments boxes was suggested by respondents from the pilot phases of this study. These comments were written as a one-off, and could not be clarified further to establish real meaning attached to them. They were therefore treated as quasi qualitative data (Wheeler and Holloway 2010) and therefore were used as contextual information that add meaning to some of the expressed feelings and perceptions.

Summary

Results show that death anxiety is positively associated with burnout. These results also show a positive and stronger correlation between death anxiety and emotional exhaustion and depersonalisation. The experience of caring for dying patients showed that some elements of caring were sources of pressure on palliative care nurses. For example, being unable to control patients' psychological symptoms was perceived as a source of pressure. Nurses working in hospitals presented with the most death anxiety and burnout, whereas nurses in the hospice showed the least levels of both death anxiety and burnout. Results from the multiple regression analysis, confirm for the first time that caring is a statistically significant unique predictor of emotional exhaustion.

The next chapter will now discuss these results in light of existing theory and their relevance to clinical practice.

CHAPTER 9: DISCUSSION

Chapter Overview

This chapter considers findings in light of existing research and current theories on death anxiety, burnout and caring. Any new insights from the findings are discussed with managers, educators and fellow researchers in mind. The qualitative data obtained from respondents' comments have been incorporated into the discussion to provide contextual insights into the respondents' thoughts and feelings about caring for dying patients. Limitations of the study are discussed and ways to reduce death anxiety and burnout suggested and strategies offered for both nurses and managers.

Introduction

The study had a high response rate (61%) which demonstrates the importance respondents placed on the topics under investigation. A methodological critique of the justification of 61% as acceptable response rate is detailed in chapter 10 of this thesis. Respondents may have perceived the study as a platform to express their views and opinions on their experience of caring for dying people. For example, they commented on the level of resources available, the level of confidence they had in symptom management and the quality of support they received from management to enable them to continue offering high quality care to this patient group. Although the primary purpose of this study was to find out the nature of the relationship between caring, death anxiety and burnout, it by extension, provided a neutral platform for nurses to share their views and express their feelings about caring for dying patients, with the hope that these will be communicated to management, and disseminated to educators and policy makers at large. The recommendations from this study are aimed at helping managers to put support mechanisms in place to ensure nurses do not experience burnout or high levels of death anxiety.

The study used measurement scales developed in the 80s and performed factor analysis on them which confirmed that they were still valid to use in today's changing social and care contexts. This study saw the development of a new measurement scale on caring, which was thoroughly tested and which confirmed a Cronbach alpha of .83 (first reported in chapter 6) which is a high level of reliability (Bryman 2008; Creswell 2009). Multiple regression tests were performed to determine predictor variables of burnout and confirmed, for the first time, that caring is a unique statistically significant predictor. These processes together, give strength to the findings and confidence to increase generalisability of the findings. The results can be used to develop measures that can be introduced at a wider scale. The key element of using these results widely was checking that the measurement scales are still relevant in today's changing care and social contexts. The discussion in chapter 7 confirmed that the older scales are still relevant to use today, despite the fact that they were first validated in the 80s. What emerged from this study using statistical test measures was that the association between death anxiety and burnout reported by previous studies can be supported. In addition, the literature review reinforced the need for this study and the findings have supported this by revealing new knowledge.

Interestingly, in this study, caring emerged as a contentious issue in the literature as it lacked definitional consensus among nurse theorists. Caring as an ontological dimension of being human has traditionally been researched using qualitative approaches. While this can provide rich and detailed insights into individual perceptions, these are not easily translated into mechanisms or strategies that can be employed across all care environments or organisations. The use of quantitative approach in this current study goes further to redress this deficit by using measurement tools and the results have been able to present data sets supported through statistical analysis.

Although, this current study was based on Mallett's (1988) study, it however, included caring as a new variable. As a direct result of including caring, it became clear that there were no existing scales to measure it, and therefore, a new measurement scale (Sources of Pressure) was developed and tested for validity and reliability for use with this study. With further refinement, this scale can be used to collect data on caring beyond this study. This is an important addition to measurement scales and particularly on caring in palliative nursing.

Although literature suggests (Maslach and Jackson 1982; Maslach 2001) that emotional exhaustion develops first and is followed by depersonalisation, results from this study show that nurses experienced emotional exhaustion as well as depersonalisation simultaneously. What this adds are new insights that, unlike previous findings (Maslach and Jackson 1982; Mallett 1988) nurses may not have to necessarily develop high levels of emotional exhaustion (EE) before they develop feelings of depersonalisation (DP). This is an important finding which will only alert managers when they measure burnout among their staff, to view its development differently. This will therefore allow managers to devise techniques to identify levels of emotional exhaustion first and develop strategies to support nurses early before they experience full impact of the burnout syndrome. It can be argued that dealing with burnout in its formative stages may prove cost-effective as symptoms are less severe, and nurses are still able to care with no absenteeism.

Social support was confirmed as an effective way of minimising the impact of occupational stress thereby consequently preventing emotional exhaustion. This finding supports previous studies, such as Mor-Barak (1988), Maslach et al (2001) and Bakker (2005) which claimed that social support has the ability to 'buffer' stressful situations against physical and mental health. However, it must be stressed that social support should be viewed as on-going input of activity and must be titrated to match the level of 'emotional involvement' nurses have with their patients. The tendency by managers to offer social support as a one off activity or twice a year must be resisted as it serves no real therapeutic purpose in preventing the impact of burnout. Such support should reflect the level of involvement nurses have with their patients, and can be part of clinical supervision and mentorship strategies

The above summary offers the basis for incorporating variables of interest for this study and the three main ones were presented earlier in figure 4 of chapter 6. Thus, the aim of this study was to investigate the relationship between caring, death anxiety and the burnout syndrome among palliative care nurses. The objectives of the study were set out to:

- Identify aspects of caring perceived as stressful when caring for dying patients;
- Examine relationship between death anxiety and burnout;
- Examine relationships between social support, burnout and death anxiety;
- Identify significant predictor variables of burnout;
- Identify differences in burnout and death anxiety scores between nurses working in hospices, hospitals and community settings

The use of correlational research design was important in order to understand the extent to which one variable (e.g. death anxiety) varies from another (e.g. burnout). Correlations are usually expressed in terms of correlation coefficients (Gomm et al 2000; Fink 2003; Field 2005), which show a perfect positive correlation as 1 and a perfect negative correlation as -1. A designation of zero suggests no correlation exist between the variables. It is well acknowledged (Gomm et al 2000; Field 2005; Tabachnick and Fidell 2007) that perfect correlations are rare, therefore, 0.8 is usually accepted as high positive correlation, and -0.8 a high negative correlation.

Results from this study show that all correlations were below the high correlation level, suggesting that the strength of the relationship ranged from weak to moderate. What is important is to view such strength or weakness in conjunction with levels of significance, and this principle was employed throughout this study.

Results from this study confirm a positive relationship or correlation between death anxiety and burnout among the scores obtained from nurses working in palliative care. This relationship suggests that as levels of death anxiety increase so do those of burnout. The relationship between death anxiety and burnout, although it shows as ranging between weak to moderate, is statistically significant at the 0.01 level. This statistical significance suggests that the likelihood of these results occurring by chance is very small, (Fink 2003; Watson et al 2006), and in this case, one in a hundred, and therefore one can be confident with the results.

Results from multiple regression analysis confirm that caring is a statistically significant unique predictor of emotional exhaustion. This confirmation is an important contribution because not only does it help palliative care nurses understand what predicts emotional exhaustion, but alerts managers, educators and other health professionals alike to try and find ways to ameliorate aspects of caring in order to minimise their impact on palliative care nurses. Managers, policy makers and educators should deal with the formative stages of both burnout and death anxiety thereby preventing associated costs of absenteeism, low staff morale and poor quality of care.

However, because there was evidence of multicollinearity between the three factors of caring (i.e. clinical, workload and perceived control) it was not advisable to run multiple regression (Pallant 2007; Field 2009) to determine which of these factors was a significant predictor of emotional exhaustion. Instead, it was deemed necessary to determine associations between the three factors and emotional exhaustion. As already confirmed in table 22, p161 when there is increased workload and clinical demands from caring, the levels of emotional exhaustion also increase.

Lessons can be learned from the Mid Staffordshire Inquiry (Francis 2010), where early signs of deteriorating care, low staff morale and many more were not recognised resulting in high and sadly preventable patient deaths within the whole NHS Trust. Although the Inquiry focused on accident and emergency, medical and surgical wards, the experiences uncovered are easily translatable to any environment where caring takes place. In palliative care, most patients are psychologically vulnerable as they try and 'deal' with their impending death and the realisation that they will no long be part of existence. In such circumstances, it is right to suggest that the last thing they need is poor quality of care from nurses who of course may not deliberately choose to be insensitive, but end up being impersonal as a way of protecting themselves from increased work pressure, emotional exhaustion (Maslach 2003), low morale and lack of management support (Francis 2010).

Results shown in table 22, p161 also confirm that when palliative care nurses feel less in control of the care they are providing, their levels of emotional exhaustion increase. This is another important contribution, because managers and other health care professionals can now use this knowledge as a basis for devising ways to support nursing staff effectively. Such intervention means early detection of emotional exhaustion thereby preventing the full blown burnout syndrome.

The results showed the sample was predominantly white British and female therefore, correlation analysis was not necessary. It must be pointed here that the nature of the relationship between death anxiety and gender; burnout and gender were not determined because of the composition of the sample which was predominantly female. It was deemed statistically irrelevant (Watson et al 2006), to attempt such a test where there were only 14 males and 193 females. Similarly, relationships between death anxiety and ethnic groups; burnout and ethnic groups were not determined because of the composition of the sample as stated above. It was for this reason also that gender was not included as a predictor variable of emotional exhaustion in the multiple regression test.

As already shown in chapter 8, two hundred out of two hundred and seven (200 out of 207) respondents who replied to this question were white British nurses, and although gender differences might be present it was not feasible to explore these in this study. However, there is scope for future research to include more males and other ethnic backgrounds where these differences can be explored.

Further to this, the paucity of ethnic groups in this study (3.4%) working in palliative care poses another challenge of representation and recruitment, especially after the Office for National Statistics (ONS) confirmed in the 2001 census, that minority ethnic groups represented almost 9% of the total UK population (Office for National Statistics 2003). The widening of the European member states, means there is also increased migration globally and to the UK in particular (Coalition Government 2010), therefore, it can be argued that this 9% of minorities will be increasing. The UK census of 2011 will probably reveal the new percentages of the different ethnic groups resident in the United Kingdom. Although cultural issues are not part of this study, they could not be ignored, because nurses are expected to provide culturally sensitive care (McGee and Johnson 2007) in general and specifically during dying and death.

Klem et al (2001) have shown that lack of recruitment from black and minority ethnic (BME) back grounds needs to be addressed by improving access to university courses from pre-registration to post qualifying stages. The impact of lack of students from BME is reflected in the paucity of qualified staff from BME, as witnessed in this current study

In addition, Wass and Neimeyer (1995); Koffman and Higginson (2005); Astley-Pepper (2005); Faull and Nyatanga (2005) and Randal and Downie (2006), all assert that family configurations are now more complex because of increasing multiculturalism, and with that ethnic backgrounds are being blended and are therefore becoming blurred. Therefore, culturally sensitive care becomes important to afford individualised death to all. More people from the BME communities need to be recruited to help with multicultural care. This approach has benefits:

- Encourages patients from BME backgrounds to access services;
- Care is provided by staff from BME back grounds and therefore increases confidence among BME patients;
- Helps improve overall quality of life for BME patients at the end of life;
- Minimises potential stress developing in staff that are not from BME backgrounds, as they may not have to feel culturally incompetent.

Aspects of caring perceived as stressful in palliative care

Several aspects of caring were associated with increased emotional exhaustion, depersonalisation and death anxiety among palliative care nurses. Below, are the aspects of caring that are to do with direct clinical care (C), workload issues (W) and areas of care where nurses perceived they lacked control (PC). Although recent literature reported by Jones and Cutcliffe (2009) highlights the difficulties of providing psychological care, it fails to specify which aspects these are.

This study is the first to identify the specific psychological aspects that are burdensome to nurses when caring for dying patients. For example, nurses who felt they were unable to control patients' psychological problems, including pain, reported increased levels of emotional exhaustion and depersonalisation. This is an important contribution to knowledge because nurses, nurse managers and educators can focus their training and education, not only on physical aspects of dying, but on understanding specific psychological needs of dying patients.

It is well documented (Tywcross 2003; Vachon and Benor, 2003) that psychological aspects of all patients are inevitably intertwined with other such attributes like social, emotional, spiritual, sexual and intellectual dimensions of being human. Therefore, care directed at psychological needs must also consider the impact on the rest of the dimensions. Provision of psychological care is fundamental to enhancing holistic care (Jones and Cutcliffe 2009), which is also central in palliative nursing. Therefore, nurses caring for dying patients also need to be supported, and Jones and Cutcliffe (2009) suggest that clinical supervision is an effective way to help reduce distress caused by emotionally charged situations, if nurses are to continue supporting patients with psychological needs.

The follow is a list of the identified aspects of caring that nurses reported as sources of pressure while caring for dying patients:

- Unable to control patients' psychological pain (PC),
- Doing your job without adequate resources (W),
- Having too much workload (W),
- Feeling excluded from clinical decision making about patient care (PC),
- Supporting children related to the dying patient (C),
- Supporting relatives by the bedside of a dying patient (C),
- Breaking bad news to relatives (C),
- Supporting relatives while viewing the body (C),
- Witnessing a difficult death (PC)

Key: C = Clinical aspects; PC = Perceived control; W = Workload

Nurses who reported increased levels of death anxiety included those who had witnessed a difficult death and those who felt excluded from clinical decision making about the patient they were caring for. Identifying these aspects of caring is an important contribution in view of previous studies not having reported similar findings.

Although previous studies, (Maslach 2001; Vachon and Benor 2003), show caring as a source of burnout, this is too broad to be meaningful, so this current study has gone further and identified specific aspects of caring which are associated with an increase in emotional exhaustion, which in turn leads to burnout. Therefore identifying specific aspects of caring as sources of emotional exhaustion helps nurses, managers and educators in their quest to prevent or minimise the development of burnout by detecting and managing early signs of emotional exhaustion.

The clinical relevance of understanding which aspects of caring lead to increased emotional exhaustion is thus:

- Palliative care nurses are repeatedly exposed to emotionally charged situations and therefore require repeated support if they are to continue providing effective quality care to dying patients. It is important that this equation is balanced and maintained;
- When nurses experience emotional exhaustion, they may, and most probably will, protect themselves psychologically by distancing or depersonalising their care from patients. Similar examples were reported in the Stafford Inquiry which sadly resulted in unexpectedly high patient mortality rates (Francis 2010);
- Nurses may then begin to perceive themselves as incompetent in their own job, thereby leading to a lack of career (job) satisfaction (Jones and Cutcliffe 2009);
- Holding such a perception of incompetence may not only affect the quality of care delivered to dying patients, but may signal an exodus of nurses from caring for dying patients, of which the implications are wide ranging

In addition to providing poor quality depersonalised care, nurses may also distance themselves from their friends and family, as the following comments from two of the respondents show:

> ***"I never feel callous towards patients, but when I get home from work I avoid contact & interaction with neighbours, sometimes friends, & occasionally family. I feel there is nothing else to give & I just don't want to go there!" 159***
>
> Lessons to be learnt from this can be that, the impact of emotional exhaustion does not only affect patient care, but nurses' social life and family relationships as well.
>
> ***"Caring for someone dying of a dreadful cancer (facial) will not leave my mind when I finish my shift" 66***

The fact that the experience of caring for someone dying from cancer can remain in a nurse's consciousness well after working hours suggests that more needs to be done to support nurses to debrief and 'offload' regularly.

Examples such as those given above do not occur overnight, but through a prolonged process where emotional exhaustion has continued unabated over a long period of time. Therefore it is important that emotional exhaustion is prevented or minimised before it develops further into a debilitating state of burnout.

Finally, findings from this current study suggest that, although around 90% of nurses working in hospices, hospitals and the community experienced moderate levels of death anxiety, the number of nurses who went on to develop high levels was much lower (table 31), with 13% of nurses working in the community presenting with the highest levels. A similar picture also emerged from the levels of emotional exhaustion (table 32) with 23% of nurses working in the community experiencing the high levels. These figures may lead to numerous conclusions but including the possibility that social support may have played a part in ameliorating levels of emotional exhaustion. To have real evidence a longitudinal study may provide data on the how emotional exhaustion develops and identify factors that moderate it along the way.

Relationships between social support, burnout and death anxiety

The literature suggests that one of the strategies to avert burnout is introducing some interacting variables such as social support (Bakker et al 2005), which help nurses to regroup and reenergise themselves. Findings from this current study suggest that, regardless of length of their experience working in palliative care, nurses who felt supported by their line managers experienced less emotionally exhausted while caring for dying patients. This may suggest that such nurses will be less likely to distance themselves from their patients, continuing to offer high quality care that is patient centred. When support is provided for nurses, it is most likely that they will use it to debrief and may not 'take work home', but be able to promote the work/life balance as advocated by Borrill (1996), the RCN (2006) and Bayliss (2006). One of the respondents working in the community setting captures the importance of being supported at work through the following quote:

> ***"I have a good social support network, I try not to take work home. My employer always enables us to off-load formally & informally through meetings & clinical supervision & debriefing. I attend very few work-related funerals (only 3 to date)" 91***

However, the contrast in feelings seems quite vivid when nurses feel unsupported as demonstrated by the comments below from two hospital based nurses:

> ***"Feel continually under pressure. Have had time off sick due to inability to cope at work, feel unsupported at work. Not enough opportunities to debrief' after difficult incidents. Feel I have been working closely with terminally ill patients for too long" 8***

The first quote may suggest that the nurse is exhibiting signs of emotional exhaustion, and believes a break from caring might help to re-energise and regroup, whereas the second comment below suggests a sense of depersonalisation and cynicism. Although both nurses show that they have a desire to care for dying patients, the lack of support for their efforts seems to be the problem. Maslach et al (2001) and Vachon and Benor (2003) warn that if emotional exhaustion and depersonalisation continue unabated, nurses may experience the burnout syndrome. One consequence of this is ill-health, which leads to absenteeism.

> ***"I sometimes feel that as carers looking after dying people, others do not look after us eg management. Lack of compassion when something goes wrong in our lives. Sometimes it seems as if our work is just a business and the financial side is more important than looking after your staff" 95***

The above comments demonstrate more support from managers is needed to enable debriefing to take place after each significant or traumatic event. Managers and educators can devise ways that are most appropriate to support nurses before they get to feel this way.

There is evidence from the Stafford Inquiry (Francis 2010) that lack of support for nurses resulted in the same nurses, once dedicated to caring, being rude, hostile to patients characterised by failures to respect patients' wishes and no longer referring to them using their preferred names. It can be argued that this behaviour signals that nurses may have exhausted their compassion, hence they appear to lack the sensitivity expected as they experience compassion fatigue (Smith 1992; Munroe 2003). The impact may affect other indirect aspects of care as highlighted by the Stafford Inquiry, where communication became impersonal and insensitive. Nurses were reported as failing to listen to patients, failing to engage properly with families and wrong information was commonly given to patients. In palliative care, the timing and provision of accurate information to patients and their families is critical. Patients and families need such information in order to make important decisions as the patient's condition might deteriorate suddenly.

Levels of death anxiety and measures of burnout between two studies

Findings from this study are consistent with those from previous studies, ((Barstow 1980; Gray-Toft 1981; Krikorian and Moser 1985; Vachon 1987; Mallett 1988; Bene and Foxall 1991), in that death anxiety correlated positively with burnout. The fact that the strength of the correlation between the two variables was weak in this study and also in Mallet's study, suggests a need for further research with a larger sample. Mallett's (1988) study reported a similar level of correlation coefficient to what this study found, and table 46 shows a comparison from the two findings.

For purposes of discussion, correlation coefficients from this current study are labelled as 'Current Doctoral study', and should not be misconstrued to suggest that the study has already been accepted and published.

Table 46: Correlations between death anxiety and burnout from Mallett's (1988) and Current Doctoral (2010) studies

Variables	Death anxiety	Direction and strength of correlation
Burnout	(.17) (.165*)	Positive and weak Positive and weak
Emotional Exhaustion (EE)	(.20) (.211**)	Positive and weak Positive and moderate
Depersonalization (DP)	(.21) (.204**)	Positive and moderate Positive and moderate
Low Personal Accomplishment (PA)	(- .01) (-.140*)	Non significant Negative and weak

Index: black = Mallett's (1988); Blue = Current Doctoral (2010)

Interestingly, in both studies shown in table 46, when levels death anxiety are correlated with each of the three components of burnout that is, (EE, DP and PA), the correlation coefficients increases slightly and are significant at p= 0.001 level. This increase takes into account the fact that low personal accomplishment scores in a different direction to the other two components.

From this analysis, it seems that burnout syndrome can be best understood by considering the scores of its three components separately. This argument has been made repeatedly throughout this thesis and some of the measurements in this thesis focussed on emotional exhaustion and depersonalisation instead of the burnout syndrome. This is a new and important contribution, (which Mallet and other previous studies do not highlight), for other researchers when measuring burnout in future samples, and for educators when facilitating lectures on the burnout syndrome. There is evidence (Weber and Reinhard 2000, Maslach and Schaufeli 2001) that burnout results from a continued increase in feelings of emotional exhaustion and cynicism, therefore detecting emotional exhaustion first may offer an early opportunity of preventing it from developing into the burnout syndrome.

There is now a need for research to ascertain which of these two variables, death anxiety and burnout develops first. Establishing this would also help to determine the independent variable, and any intervention would be aimed at manipulating it, in order to affect the dependent variable (Bryman 2004; Polit and Beck 2008). This highlights an important gap which could form a basis of future research.

Relationships between caring, death anxiety and burnout

This study is the first to investigate the tripartite relationship between caring, death anxiety and burnout. The study also investigated the relationship between the different aspects of caring and death anxiety/burnout, therefore adding, albeit in a small way, new knowledge to caring in palliative care settings. This study has confirmed in table 37, the specific aspects of caring that are perceived as sources of pressure by palliative care nurses.

In addition to showing relationships between aspects of caring, burnout and death anxiety, it was considered relevant to also show whether experience made a difference in the nature of the relationship. Experience, (discussed in more detail below) is thought to be critical for nurses who develop intuitive practice and can easily home in on a situation (Benner 1984; Castledine and McGee 1998). The assumption is that with experience and expertise nurses would be familiar with death in this case, and therefore may not feel anxious about their own death.

The findings from this study suggest that even for experienced nurses, each death is a different experience for them to cope with. This is important to change attitudes of managers from expecting experienced nurses to cope with witnessing death repeatedly, to recognising that they too require social support if they are to continue caring for dying patients.

This has important clinical relevance, in light of different types (cultural) of dying patients that nurses care for, in that they need a wider cultural frame of reference if they are to anticipate the needs for each patient who is dying.

Emotional investment

As Vachon (2003) and Munroe (2004) claim, nurses who give emotional care continually end up experiencing emotional exhaustion themselves, which leads to depersonalisation and ultimately to the burnout syndrome.

When emotional investment through caring is evident, it can be argued that, in order to avoid or minimise burnout, nurses may benefit from taking "time out" from the clinical practice to re-energise and this point is captured clearly by one of the respondents who says this about caring:

> ***"Emotionally and physically draining. Nursing in palliative care has a shelf life, approx 5 years, after that its harder to cope, sickness levels increase. However, most rewarding job I've done nursing over 30 years." 63***

What is interesting from this quote is that despite the perceived emotional and physical drain, caring for dying patients is still rated as most rewarding. Therefore, nurses may continue to care for dying patients regardless of the emotional hardships. It is important that research is undertaken to ascertain if such breaks are helpful for all nurses caring for dying patients. The length of such breaks would also need to be determined to allow enough time for re-energising by nurses concerned.

It is possible that some nurses, like the respondent quoted below, may feel caring for dying patients over longer periods helps with her/his own personal growth, and is therefore something worth pursuing.

> ***"When caring for the dying for a number of years it makes your interaction with patients change to become deeper and meaningful. Early career physical aspects are focused on more. Working at a more emotional/spiritual level makes you look at yourself more and why we respond like we do!" 155***

Others may see it as a privilege which can only demonstrate the paradox of emotions experienced by nurses when they care for dying patients.

> ***"It's a privilege, you feel quite honoured to be involved in such a private matter ie birth/death of someone" 114 & 112***

Based on these differing views, it is logical to suggest that caring for dying patients presents a paradox of emotions and therefore demonstrates why managers should regard supporting palliative care nurses a high priority.

It is possible that some nurses may be able only to focus on the positive aspects of caring, which may help them to avoid experiencing the effects of stressful situations found in caring. In that case, such individuals may continue caring as this respondent clearly articulates:

> ***"There is a positive element to helping pts have a good death which balances the scale of stress involved in the caring during the dying process" 29***

However, it must be pointed out that maintaining a positive attitude to caring, relies on effective cognitive functioning, and evidence discussed earlier in chapter 3 (Rolfe and Freshwater 2001), suggests that caring can eventually lead to psychological distancing, therefore managers still need to be alert to this possibility. For example, efforts from continual professional development (CPD), clinical supervision and mentorship should all help to support palliative care nurses cope with care of dying patients.

Experience, death anxiety and burnout

Experience of caring for dying patients was a focus for this study. As shown in chapter 8, respondents were split into two groups one with less than 10 years experience and the other with over 10 years experience. In this context, experience is taken to concur with Gadamer's (1989), and de Vocht and Nyatanga's (2006) idea that it is not merely the passage of time while someone is engaged in an activity, and in this case, caring for dying patients, but instead, it is the refinement of theories, thoughts and learning through the encounters with death and dying episodes.

Although, it was difficult to ascertain whether this type of experience as espoused by Gadamer existed in the respondents for this study, it was however, felt that longevity in post (although not completely accurate assessment of experience on its own) was the only likely determinant available to use as a measure of their experience in palliative care. The use of longevity can be justified as a valid criterion, if we consider as already discussed in chapter three, that burnout is the end result of long exposure to chronic job stressors (Maslach 1996; Weber and Reinhard 200; Jenkins and Elliott 2004). The assertion suggests that burnout is a 'condition' or syndrome that develops over years and through different phases.

Admittedly, the cut off point at 10 years was also another difficult decision, but considering evidence from other fields of study (Benner, 1984 and 1996; Woolery 1990, Hampton 1994), minimum of ten years experience seems to suggest mastery phase in most activities to do with knowledge and skills acquisition. The complex nature of palliative care means that most nurses would have encountered a range of deaths and dying episodes in the first 10 years but not expected to have developed intuitive abilities in caring or assume mastery of their roles. This assertion is also in line with Benner's idea of a minimum of 10 years before one can begin to function as an expert nurse (Benner et al 1996).

The findings suggest that some aspects of caring for dying patients (for example those in table 37) may provoke these nurses to think of their own death more, thereby raising the prospect of their own death to the level of consciousness. The following comment from one of the respondents goes some way in explaining the above and also shows a different type of fear that may arise:

> ***" I sometimes wish I had less insight into the dying process. Instead of fear of the unknown, I think I may now have fear of the known. Is that worse?" 158***

It is important for managers to understand that for these nurses and many others who may be thinking in this way, effective ways of supporting them is fundamental if they are to continue to provide quality care. Such nurses may need time and space to debrief and discuss their fears in order to reconcile them with reality.

Death anxiety and burnout in hospital, community and hospice nurses

This study focussed on three distinct settings all different in terms of the physical locations. These are hospices, hospitals and the community settings. Results from this current study reveal that hospital nurses show the highest levels of death anxiety and burnout than the other two settings. Nurses from the hospice showed least levels of death anxiety whilst nurses from the community showed most levels. This finding appears consistent with previous studies such as Payne et al's (1998) which reported that hospice nurses experienced the least levels of death anxiety. In terms of emotional exhaustion, there were very small differences but nurses from the community showed highest levels whilst nurses from the hospice showed least levels. These are important findings, but what is not yet evidenced is what mechanisms help hospice nurses to experience such low levels of death anxiety and emotional exhaustion. This would be a basis for future research to establish the factors that contribute to such low levels and whether there are any structures in place used to offer social support to nurses.

Given these results, it appears that, although nurses in these three settings care for dying patients, the difference may be the level and types of support available for nurses. Hospices in the UK are independent to set their own standards of care and tend to include social support for their staff (Payne 1998; NCPC 2003). According to Doyle and Hanks (2005) observation, nurses working in hospices seem to be more autonomous than those working in other palliative care settings which suggest that they are more involved in decision making about the care of patients under their care. This claim can be supported by the findings from this current study where one of the aspects of caring found to provoke emotional exhaustion was not being included in decisions about the future of patients under one's care. In addition to autonomy, Randall and Downie (2006), claim that the nurses working in hospices often receive support in the form of clinical supervision a strategy proven to help personal and professional development (Bayliss 2006).

Another possible explanation is that nurses may not be able to plan care as they would if the patient were in hospital or hospice with facilities and resources in the same place. The fact that, nurses are 'visitors' in a patient's home may suggest that the nature of the relationship changes, in that they may not have as much control of the environment, in addition to being alone without the immediate support of the multidisciplinary team often found in hospices. All these factors may contribute towards high levels of death anxiety and emotional exhaustion

Hospitals are part of the large National Health Service, and the same nurses care for both terminal and non-terminally-ill patients on the same ward. This type of care creates competing philosophies with different care outcomes; one being, a dignified death (WHO 2002) while the other is to achieve full independence and discharge back into the community as quickly as possible (Twycross 1994; Ellershaw and Wilkinson 2003, and Doyle, et al 2005). It can be argued that such focus and pace of care might be a source of death anxiety and emotional exhaustion (burnout) among nurses working with dying patients, because the same nurse has to re-focus the intended outcomes of care between the different patients. This means, on an emotional level, the nurse may end up oscillating between cure and care, which may be emotionally exhausting.

It is well documented (Doyle, et al 2005; Ellershaw and Wilkinson 2003) that symptom control is not as effective in hospitals when compared to hospices and other palliative care settings. The implication is that patients may be dying in pain which could also distress relatives. This study has shown that, if hospital nurses are witnessing deaths characterized with pain and distress, their own stress and anxiety levels will rise. Witnessing such deaths, may also make nurses more anxious about their own mortality. Such deaths may also be emotionally draining as nurse may feel ill equipped to control distressing symptoms. Inability to control distressing symptoms has been shown in this study to be associated with rising levels of death anxiety and burnout.

Areas with no correlation between variables

Inevitably, there were some areas in the study that emerged with no correlations; the following section highlights these areas:

- No correlation was found between age and death anxiety among nurses
- Similarly, there was no correlation between age and burnout. This was also true when using the three components of burnout, that is, emotional exhaustion, depersonalisation and low personal accomplishment. This finding is contrary to early study by Maslach (2003), who reported that burnout was positively correlated with young age. Maslach claimed that younger people lacked work experience and were therefore prone to developing burnout.
- Nurses with experience of less than ten years did not show relationship with either death anxiety or burnout. This finding was contrary to Maslach's (2003) study, which reported that most workers developed burnout within the first years of their career. This period ranged from one to five years depending on which sector one was working. For example people working in psychiatric services had their critical period of developing burnout between one and two years. Those in social services ranged between one and five years.

- There was an inverse relationship between performing last offices and death anxiety. This means that the more nurses performed last offices, the less they experienced anxiety about their own death. This result seems to suggest that nurses may look forward to performing last offices as a way of closure. It is interesting to review this possibility and understand it in light of current thinking. The following section briefly discusses how last offices can be used as closure for nurses and the patient they cared for.

Closure with the dead patient

Results from this study suggest that nurses may 'use' performing last offices as a way of closure with the dead patient. Results show an inverse relationship between performing last offices and nurses' levels of death anxiety. These findings support results from an earlier study by Kwan (2002), which found last offices to be rewarding. When performing last offices, nurses are ideally aiming to present a 'body' that is calm and peaceful. Such an image is believed (Kwan 2002) to be ideal for those paying their last respects to capture as a lasting memory of the dead person before funerary rituals commence.

For the bereaved, viewing this peaceful body may be the first positive step of a critical transition moment in their life without the dead person (Kwan 2002). When performed well, last offices can facilitate grief and give purpose at a time when the bereaved are liable to feel lost and emotionally helpless (Worden 1991; Faulkner 1995).

It can be argued that viewing such a peaceful appearance of the body will help to emotionally calm the bereaved. For those performing last offices, Kwan (2002) claims there are five main benefits, namely:

- Acknowledgement of the reality of death;
- Fulfilment of caring responsibility by completing a traditional obligation;
- A sense of completeness (that is, closing the chapter with the patient);
- Process and platform for conveying gratitude and respect to the deceased;
- Honouring the body by making the deceased look 'good'

From this brief summary, palliative care nurses in this study may have felt it a privilege, and part of their traditional and professional obligation to perform last offices to help the bereaved. For nurses, the suggestion that last offices may provide a sense of completeness in terms of 'closing a chapter with the dead patient' may be true judging by the comments from one of the respondents, who was off duty when a patient died:

> ***" I felt I needed closure when the patient died when I was off duty. I knew I would not see them again to wash them or say goodbye. I feel guilty bringing work home and talking about these patients to my family" 134***

Ideally support should be offered after each death (or on return to work for nurses who are off duty when death occurs) so that any debriefing is specific to that death, thereby reducing the long term impact on the nurse.

Therefore, for nurses the need for closure through performing last offices and the desire to help relatives with their bereavement are probably the most persuasive explanations of the inverse correlation found in this study.

These comments and the rest of the findings from this study suggest a need to support nurses who care for dying people in order to reduce their levels of death anxiety and burnout. There are numerous ways such reduction can be achieved, and the next section discusses some of these. It is important that nurses lead in strategies to reduce their death anxiety and burnout and employing organisation should play their own part as well.

Reducing death anxiety among palliative care nurses

Reducing death anxiety has to start with changing people's attitudes towards death. It is important for society at to openly talk about death in order to increase its familiarity and thereby reduce its fear among people. One strategy is to enable where possible, patients to die away from institutions like hospitals and in their own homes or those of willing family members. Enabling this to happen means dying is experienced in family homes and young family members can also be involved and witness death early in their lives.

Despite increased literature and coverage of death and dying experiences, one in four people in the UK think death is a taboo subject (DH 2008). The end of life care strategy recently published by the Department of Health (DH 2008) in the UK focuses on raising the profile of death and dying by talking about it across society as a whole. This will include engaging with schools (primary and secondary), different faith groups, funeral directors, care homes amongst others. At a national level, the Government will work with national bodies to form coalitions such as 'Dying Matters', (Addicott and Ashton 2010), which will help raise the profile of death and dying across adults in society (DH 2008).

It is important to realise that, such change will not happen overnight as this involves attitude change which is about altering perceptions and deeply held views and beliefs. What may make attitude change difficult is the fact that everyone accepts the certainty of death, but will not always contemplate their own death as a possibility. It is this psychological 'gap', which according to Williams (2005) and Nyatanga (2008), offers a possible explanation as to why most people find it difficult to talk openly about death, let alone accept it.

In clinical practice, it is important to ensure that nurses are supported all the time through preceptorship (Sharples and Elcock 2011), that is, for first four to six months of starting in new posts, and mentorship and clinical supervision, thereafter. The ideas of preceptorship and mentorship ensure that newly qualified or appointed nurses are given the necessary support they need as they develop competences in the new field of work (Morton-Cooper and Palmer 2000).

Managers need to accept that although the process of providing preceptorship and mentorship support requires extra time and resources in the short term, it is a worthwhile investment in the long term as these nurses will be better able to 'handle' stress and thereby preventing the burnout syndrome affecting their performance or the extreme cases of absenteeism. If left unsupported, it is possible from the evidence given so far particularly in chapter 3, that most nurses will develop burnout and therefore will be off sick from caring.

Finally, if, as suggested by Psyszczynski (1999), death anxiety is viewed as terror, it will require more than one nurse to manage it, hence the need for nurses to work in unison. This suggests that all palliative care nurses may need to adapt a similar cognitive pattern of thinking about death, so that their behaviours are congruent, in order to facilitate the group's (nurses) ability to manage the 'terror' of death anxiety. Working in multi-disciplinary teams must be enhanced as a source of support while learning from differences in approach to care.

There is evidence, Psyszczynski (1999); Lawton, (2000); Kastenbaum, (2000), and Sani et al (2009) that individuals use groups to buffer their mortality salience anxiety and palliative care nurses would be no different. It is therefore important that multi professional teams found in palliative care are effective and offer support to each team member. More important, is that managers should offer support to such teams through regular up dates for individual members and also as a group.

Reducing burnout among palliative care nurses

There are several ways of reducing burnout among the nurses (Weber and Reinhard, 2000; Maslach 2003). Discussion will start by considering strategies that can be used at a micro (personal nurse) level and then move on to examine strategies at organisational and national levels. The micro level approach is important as it not only emphasises the need for individual nurses to help themselves first, but recognises the stringent financial cuts currently prevailing, where employers might be fo4ced to cut funding for supportive strategies. The micro level strategies encourage those individuals who may not always be comfortable expressing their anxieties and difficult personal emotional situations in groups, and therefore learning to help themselves would help overcome such issues.

For individuals, it is important to recognise that the same strategy may work for some and not work for others. It is also true that some strategies may require peers to be involved as well so that success is achieved. Some of the individual strategies for minimising burnout will now be highlighted and discussed in light of the three dimensions of burnout, that is, emotional exhaustion (EE), depersonalisation (DP) and low personal accomplishment (PA).

Setting realistic personal goals

(Strategy is to manage EE and DP)

It is probably a tendency of most nurses working in palliative care to want to achieve the best for all patients. Some of the goals set may be idealistic, and when they are not achieved may result in nurses feeling less interested in the well-being of patients, therefore depersonalisation of care occurs. The strategy is to realise that the reality of caring may not always support the ideal, therefore there is a need to set goals that are realistic and achievable. Nurses have to always to remind themselves that goals set should take into account the reality and context of the situation. For example, planning to spend two hours assessing each newly admitted patient to the hospice when there could be a total of 5 patients admitted on the same day, may not be realistic. Nurses should avoid work overload that may make their practice unsafe.

Resisting the temptation to work harder

(Strategy is to manage EE and DP)

When nurses are overwhelmed with workloads, the tendency is to work even harder in order to catch up and be in control again. By so doing, they in fact put more pressure/stress on themselves and end up doing more of the same, and thereby increasing the levels of emotional exhaustion initially, and then later may develop a cynical dislike (psychological distancing) of the patients they are supposed to care for. It is quite possible that nurses may even begin to perceive themselves as incompetent, which can affect the quality of care they give.

The strategy is to work smarter, and that may include reviewing the workload, prioritising work and even delegating more (Covey 1990). If there is too much workload, a discussion with peers and manager is important to find a way of rebalancing the workload if needed. Working smarter also means knowing one's strengths and weaknesses and the best time of day to perform activities.

Breaking the continuity

(Strategy to manage EE)

Taking into account the last two strategies above, nurses often find themselves working continuously with dying patients' emotional needs, and this can eventually take its own 'toll' on the nurses (Smith 1992; Maslack 2003; Vachon and Benor 2003). The strategy is to break the continuity by taking breaks (eg short holidays) at regular intervals to allow a psychological distance between the nurse and caring. Such breaks can also allow rejuvenation of nurses or what Maslach (2003) calls, 'emotional breathers' as they enable the nurse to 'cool off' emotionally. Depending on where nurses work, they can negotiate with their managers to rotate to different care environments as a way breaking the continuity of caring for dying patients where it is the main issue.

Investing in education and training – Individual

(Strategy to manage EE, DP and PA)

The current economic climate characterised with severe financial cuts tends to result in all education and training for health care professionals in general and nurses in particular being cancelled. The impact may be that nurses are not given a platform to reflect on their own practice, while learning further about how patients at the end of life might react and what their needs might be. This practice may lead to nurses continuing to do things as before and at times to their care not being sensitive to the needs of the patients. Sadly when nurses are deprived of essential education their creativity suffers and patients often are the recipients of stale care.

The strategy is to negotiate with employers to be allowed time out for studies and for nurses to contribute towards the cost their own education where funding is really scarce. Nurses should also engage more with e-learning or distance learning which allows flexibility and less travel time. Finally, all nurses should be keeping themselves up to date through reading relevant publications.

The following section discusses strategies which organisations and the government should adopt as a way of reducing burnout among palliative care nurses.

Investing in education and training - organisational

(Strategy is to manage EE, DP and PA)

While this is a personal strategy, it works better if it is well supported by both the organisation and the current Government, therefore it is also an organisation strategy. Although, during financial hardships, there may appear to be benefits in terms of savings by organisations when they cut or stop all education and training, the reality is that this can only be 'false economy' because long term, nurses may go off sick due to burnout, and the overall care provided will suffer. This may result in probably increased complaints from bereaved relatives and complications in their own bereavement as a result of witnessing undignified deaths of their loved ones. Nurses may start to feel cynical about caring and perceive themselves as less competent (Maslach 2001; Vachon and Benor 2003).

The strategy is to negotiate with nursing staff and offer them time out and for them to partly self-fund as a short term measure. Organisations should encourage more in-house training, preceptorship for new staff, mentorship for all staff and also develop closer links with universities to deliver some of the training in the work place.

Promoting education through E-learning

Employers can purchase e-learning materials and make it available to all their staff. This has many benefits particularly were professionals are working full time and and experiencing a shortage of staff. Professionals can study for free on these e-programmes. Secondly, professionals can learn in their own time and when it suits them best.

Investing in social support

(Strategy is to manage EE and DP)

Several commentators including Barnes (2001); Hulbert and Morrison (2006); Smeija, et al. (2006), claim that social support has a huge impact on reducing stress in life in general and in the work place in particular. Social support can be viewed as any protective intervention to buffer or cushion the individual from stressful events, before they develop to more serious conditions like burnout. Caring for patients at the end of life involves being exposed continuously to their death and dying experiences, with the nurse offering emotional support all the time, therefore their protection is paramount.

Social support as an effective strategy

Out of all the different strategies offered to ameliorate burnout, enacted support seems to be most relevant for nurses working in palliative care settings, as it targets symptoms of emotional exhaustion. Enacted support can be multi faceted to include emotional support (e.g. talking, listening and focussing on how one is feeling), problem solving (eg discussion and information giving), and environmental action (eg actual intervention to reduce the stress) (Barnes 2001; Smeija, et al 2006; Ringdal, et al. 2007). This type of support can be offered through clinical supervision on a regular basis.

Ideally, clinical supervision should be provided on an ongoing basis (Morton-Cooper and Palmer 2000; Bayliss 2006), even before a crisis arises. Employers and managers would have a responsibility of budgeting for this service to enable every staff member to access it. One way of reducing costs is to train existing senior employees as clinical supervisors, so that they could offer support to others as part of their job.

When executed properly Ringdal et al (2007) claim that social support can help others in three main ways:

- Emotional support - which involves communication of caring and concern and offers a platform for expressing one's feelings safely. It works by reducing distress and at the same time increasing self-esteem;
- Informational support - which provides information used to guide and is believed to enhance perceptions of control of situations;
- Instrumental support - which is also called practical support, that is, the actual provision of practical assistance and materials which all help the other person to gain control over the situation.

Finally, it is also important that managers and employers regularly monitor staff through occupational health departments, for early signs of emotional exhaustion and death anxiety. Such monitoring can be undertaken by measuring the components of burnout using the Maslach Burnout Inventory, and death anxiety using the Templer's Revised Death Anxiety Scale. Because burnout is a syndrome, it is important for managers to monitor its three components for any early signs of emotional exhaustion, which can be dealt with whilst in its formative stage, and more cost-effectively.

Conclusion

The findings from this study are consistent with previous studies particularly those in North America. However, these studies were undertaken in the 80s, which means this current study is timely. Death anxiety was positively associated with the measures of burnout. This study was probably the first to confirm, through multiple regression, that caring is a unique statistically significant predictor variable of emotional exhaustion. Because emotional exhaustion is the first phase in the development of burnout, it is plausible to conclude from these findings that caring is by extension also a predictor of burnout.

There were important contributions from the findings, and clear implications for practice were highlighted for managers, policy makers and educators. This study confirmed how central caring is in the development and prevention of both death anxiety and burnout. Therefore, it is important for managers to understand the aspects inherent in caring, as shown in table 46, that may induce death anxiety or burnout, so that they can devise the most effective strategies to support nurses. It is true that nurses may continue to care for dying patients even if they know they will end up being physically and emotionally exhausted. The consequences are far reaching, in terms of ill health, poor care provision and absenteeism.

Therefore, managers and educators need to be alert to this and find ways to support and protect nurses as they continue to care for dying patients and allow them to re-energise regularly before they reach the burnout stage. A number of strategies were offered for both nurses and managers to adopt in an attempt to reduce levels of death anxiety and burnout among all palliative care nurses. Early detection of emotional exhaustion offers the best solution in combating burnout in a more cost-effective way because at this formative stage, nurses are still functional and providing palliative care. Doing it this way means that everybody is likely to win, that is, nurses stay healthy and avoid absenteeism, employers cut down on potential costs of hiring agency nurses to cover for absenteeism and patients continue to receive high quality of care. When this happens, it is plausible to suggest that the quality of life for patients is enhanced and death may be dignified for their families as well.

CHAPTER 10: METHODOLOGICAL CRITIQUE

Chapter overview

The chapter is a critique of the methodology used and highlights its strengths and weaknesses. The decision trail for choices made is discussed in light of this exploratory study.

Strengths of the study design

One of the strengths of this study is its use of correlational survey research design to measure mathematically relationships between variables of death anxiety, caring and burnout. The study included caring as a variable, which is the first time any study had examined it and its relationship with death anxiety and burnout. The aim of the study was to investigate the relationships between caring, death anxiety and burnout and not to establish causal effects between them. Therefore, a correlation approach was the most appropriate measure to establish the nature of the relationships (Parahoo 2006, Polit and Beck 2008; Bryman 2008; Bowling 2009; Creswell 2009). Correlation can confirm whether a relationship between variables exists or not, but without suggesting that one variable caused the other to change or react. The only reliable conclusion to be made from this approach is to claim a positive or negative relationship between the variables of interest, and which can be graded as strong, moderate or weak. The strength of using correlation is, according to Field (2005), and Tabachnick and Fidell (2007), that it produces a correlation coefficient that can determine the strength and direction of the relation, that is, from perfect relationship, which could be positive (1) or negative (-1) to no relationship (0) between the variables of interest.

This study achieved a response rate of 61%, which according to the purpose and exploratory nature of this study is acceptable. However, it is hard to find consensus on what is an acceptable response rate. For example, Bryamn and Cramer (2001) would consider the response rate for this study at 61% acceptable for generalisability, and Kumar (2011) would confidently accept a 50% response rate; whereas, Mangione (1995) argued that response rate between 50-60% is barely acceptable.

On the other hand, Passmore, et al (2002) argue that generalisability is impossible with a response rate below 70%.

Although there are these different permutations or schools of thought on what is acceptable response rate, all these commentators and also Parahoo (2006) and Oppenheim (1992) included a caveat or proviso in their arguments, that is, the acceptability of a response rate may vary according to the purpose and nature of the study. Admittedly, it is important to achieve a high response rate as this indicates greater representativeness of the sample and therefore researchers can have confidence in generalising their findings. However, the fact that this current study was exploratory in nature meant that a 61% response rate was considered to be acceptable but without forgetting the 39% non-responders, as they most often have different views and perceptions from those who responded (Parahoo 2006; Kumar 2011). However, it is not always clear why participants may not respond, and all that can be done is end up speculating possible explanations. For example, they may be too stressed out to respond, or not stressed at all but can not be bothered to respond. The truth is we may never know, therefore raising the question of whether it is worthwhile speculating on reasons for non-response as we will never know becomes academic. One possible way forward is for future research to be undertaken with a much bigger sample and try and achieve an even higher response rate than 61%.

This study followed procedures that would enhance its rigour and ethical soundness. In addition to MREC approval, further ethical approval was gained from Research and Development (R & D) departments across the NHS Trusts and hospices. The use of a contact person in each study site was a strength in that, it ensured respondents' anonymity were preserved; there was no direct contact between them and the researcher. Each contact person identified potential participants within their organisation using the agreed inclusion/exclusion criteria. Information giving meetings were arranged between the researcher and contact persons, where the study and role of the contact persons were explained. The strength of such meetings was that contact persons felt included in the study, had a platform to ask questions and were actively engaged with the process as a group.

Two reminder letters were sent out via contact persons, and the strength of this was that respondents were further assured of their anonymity.

Reminders

It was important to give all respondents a chance to express their views in this study. Therefore two reminders were sent out at separate intervals that is, at six and eight weeks, after the first questionnaires were sent out. These reminders generated a handful of responses, which were included with the main data for analysis. It can be argued that data yielded from reminders may have been biased and therefore considered not to be valid because the respondents may have felt pressurised to return the questionnaires and may not have answered the questions truthfully, as they may have felt rushed. However, the same could be said about the first set of questionnaires, since there was a deadline by which to return the completed forms. It is extremely difficult to judge whether self-report questionnaires, be they reminders or first set sent out, were answered truthfully, as there is no objective way of verifying this. The fact that only a handful of questionnaires were received after reminders were sent out, the issues of validity and generalisability would not have been threatened.

Another strength of this study was the use of qualitative comments from respondents, which added richness and meaning to the numerical data. As discussed in chapter six, comment boxes were left at the end of each questionnaire for participants to add any comments, feelings and thoughts they might have about caring for dying patients. These comments, although few, have expanded textually on some of the responses given on the self report scales, thereby adding meaning to respondents' feelings and thoughts about caring for dying patients. To this end, the comments helped to address, in a small way, what most commentators such as Gillham (2000) and Cresswell (2009) regard as the weakness of quantitative methods of collecting data. It was a strength also that these comments were not based only on the last few questions answered on the questionnaires (Kumar 2011), but reflected questions asked at the beginning as well as the middle and end of the questionnaires.

Sampling

The use of convenience (non-probability) sampling for this study does not seem to be a weakness, contrary to O'Leary's (2007) claim, that this type of sampling limits the potential for generalisability of findings. Although O'Leary argues that quantitative studies should use randomisation, there is sufficient evidence (Bryman and Cramer, 2001; Bryman, 2008 and Cresswell, 2009) that most quantitative researchers are choosing or forced into convenience samples, because of problems with low response and attrition rates. For example, Bryman and Cramer (2001) cite published reviews which examined sampling methods used in 126 quantitative research studies, and found that only 21 were based on probability sampling. The rest encountered problems of low and declining response rates which often affect their random qualities. From this observation, Bryman and Cramer (2001) argued cogently that the difference in the relative representativeness between the two types of samples may be academic as they are not as distinct as first thought. It was with this in mind that a convenience sampling strategy was perceived as acceptable for this current study. The convenience of availability and accessibility of the sample was also a major factor in deciding the appropriateness of this technique.

Measurement scales

The use of existing self report measurement scales was an advantage and a strength in that their validity and reliability were already tested and established. The revised death anxiety scale (RDAS) was tested by a number of researchers including Neimeyer and Brunt (1984), Thorson and Powell (1988) and Neimeyer and Brunt (1995) with several large and diverse samples. Factor analyses of data showed that internal consistency was high with Cronbach Alpha reliability of .80, (n= 599) when tested with the smallest sample.

The RDAS was tested for this study for internal reliability and had a Cronbach Alpha of .85, (n= 205). According to (Bryman and Cramer 2001), this is an acceptable level, and therefore in selecting it, one can be confident that this measurement scale is internally reliable and measuring items from the same conceptual domain (Bowling 2005).

The use of the Maslach Burnout Inventory (MBI)was also a strength in that it is the most popularly used measurement scale for burnout among most researchers world wide. The MBI was tested for internal consistency for this study and the reliability of the scale was estimated at Cronbach's alpha of .70, (n=204), therefore in selecting it, one can be confident that it is measuring items from the same conceptual domain (Bowling 2005).

More importantly was that this study showed that such scales, although first validated in the 80s, are still valid to use in today's changing social and care contexts. This is an important confirmation for other researchers who can now have confidence in using the scales in future research.

The new scale (Sources of Pressure) which was developed for this study was tested for validity and reliability and factor analysis confirmed the three main factors comprising the scale. This is an important step in developing a measurement scale that can (after further refinements) be used in the future to measure aspects of caring in palliative care.

The use of data from self-report measurement scales is a positive decision, despite criticism from researchers such as Alarcon et al (2009), that such data leaves the results vulnerable to common bias variance. For this study, allowing participants to self-report recognises that they are in fact the best placed to report on their own perception of death anxiety and feelings of burnout. This decision of allowing self report is consistent with Spector's (2006) who endorsed the use of data obtained in the same way. Therefore, considering the time frame for this study, self-report scales were deemed the most appropriate vehicle to collect such information and therefore preferred.

Limitations of the study

Despite the important findings from this study, there were some limitations which need to be considered. The research questionnaires for this study were sent to an identified contact person within each organisation to ensure anonymity and for them to distribute further to participants. Thus there may have been some bias in selecting the nurses or omission of some all together, who may have provided more or different data for analysis.

Second, working under staff shortages, nurses may not have found enough time properly to complete the questionnaires, or complete them at all. Working under staff shortage can translate into quantitative work overload, which can lead to stress and burnout. Quantitative work over load was discussed in chapter 3 using findings from Zellers and Perrewe (2000) and Pines (2002) which concluded that such work over load stretches nurses' resources by placing more demands on their time. Working under such conditions, nurses may not have given priority to completing the research questionnaires, and as a result, their views could not be incorporated into the findings.

Third, it was not ethically possible to ascertain the views of palliative care nurses who were already on sick leave through burnout. It can be argued that their views may have offered different insights into burnout and death anxiety.

Fourth, methodologically, this study could have employed a combination of methods like Payne et al (1998) when they used both quantitative and qualitative research approaches in their study. The use of structured interviews as a follow on from questionnaires could have provided rich and more in-depth descriptions and explanations of how participants felt about caring for dying patients. Combining methods tends to provide a deeper understanding of the meaning attached to responses. While this is persuasive to employ, this type of method requires a lot more time and resources to complete and therefore can be resource intensive. The time limit for the current study meant that this method was not the most practical to use, and therefore was not preferred this time. This study has highlighted this point, and future research can use these methods and try to ascertain more in-depth data.

Fifth, the decision to use non-parametric tests, was based largely on non-normal distribution of the data collected (Bryman 2008), and coupled with a requirement the fact that data were not derived from a random sample. Use of non-parametric tests yields less powerful results, therefore leading to reduced confidence in generalisability of findings.

Sixth, empathy was not measured for this current study, despite being discussed in chapter two as an integral attribute needed in caring for dying patients. However, it is recommended for future research in order to establish whether repeated exposure to death and dying (as is the case with palliative care nurses) could eventually lower nurses' levels of empathy as a result of compassion fatigue. Compassion fatigue 'forces' carers to adopt a psychological defence mechanism of depersonalisation (Maslach 2001), which inevitably leads to poor patient experience as it affects the quality of care.

Seventh, from the literature review, not all identified variables, for example personality, religiosity, education level and co-dependency, were included as variables for investigation for this study. It is now well documented (Alarcon et al 2009) that personality factors like locus of control, self-esteem, hardiness, extraversion just to name a few, play an important part in how burnout develops in different people. Therefore future research can focus on these different personality factors and how they contribute to the experience of burnout among palliative care nurses. Co-dependency was discussed early in chapter two but omitted as a variable for this study. This is a limitation which should be address in future studies where co-dependency should be measured using the Holyoake Codependency Index and the scores correlated with those of burnout.

Eighth, the inclusion in the sample of nurses with three months experience of caring for dying patients may have been an oversight, since the development of burnout takes much longer than three months to be realised. However, having said that, results from this study have shown that length of time caring for dying patients is not correlated with burnout, emotional exhaustion or death anxiety, therefore this limitation may be academic, as it makes no difference in how respondents perceived death anxiety and burnout in this study. However, for future studies it may be advisable to consider the minimum cut off point (eg 1 year) of experience for nurses to be included in the study, as this will allow them more time to experience dying and death episodes of patients.

Finally, caution with the interpretation of findings is needed as data were collected in 2005, a period of the heightened terrorist activity in London, Birmingham and parts of continental main land Europe. The activities like London bombings could have resulted in most people's (including study participants) levels of death anxiety being raised especially with 57 people confirmed dead by the metropolitan police in London alone. It is likely that these terrorist activities may have acted as confounding factors for participants' increased level of death anxiety in this study.

Caution explained

The impact of war on levels of death anxiety of ordinary people is well documented by Abdel-Khalek following the military invasion of Kuwait by the Iraq army (Abdel-Khalek 2000; Abdel-Khalek 2002). Abdel-Khalek (2002) reported an increase in levels of death anxiety in ordinary Kuwait people after their country was invaded by the Iraq army. Abdel-Khalek had estimated the levels of death anxiety of the Kuwaitees before the invasion, therefore he was able to use the results as a baseline for the subsequent measurements following the invasion.

Terrorism and war were included as confounding variables, to acknowledge that during the time of data collection in 2005, participants also experienced the London bombings (twice in July 2005), Birmingham City attacks soon after and the Madrid train bombings. The war against terrorism and subsequent military invasion in Iraq and Afghanistan involving British forces was high in media coverage, and most likely on the minds of study participants. This period had security alert levels raised to critical level (which equates to the highest level possible) and the presence of armed police on UK streets and main airports was common occurrence.

Using Abdel-Khalek's (2002) findings, the point to emerge is that, because of the security situation at the time of data collection, the levels of death anxiety among the study sample may have already been heightened before data were collected. It is likely that some participants in the sample may have had relatives and loved ones involved in the war or terrorist attacks, and this would have had a major impact on their view of death and subsequently levels of death anxiety. It is from this background that a cautious and conservative interpretation of the results from this study was carried out.

Summary

Despite this study's limitations it is perhaps plausible to suggest that some generalisation of this study's main findings be made to the population of all palliative care nurses. Correlation designs are preferable when studies, such as this current one, look to establish associations between variables of interest (Bryman 2008; Creswell 2009). The sample size was large enough to provide normal distribution of data which permitted use of some parametric tests. Where normal distribution could not be established non-parametric equivalents were used.

The use of convenience sample may have its critiques, but its use with this study, has been argued as the best possible strategy given some of the problems of randomisation. This chapter clearly demonstrates the methodological rigour and ethical soundness of this study, which is important for readers to have confidence in the findings.

Finally, it is important that any limitations identified from this study are scrutinised to see if future research can be initiated to address them. This is an important aspect of this study, and indeed any research study, so that new knowledge can be generated. The next chapter will not only conclude the study but will make some recommendations for future research based on lessons learnt from this study.

CHAPTER 11: CONCLUSIONS AND RECOMMENDATIONS

Chapter overview

This is the final chapter of the thesis. It focuses on conclusions drawn from the study, and then makes recommendations for future research. Some of the recommendations are drawn from identified limitations and other from study findings. The chapter gives detailed strategies for managers to use to help reduce both death anxiety levels and measures of burnout. Ways of supporting palliative care nurses are given with emphasis placed on early intervention. Recommendations for educators and researchers are also offered in light of the findings from this study.

Conclusions from the study

Idealists like Emmanuel Kant (1724-1804, translated by Stokes 2006) would argue that, academic and statistical arguments must translate into practical application. He saw no benefit in dealing with these two ideas separately or in parallel. He argued that to have experience alone without theory is blind and on the other hand, to have theory on its own without experience is mere intellectual play. Having subscribed to Kant's argument, it was essential to show the clinical importance or utility of this current study.

To this end, the study findings show that some aspects of caring such as, not being able to control patients' psychological symptoms or nurses feeling excluded in clinical decision-making, contribute to increasing levels of death anxiety and emotional exhaustion leading to burnout among these nurses. Inability to provide psychological care has recently been reported by Jones and Cutcliffe (2009), not only as contributing to feelings of pressure or stress, but as detracting from empathic care, which is a crucial component when caring for dying patients. The importance of empathic care was detailed in chapter 2, where care is characterised with genuineness and sensitivity towards the other person's needs. This has important clinical implications, because, without empathic care, dying patients may not be afforded the individualised and dignified death that is unique to them. This may have further negative implications on their relatives as they come to terms with their loss, grief and bereavement.

Acknowledging nurses' contribution

Results from this study indicate the possibility of improved care for dying patients if nurses who are more experienced in decision-making are consulted when key decisions are made about patients under their care. Including such nurses allows them to contribute valuable insights about caring, and to feel a valued member of a multi-disciplinary team structure (Tywcross 2003; WHO 2002) which is central to effective palliative care provision. Including such nurses may mean that they do not feel inadequate because their best efforts go unnoticed or are not regarded.

Achieving effective control of symptoms gives confidence to nurses and a sense that they are helping patients die without suffering (Morse 2005; Bayliss 2008). Confidence comes with a sound knowledge base, which means all nurses need to be kept up to date with new thinking and treatment options for distressing symptoms particularly at the end of life. Keeping palliative care nurses up to date with symptom control treatments maximises their ability to be creative while providing the best quality of care possible which is likely to enrich the patient's experience. A lack of knowledge would have implications on nurses' practice which may result in poor quality of care. Nurses may feel less competent in their roles, experience job dissatisfaction and may result in some nurses moving jobs or leaving the profession all together. A more subtle problem discussed earlier is that of presenteeism, which is characterised by nurses distancing themselves from patients, erratic performances, drug errors and errors of judgement in their dealings with patients and their relatives. Serious consequences highlighted by this study might be that nurses become unwell as a result of burnout, which will in turn lead to absenteeism (Maslach, et al 2001). With absenteeism comes increased shortage of staff which will affect the overall quality of care. In some cases, extra costs are incurred by employing agency staff which affects continuity of care and subsequently nurse-patient relationship. All these may affect the quality of care received by patients and most likely impact on the dignity of their dying.

One of the wider implications is the impact such perceived failure might have on bereaved relatives. Similar situations were reported in the Stafford Inquiry (Francis 2010), but what is more worrying and can not be repeated is the high number of unexpected deaths and the difficult and painful bereavement periods for families thereafter. One extreme impact is pathological grief experienced by bereaved relatives (Worden 1991; Leming and Dickinson 2005), who might end up seeking medical and nursing care from the NHS. Providing care for such relatives has its own cost implications on the health service which is already facing financial constraints. What is important from a palliative caring perspective is being mindful to provide care that does not adversely impact on relatives and compound their grief with memories of suffering they witnessed as their loved one died.

Significance of the link between death anxiety and burnout

This study has shown that when levels of death anxiety increase so do those of burnout. This suggests that death anxiety and burnout are intertwined or linked and therefore providers and managers of palliative care need to be alert to the fact that what provokes the development of one of them will have an impact on the other one. Sherman (2004); Maslach, et al (2001); Mallett (1988) suggest that raised levels of death anxiety and burnout lead to poor quality of care as nurses review their own existential vulnerability and coping resources are depleted. The results from this study support this view and have also shown that aspects of caring which include heavy workload and perceived lack of control contribute to feelings of emotional exhaustion, depersonalising care, low competence, and may eventually lead to the burnout syndrome. It is important that in addition to understanding that heavy workloads may lead to all the above outcomes, managers should also be aware that some of the workforce may present with 'presenteeism', a phenomenon which suggests that, although they may be physically present at work, they are no longer able to function effectively in their roles. It is likely that significant errors and poor clinical judgements may occur as a result of presenteeism and patient care will suffer as a result.

When nurses experience work related stress and burnout, Palmer, et al (1994); Johns (2000); Rolfe and Freshwater (2001), suggest encouraging them to use reflective practice as a form of support. As already highlighted earlier in chapter three, reflective practice relies heavily on cognitive ability to recall incidents, and yet burnout reduces or obscures cognitive ability to think clearly let alone recall critical incidents. Therefore, the use of reflective practice with individuals experiencing burnout might not be as beneficial as first thought. The results of this study show a positive association between burnout and death anxiety, therefore, it follows that reflective practice may not benefit those with high levels of death anxiety either. In addition, encouraging the use of reflective practice with nurses experiencing increased levels of death anxiety might make their levels even higher or worse because the process itself makes them relive the very situation that is initially causing their death anxiety. To this end, educators need to find alternative ways to learning where reflective practice is compromised. For managers, there is an urgent need to utilise different strategies to support nurses in clinical practice, and social support seems most appropriate intervention.

Aspects of caring and their clinical relevance

The clinical relevance of understanding aspects of caring that lead to increased emotional exhaustion is thus: for providers of palliative care such as managers, the list offered below can be used a guide of warning signs and symptoms to look for in detecting early signs of burnout:

- When nurses feel emotionally exhausted, they tend psychologically to protect themselves by distancing themselves and their care from patients;
    - Managers need to look for changes in attitudes and patterns of behaviour towards patients and fellow professionals;
- Nurses may then begin to perceive themselves as incompetent in their own job;
    - Managers need to look for signs of reduced confidence, and hesitancy in decision making, and at times unusual errors of judgement;

- Holding such a perception of incompetence can affect the quality of care delivered to dying patients and their relatives;
    - Managers need to look for changes in the thoroughness of care being provided and the quality of documentation of the care. There may be increased complaints from relatives about the care being provided to the dying patient;
    - Monitor for complaints of poor communication skills with patients and relatives. Poor communication may suggest distancing by nurses as a way of protecting themselves from emotional exhaustion;

- In addition to providing poor quality of care, nurses may distance themselves from their friends and family, which could signal the beginning of social isolation and erosion (Astley-Pepper 2005);
    - Managers need to look for changing patterns in areas to do with interaction with professional colleagues and unusual drug administration errors. They also need to monitor increases in absenteeism and deteriorating staff morale in general.

This study strongly supports findings from previous studies, especially Mallett's (1988) study, cited earlier in chapter 5 regarding the relationship between death anxiety and burnout. The fact that these studies have independently arrived at similar findings, suggests that, despite caution expressed regarding the timing of the study, it does support the case for cumulative validity, which in turn increases the possibility of generalisation. Thus cumulative validity according to Hammersley (1992); Polit and Beck, (2008); Bryman (2008); and Cresswell (2009), denotes typicality of the phenomenon under study, although that phenomenon may not, in itself, be representative.

Caring as a predictor variable of burnout

Prior to this study, there was little evidence of caring being identified and confirmed as a statistically significant predictor variable in the relationship with burnout. While this findings is an important contribution to knowledge, it is now essential that this important finding is retested at widely and with larger sample in future studies. At the same time, future research should focus on refining and testing the newly developed 'Sources of Pressure Scale' that measures caring.

This study established, (summarised in table 46) the specific aspects of caring which present as sources of pressure among nurses when caring for dying patients. This knowledge needs to be used in order to support nurses in practice and develop education and training material specific to palliative care. Only this way, will it be possible for nurses to be adequately prepared for their role, and supported in a manner that enables them to maximise opportunities; an essential element for the service if nurse can keep up to date.

This study showed that, it is essential to understand burnout by examining its three components of emotional exhaustion, depersonalisation and low personal accomplishment. This is an important recommendation in light of existing evidence which clearly suggests that emotional exhaustion is the first to develop (Maslach et al 2001), and if it continues unabated, it will lead to burnout. In addition, it is important for managers to realise that, burnout can be dealt with effectively in its formative stages (emotional exhaustion) at which point nurses are still able to function in their jobs as symptoms of emotional exhaustion are less severe. Managers need to understand that it is pragmatic and cost effective to prevent burnout through early detection measures which means a reduction in ill-health and overall absenteeism among nurses caring for dying patients can be achieved.

Findings from this study suggest that nurses working in hospice settings reported lowest levels of death anxiety and emotional exhaustion. However, nurses working in hospitals had the highest levels of death anxiety and emotional exhaustion. These are important findings but now need further research to understand what helps to minimise these levels, so that the strategies they use can be tested in other clinical areas.

There is evidence that, an increase in people dying at home is evident (DH 2008) and predicted to carry on rising (Addicott 2010), there are challenges inherent with this shift of location of death. It is clear that the previous and now the current coalition governments are actively encouraging this shift to happen (Addicott 2010). An increase in people dying at home brings with it more exposure to death and dying experiences for community nurses, thereby are likely to increase their emotional involvement with dying patients. This has clear implications for policy and practice, in that it offers a unique opportunity to be proactive in developing supportive strategies for community nurses before the predicted influx of patients preferring to die at home starts.

Another key area of this thesis was that caring was a significant predictor of emotional exhaustion. As already argued in this thesis, it was important to detect early signs of burnout, the first of which is emotional exhaustion, and therefore equally important to identify predictor variables of emotional exhaustion first, which will help in the prevention of burnout. The study also confirmed that caring was a core activity for palliative care nurses and cannot be ignored. Given the above points, it is important that managers recognise and support even those nurses who demonstrate positive care attitudes, whilst offering intense interventions for those who may be most distant from caring as they may already be on the road to burnout.

Recommendations for future research

In initiating further research, qualitative comments from respondents in this study also provide strong support for further work in this area.

- Findings from this study support previous studies that social support helps in moderating the impact of burnout, while raising questions about the actual types of support that are most effective. Therefore there needs to be urgent research to ascertain the best format through which to provide this support.
- This study discussed the role empathy plays in caring in palliative care settings, but did not include it as a variable for this current study. Future studies should investigate whether repeated exposure to death and dying experiences (as is the case with palliative nursing) is associated with low levels of empathy and compassion fatigue. The research should also investigate the impact of low empathy on the quality of caring for dying patients.
- With the establishment of the relationship between death anxiety and burnout, it becomes imperative to explore the impact of personality factors in the development of these two variables. Therefore it is recommended that a study be undertaken exploring how the different personality factors contribute to the experiences and development of death anxiety and burnout among nurses working in palliative care.
- Although results from Jun et al's (1999) study concluded that co-dependency was positively correlated with high scores of burnout, this could not be confirmed here, as co-dependency was beyond the scope of this study. It is therefore recommended that future research be undertaken using the Holyoake Codependency Index on a UK sample to include males as well as females and investigate the relationship between co-dependency as a personality trait, and measures of burnout. The research can also establish whether co-dependency may contribute to the development of burnout or vice versa.

- This study has suggested a guide for managers to help them identify early signs of burnout through measuring emotional exhaustion; however, it is recommended that a study be undertaken to produce a more comprehensive guide from the list offered in this thesis that can be used with all managers of nurses caring for dying patients.
- Another study is recommended to identify core education materials educators need to help address the impact of death anxiety and burnout, particularly emotional exhaustion, with nurses working in palliative care. Some of this education can be extended to student nurses well before they start caring for dying patients
- More work is needed to expand and refine the newly developed Sources of Pressure Measurement Scale which measures aspects of caring. The revised scale should be tested with larger samples, and then subjected to multiple regression to identify which aspects of caring are significant predictors of emotional exhaustion (i.e. burnout).
- Finally, nurses who are already absent from work through burnout were not included in this study, and yet they are the ones experiencing the full blown impact of burnout and could have offered important insights into burnout. It is recommended that a separate study be undertaken to include these nurses (on their return to work), and elicit their views and perceptions of their absenteeism, burnout and experiences of living with and recovering from it. It is possible that from such a study other indicators of absenteeism may emerge. It can be argued that, it is highly unlikely for burnout to be stated as the reason for nurses' absenteeism, because doctors may not focus on the syndrome, but instead on such aspects or overt symptoms as stress, tiredness, agitation and high blood pressure. It is also important for current managers of those already on sick leave through work related burnout, to resist the urge to recall or rush them back to work before they full resolve their symptoms. Managers should work closely and take advice from their Occupational Health departments and doctors. It is important that such nurses are allowed maximum rest and where necessary counselling support. However, in some cases sedative medication be used, but doctors should provide guidance on such treatment plan.

Conclusion

For many nurses, and in particular those working in palliative care, death is a frequent reality. Regardless of experience, knowledge base and understanding palliative care nurses have to deal with and cope with death and dying experiences as part of their day-to-day work. This means helping individual patients and their families cope with death and dying. Thus, nurses have a central responsibility for providing emotional and psychological support for the very phenomenon of death that most threatens their own ephemeral existence. Even though, confronting the inevitability of death and its related anxiety is a universal psychological problem faced by many human beings (Kiekergaard, 1947; Heidegger 1962, Neimeyer 1994; Kastenbaum 2000; and 2008), for palliative care nurses, caring provides a constant reminder of their own mortality. Comments from respondents reinforce this view and also indicate that, whilst they find caring for dying patients as emotionally taxing and stressful, it is also a privilege to be part of the patient's journey towards death. It is this that keeps them at the patient's bed side even when they are aware they may be themselves 'struggling' to cope both emotionally and physically. Such caring behaviour clearly highlights a paradox of feelings among many nurses. The implication from this is that nurses will continue to care regardless of the consequences on their own health and well-being. This way of caring was discussed in detail in chapters two and three, and shown to be a manifestation of emotional exhaustion and distancing oneself from patients. For managers the implications are that urgent supportive strategies such as clinical supervision, coaching and mentorship should be used to identify early nurses who may be unable to recognise within themselves the impact of this paradox. Only this way can managers minimise the incidence of burnout among nursing staff and through that increase their own well-being.

It is important that managers, researchers and educators welcome the fact caring for dying patients exposes nurses to death and dying episodes of their patients. Any attempts to support nurses must include strategies that help to prevent or minimise levels of death anxiety among the nurses. Through such support, nurses can find opportunities to reflect, re-energise and banish death anxiety.

Some of the qualitative comments from nurses in this study gave insights into their feelings: some were ambivalent, while others seemed to look for permission to take a break every now and again from caring for dying patients.

This thesis is the first to confirm that the activity of caring is a statistically significant predictor of emotional exhaustion. It then proceeded to identify which aspects of caring were ‘responsible’ for the development of stress/pressure among palliative care nurses. The findings are important for managers and educators as they can now plan training programmes to support nurses’ professional development.

The benefits of all the approaches so far are wide ranging, including increased job satisfaction, more confidence and raised self-esteem and thus cutting down on levels of absenteeism, and reducing the overall cost of caring. For the dying patients, this will mean a continuity of high quality care with the same nurses, through a relationship that helps to maximise their quality of life. Once patients’ quality of life is achieved most professionals agree that a peaceful and dignified death will follow. It is important here, to stress, that this peaceful and dignified death would be from the patient/family’s perspective. The impact of a dignified death is likely to help with grief process and bereavement period for relatives. When care is provided in this way, and nurses feel well supported, with low levels of death anxiety and burnout, it represents a legacy of caring that all nurses working in palliative care settings wish to leave behind.

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APPENDICES

APPENDIX 1

DATA COLLECTION TOOLS

SECTION (A): SOURCES OF PRESSURE AND SOCIAL SUPPORT SCALE

- **If you have recently experienced death of a close relation, we advise you not to complete this questionnaire. Please tick box and return this questionnaire** ☐
- **If you have not worked in palliative care for a minimum of three months, please do not complete this questionnaire. Please tick box and return this questionnaire** ☐
- **If you are unable to complete this questionnaire for any other reasons , please tick box and return this questionnaire in the self-addressed stamped envelope** ☐

1. Please indicate your gender by ticking appropriate box

Male ☐

Female ☐

2. Please indicate your age last birthday ------------

3. Please tick a box below that closely describes your status. Are you:

Living alone ☐

Living with other(s) ☐

4. Please indicate your ethnic background by ticking appropriate box on the right below:

Black ☐

White ☐

Asian ☐

Chinese ☐

Mixed ☐

Other (please specify) ☐

5. Please indicate the location where you work.

Hospice ☐ **Community** ☐ **Hospital** ☐

Other (please specify) ☐

6. How long (in years and months) have you been caring for dying **adult** patients on a continual basis? (Please ignore any breaks in service of not more than 18 months).

Years: ----------- **Months**: ------------

7. How long is it since you were present (i.e. witnessing the death) when a patient died?

e.g. 2 weeks ago, a month ago etc ---------------------

The following *elements of care* questions have been identified as sources of pressure for professionals caring for dying patients.

To what extent do you agree or disagree that the following statements are sources of pressure for you in your job.

		Very Strongly Agree	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**	**Very Strongly Disagree**
8	Inability to control patient's physical pain	☐	☐	☐	☐	☐	☐
9	Having to break bad news to relatives	☐	☐	☐	☐	☐	☐
10	Lacking clarity of your own role	☐	☐	☐	☐	☐	☐
11	Having to support relatives by the bedside as the patient dies	☐	☐	☐	☐	☐	☐
12	Inability to control patient's psychological symptoms	☐	☐	☐	☐	☐	☐
13	Feeling excluded from clinical decision making process about patient care	☐	☐	☐	☐	☐	☐
14	Having to support relatives while viewing the body of the dead patient	☐	☐	☐	☐	☐	☐
15	Having to witness a difficult death of a patient	☐	☐	☐	☐	☐	☐
16	Being asked to do your job without adequate resources to complete it	☐	☐	☐	☐	☐	☐
17	Having to support young children related to the dying patient	☐	☐	☐	☐	☐	☐
18	Having to perform last offices	☐	☐	☐	☐	☐	☐
19	Having too much work load to deal with	☐	☐	☐	☐	☐	☐
20	Being expected to do your job well without administrative/secretarial support	☐	☐	☐	☐	☐	☐

The following questions ask about the support you receive from your manager(s).
In your current job, to what extent can you count on your manager(s) to:

		Not at all	**To a small extent**	**To a moderate extent**	**To a great extent**	**Completely at all times**
1	Listen to you when you want to talk about problems at work	☐	☐	☐	☐	☐
2	Back you up at work	☐	☐	☐	☐	☐
3	Help you with difficult tasks at work	☐	☐	☐	☐	☐
4	Help you in a crisis situation at work, even though they would have to go out of their way to do so	☐	☐	☐	☐	☐
5	Protect you from outside criticism - such as other Health care professionals, patients and relatives	☐	☐	☐	☐	☐

Source: (Borrill et all 1996)

SECTION B: REVISED DEATH ANXIETY SCALE

Please indicate on the scale, by encircling the appropriate number, to what extent you agree or disagree with the statement. Please note some statements are framed negatively and you need to read them carefully.

If you strongly agree with the statement …**I am not afraid to die**….., circle 5, if you strongly disagree with the statement, circle 1 (as demonstrated below).

There are no right or wrong answers. We are only interested in your perceptions of death.

Sample example only

Strongly disagree	[✓ 1]	2	3	4	5	***Strongly agree***

1. I fear dying a painful death.

Strongly disagree	1	2	3	4	5	Strongly agree

2. Not knowing what the next world is like troubles me.

Strongly disagree	1	2	3	4	5	Strongly agree

3. The idea of never thinking again after I die frightens me

Strongly disagree	1	2	3	4	5	Strongly agree

4. I am not at all anxious about what happens to my body after burial

Strongly disagree	1	2	3	4	5	Strongly agree

5. Coffins make me anxious

Strongly disagree	1	2	3	4	5	Strongly agree

6. I hate to think about losing control over my affairs when I am dead and gone

Strongly disagree	1	2	3	4	5	Strongly agree

7. Being totally immobile after death bothers me.

Strongly disagree	1	2	3	4	5	Strongly agree

8. I dread to think about having an operation

Strongly disagree	1	2	3	4	5	Strongly agree

9. The subject of life after death troubles me greatly

Strongly disagree	1	2	3	4	5	Strongly agree

10. I am not afraid of a long, slow dying process

Strongly disagree	1	2	3	4	5	Strongly agree

11. I do not mind the idea of being shut into a coffin when I die

Strongly disagree	1	2	3	4	5	Strongly agree

12. I hate the idea that I will be helpless after I die

Strongly disagree	1	2	3	4	5	Strongly agree

13. I am not at all concerned over whether or not there is an afterlife.

Strongly disagree	1	2	3	4	5	Strongly agree

14. Never feeling anything again after I die upsets me.

Strongly disagree	1	2	3	4	5	Strongly agree

15. The pain involved in dying frightens me.

Strongly disagree	1	2	3	4	5	Strongly agree

16. I am looking forward to a new life after I die.

Strongly disagree	1	2	3	4	5	Strongly agree

17. I am not worried about ever being helpless.

Strongly disagree	1	2	3	4	5	Strongly agree

18. I am troubled by the thought that my body will decompose in the grave.

Strongly disagree	1	2	3	4	5	Strongly agree

19. The feeling that I will be missing out on so much after I die disturbs me.

Strongly disagree	1	2	3	4	5	Strongly agree

20. I am worried about what happens to us after we die.

Strongly disagree	1	2	3	4	5	Strongly agree

21. I am not concerned with being in control of things.

Strongly disagree	1	2	3	4	5	Strongly agree

22. The total isolation of death is frightening to me.

Strongly disagree	1	2	3	4	5	Strongly agree

23. I am not particularly afraid of getting cancer.

Strongly disagree	1	2	3	4	5	Strongly agree

24. I will leave careful instructions about how things should be done after I am gone.

Strongly disagree	1	2	3	4	5	Strongly agree

25. What happens to my body after I die does not bother me.

Strongly disagree	1	2	3	4	5	Strongly agree

Other comments:

Would you now like to **list** any other comments related to your experience of caring for dying patients. Please use the box below

• • • • • • • • •

Appendix 2

Maslach Burnout Inventory - Human Service Survey

HOW OFTEN:	**0**	**1**	**2**	**3**	**4**	**5**	**6**
	Never	A few times a year or less	Once a month or less	A few times month	Once a week	A few times a week	Every day

How Often
0-6 **Statements:**

1. ______ I feel emotionally drained from my work.
2. ______ I feel used up at the end of the workday.
3. ______ I feel fatigued when I get up in the morning and have to face another day on the job.
4. ______ I can easily understand how my patients feel about things.
5. ______ I feel I treat some patients as if they were impersonal objects.
6. ______ Working with dying people all day is really a strain for me.
7. ______ I deal very effectively with the problems of my patients.
8. ______ I feel burned out from my work.
9. ______ I feel I'm positively influencing other people's lives through my work.
10. ______ I've become more callous toward people since I took this job.
11. ______ I worry that this job is hardening me emotionally.
12. ______ I feel very energetic.
13. ______ I feel frustrated by my job.
14. ______ I feel I'm working too hard on my job.
15. ______ I don't really care what happens to some patients.
16. ______ Working with dying people directly puts too much stress on me.
17. ______ I can easily create a relaxed atmosphere with my patients.
18. ______ I feel exhilarated after working closely with my patients.
19. ______ I have accomplished many worthwhile things in this job.
20. ______ I feel like I'm at the end of my tether.
21. ______ In my work, I deal with emotional problems very calmly.
22. ______ I feel patients blame me for some of their problems.

You have now completed the questionnaires. **Thank you** for taking the time to answer the questions. **Please feel confident that all answers will remain confidential.**

If you should feel upset and have the need to speak to someone after completing this questionnaire, here are some useful telephone numbers:
Cruse bereavement care **0870 167 1677** (National helpline, can also arrange face to face talk)
Samaritans **0845 790 9090** (listening service only)

Please note that, I am unable to provide you with any counselling support, as I am not qualified in this area, but feel free to contact me for further information about the study as per my covering letter.

Thank you.

Appendix 3

MREC Letter of Approval

04 May 2005

Mr. Brian Nyatanga
Senior Macmillan Lecturer
University of Central England
Faculty of Health & Community Care, Division of Oncology, Palliative
Care, & MEU. Bevan House, Westbourne Rd
Edgbaston, Birmingham
B15 3TN

Dear Mr. Nyatanga

Full title of study: ***An Investigation of the relationship between exposure to death an dying,(Caring) levels of death anxiety and burnout among nurses i palliative care***
REC reference number: ***05/MRE07/18***
Protocol number:

Thank you for your letter of 14 April 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman and Dr S Bain. Reference is made to a Consent Form but this was not included in the revised documentation. However, it was felt that the explicit consent form was not really necessary and the Committee did not request one. Therefore please take this out of the paperwork.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The Committee has designated this study as having "no local investigators". There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application		30/01/2005	11/02/2005
Application - Revised	4	07/04/2005	15/04/2005
Investigator CV			11/02/2005
Protocol	1	20/12/2004	11/02/2005
Covering Letter	1	30/01/2005	11/02/2005
Covering Letter		14/04/2005	15/04/2005
Letter from Sponsor		21/09/2004	24/02/2005
Copy of Questionnaire	Revised Death Anxiety - 1	30/01/2005	11/02/2005
Copy of Questionnaire	MBI-HSS		11/02/2005
Participant Information Sheet	1	30/01/2005	11/02/2005
Participant Consent Form	1	30/01/2005	11/02/2005
Response to Request for Further Information		14/04/2005	15/04/2005
Supervisor C.V			11/02/2005
Letter - Confirmation of part one - Pass		21/09/2004	11/02/2005

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/MRE07/18 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project,
Yours sincerely,

Anne McCullough [Mrs] *on behalf of*
Dr Jammi Rao FRCP FFPHM
Chair
E-mail: anne.mccullough@bbcha.nhs.uk

Enclosures Standard approval conditions

Appendix 4:

Covering letter

Date: as postmarked

Dear

Study Title: Relationship between exposure to death and dying (Caring), levels of death anxiety and burnout among nurses in palliative care

I am conducting research to investigate the nature of the relationship between regular exposure to death and dying, levels of death anxiety and burnout among nurses who work with terminally ill patients in palliative care settings. I am researching this area under the academic supervision of Drs. Slater and Fitzsimmons, both of whom are based within the Faculty of Health Sciences at Swansea University.

I am interested in investigating the impact that witnessing someone else's death and the dying experiences while caring for patients has on nurse specialists working in palliative care. The impact of such exposure will be most likely reflected in the levels of death anxiety for each individual. Your views and opinions are therefore very important to this study. Your views will be used collectively to decide on recommendations on support structures and education strategies necessary to ensure that high quality care continues to be delivered to dying patients without any emotional cost on the health care professionals.

Death anxiety is a difficult emotion or reaction to understand and capture clearly, therefore the attached questionnaire was developed to include all the components that make up one's overall outlook to life. You will find that section A of the questionnaire asks you questions that includes personal details and experiences of caring for dying patients. Section B is based on a scale format with numbers from 1 to 5 for each item. There are 25 items to this section and you are asked to circle the most appropriate number in response to each statement. I have included an example at the top of section B.

You may choose not to complete this questionnaire if you have recently experienced a close personal death.

The second questionnaire will measure the levels of burnout using 22 item statements. The format is very similar to that of the death anxiety questionnaire.

For example if your response to statement 1 (I feel emotionally drained from my work) is 'every day' then you write 6 against statement 1. If after reading this you still feel unclear of what to do, please contact me on 0121 331 6180 (office) or 07793 118728 mobile. I have also included detailed information about the study on the participant information sheet.

I am aware that I do not know your own personal circumstances or cultural beliefs regarding loss, grief and bereavement, and therefore would like to remind you that you can opt out of completing this questionnaire at any time, and for what ever reason. However, if after completing the questionnaire, you feel the need to talk to someone, I have put two contact numbers at the end of the questionnaire for national specialist services that you could use.
Please note that the questionnaires are anonymous and you do not have to put your name on it. All information you provide will be treated in strict confidence.

I would be very grateful if you could complete and return the attached questionnaire in the self-addressed and stamped envelope provided by
(four weeks from the date of posting latest). It should take you no more than 30 minutes to complete this questionnaire.

Thank you for taking the time to complete the questionnaires. Your views are important to this study.

Yours sincerely

Brian Nyatanga
Doctoral candidate, and Macmillan Senior Lecturer

Study reference: 05/MRE07/18

Appendix 5

Participant Information Sheet

Title of study: Relationship between exposure to death and dying (Caring), levels of death anxiety and burnout syndrome among nurses working in palliative care.

I am inviting you to take part in a research study. Before you decide to do so, it is important for me that you understand why the research is being done and what your involvement will be. Can I therefore ask you take time to read the following information carefully and discuss it with others, if necessary. Please feel free to ask if there is anything that is not clear or if you would like more information.

Why this study is important

The aim of this study is twofold;

First, to understand whether being exposed to death and dying experiences of adult patients contributes to the development of death anxiety and or burnout syndrome in nurses who work in palliative care settings.

Second, to determine whether factors such as age, gender, cultural background and support at work may change the way we view and feel about our own death. While some studies have investigated the relationship of these factors, no study in the UK to date has looked at it from the nurses' point of view. Understanding the possible impact of being exposed to death and dying of others may help policy makers to device mechanisms that support health care professionals while undertaking such emotionally charged work in palliative care settings. This would help to improve the quality of care for dying patients.

This small study is part of my doctoral degree programme and will comprise a questionnaire on death anxiety and another one on burnout for you to complete and return to me.

Why me?

First, I am seeking to involve nurses who regularly work with dying patients and their families, and have witnessed at least a death of a patient. These professionals are those working in palliative care settings where death tends to occur regularly. Second, I am also looking for nurse specialists who are willing to share honestly their views about death and dying and how they feel about the emotional demands of caring for dying patients.

Your employer has helped to identify you as meeting what I am looking for to include you in the study. This is only permission to access your name and work address so that I can contact you to request for your participation in the study.

Do I have to take part?

Taking part is voluntary on your part, so it is up to you to decide whether you want to take part or not. If you decide to take part, you will be asked to complete two questionnaires included in this pack. Please note that your decision to take part or not will not affect your involvement or relationship with your employer.

What will happen if I decide to take part?
You will be expected to complete the revised death anxiety questionnaire and the burnout inventory enclosed and return them to me within four weeks, so that I can analyse the responses. The time for completing the questionnaires should not take more than 30 minutes and therefore requires your concentration for that period.

Do I need to read up on the topic first before completing the questionnaires?
There is no preparation required for completing these questionnaires. It is your experiences and views on death and dying that I would like to know about.

What will happen to the results from this study?
A thesis will be prepared, based on the findings of the study. I will be publishing in the nursing and medical press the findings from this study once I have been awarded my doctorate degree. All publications will not identify you as the participant in the study.

Will my taking part remain confidential?
All information collected from the questionnaires and your personal details will be kept strictly confidential. No names or work place details will be identified in the study. As you can see, the questionnaires are anonymous, and there is no way of identifying your name.

Who is funding this research study?
This is an academic piece of work towards my doctoral qualification. There is no funding secured for the research. However, my employer has paid my tuition fees to study at the University of Wales Swansea.

What if I still have questions I want to ask about this study?
For any further information, please telephone me on 0121 331 6180 (work), or 07793 118728 (mobile).
Should you prefer to write to me direct, please send all correspondence to:
Brian Nyatanga, University of Central England, 120 Bevan House, Westbourne Road, Edgbaston, Birmingham B15 3TN

Who am I to undertake this research?
I have had a long standing interest in death and dying in this country. In my current role as senior lecturer, I share ideas around death and dying with students who are studying for their degrees. I would like to continue to share new knowledge, particularly from my own research about death anxiety. I have published widely in nursing press including my classic book entitled "Why is it so difficult to die?" I am very interested in the psychology of dying and now the impact, on nurses, of caring and witnessing the death and dying experiences of adult patients.

NB. This information sheet is for you to keep.
Thank you for taking part in this study
Version 1 Date 30/01/2005

Study Ref. No. 05/MRE/07/18

Appendix 6

Reminder letter

Date as postmark

Dear Participant

Re: Questionnaires on a research study by Brian Nyatanga.

Recently, two questionnaires (one on death anxiety and the other on burnout) were sent out to you to complete and participate in a research study on the relationship between exposure to death and dying (Caring), death anxiety levels and burnout among nurses working in palliative care settings.

I am responsible for the administration of this study so that you remain anonymous to the researcher (Brian Nyatanga), as part of ensuring total anonymity according to the ethical guidelines of this research study.

My records show that we have not received your questionnaires back, and I would like to remind you to complete and return them even if your given deadline has now expired. Because this is an important area of study it is crucial that your views are included, so that improved ways of working can be recommended which also reduce the possibility of burnout and high levels of death anxiety among nurses.

There was a self addressed and stamped envelope enclosed with the questionnaires for your use. However in case you have misplaced this, please send your questionnaires to Brian Nyatanga on the address below.

c/o Yulander Charles
University of Central England
Department of Community Care and Social Work
Bevan House
Westbourne Road,
Edgbaston
Birmingham
B15 3TN.

If you have mislaid your questionnaires, please contact me direct on 0121 331 6186 and I will send you some more.

Thank you for your support and look forward to receiving your questionnaires.

Yours sincerely

Yulander Charles (Administrator)

On behalf of Brian Nyatanga