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# **Living with Chronic Obstructive Pulmonary Disease:**

## **The experience of patients and their carers**

By  
**Heather Antoinette Williams**

BSc. (Hons) Nursing Studies  
BSc. (Hons) Community Nursing

A thesis submitted to the School of Health Science  
Swansea University

for  
the Degree of Doctor of Philosophy  
2007

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## ABSTRACT

This thesis explores the subjective experiences of patients and carers living with chronic obstructive pulmonary disease (COPD), a degenerative respiratory condition. It aims to improve understanding of the illness trajectory experienced by sufferers as they respond to the physical and psychological impact of COPD on their body, self-identity, relationships and daily living.

The illness COPD is poorly recognised by health policy makers, the media, health professionals and patients alike, despite being predicted to become the third leading cause of death worldwide by 2020. Even less is known about the lived experience of COPD as perceived by the individuals themselves.

A qualitative approach based on symbolic interactionism was employed to collect and analyse narrative data obtained from a purposive sample of 53 patients with moderate to severe COPD and 15 family carers.

Exploration of the illness trajectory through narratives recounted by patients and carers highlighted the impact of COPD on their lives. The study identified conceptual illness phases experienced by patients as: the early days, adapting to changes in self and lifestyle, the daily struggle and living with severe COPD: fears and facing the future. Individuals revealed how they perceived their disabled body, dependency on others, and the cumulative life losses they experienced, together with feelings of vulnerability, as contributing to a sense of altered self and identity. The illness phases were reflected in the role of the relative who moved through the transitional phases from being a caring relative to a care-giving relative, caring through crisis periods, and eventually becoming a full-time carer.

The study provides insights into the perceived issues and concerns of patients and carers living with the consequences of COPD. It may provide lessons for health professionals, which will contribute to more appropriate and acceptable healthcare to support patients with COPD and their carers.

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## ABBREVIATIONS

ACP/ACCP	American College of Physicians/American College of Chest Physicians
ADL	Activities of daily living
ATS	American Thoracic Society
BESC	Bronchitis Emphysema Symptom Checklist
BLF	British Lung Foundation
BMA	British Medical Association
BMI	Body Mass Index
BTS	British Thoracic Society
CFC	Chlorofluorocarbons
COAD	Chronic obstructive airways disease
COPD	Chronic obstructive pulmonary disease
CRQ	Chronic Respiratory Questionnaire
DoH	Department of Health
FEFR	Forced Expiratory Flow Rate
FEV1	Forced Expiratory Volume in 1 second
FPI	Functional Performance Inventory
FVC	Forced Vital Capacity
GHS	General Household Survey
GMS	General Medical Services
GOLD	Global Initiative for Chronic Obstructive Pulmonary Disease
GP	General Practitioner
HRQOL	Health Related Quality of Life
JCS	Jalowiec Coping Scale
LREC	Local Research Ethics Committee
LTOT	Long term oxygen therapy
LVRS	Lung Volume Reduction Surgery
MRC	Medical Research Council
NCCC	National Collaborating Centre for Chronic Conditions
NETT	National Emphysema Treatment Trial
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NOTT	Nocturnal Oxygen Therapy Trial
NRT	Nicotine Replacement Therapy
NSF	National Strategic Framework
ONS	Office for National Statistics
QOL	Quality of life
PEFR	Peak Expiratory Flow Rate
pMDI	Pressured Metered Dose Inhaler
RCP	Royal College of Physicians
RVC	Relaxed Vital Capacity
SGRQ	St. George's Respiratory Questionnaire
SIP	Sickness Impact Profile
SOB	Shortness of Breath
VAS	Visual Analogue Scale
WHO	World Health Organisation



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## **1.0. Chapter 1: Introduction**

### **1.1 What is this thesis about?**

This thesis describes and explores the nature and psychosocial impact of the medical condition Chronic Obstructive Pulmonary Disease (COPD) upon the lives of individuals and their family carer. The study investigates living with COPD from a qualitative sociological approach based on symbolic interactionism. Study participants were interviewed to obtain accounts through narrative expression of their perceptions and experiences of living with COPD. The narrative accounts, or patient stories are explored to gain an understanding of the participants' perceived significant clinical and conceptual issues experienced along the illness trajectory of living with their COPD.

COPD is an umbrella term for a number of similar conditions including chronic bronchitis, emphysema, chronic obstructive airways disease and chronic asthma. Although each condition is pathologically different all are characterised by lung damage, which over a period of time impairs airflow in and out of the lungs causing breathlessness (British Lung Foundation, 2005). COPD is an incurable degenerative condition with a poor prognosis (Siafakas et al, 1995). The most up-to-date definition of COPD states:

“COPD is a preventable and treatable disease with some significant extra-pulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterised by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases” (Global Initiative for Chronic Obstructive Lung Disease, GOLD Executive Committee, 2006:6).

Despite this optimistic definition of COPD, the health and well being of patients with severe COPD, even those receiving excellent care, will decline (GOLD Executive Committee, 2006).

Tobacco smoking is the most common cause of COPD but the disease can be attributed to occupational pollutants or in rare cases is due to a genetic hereditary condition (GOLD Executive Committee, 2006; National Collaborating Centre for Chronic Conditions (NCCC), 2004). COPD is generally detected from mid age onwards and often co-exists with other diseases related to smoking or advancing age (GOLD Executive Committee, 2006).

As the disease progresses, the symptoms of breathlessness and fatigue become more pronounced and restrict the individual's normal level of activity and mobility. Individuals with COPD tend to limit their activities to avoid causing further breathlessness but in doing so they lose muscle tone and level of exercise tolerance. A negative cycle of breathlessness, anxiety and disability ensues (Cooper et al, 1995). Anxious to avoid accentuating the shortness of breath, individuals with COPD lead self-imposed restricted lifestyles often resulting in reduced functional ability, reduced participation in recreational activities, become house-bound and socially isolated (British Lung Foundation, (BLF), 2005). Eventually the symptoms of COPD impact upon taken-for-granted basic activities of daily living, challenge individual coping styles and often negatively affect an individual's personal sense of identity and integrity (Charmaz, 1987; Kline Leidy and Haase, 1999).

As the severity of disease increases (airflow limitation), breathing problems are compounded by air pollutants, bacterial or viral infections which result in flare-ups medically termed an 'acute exacerbation' of COPD (McCrory et al, 2001). Acute exacerbations of COPD are recognised by a sustained increase in breathlessness, productive cough with purulent sputum together with possible fever and general malaise (Rodriguez-Roisin, 2000). Acute exacerbations of COPD account for 12% of hospital admissions with average patient stay of 11 days (Lung and Asthma Information Agency, 2003). The Report of the National COPD Audit found that of the patients admitted to hospital with an exacerbation of symptoms, 15% had died within the 90-day follow-up (Anstey et al, 2004).

Since the introduction of national and international guidelines for the diagnosis and management of COPD, medical treatments are recommended, following care pathways for pharmacological treatments. However, there is considerable evidence that generally COPD management is still not being performed in accordance with the

guidelines (GOLD Executive Committee 2006; NCCC, 2004). Active participation by primary care practitioners to raise public awareness of the hazards of exposure to risk factors and for opportunistic smoking cessation counselling is recommended (GOLD Executive Committee, 2006, NCCC, 2004, BTS, 1997).

Medical discharge from hospital to home, following an exacerbation often lacks the support of social and healthcare services. This is often despite the patient experiencing fluctuating physical symptoms of the disease and complex psychosocial problems, such as depression and social isolation associated with a deteriorating chronic illness (Gore et al, 2000; Skilbeck et al, 1998).

Recent research has raised awareness of unmet palliative needs for terminally ill end-stage patients with COPD and their family carers (Skilbeck et al, 1998; Jones et al, 2004, Gore et al, 2000; Lynn et al, 2000; Edmonds et al, 2001; Elkington et al, 2004). Terminally ill patients with COPD have been found to have the same level of need as cancer patients but often do not receive the same level of specialist palliative care (Addington-Hall et al, 1998; Edmonds et al, 2001; Gore et al, 2000).

An unpaid and untrained family carer supports many patients disabled by COPD at home. There are reported to be 5.2 million carers in the UK. Both patients and carers receive inadequate social or healthcare services in dealing with the effects of COPD (Office for National Statistics, (ONS), 2000b; ONS, 2000c; Skilbeck et al, 1998).

## **1.2. Epidemiology of COPD**

COPD is a major cause of death and disability globally, accounting for approximately 2.7 million deaths in 2000 and estimated at being currently the fourth leading cause of death in the world (WHO, 2002; Lopez et al, 2006). Estimated as the fastest growing cause of death amongst the world's developing countries, COPD is predicted to become the third leading cause of death and fifth cause of disability world- wide by 2020 (Murray and Lopez, 1996; Murray and Lopez, 1997). However it has been highlighted that such estimates should be interpreted with caution due to disparities between different research methods and between national guidelines for disease frequency, staging and classification, (Lopez et al, 2006; Lacasse et al, 2001; Grossman, 2000; Espino et al, 2001; Hurd, 2000).

In England and Wales, 28,000 deaths were attributed to COPD, being the sixth most common cause of death in 1999 (ONS, 2000a). Although at least 1% (600,000) of the total population of the UK are known to have COPD (Calverley and Bellamy, 2000); estimates suggest a potential prevalence from 1.5 to 3 million people having COPD (National Collaborating Centre for Chronic Conditions, 2004; Stang et al, 2000), with up to 75% of Europeans with undiagnosed COPD (Rudolf, 2000).

The UK has one of the highest death rates from COPD in Europe (BLF, 2003), with a five-year survival in approximately 75% of mild cases and 27% in severe cases (Soriano et al, 2000). Although men have higher prevalence and mortality rates there is evidence of an increasing greater prevalence of COPD in women (Soriano et al, 2000). One in eight acute medical hospital admissions in adults is due to COPD (Stang et al, 2000) with more than five times this number for asthma taking up hospital bed days (British Lung Foundation, 2006). Investigating hospital admissions for an exacerbation of COPD, one study found that 50% require intensive treatment, 10% will die in hospital, 33% will die within six months of discharge and 43% die within one year (Stoller, 2002). A British Lung Foundation survey of 1400 respondents with COPD found that in the previous 12 months 10% spent at least a month in hospital due to an exacerbation, 44% spent more than a month recovering at home from an exacerbation, 25% of these were virtually housebound for three months or longer. These data demonstrate the extent of the impact of the illness on lifestyle (BLF, 2003). The same report found that 83% of respondents indicated that the fear of an exacerbation limited their ability to enjoy activities and 64% feared being a burden to their family (BLF, 2003).

Although COPD can be caused by occupational dusts or chemicals, indoor air pollution and in rare cases due to alpha-1 antitrypsin enzyme inherited deficiency (1% of the COPD population), 95% of COPD cases are caused by cigarette smoking (British Thoracic Society, 1997; GOLD Executive Committee, 2006). Tobacco smoking and the incidence of COPD are both associated with socio-economic deprivation (Prescott et al, 1999). In 1996, 12% of professional men smoked as compared to 40% of unskilled manual workers (DoH, 1999). The Acheson Report (1998) highlighted the link between smoking and health inequalities and stated that current approaches to tackle the problem of smoking were not sufficient. The white

paper that followed 'Smoking Kills (DoH, 1999) stated that £60 million would be invested into NHS services to help reduce smoking in the UK. In addition to government action on advertising, taxes, clean air public campaigns, and strategies aimed at discouraging young people to smoke, free introductory nicotine replacement therapy was to be offered to smokers receiving social security benefits (DoH, 1999).

The risk of developing COPD has been found inversely related to socio-economic status, but the role of air pollutants, crowding, poor nutrition or other factors is unknown (GOLD Executive Committee, 2006). However, children of smokers have been found more likely to develop lung illness than those children of non-smoking parents (Cook et al, 1997-8).

The financial burden of COPD in terms of hospital costs in 2001-2 in the UK amounted to an estimated £587 million (Stang et al, 2000). Overall the cost, to the NHS for caring for patients with COPD is estimated at over £800 million per year (British Lung Foundation, 2006).

### **1.3. Historical background and extent of the problem**

Despite the prevalence of COPD in the British population, COPD has been described as a largely neglected medical and social problem with widespread under-diagnosis and under-provision of care (Williams, 1989; Williams and Bury, 1989; Williams, 1993; Partridge, 2003; Halpin, 2004; Crompton, 2002). It has been identified as a poorly recognised and misunderstood condition having a low public profile and receiving low professional priority despite its high mortality (Buist, 2006; BTS COPD Consortium 2001; Rennard et al, 2002; Partridge, 2003; Halpin, 2004; Crompton, 2002).

Insufficient funding for research into COPD, poorly targeted research, not directed at the key issues, or indeed missing the patients' perspective; that quality of life and health status may be more important than lung function measures, have contributed to the low profile of COPD (Partridge, 2003). In addition, despite recent evidence for the benefits of pulmonary rehabilitation for individuals with COPD, many regional areas of the UK still have no rehabilitation schemes, which contribute to inadequate COPD management (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation

2001; Partridge, 2003). Medical indifference to non-pharmacological management, lack of scientific evidence, poor funding and ineffective consumer demand are historical reasons attributing to poor provision of pulmonary rehabilitation for people with COPD (British Thoracic Society Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001).

The BTS statement commented that current professional opinion towards COPD is changing, in response to the emerging scientific evidence that supports the benefits of management interventions such as smoking cessation and pulmonary rehabilitation (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001). Benefits of pulmonary rehabilitation have been demonstrated to increase exercise capacity, improve self-esteem, increase independency and reduce health services (Griffiths et al, 2000; Lacasse et al, 1997; Benzo et al, 2000).

However, the publication of two WHO documents outlining an approach to the prevention and management of COPD and its implementation strategy (WHO, 2001; 2002) and the introduction of national and international guidelines on the diagnosis and management of COPD have recently raised the profile of the illness for health professionals (American Thoracic Society, (ATS), 1995; Siafakas et al, 1995; BTS, 1997; GOLD Executive Committee, 2006; National Institute for Clinical Effectiveness, (NCCC), 2004, British Medical Association, 2006). In addition the new General Medical Services contract implemented in 2004, included COPD as one of ten disease areas in an initiative of the quality and outcomes framework, and emphasised COPD as a new priority within primary care (British Medical Association, 2006). However, although mortality rates of COPD in the UK currently exceed those from ischaemic heart disease, no National Strategic Framework yet exists for respiratory disease. This framework is currently pending and due to be published in 2008 (DoH, 2006).

Cigarette smoking is the major risk factor for COPD (GOLD Executive Committee, 2006) and smoking cessation is the most important management strategy to affect patient outcomes positively at all stages of their disease (BTS, 1997). However, support for patients to quit smoking has been limited or ineffective (Kava, 2000). Although adult smoking rates have fallen since 1980, the rising prevalence of young

women smoking, the cumulative effect of pack-years of women smoking and an aging population is predicted to increase the present burden of COPD in the UK (Soriano, 2000). Likewise tobacco consumption is rising in developing countries, which predicts increasing prevalence in future years (Lopez et al, 2006; Murray and Lopez, 1997). Research evidence suggests that there is a higher incidence of smokers developing COPD than previously estimated (Lundback et al, 2003).

Paradoxically, whilst emphysema, chronic bronchitis and lung cancer have long been associated with cigarette smoking, respiratory disease has not received the same level of attention, commitment of resources or research into health care and treatment (Whyte, 2006; Shovelton, 2006; Partridge, 2003). Chronic respiratory diseases associated with smoking have been considered self-inflicted conditions. This despite a history of wartime government free rationing of tobacco and ongoing media tobacco promotion until the banning of tobacco advertising in 1972 (Partridge, 2003; Doran, 2002). Whilst there have been long-term concerns over the effect of tobacco on health since the 1950's and a substantial body of research evidencing links with ill-health (Doll, 1959; Fletcher and Peto, 1977); it was not until 2003 that the government actively took action to curb tobacco promotion (Doll, 1959; Partridge, 2003; Doran, 2002). It was not until 2006 that sponsorship for tobacco ended (DoH, 1999). Likewise chronic respiratory conditions associated with occupational dusts and chemicals such as for miner's lung were considered an occupational hazard and not officially acknowledged until recently (Bloor, 2000, Bloor, 2002).

COPD has an insidious and vague onset, and individuals do not recognise their smoker's cough as a subtle indicator of early disease and often do not consult their doctor until later into the disease, when symptoms become pronounced and problematic (Gold Executive Committee, 2006). Individuals typically tolerate symptoms and consult their GP late into the disease (van Schayack et al, 2002; Renwick and Connolly, 1996). Of the estimated three million people in Britain with COPD many remain undiagnosed (Stang et al, 2000). Despite 7 out of 10 heavy smokers experiencing one or more symptoms a MORI survey found that 65% of the population had not heard of the condition COPD (Crompton, 2002). Halpin (2004) suggested that despite COPD being the fifth most common cause of death in the UK, accounting for one in ten GP consultations for the over 60's and a principal cause of



hospital admission, many doctors remain unaware of its prevalence. Until recently medical diagnosis of COPD has relied purely upon clinical symptoms, often allowing the disease to go undetected or mis-diagnosed until patients present with severe stages of the disease (Calverley and Bellamy, 2000). Even death certificates have been found to under or mis-diagnose COPD as main cause of death (Vilkman et al, 1997; Espino et al, 2001).

Spirometry is recommended as a key diagnostic test for individuals having a history of cough, sputum production or dyspnoea in order to both confirm COPD and quantify lung function impairment (NCCC, 2004; GOLD Executive Committee, 2006; BTS, 1997). **Appendix 1: Spirometric Classification of Disease Severity.**

Spirometry is a simple test; the patient is asked to exhale into a mouthpiece connected to a spirometer in order to obtain measurements of forced expiratory volume in one second (FEV1), relaxed vital capacity (RVC), and forced vital capacity (FVC) and the ratio of FEV1/VC. The usefulness of the procedure depends upon the accuracy of the spirometer and the competence of the operator (Gibbons, 2002). Previous under-use of spirometry within GP practices has contributed to the under-diagnosis and lack of confirmation of COPD (Mooney, 2000). Despite national guidelines recommending the use of spirometry confirming COPD to improve diagnostic rates (BTS, 1997; Halpin, 2004), spirometry for routine screening has been argued as not being feasible in the general practice, due to higher priority demands on time and resources (Boom et al, 1998). However, the quality indicator points offered by the GMS contract for detecting newly diagnosed COPD patients has led to an increase in spirometry testing performed in primary care, but without consistency of testing quality (den Otter et al, 2000).

Medical diagnosis of COPD may be complicated by the co-existence of asthma whose symptoms are similar to, but unlike COPD are reversible in response to medication, thus masking the presence of mild to moderate COPD (BLF, 2005; van Manen et al, 2001). Mis-diagnosis of COPD or confusion over management has often led in the past to COPD being treated medically as asthma (Mooney, 2000). Many of the pharmacological treatments used for COPD are the same as those used in asthma. This has led to questioning their 'appropriateness' as they often only provide partial relief and are of limited benefit (Partridge, 2003, Celli, 2000). More focused research

investment is needed both to discover new drugs to treat COPD specifically and for new antiviral agents to treat acute exacerbations (Partridge, 2003).

Co-morbidity in patients with COPD is fairly common, with patients often having other smoking related diseases such as ischaemic heart disease or lung cancer as well as other conditions related to aging, such as: depression, diabetes mellitus, dementia or arthritis (GOLD Executive Committee, 2006). One study found up to 23 different diseases, one or more of which was co-existing with COPD in 73% of subjects (van Manen et al, 2001). Symptom control or disease-related problems of these other conditions including locomotive diseases, insomnia, depression, heart failure or cancer may have more urgent needs and take precedence over the COPD symptoms so allowing COPD to remain undetected until the latter stages of the disease.

Management of COPD has traditionally been less than optimal and may in part be attributed to a lack of systematic evidence based research into COPD management, in conjunction with the limited number of nation wide specialist respiratory physicians (Partridge, 2003; Crompton, 2002). Effective management of COPD is thus variable, dependent on the availability of appropriate resources and the degree of professional interest in respiratory conditions within the geographical area in which the patient lives (Partridge, 2003).

Hospital admissions during mid winter tend to peak, which contributes towards crisis situations of inpatient bed shortages in recent years, a situation blamed on a lack of regional planning for COPD (Partridge, 2003). The introduction of Intermediate care schemes such as the Acute Respiratory Assessment Service or 'Hospital-at-Home' have been implemented to ease the pressure on inpatient beds, provide cost-effective care and increase patient satisfaction (Gravil et al, 1998). However studies investigating their benefits have found contradictory or inconclusive findings regarding readmission to hospital, reduced number of bed days, mortality and patient satisfaction (Johnson et al, 2001; Shepperd et al, 1998; Smith et al, 2001; Davison et al, 2006; Schofield et al, 2006). A Cochrane review of six trials suggested that not all patients with COPD were suitable to receive outreach care but approximately 25% or more patients with acute exacerbations of COPD could be safely cared for at home with support of a multidisciplinary team (Ram et al, 2004). Although homecare

schemes are the preferred option for most patients and carers (Ojoo et al, 2002); Shepperd et al, (1998) noted that a few patients feel psychologically safer being monitored in hospital for an exacerbation. Reviewing Hospital-at-Home versus inpatient care, Shepperd and Iliffe (2005) found carers expressed less satisfaction with the Hospital-at-Home care. Based on recent evidence the British Thoracic Society has supported the treatment model of Intermediate care which bridges the interface between hospital and community enabling patients to remain cared for at home for longer (British Thoracic Society Guideline Development Group, 2007; Ram et al, 2004).

Despite these recent developments the bulk of the care for chronically ill patients in the community continues to fall heavily upon family members, many of who are employed or have impaired health themselves (Office for National Statistics, 2000a). As the disease and symptoms of COPD become progressively disabling, relatives become unpaid carers as they spend many hours looking after the ill person. More women than men are likely to be carers and are more likely to experience mental health problems due to stress as their caring hours increase (ONS, 2000b; ONS, 2000c; Hirst, 2005). Despite some studies identifying feelings of loss of freedom, increased responsibilities and an expressed need for support (Ohman and Soderberg, 2004), other studies have demonstrated resistance to, and the under-utilisation of, formal supportive services (Caron and Bowers, 2003). The need to include the caregiver in patient assessment and decision-making has been highlighted therefore as vital to establish appropriate and acceptable formal support services (Emlett, 1996).

Long-term oxygen therapy (LTOT) is the only pharmacological treatment proven to extend life expectancy (GOLD Executive Committee, 2006). Studies in the 1980's indicated that home oxygen for some COPD patients would increase life expectancy and improve a sense of well being (Nocturnal Oxygen Therapy Trial, 1980, Medical Research Council Working Party, 1981). However, a report by The Royal College of Physicians (1999) highlighted problems with patients on Long Term Oxygen Therapy (LTOT) across the UK. Concerns included variability in prescribing habits for oxygen concentrators, poor adherence to existing guidelines and a lack of organised follow-up and monitoring arrangements for patients (Wedzicha, 1999). In the wake of the recommendations, the British Thoracic Society published the first clinical guidelines

for oxygen assessment and a new oxygen service was implemented February 2006 in England and Wales (BTS, 2005; DoH, 2006).

#### **1.4. Emphasis upon shared care, patient participation and empowerment**

The last decade has seen an increase in media and government smoking cessation campaigns and initiatives such as 'National No Smoking Day' and more recently the statutory legislation, banning smoking in public places in England, Northern Ireland, Scotland and Wales. These developments have stirred public awareness to the risk of smoking associated killer diseases such as lung cancer, coronary heart disease and respiratory disease.

In addition chronic disease management or the term 'living with a long-term condition' has been given government priority through a number of policy documents and initiatives to address the increasing impact of chronic disease on patient quality of life and health care resources (Chamberlain-Webber 2004, NCCCC, 2004). A number of health policies have been published in the attempt to move towards encouraging active individual participation in healthy behaviours and lifestyles to reduce the risks of these diseases. The Expert Patient Programme (DoH, 2001) and The NHS Improvement Plan (DoH, 2000) aim to increase health and cost benefits of effective chronic disease management by improving information for patients and improving the support and care provided in primary care. However, unlike asthma, COPD again was notably absent from these documents, which omit it from the information of chronic conditions discussed. However emphasis is placed upon empowering all patients with a chronic condition, through informed patient participation and partnership-in-care with health professionals to improve individual coping and reduced dependency (DoH, 2004; Kings Fund, 2005). Patients are encouraged to manage their own conditions with the back up of personalised professional support led by community matrons based on evidence based care such as National Strategic Frameworks (NSF), and NCCC guidelines to reduce hospital admissions and improve patient satisfaction (DoH, 2004a). The concept of the expert patient is one who will take control over his or her life, to reduce disease symptoms, to improve quality of life, to increase self-confidence, efficacy and resourcefulness and improve concordance with professional treatment (DoH, 2001). Empowerment can facilitate informed and effective decision

making, increased patient satisfaction, and compliance to medical treatments (Holman and Lorig, 2000).

However, it has been suggested that effective communication, information giving and patient empowerment are not regular practices (Clark and Gong, 2000). Poor doctor – patient relationships (Oliver, 2001), a lack of consistency in professional advice and support for patients (Chambers, 2006) or differences in health beliefs between patient and professional (Conrad, 1985) have been suggested as common problems. Studies have highlighted how the notions of expected patient compliance with treatment and professional advice and that of patient self-reliance are contradictory (Thorne, 1990; Thorne et al, 2000). Professional attitudes towards patient's expertise in chronic illness are often sceptical, judgemental or dismissive (Thorne et al, 2000). Other researchers have highlighted how many chronically ill patients have a superior understanding of their disease at the individual level compared to their health professionals, whose knowledge of the disease is generalised (Brown and Piper, 1995). However, some patients have demonstrated that they want to receive information but prefer to leave the decision-making to health professionals (Guadagnoli and Ward, 1998) while other patients prefer no participation at all (Savage and Armstrong, 1990).

For individuals with COPD, life quality rapidly deteriorates as the illness progresses to the severely advanced end-stage of the disease process. Studies have shown how end-stage COPD patients experience symptoms as severe or even more severe than cancer patients. These patients have unmet needs and do not routinely receive specialist palliative care services but would benefit from this approach (Skilbeck et al, 1998; Addington-Hall et al, 1998; Gore et al, 2000; Edmonds et al, 2001). The principle of the palliative approach is not only to control symptoms but to integrate and centralise the physical, psychological, social and spiritual aspects of care around the individual patient and their family needs and wishes (Twycross, 2003). Hence in the quest to provide improved patient care, integrated approaches are needed to bridge tensions between the various approaches to include evidence-based healthcare yet to empower patients and respect their autonomy in healthcare related decision-making (Grol, 2001).

### **1.5. Rationale for studying COPD from an interpretive sociological perspective**

Despite the Department of Health's recognition of the importance of the role of patients as experts in managing their conditions (DoH, 2001), there is little published evidence regarding the opinions and experiences of individuals with COPD, their families or the healthcare staff involved in their care (Taylor et al, 2004). The voices of those most directly affected are missing from the literature. Most writing on COPD focuses upon the bio-medical approach and investigates the impact of pharmacological interventions upon the disease process or attempts to characterise and predict specific characteristics, which affect quality of life or functional status. These positivist quantitative studies attempt to investigate quality of life by generating numerical data based upon objective measurements to compare, test and identify correlations or predict variables in order to generalise statistically significant findings. Using a quantitative approach for studying quality of life issues of individuals living with COPD raises three concerns.

The first concern is that most quantitative studies investigating living with COPD, use questionnaires or interview-based instruments to measure quality of life, functional status or various other domains related to living with the illness in order to assess the effectiveness or impact of individual factors or interventions upon quality of life or health-status outcomes (Draper and Thompson, 2001; Curtis and Patrick, 2003). Such studies can be useful within organisations to use numerical data as health indicators from which to generalise findings such as mortality rates, number of hospital admissions and lung function parameters (Curtis and Patrick, 2003). However, from an interpretivist point of view, isolating variables to measure and evaluate patient outcomes is not in keeping with the qualitative approach and is epistemologically flawed. Many research authors question employing traditional methods within the positivist paradigm as epistemologically inappropriate for the investigation of patient experiences (Benner, 1985; Denzin, 2001; Silverman, 2001). As an alternative a heuristic or interpretive strategy is recommended which avoids the isolation of variables and enables the person to be studied holistically, in depth (Benner, 1985). A qualitative inductive approach facilitates more meaningful understanding of the unique issues and concerns of the individual whose life situation is taken into account.

Draper and Thompson (2001) suggest quality of life be determined in terms of one's status as a human being which necessitates respect for patient individuality, individual choice and decision-making in order to enhance personal autonomy and dignity of the individual. The aim of this study is to obtain detailed accounts of the multiple aspects of the holistic experience of living the illness trajectory of COPD.

Secondly, concerns have been voiced over the appropriateness and suitability of some instruments used in practice to measure concept domains such as breathlessness or an exacerbation, since these phenomena are poorly understood or defined in measurable terms and thus raise issues of credibility and validity, (Celli, 2000; Davies and Williams, 2005; Burge and Wedzicha, 2003; Pauwells et al, 2004). Other researchers have highlighted technical difficulties, as some generic instruments used have been found to be not sufficiently disease-sensitive to pick up subtle changes in COPD-specific outcomes (Engstrom et al, 2001; Guyatt et al, 1999; Mahler, 2001; Kline Leidy et al, 2003).

A third concern is that criteria seen as useful indicators for health care provision by health professionals may appear unimportant or irrelevant to the patient (Sutcliff and Holmes, 1991). Concepts such as quality of life, health status and coping will be unique to the individual and change over time, being culturally specific and having a different meaning for each person, and thus cannot be measured or defined in standardised terms but needs to be understood from the patient's perspective (Gerhardt, 1990; Price, 1996; Morse, 1991; Morse and Carter, 1996; Benner, 1985; Benner and Wrubel, 1989). Within this approach patient self-reports of health related quality of life are increasingly recognised as important outcomes of medical care (Guyatt et al, 1993; Curtis and Patrick, 2003).

Gaining a deeper understanding of the experience of living with COPD based upon the sensitive and often subtle issues raised, gives insight into the health and social care needs of this patient group. In particular, qualitative heuristic methodologies have been highlighted as a means of conducting rigorous and ethically sensitive research in palliative care (Clark, 1997; Seymour and Clark, 1998; Seymour and Ingleton, 1999). An interpretive methodology enables patients with severe COPD, who are often vulnerable and disempowered, together with their carers, to voice their particular

concerns, which may be otherwise ignored, overlooked or undetected (Draper and Thompson, 2001; Seymour and Ingleton, 1999).

Based upon the above rationale, in order to gain an understanding of patient and carer experiences of living with COPD, this health research study chose to use a qualitative interpretivist strategy which explores and recognises the individual patient experience from the insider's perspective. Although the findings of this study will not be generic, as in traditional research, it is intended that they should be credible, through detailed documentation of the research procedure, and transferable to a similar population of patients living with COPD to obtain similarly understood findings (Mays and Pope, 2000).

#### **1.6. The researcher's interest in the experience of living with COPD**

Unlike acute illnesses, which are usually treated and cured by health professionals over a relatively short space of time, it is assumed that individuals with COPD, as with other chronic conditions, learn to manage their lives, incorporating their illness into their daily living. In the absence of a medical cure, quality of life for chronically ill persons has been said to depend upon the individual's development of self care and decision-making skills together with the ability to access appropriate and supportive healthcare services (Thorne et al, 2000).

The researcher working as a qualified nurse, caring for respiratory compromised patients on a medical ward, noted high admission rates of patients with uncontrolled symptoms of COPD. The inpatients demonstrated a wide range of coping skills and varying levels of well being, irrespective of their lung disease severity. These observations led to speculation over how and why some patients with COPD appear to manage the symptoms and their consequences with fortitude and a positive outlook while other patients became distressed or heavily dependent upon nursing staff.

Many patients with severe illness experienced frightening symptoms causing alarm and anxiety and required intensive supportive care alongside the pharmacological treatment for symptom relief. Acute crisis exacerbations of symptoms were relatively short-lived, ranging from a few hours to a few days, followed by recovery of baseline



symptoms and discharge home. Although selected patients were prescribed for long-term oxygen therapy and would attend outpatient clinics for monitoring, others were referred to social services for home-care. Many COPD patients would not receive ongoing support and follow-up on discharge home from hospital. This situation contrasted with cancer patients who received on-going oncology and Macmillan support from time of diagnosis. As noticed elsewhere, COPD patients generally received no ongoing professional healthcare support at home to manage the illness or its impact despite often having considerable psychosocial and physical care needs (Skilbeck et al, 1998; Guthrie et al, 2001). Subsequent to recent IT deployment General Practitioners were informed of changes in patient medication by letter on patient discharge. These discharge letters frequently went astray or were received several weeks after the patient had returned home.

The researcher noted that most patients with COPD were unsure generally about the nature, management, and future course of their condition and were often concerned about how they would cope once discharged back home. These observations in conjunction with the availability of very few up to date publications, led the researcher to pursue a study of patients with COPD.

### **1.7. Overview of study**

This chapter has introduced the subject topic of COPD as an increasing major world-wide threat to morbidity and premature mortality. Vague symptoms, uncertain diagnosis and low professional priority have in the past contributed to a low public awareness of the illness COPD. Symptoms of COPD are characterised by the predominant breathlessness and/or dyspnoea and fatigue, which progressively restrict normal daily activities of living and impact negatively upon the physical and psychosocial functioning of the individual and on the quality of life for both patient and carer.

Current government policy places emphasis upon professional health and social care management of long-term conditions, such as COPD within primary and intermediate care. The successful management of chronic illness in the community aims to prevent unnecessary hospital admissions, to benefit the NHS economy and the individual patient alike. However, there is evidence that patients with COPD frequently have

little or no healthcare support within the primary care environment until their symptoms flare up into an exacerbation, often resulting in an acute hospital admission. As the illness progresses to the severe stages of COPD, patients often receive fragmented ad hoc healthcare together with no equivalent specialist healthcare services as compared to those with malignant disease (Edmonds et al, 2001; Gore et al, 2000).

The aim of this study is to explore and understand the experience of living with COPD from the perspectives of individuals with COPD and their carers, highlighting the subjective concerns and issues raised by the study's participants. Although the findings of this study are not representative in a statistical sense (Williams, 1993), it is intended that they will contribute towards a theoretical understanding of the experiences explored and based upon their ability to be replicated in future studies, be recognised as issues of professional concern (Denzin, 2001).

In order to obtain insights into the lived experiences of patients with COPD and their carers, the research problem led to two specific research questions being posed to the study's participants. These were: "what is it like to live with your respiratory illness?" and: "can you tell me about your respiratory condition?"

Chapter 2: The literature review identifies the vast amount of literature on COPD and concludes that much of the research has been based upon the use of the bio-medical model to investigate, compare or correlate variables of COPD to evaluate or predict health status outcomes. Indicators of health related quality of life, coping, functional status or functional capacity is well represented in the literature. However, findings are frequently confusing, conflicting or difficult to compare as different research tools are used to evaluate variables and outcomes. The few qualitative studies exploring the subjective experience or perceptions of living with COPD are identified and compared with the findings of this study.

Chapter 3: The methodology chapter describes the research approach and methods used within this study; analytical comparisons are made with the alternative qualitative methods of grounded theory, phenomenology and the case study. This provides a rationale for taking up the interpretivist framework based upon the

symbolic interactionist approach influenced by George H. Mead (1937) and Herbert Blumer (1969).

The data chapters, chapters 4 – 7 present the findings of this study, each chapter chronologically depicting the conceptual but ill-defined stages of the illness trajectory of COPD.

Chapter 4: Living with COPD: The early days; describes the vague onset of the symptoms of COPD and explores how and when individuals seek medical advice, usually during times of crisis and first hospital admission for an acute exacerbation of symptoms. It is generally during this time that identification of the illness occurs and COPD is diagnosed. Patients' health beliefs related to tobacco smoking and the causes of COPD are explored.

Chapter 5: Living with COPD: Adapting to changes in self and lifestyle; explores how individuals manage the changes in lifestyle due to the illness impacting upon normal daily activities. As a consequence of the impact of progressive symptoms upon self and functioning, this chapter explores how patients strive to maintain a sense of normality by the adaptation of routines, the individualisation of medical therapies to suit ones-self and the incorporation of the changes brought about by the illness into normal daily living.

Chapter 6: Living with COPD: the daily struggle; highlights the constant difficulties of carrying out the simplest of activities within daily living and the relentless battle against breathlessness and the difficulties it imposes on daily life. The impact of the relentless symptoms are explored as they restrict and limit physical independence imposing increased dependency on others and with it a sense of altered self, self-worth and self-identity.

Chapter 7: Living with COPD: fears and facing the future; exposes individuals' concerns related to the constant preoccupation of maintaining a steady breathing pattern to avoid breathing difficulties. At this advanced stage of the illness, patients tend to consider their future, which includes thoughts on death and dying. In a very few cases individuals are faced with the possibility of disease remission via lung surgery. Participants' perceptions of their illness course are explored as they

experience multiple losses associated with the impact of the disabling illness, their exposed vulnerability and their continuing uncertainty about prognosis and life expectancy.

Chapter 8: Living with COPD: the carer's experience; describes how family carers perceive and experience their role as a carer for their relative with COPD, which is represented as going through three stages of caring. These stages are conceptualised as: the transition from being a caring relative to becoming a care-giving relative; caring through crisis and finally becoming a full-time carer. Although the caring role was perceived as exhausting, paradoxically a quarter of the participants with COPD (n=13) lived alone or did not have a recognised carer.

Chapter 9: The discussion, implications and final conclusions; discusses the implications of the issues raised by the study's findings in relation to existing work on COPD. This chapter identifies the limitations of the study and makes recommendations for further research.

## **2.0. Chapter 2: Literature review**

### **2.1. Introduction**

The aim of this literature review is to a) identify the current state of knowledge of COPD within the context of living with a chronic illness and b) to consider previous work on COPD, highlighting its relevance to the findings of this study.

In the tradition of inductive research the literature review was undertaken following fieldwork and data analysis of the study, so as not to pre-structure the focus of empirical work. Topic areas related to COPD, which were lacking or limited in the existing literature are highlighted thereby giving justification for the purpose of this study and its contribution to the knowledge base of COPD (Hart, 2001).

The review is organised so as to identify, appraise and, where appropriate, incorporate insights from the available research studies on Chronic Obstructive Pulmonary Disease and to draw some general and specific conclusions from the work done to date, in relation to this study. Research in the field was considered in terms of substantive findings, the methods employed and their appropriateness, and the underlying theoretical frameworks used.

Living with COPD, as with other chronic illnesses:

“Is like life itself, a multi-phenomenal experience and therefore a multi-layered object of analysis” (Kelly and Field, 1996:241).

Therefore a review of the literature necessitated an examination of the physical biomedical, psychosocial and societal factors, as well as the theoretical/ conceptual influences, which impact on the individual's experience of living with the condition COPD. However the literature search on COPD quickly revealed the dominant position of traditional medically oriented research using quantitative approaches, and a relative dearth of qualitative studies.

## **2.2. Literature review search strategy**

The review looks at the existing literature in an attempt to shed light on the following research questions:

- What is it like to have COPD?
- What is it like to care for a relative with COPD?
- What are the issues, concerns and problems of living with COPD?
- What areas warrant further investigation of the concerns of people living with COPD in order to contribute towards the planning of future improvements in care?

Due to the relative paucity of the literature, both quantitative and qualitative studies are included to shed light on the above questions about living with COPD.

## **2.3. Search strategy for published and grey literature**

The COPD literature was identified from various sources including both electronic searches and manual tracking. The electronic searches were set up to retrieve any work which cited COPD, emphysema, and chronic bronchitis in the title or abstract. Additional terms of living with, experiencing, coping with and, quality of life were incorporated into the search to extract more qualitative studies. The subject areas of chronic illness, family carers and caring were also searched to find information relevant to caring for a person with COPD. Online searches on the world wide web included a search of healthcare, nursing and sociological orientated bibliographic databases including; CINAHL (Cumulative Index to Nursing and Allied Health Literature), BNI (British Nursing Index), EMBASE, PUBMED-MEDLINE, PSYCHINFO, COCHRANE LIBRARY, ASSIA (Applied Social Sciences Index and Abstracts), WEB OF SCIENCE, and NeLH Care Pathways Database. Other web sites were accessed for background information such as NMAP (Nursing Midwifery and Allied Health), OMNI (Organising Medical Networked Information), Database of ABSTRACTS of Reviews of Effectiveness (DARE), and from organisations including The Global Strategy for the Diagnosis, Management and Prevention of COPD (GOLD Executive Committee, 2006; British Thoracic Society (BTS), British Lung Foundation (BLF); various Department of Health Papers, and the National Institute for Clinical Effectiveness (NCCC) guidelines for COPD. Only articles

written or translated into English were retrieved and no date restriction was imposed on the search. Guidance for developing expertise in searching electronic databases was sought from the hospital and university librarians.

The electronic searches were supplemented by library searches for subject books and articles, scanning bibliographies, index citations and lists of references and gaining relevant information from research support group meetings and workshops, the hospital librarian and the researcher's supervisor. Unpublished material such as conference abstracts from RCN Respiratory Nursing Conference, British Thoracic Society and PhD theses that cite COPD, emphysema, chronic bronchitis in the title, were also reviewed for relevant information.

#### **2.4. A sociological approach to studying chronic illness: Historical background**

The 'chronic illness experience' field of study has developed dramatically since the 1970s for several interrelated reasons (Bell, 2000; McKeown, 1979). Notably, chronic illnesses have become increasingly more prevalent than acute conditions since the 1960s due to the success of modern medicine and surgical intervention for the treatment of infection, trauma or acute disease (Gerhardt, 1990). Many conditions for which there is yet no permanent cure, benefit from contemporary drug therapy to alleviate flare-ups, exacerbations, or rapid disease degeneration allowing the condition to manifest as an ongoing long term chronic illness which 'never entirely disappears' (Kleinman, 1988:7). Hence more people are living longer and many individuals of this aging section of the population live with a chronic condition in the 'remission society' (Frank, 1995: 10), where people are well but are not considered completely cured from an ongoing illness condition.

During this same era, health policy and philosophy had begun to recognise the need to provide holistic care for patients as opposed to medically treating the disease in isolation (Eisenberg, 1977). As life expectancy of the population has increased, then so quality of life issues have become medically important, with a shift from curative interventions to rehabilitation care (Gerhardt, 1990; Williams, 1989). As a consequence, much of the psychosocial or medical sociological research on chronic

illness has focused upon specific factors which influence or shape quality of life issues or coping, faced by individuals with a degenerative debilitating condition.

Involving the patient in treatments and encouraging patients to take on responsibility for their own health has led to a move towards a more patient-centred philosophy of health care, with increased patient knowledge, patient empowerment and a more equal power relationship between patient and doctor (Bell, 2000). At this time many sociologists have turned from studying 'sociology **in** medicine', medically defined social problems and causes of ill-health, to studying a 'sociology **of** medicine' with many employing an approach of symbolic interactionism; studying illness from the patient's perspective (Charmaz and Olesen, 1997). The interpretivist approach within sociology of medicine studies is challenging the traditional dominant medically centred role and seeks to understand the patient's perspective, based upon agency and lived experience (Bell, 2000; Bury, 2000).

Interpretivist sociological work makes the assumption that individuals have a sense of self which is related to the body and is central to all human conduct; through the concepts of self-conception and social identity (Mead, 1934). Against this background, interpretivist sociologist researchers propose conceptual explanations for the way individuals manage and perceive themselves as they adapt to living with a chronic illness (Charmaz, 1987, 1995; Corbin and Strauss, 1987; Bury, 1982). Many studies on chronic illness have taken a subjective approach to elicit a deeper understanding of how individuals experience and manage chronic illness in their daily lives (Davis, 1963; Strauss et al, 1984; Conrad, 1990; Corbin and Strauss, 1988; Bury, 1991; Charmaz, 1983, 1987, 1995; Williams, 1984).

The research approach to understanding illness from the insider's view point (Conrad, 1990), has gathered momentum over the last two decades and has taken on more recent significance following changes in social policy and the government's aim to tackle chronic disease management as highlighted in key initiative papers: The NHS Improvement Plan (2004) and The Expert Patient: A New Approach to Chronic Disease (DoH, 2001). More specifically for respiratory disease, the British Thoracic Society have recently published a report "The Burden of Lung Disease" (BTS, 2006)



and the British Lung Foundation has published “Lost in Translation: Bridging the Communication Gap in COPD” (The British Lung Foundation, 2006).

Sociologists have recognised the importance of studying the families of ill persons, as chronic illness impacts upon the lifestyles of not only the patient but also on family members (Corbin and Strauss, 1984; Anderson and Bury, 1988). Chronic illness often causes disablement, which may be publicly visible or discretely disguised and can cause a heavy burden and dependency upon family members for practical management and /or moral support (Anderson and Bury, 1988; Voysey, 1975; Corbin and Strauss, 1988).

Although the functionalist bio-medical framework used in researching patients with disease is being increasingly replaced by sociological and conceptual approaches (exploring the patient’s psychosocial responses to illness), both approaches have been criticised as not being sufficiently comprehensive to encompass all aspects of the illness experience (Bury, 2000; Turner, 1992; Frank, 1990). The functionalist model influenced by the writings of Parsons, (1951) de-emphasises individuality and examines patient recovery from the dependent sick role. Typical of chronic illness, COPD does not usually allow complete recovery and frequently patients become more disabled and dependent upon others as the illness progresses. This has negative connotations within the sick role framework (Bury, 2000).

Sociological approaches using grounded theory to investigate the chronic illness experience generate rich in-depth data. However, this approach has been criticized as being too theoretical (Frank, 1990; Conrad, 1990). Critiques have highlighted the lack of attention to the corporeal component: the ignoring of the physical body and the downplaying of basic bodily symptoms in some social constructions of the defined illness experience (Turner, 1992; Bury, 2000; 1997; Frank, 1995; Kelly and Field, 1996). Typically these studies employ the grounded theory analysis approach by which qualitative data is coded by theme and categorised. Excerpts are highlighted to illustrate the researcher’s interpretation of the conceptual patterns grounded in the data (Conrad, 1990). Some sociologists suggest that in searching for patterns through this coding and categorising technique, the data is fragmented and meanings are taken out of local context thereby disembodimenting the illness experience (Ellis, 1995; Riessman, 1993; Burnard, 1995). In isolating aspects of the experience and breaking

away from the entirety of the experience it has been argued that the positive, adaptive and creative ways in which individual patients deal with the disruptions in their lives are missed (Frank, 1990; Bury, 2000; Mishler, 1995; Riessman, 1993).

The methodologies of grounded theory and phenomenology have been criticised for being reductionist in approach by taking data out of context and categorising them into conceptual fragments to obtain the 'essence' of the experience. However, many such studies have revealed rich detailed conceptual analyses of the experience associated with living with chronic illness (Charmaz, 1983; 1987; 1995; Morse and Carter, 1996).

Patient story-telling or narrative expression is recognised by some social scientists as an important way in which individuals can construct and convey meanings about their illness experience and suffering (Williams, 1994; Riessman, 1990; Gerhardt, 1990; Mishler, 1995; Hyden, 1997; Lucas, 1997). Narrative refers to the 'longer stretches of talk' that link significant events within a temporal ordering to reflect and reconstruct the experiences of the narrator (Riessman, 1990). Narrative is shaped not only by the 'what' and 'how' selected by the narrator in each telling, but is influenced by situational factors such as interaction between the narrator and listener (Mishler, 1995; Riessman, 1990; Hyden, 1997). Narrative has been defined as:

“A discourse that consists of a sequence of temporally related events connected in a meaningful way for a particular audience in order to make sense of the world and/or people's experiences in it” (Hinchman and Hinchman, 1997:xvi).

Narratives and thematic analysis as a research methodology are particularly suited to understanding the illness experience in its entirety, in contrast to the categorical methods of other interpretivist approaches, or studies from the clinical and behavioural sciences which use symptom scales, checklists and survey questionnaires, and thereby also isolate component aspects of an experience (Conrad, 1990; Kleinman, 1988).

Recognising that both biological and social aspects make up the chronic illness experience including intrusive symptoms, disruption to daily routines and changed behavioural patterns, chronic illness has been referred to as a multi-phenomenal experience, which requires investigation and understanding by means of multiple research approaches and methods (Kelly and Field, 1996).

An empathetic understanding of the individual illness experience as perceived from the patient's perspective fits with the therapeutic commitment of the nursing role within the patient-nurse relationship (Benner and Wrubel, 1989; Benner, 1985). Irrespective of the study method employed, COPD like many other chronic illnesses is long-term, permanent and causes significant upheaval and disruptions in a previously established lifestyle (Kelly and Field, 1996; Conrad, 1987; Gerhardt, 1990; Bury, 1997).

Defined from a sociological stance, chronic illness is characterised by an insidious onset, a fluctuating course and an uncertain outcome (Bury, 2000). Because of the changes in character and consequences along its pathway, chronic illness has a temporal dimension or 'illness trajectory' or career (Corbin and Strauss, 1988: 225).

In their studies, Corbin and Strauss (1988, 1992) extended the trajectory work initially conceptualised by Glaser and Strauss, (1968) who theorised three different trajectories of dying. Pulmonary disease was classified as an 'entry-re-entry death', depicting how patients with chronic respiratory disease experience frequent acute deteriorations followed by periods of recovery; each acute episode resulting in a decline in health (Glaser and Strauss, 1968). Along the chronic illness journey, the individual experiences physical and psychological suffering, impaired functioning and disability as well as social and financial consequences (Bury, 1982; Charmaz, 1983; 1987; Strauss et al, 1984; Anderson and Bury, 1988; Radley, 1989, 1993). Bury (1982) referred to these significant events or changes in lifestyle as: "biographical disruptions".

Interpretive sociological studies of the experience of chronic illness emphasise how disrupted biographies alter both the physical body and the person's self-conception or sense of identity over biographical time (Charmaz, 1983, 1995; Bury, 1982; Corbin and Strauss, 1988). People with chronic illness who experience a loss of self due to

reduced body functioning and an altered self-image often reassess themselves and reconstruct a new identity of the self; living with and in spite of the illness (Charmaz, 1983; 1995; Williams, 1984; Bury, 1982). Other recurring themes arising from the sociological study of chronic illness include concerns with managing medication and regimes (Armstrong, 1987; Peyrot et al, 1987; Kelleher, 1988), dealing with uncertainty (Davis, 1963; Bury, 1982; Wiener, 1975; Nyhlin, 1990; Charmaz, 1983), family relationships (Davis, 1960; Strauss et al, 1984, 1985; Corbin and Strauss, 1988, 1984) and living with stigmatisation (Goffman, 1961).

## **2.5. What is known about COPD as a chronic illness?**

COPD follows a typical temporal course of chronic illness as defined above, typified by a vague onset, a fluctuating course and an uncertain life expectancy (Bury, 2000; Glaser and Strauss, 1968). Despite being a significant cause of mortality in the UK, COPD has been considered with much uncertainty by both individuals experiencing the symptoms of the illness and by the public at large (Buist, 2006). This situation may have arisen for several reasons. Firstly, COPD is usually ill defined in terms of its onset, temporal progression and prognosis, with disease severity not clearly correlated with functional capacity or quality of life (Leidy, 1995; Engström et al, 2001). Secondly, COPD has not been considered a high priority disease for professionals, as treatment is limited and death usually occurs only after years of progressive decline (Williams and Bury, 1989). Thirdly, health policy for COPD has lagged behind that for other chronic illnesses prior to the recent national and international guidelines and other policy initiatives (British Medical Association, 2003; British Thoracic Society, 1997; British Lung Foundation, (2006); National Collaborating Centre for Chronic Conditions, (2004); Global Strategy for the Diagnosis, Management and Prevention of COPD, (Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD Executive Committee, 2006; American Thoracic Society, 1995; Siafakas, 1995).

In the quest for effective management of symptoms and to identify relationships between variables impacting upon health status and the quality of life, much of the research on COPD has been predominantly quantitative (Janssens et al, 2000; Curtis and Patrick, 2003; Graydon et al, 1995; Engström et al, 1996; Guyatt et al, 1993). For example, some studies seek to measure gains achieved in functional performance

through pulmonary rehabilitation schemes (Lacasse et al, 1997) and to measure smoking cessation success rates (West et al, 2000). However, in keeping with the trend towards holistic and patient-centred care, and in recognition that dyspnoea is a subjective symptom of COPD, a few recent studies have focused upon patient perceptions of how the symptoms of COPD impact upon their quality of life (Robinson, 2005; Fraser et al, 2006; Seamark et al, 2004; Barnett, 2005).

COPD typically takes a deteriorating trajectory irrespective of how well the disease is managed (Cicutto et al, 2004). Sudden acute deteriorations generally show improvement following active hospital inpatient care, which may falsely conceal the overall steady decline in health of patients with COPD (Murtagh et al, 2004). As the disease progresses in severity, patients with COPD experience symptom burden comparable with cancer patients, but frequently do not receive the same palliative or specialist health and social care services (Addington-Hall et al, 1998; Gore et al, 2001; Edmonds et al, 2001). Recent studies have suggested that this disparity exists in part due to the uncertainty and unpredictability of the COPD illness trajectory, which makes prognosis and end of life planning difficult (Teno et al, 2001; Murtagh et al, 2004).

## **2.6. The principal symptoms of COPD: Breathlessness, dyspnoea and fatigue**

Progressive disabling breathlessness or dyspnoea on exertion or at rest is the most characteristic symptom of COPD (BTS, 1997; Janssens et al, 1999; Mahler et al, 2001) and has arguably the greatest impact on patients' level of functioning and quality of life (Williams, 1993; Lee et al, 1991; Ferreira et al, 2003). The pathophysiology of dyspnoea is associated with clinical conditions in which the respiratory system is subjected to increased mechanical load, increased ventilation and the respiratory muscles being weakened, as notably characterised in emphysema with severe hyperinflation (Manning and Schwartzstein, 1995).

West and Popkess-Vawter (1994) noted that the terms breathlessness and dyspnoea have been used interchangeably in the literature and suggested that dyspnoea is laboured difficulty in breathing observable by another person, while breathlessness is the subjective experience of laboured breathing with or without abnormal pulmonary functioning. However, other definitions of dyspnoea have included the individual's

subjective perception and response to the sensation (McCord and Cronin Stubbs, 1992; Carrieri et al, 1984; Mahler, 1996; 2001; Cambell, 1996; Janssens et al, 2000; Parshall, 1999). DeVito, (1990) noted that previous work on dyspnoea focused primarily on three areas: (1) investigating the mechanics of dyspnoea, (2) identification of physiological and psychological correlates of dyspnoea and (3) the efficacy of techniques used to manage dyspnoea. Based on comparative measurements of perceived inspiratory effort, breathing pattern and operational lung volumes between normal individuals and those with chronic airflow limitation, O'Donnell et al (1997) suggested that the respiratory sensations described are related in part to a disparity between effort and ventilatory output occurring due to thoracic hyperinflation. Other researchers question the appropriateness or accuracy of measuring dyspnoea, due to it not being a single entity and its underlying mechanism not being fully understood (Davies and Williams, 2005; Meek, 2004). McCarley, (1999) noted a lack of differentiation between acute and chronic dyspnoea in the reviewed literature 1980-1998, and put forward a model for chronic dyspnoea to guide clinical interventions in clinical care. Moody et al, (1991) suggested that dyspnoea has both a sensory component and a response component with most studies focusing upon the former resulting in a lack of knowledge in other aspects of dyspnoea.

Studies have found dyspnoea associated with, anxiety (Dudley, 1980), certain personality traits (Moody et al, 1991) and emotional factors (Janson-Berkie et al, 1986). However, a study by Carrieri-Kohlman et al, (1996) suggests that individuals experiencing dyspnoea can perceptually differentiate the intensity of the sensation from its affective components. Due to the complex interaction existing between the sensation of dyspnoea and affective states of anxiety and depression, studies frequently attempt to quantify both characteristics including measures such as the 'Hospital Anxiety and Depression scale' (Smoller et al, 1996; Janseens et al, 2000).

Using the term dyspnoea, Kinsman et al, (1983) investigated the experiences and symptoms related to shortness of breath in patients with chronic bronchitis and emphysema during times of breathing difficulties and concluded that dyspnoea occurs as a 'heterogeneous set of individual symptoms' and developed the well-used 'Bronchitis-Emphysema Symptom Checklist', (BESC). In this study Kinsman and colleagues identified eleven conceptually distinct categories of symptoms including:

dyspnoea, fatigue, poor sleep, congestion, anxiety, irritability, decthexis, helplessness-hopelessness, poor memory, peripheral/sensory complaints and alienation (Kinsman et al, 1983).

Different types of dyspnoeic sensations have been distinguished between patients with COPD and patients with other disease categories; emphysema or chronic bronchitis. Experiences of air hunger, gasping, heaviness and effort of breathing have been described by emphysema and bronchitic patients (Simon et al, 1990). Whilst descriptions of more or less constant dyspnoea, shortness of breath, 'hard to breathe' and 'needing-more-air' sensations by COPD patients (Janson-Berjklie et al, 1986). There has also been consistent reporting of inspiratory difficulty, "cannot get enough air in", and shallow breathing by patients after exercise with chronic airflow limitation compared to normal subjects (O'Donnell et al, 1997). Fatigue has been associated with dyspnoea in COPD patients, causing functional limitations in cognitive, physical and psychosocial domains thus impacting upon the general quality of life (Potempa, 1993; Ream and Richardson, 1996; Lee et al, 1991; Graydon and Ross, 1995; Theander and Unosson, 2002). Using a detailed schedule, Small and Lamb (1999) investigated fatigue in COPD patients and found the symptom fatigue distinguishable from ordinary tiredness, in being persistent and inextricably linked to laboured breathing. The literature on dyspnoea and fatigue identify similar precipitants and strategies of coping, but does not distinguish the extent to which either factor contributes to or is distinct from the other (Small and Lamb, 1999; Baker and Scholz, 2002).

Based upon the theoretical framework of stress and coping (Lazarus and Folkman, 1984) some studies have investigated how patients with COPD cope with dyspnoea and the impact of breathlessness upon daily living. These studies have highlighted the use of both problem and emotion-focused strategies to overcome interlinked difficulties. Strategies used included: positive thinking about one's situation, accepting physical limitations and making normalising changes in daily lifestyle (Small and Lamb, 1999; Kohlman Carrieri and Janson-Bjerklie, 1984). Energy conservation, pacing oneself and seeking help from others were activities identified as reducing or minimising the risk of increased breathlessness and fatigue (Barstow, 1974; Fagerhagh, 1973; Kohlman-Carrieri and Janson-Bjerklie, 1986; Narsavage and

Weaver, 1994; Leidy, 1995; Small and Lamb, 1999). As with other illnesses, patients with COPD report having good and bad days according to fluctuating symptom severity and symptom control (Charmaz, 1991; Leidy and Haase, 1999; Fraser et al, 2006).

Investigating the relationships between dyspnoea, physical activity and fatigue, Woo, (2000) found positive correlations. Whereas Larson et al, (1996) reported a significant correlation between physical activity and dyspnoea but not with fatigue. Woo, (2000) however, suggested that differences in the percentage of the gender of participants may account for the discrepancy in the findings of these two studies where the relationship between physical activity and fatigue may be more specific to females than males. In small qualitative studies, participants' highlighted breathlessness and tiredness as the most salient and troublesome symptoms associated with COPD. Breathlessness and fatigue have been highlighted as restricting daily activities, resulting in loss of liberty, social isolation and role within the family (Seamark et al, 2004; Barnett, 2006). These studies have found severe breathlessness and dyspnoea associated with patient self-reported feelings of panic, fear and anxiety (Seamark et al, 2004; Barnett, 2006; Robinson, 2005).

Elofsson and Ohlen (2004) explored the views of six persons living with COPD in old age and unsurprisingly found individuals describing life as hard work as they endured daily difficulties as a consequence of being breathless. Breathlessness, tiredness and a tendency to cough have been highlighted as causes for reduced dietary intake leading to significant but often overlooked symptoms of depressed appetite, weight loss and low body mass index in patients with COPD (Odencrants et al, 2005). Breathlessness, tiredness and coughing, particularly in company, have been highlighted as negatively impacting upon the activities of eating, chewing, swallowing, cooking and grocery shopping by participants in qualitative studies (Odencrants et al, 2005; Barnett, 2005). Low body mass index (BMI) has been found associated with increased mortality and hospitalisation rates regardless of stage of disease (Landbo et al, 1999; Chailleux et al, 2003).

## **2.7. Acute exacerbations of COPD**



The term exacerbation or flare up is used extensively by health professionals and within the literature on COPD, but researchers have noted the absence of a consensus definition (Anthonisen et al, 1987; Rodriguez-Roisin, 2000; Stoller, 2002; Burge and Wedzicha, 2003; Pauwells et al, 2004). Arguably there is no objective rating system to assess symptom severity (McCrory et al, 2001). However, a recently recognised definition defines an exacerbation of COPD as:

“An event in the natural course of the disease characterised by a change in the patient’s baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication in a patient with underlying COPD” (GOLD Executive Committee, 2006: 62).

The GOLD Executive Committee, (2006) state that exacerbations are categorised in terms of clinical presentation, the number of symptoms (Anthonisen et al, 1987), and/or healthcare resources utilisation (Rodriguez-Roisin, 2000).

Spirometry testing using FEV1 (Forced Expiratory Volume in one second) values, essential for the confirmation of COPD diagnosis, has been found of limited sensitivity in detecting changes in clinical condition as compared to arterial blood gas values (McCrory et al, 2001) or qualitative evaluations of symptoms (Niewoehner et al, 2000; Seemungal et al, 2000). However, despite its inaccuracy and the difficulty in using it during an exacerbation, spirometry has been criticised for being the chosen instrument to evaluate FEV1 changes in respiratory function possibly due to its ease and safety to use (McCrory et al, 2001; GOLD Executive Committee, 2006; Celli, 2000).

Self-reporting methods such as the Medical Research Council Dyspnoea scale or the Borg scale are commonly used to measure degree of dyspnoea (Mahler, 2001, Kendrick et al, 2000; Borg, 1982; Fletcher et al, 1959). Based upon internationally recognised principal symptoms of COPD, Kline Leidy and associates (2003) developed ‘The Breathlessness, Sputum and Cough Scale’; a brief three-item patient reported outcome measure represented by a single cumulative score.

As patient symptoms significantly worsen prior to an exacerbation (as compared to lung function values), Seemungal et al, (2000) suggest that patients should be encouraged to report symptoms earlier for prompt treatment as, earlier therapy reduces severity and duration of exacerbation. However, studies have found that approximately 50% of COPD exacerbations go unreported (Seemungal et al, 1998), with patients underestimating the severity of an exacerbation (Rennard et al, 2002) and up to a third of patients with COPD do not recognise the warning symptoms (Kessler et al, 2006). In a study investigating patient's understanding of COPD exacerbations, only a tiny proportion of the COPD population understood the term 'exacerbation', preferring instead to use the terms 'chest infection' or 'crisis' instead (Kessler et al, 2006). However, of the patients who were aware of an imminent deterioration in symptoms, many responded by self-medicating rather than contacting a physician (Kessler, 2006).

A review comparing national guidelines on COPD identified common criteria or recognisable symptoms characterising an exacerbation of COPD (National Guidelines Clearinghouse, 2005). These included, worsening dyspnoea, increased sputum purulence and an increase in sputum volume (ACP/ACCP, 2001; Finnish, 2004; GOLD Executive Committee, 2006; NCCC, 2004). Other recognised accompanying symptoms which may be present during an acute exacerbation include; general malaise, fatigue, depression, insomnia and confusion (GOLD Executive Committee, 2006; NCCC, 2004; ATS, 2001; BTS, 1997). Acute exacerbations are recognised to occur more frequently in patients with more severe COPD and are often present with complex co-morbidities, which can lead to respiratory failure and emergency hospital admission (ATS, 1995; BTS, 1997; BLF, 2005). Frequent exacerbations in the previous year, daily cough, daily wheeze and daily cough plus sputum have been found to be predictive of ongoing frequent exacerbations, suggesting a significant impact upon the patient's quality of life (Seemungal et al, 1998). Prolonged recovery after an acute exacerbation of symptoms has been found to be associated with increased dyspnoea and a cold at the onset of the exacerbation with some patients not recovering to their forced Expiratory Flow Rate (FEFR) baseline levels; indicative of a steady general decline in the patient's lung function and well-being (Seemungal et al, 2000). Patients with severe lung disease having greater frequency and severity of exacerbation have been found to be more likely to fail to respond to medical treatment

within 4 weeks as compared to other COPD patients (Dewan et al, 2000). Likewise, Niewoehner et al, (2000) found an association of FEV1 measurements with clinical outcome in patients with COPD exacerbations, noting that an increase in FEV1 at study entry was strongly associated with the relative risk of treatment failure at 30 days by 20%; where treatment failure was classified as death, intubation, re-hospitalisation or intensification of therapy.

It has been recommended that following an exacerbation the implementation of the BTS (1997) guidelines on closer outpatient monitoring, increased social services input and medical care packages can improve the quality of life of patients with COPD (Seemungal et al, 2000; Gravit et al, 1998; Dheda et al, 2004). Kessler et al, (2006) noted that little is known about the patient experience of an acute exacerbation of COPD, as instruments measuring health-related quality of life do not consider all disease specific effects on physical and psychological well-being, and found that physicians tend to underestimate the impact of an exacerbation as compared to patient reports.

Fear, anxiety, panic, helplessness and urgency of patient needs are common themes of the experience of an acute exacerbation of COPD highlighted by qualitative studies (Hill Bailey, 2001, 2004; Heinzer et al, 2003; DeVito, 1990; Kessler et al, 2006). Claiming to be the first study to explore in depth the subjective experience of being acutely breathless, Hill-Bailey (2001) interviewed ten COPD patients and their carers during an acute exacerbation event and revealed a fear of death associated with severe breathlessness. In a later study using narrative analysis, Hill-Bailey (2004) explored the experience of acute dyspnoea in COPD patients and found that through narrative expression, patients highlighted their emotional vulnerability, closely relating the experience of anxiety to their intractable breathlessness. Hill-Bailey (2004) suggested that anxiety was an important indicator of increased dyspnoea. This is in contrast to an earlier study by Carrieri Kohlman and colleagues (1993) who suggested that raised anxiety in COPD patients preceded and contributed to the experience of increased dyspnoea. Heinzer et al, (2003) found that patients with COPD valued the presence of those nurses who recognised and addressed the immediate needs of the breathless patient within a calm unrushed environment.

## 2.8. Coping with COPD

In a review of the psychosocial literature on Chronic Obstructive Airways Disease (COAD), Williams (1989) noted the paucity of British studies on chronic respiratory illness despite the extent of the disease and its consequences. He supported the point made by Guyatt et al (1987) that the existing systematic investigation into COPD, relies heavily upon the application of measures developed for general or psychiatric populations and suggested that vital areas of impairment may be missed in COAD patients. Williams (1989) noted that the only studies investigating daily living problems of individuals with COAD were mainly small or anecdotal, lacking in scope and highlighted a need for systematic qualitative research focusing upon the insider's perspective of living with the illness.

A review of the literature on coping with COPD identified two distinct areas of work. Firstly, the majority of psychosocial studies used psychometric measures to evaluate specified domains of coping. Fewer sociological studies were found which sought to understand the individual's experience of coping with COPD. Czajkowski and McSweeney (1996) reviewed the literature investigating the role of psychosocial factors in COPD and found that due to the chronicity and severity of symptoms, many patients who lack adequate psychosocial assets and resources typically experience negative effects on their coping and health-related quality of life. Reviewing the psychosocial concomitants to rehabilitation in COPD, Dudley *et al* (1973) suggested that patients with greater psychosocial assets are more likely to deal more effectively with the disease. These psychosocial assets were listed as having a vital interest in life, adequate financial resources, social support, ability to cope and adapt to lifestyle changes, and personal characteristics conducive to managing a chronic illness (Dudley et al, 1980).

Secondly a group of studies focusing upon psychosocial investigations into coping with COPD used the 'Stress, Appraisal and Coping' theoretical framework developed by Lazarus and Folkman (1984), which identifies problem-solving and emotion-focused strategies to alter the perceived situation. The 'Jalowiec Coping Scale', (JCS), consisting of a questionnaire rated 1 to 5 on a Likert-type scale, has been frequently used to measure coping. Small studies of patient coping with COPD using the JCS to determine the most frequently used style of coping demonstrated inconsistent findings

(Parsons, 1990; Herbert and Gregor, 1997), but larger studies found the 'optimistic' and 'confrontive' styles of coping to be the most effective and frequently used approaches used by patients with COPD (Wu et al, 2001; Baker and Scholz, 2002).

Royer, (1998) suggests that individuals tend to resort to cognitive strategies to normalise the impact of their chronic illness on daily living when behavioural strategies become no longer effective.

In exploratory studies based upon Ajzen's (1985) theory of planned behaviour, McBride (1993, 1994) sought to explore attitudes toward the endeavours thought to increase activity tolerance due to the impact of COPD on the individual. Content analysis carried out upon interview data identified three themes: acceptance and resignation, determination and perseverance, and impatience and intolerance (McBride, 1993).

Within the sociological literature concerned with 'coping with chronic illness', Bury (1991) has advocated the use of three distinct terms to clarify the confusion over different conveyed meanings of the term coping. He suggested the use of the term coping (a) to depict a cognitive process whereby the individual learns how to tolerate the effects of the illness and maintains a sense of personal worth despite the illness, (b) as strategic management of the illness within social context and mobilisation of resources to one's advantage, and (c) as style, the way in which people respond and present salient aspects of their illness according to cultural and societal influences (Bury, 1991). Classification of the available literature using the above criteria is however made difficult as much of the work on adapting or coping reflects multiple complexities of social living and interaction associated with coping as well as addressing numerous health-related quality of life issues associated with living with COPD.

Williams and Bury (1989) investigated the consequences of having a respiratory disorder within the framework of "Impairment, Disability and Handicap" (World Health Organisation, 1980) and found that the wider social circumstances and social class background of the patient influences the prevalence and degree of social disadvantage in coping with the illness. Earlier works investigating the coping techniques used by persons with emphysema highlighted how strategies were used in

the attempt to maintain control over their own lives to retain self-reliance by balancing the demands of time, energy and money (Fagerhagh, 1973; Barstow, 1974; Chalmers, 1984). Fagerhaugh (1973) referred to these commodities as basic mobility resources required for mobility and sociability. Coping strategies included the simplification of activities, planning ahead and purposeful pacing of oneself to overcome fear and mobility difficulties due to breathlessness, avoiding the display of symptoms in public and negotiating compliance to medication Fagerhaugh, 1973; Barstow, 1974; Chalmers, 1984; Barnett, 2005; Fraser et al, 2006).

Fraser et al, (2006) explored living with COPD from the patient's perspective within a hermeneutic phenomenological framework and identified three main conceptual themes to describe coping. These themes were 'knowing what works', 'hanging on - barely', and 'losing control-gaining control'. The theme 'knowing what works' was self-explanatory in terms of strategies to minimise breathlessness, 'hanging on – barely', depicted the struggle experienced in keeping the breathlessness under control and in dealing with its impact on daily living. The third theme described their lives as a balance between lifestyle losses and compensatory adaptive coping strategies (Fraser et al, 2005).

Other qualitative studies noted that patients felt they could cope better if they had more information about their disease (Robinson, 2005; Schofield et al, 2006). Schofield et al, (2006) demonstrated that patients with better coping skills avoided hospital admissions by recognising warning symptoms and seeking prompt attention. The National Collaborating Centre for Chronic Conditions (2004) recommends information and support in the form of self-management plans for patients in order to improve coping and disease management.

A small grounded theory study of hospitalised patients with COPD, who required nursing assistance with body care, explored coping in terms of maintaining personal integrity, (Lomborg et al, 2005). Three themes 'not letting go', 'coping with dependency' and 'minimising the risk of escalating breathlessness' were identified in order to preserve a sense of self. The authors noted that, although assisted body care was recognised by patients as preserving personal integrity (for example, keeping clean), paradoxically the interventions could also threaten personal integrity (as in

being rushed). Hence the quality of nurse-patient interactions was highlighted as a pivotal concern within nursing care practice for patients with COPD (Lomborg et al, 2005).

## **2.9. Psychological symptoms in COPD**

Depression and low mood have long been associated with the condition of COPD (Agle and Baum, 1977; Dudley et al, 1980, 1988; Williams, 1989; Kaplan et al, 1993; Mikkelsen et al, 2004). A prevalence of over 40% has been demonstrated for severe depression in patients with COPD (Yohannes et al, 1998; Yohannes et al, 2000) while mild depression is commonly found in patients with COPD (Yohannes et al, 2003). A high prevalence of depression has been identified in COPD patients receiving long-term oxygen therapy (Lacasse et al, 2001) and in patients with severe COPD (Gore et al, 2000), both studies noting that many COPD patients are not medically diagnosed or treated for their clinical depression. Yohannes et al, (2003) suggested that depression is likely to have a serious impact on patient compliance with prescribed medication, earning capacity, relationships and self-care. However a systematic review investigated case-control studies of the prevalence of depression in patients with COPD and concluded that the empirical evidence of a significant risk of depression in patients with COPD remains inconclusive (van Ede et al, 1999).

Studies have suggested that fatigue is inextricably linked to laboured breathing and the negative mood status (Small and Graydon, 1992; Ream and Richardson, 1997; Small and Lamb, 1999). Andenaes et al, (2004) found that psychological distress, in terms of depression, anxiety and panic attacks was strongly related to COPD patients' subjective perception of their quality of life, while health status and disease severity were only weakly linked. The authors recommended further investigation into personal characteristics to account for the unexplained variance in findings (Andenaes et al, 2004).

## **2.10. Functional Status and Performance**

A comprehensive review on functional performance of persons with COPD within the literature between 1980 and 1994 highlighted several issues (Kline-Leidy, 1995). Kline-Leidy (1995) noted that there was not only a lack of consensus over terms

within the literature but also questioned the suitability of instruments used to gain valid measurements. The most consistently used tool was the 'Sickness Impact Profile' (SIP); a 136-item instrument which was originally devised as an indicator of health status by measuring perception of the impact of illness on behaviour, tested for validity elsewhere (Bergner et al, 1981; DeBruin et al, 1992). Likewise in a descriptive-comparative study Engström et al, (1996) found that in patients with COPD, the use of a generic self-assessment questionnaire was not sensitive enough to detect functional status and well-being in patients with mild to moderate COPD, but was more useful for to discriminate between patients with more severe loss of pulmonary function.

Kline-Leidy's review highlighted dyspnoea in COPD patients as the most significant factor in contributing to functional difficulties despite being only weakly correlated with pulmonary dysfunction, findings which are supported by others (Kline-Leidy, 1995; Eakin et al, 1996; Mahler and Harver, 1992; Wegner et al, 1994; Hajiro et al, 1999). Yeh et al, (2004) using the 'Functional Performance Inventory' (FPI) found dyspnoea the most likely variable to affect health perception, fatigue, mood, exercise tolerance and ultimately functional performance (Yeh, 2004). Kline-Leidy (1995) argues that although disease severity does not seem to play a clinically significant role in functional performance but may indirectly through the impact of its symptoms.

Although anxiety and depression were seen as significant predictors influencing functional performance in some studies (Gift and Cahill, 1990; Gift et al, 1986; Williams, 1989), many individuals with symptomatic COPD were not anxious, depressed or dysfunctional, suggesting that other factors play a part. Mood states may be influenced by the availability of personal assets or resources, which contribute to a sense of self-efficacy or 'mastery', psychosocial well-being and higher levels of functional performance (Kline-Leidy, 1990; Moody *et al*, 1990; Weaver and Narsavage, 1992). Kline-Leidy (1990) suggested a need for further research into psychosocial resources as opposed to psychological symptoms as contributors to functional performance in individuals with COPD. Engström et al, (1996) investigating well being and functional status found low correlations between the indices of pulmonary function and affective status suggesting this may point to factors outside the clinical domain which influence well-being.



Perplexed by the inconsistent findings and difficulty in explaining variations in functional performance and treatment effects suggesting problems of sensitivity in assessment tools or in theoretical assumptions underlying quantitative efforts, Kline-Leidy and Haase (1996) undertook a small qualitative study to describe functional performance from the perspective of the people with COPD. Each participant was asked to describe his or her activities of a typical day. Thematic analysis of the interview data identified seven categories of activities: household maintenance, movement, family activities, social activities, work, altruistic avocation and recreational. Factors influencing functional performance were identified within two categories, 'intruders' such as fatigue, shortness of breath, and side-effects of medication; and 'enablers' including knowing, planning, pacing, assistive devices and personal assistance (Kline-Leidy and Haase, 1996). The authors noted how the activities carried different meanings not only between men and women but between each individual influenced by individual life experiences, skills and values, and concluded that healthcare approaches should take into consideration the client's experience and accumulated wisdom (Kline-Leidy and Haase, 1996).

The same interview data were used in a later study to explore functional status from the patient's perspective and showed that patients with COPD face an ongoing challenge of preserving personal integrity as they encounter physical changes that interfere with day-to-day activities (Kline-Leidy and Haase, 1999). It was suggested that two conceptual characteristics are central to the sense of personal integrity, 'effectiveness' through being able, and 'connectedness' through being with others (Kline-Leidy and Haase, 1999). The authors demonstrated how being able was a changing concept in the lives of individuals with symptomatic COPD as they adapted to lifestyle changes and limitations. The authors pointed out that the concept of connectedness has similar connotations to caring which is a key concept of nursing practice (Leidy and Haase, 1996; Morse et al, 1991; Benner and Wrubel, 1989). Interestingly, in the above study, participants' sense of connectedness with their healthcare professionals was noted as often lacking and would depend upon a sense of trust and previous positive encounters (Leidy and Haase, 1999).

## **2.11. COPD and health-related quality of life**

The term 'health related quality of life' (HRQOL) is frequently used in the literature to assess level of patient health status and satisfaction, and to validate treatments, practices and policies affecting the lives of patients with COPD. However, Williams (1989) noted that the literature provides no generally agreed conception of quality of life and found that assessment criteria varied from study to study. Curtis et al, (1997) suggested that health related quality of life is the degree to which a patient's health status affects his/her self-determined evaluation of satisfaction. Health-related quality of life exists independently from functional status but each may influence the other or have minimal correlation (Curtis and Patrick, 2003). Several definitions of quality of life exist in the literature (Oleson, 1990; Testa and Simonson, 1996), most acknowledging physical, psychological, social and, occupational domains of the construct (Fallowfield, 1990). Curtis and Patrick, (2003) point out that within research and healthcare the term health-related quality of life generally refers to an individual's state of well-being or health outcome as a consequence of healthcare intervention. Quality of life however includes aspects of the environment that may or may not be affected by health or treatment (Curtis and Patrick, 2003).

Health related quality of life has become increasingly recognised as an important outcome of health care interventions (Guyatt et al, 1993; Mahler, 2000). Mahler (2000) states that HRQOL determinants have become more important than lung function tests to assess well-being of patients, as patients themselves are more concerned about symptom relief and improved functioning with the illness rather than objective physiological measures of the disease. This has particular significance for patients with chronic conditions such as COPD as health policy trends move towards increased care in the community (DoH, 2004, 2005).

Ketelaars et al, (1996) noted that, as the incidence of COPD is increasing and COPD patients are for the most part treated at home, it is imperative to understand the consequences of the disease on health-related quality of life issues within the ordinary daily lives of these individuals. However, most of the literature on HRQOL in COPD is quantitative and is measured by generic instruments that provide a summary of HRQOL, disease-specific instruments or both, to determine effects of the disease and the efficacy of treatments for the disease. Commonly used generic measures are The Nottingham Health Profile, Sickness Impact Profile, (SIP), and SF-36 questionnaire,

whilst the St. George's Respiratory Questionnaire, (SGRQ), Chronic Respiratory Questionnaire, (CRQ), and Borg VAS are specific instruments used for COPD populations (Curtis and Patrick, 2003). In a review 1994-1997, Cullen, (1999) identified a total of 37 measures for HRQOL in COPD, 10 of which were disease-specific questionnaires but recommended further research as to which should be integrated into standards of care.

Problems in COPD studies have been highlighted, as generic instruments are often used in isolation and may be insensitive in detecting small changes in quality of life outcomes in COPD specific populations (Mahler et al, 2000). Although significant relationships have been identified between disease severity and physical functioning, energy and health perception (Viramontes and O'Brien, 1994; Ketelaars et al, 1996; Okubadejo et al, (1997), only weak relationships between pulmonary function and HRQOL have been demonstrated (McSweeney et al, 1982; Kaplan et al, 1984; Guyatt et al, 1987, Schrier et al, 1990; Viramontes and O'Brien, 1994; Wijkstra et al, 1994). Most studies investigating quality of life in COPD conclude that psychosocial factors must account for unexplained mediating effects of disease severity on quality of life (McSweeney et al, 1982; Prigatano et al, 1984; Schrier et al, 1990; Engström et al, 2001). Self-esteem, depression, social support and age have been found to have a direct effect on quality of life in patients with COPD, suggesting that personality may affect the manifestation of symptoms and influence patient behaviour independent of severity of illness (Anderson, 1995; Moody et al, 1991).

Seemungal et al, (1998) found health related quality of life measured by SGRQ scores significantly worse in the group of patients who experienced more frequent exacerbations. Consequently the findings suggest that patient quality of life is related to COPD exacerbation frequency (Seemungal et al, 1998), and reduced quality of life has been found related to hospital readmission (Osman et al, 1997).

Dyspnoea, the characteristic symptom of COPD has been found to be a better indicator of HRQOL than disease severity characterised by guideline staging (Hajiro et al, 1999; Wedzicha et al, 1998; Ferreira et al, 2003). Hajiro et al, (1999) compared levels of subjectively perceived dyspnoea ratings with the standardised American Thoracic Society (ATS, 1995) disease severity staging as indication of HRQOL in

COPD patients and concluded that health related quality of life was more clearly separated by level of dyspnoea than by the ATS disease staging. However a larger study investigating the relation between the ATS staging system for COPD and HRQOL demonstrated a decreased HRQOL with increased stage of COPD measured by FEV1 / FVC pulmonary function values and lower than predicted HRQOL scores in patients with stage 1 mild COPD suggesting clinical relevance for patients in the early stages of the disease (Ferrer et al, 1997).

Health-related-quality-of-life scores using generic and disease-specific measures have been found to be independent risk factors for respiratory and all cause mortality; also shorter survival have been linked to worse HRQOL scores (Domingo-Salvany et al, 2002). Unlike the studies by Antonelli et al (1997) and Connors et al, (1996), Domingo-Salvany et al, (2002) found no relationship between co-morbidity and mortality in patients with COPD. Despite the overwhelming abundance of studies investigating determinants of HRQOL in patients with COPD, and some studies deducing strong correlations, overall findings are complex and/or inconclusive. Although some researchers argue for the validity of quantifying specific domains of health related quality of life for healthcare evaluation (Guyatt et al, 1987, 1993; Mahler, 2000), others consider a qualitative approach more appropriate to obtain data which is not isolated from local contexts to provide insights and an understanding into the interrelated issues which affect patients' health related quality of life (Williams, 1993; Hill Bailey, 2001; Draper and Thompson, 2001).

In a qualitative study, Nicholson and Anderson, (2003) used focus groups to examine quality of life of individuals living with chronic bronchitis. Thematic analysis of the detailed descriptive data identified three key areas of significance highlighted by the participants, including: the physical effects of the disease; impact on family and social relationships; and emotional reactions, life disruption and self-esteem (Nicholson and Anderson, 2003). Further conceptual analysis revealed issues of feelings of blame for being a burden, self-distaste and lowered self-esteem, and the importance of active engagement in negotiating ways of managing the changing disease process and its impact on daily life (Nicholson and Anderson, 2003).

## **2.12. Gender and COPD**

The predominant profile of men with COPD is now changing as more women are acquiring the disease, due mainly to changes in smoking habits (British Thoracic Society, 2006). Some studies suggest that women may be more susceptible to the effects of tobacco smoke than men (Silverman et al, 2000). Kline-Leidy (1995) highlighted that previously most research studied men, or at least predominantly male populations, a situation, which is likely to change in the future to reflect the increase of COPD in women.

In a large retrospective cohort study taken from the General Practice Research Database, Soriano et al, (2000) found that between 1990-1997 the annual prevalence rates of physician diagnosed COPD in women rose continuously to the rate of that in men in 1990. An increase in the prevalence of COPD was observed in all ages of women compared to the plateau noted in the prevalence of men from the mid 1990's (Soriano et al, 2000). Noting that very few studies exist which investigate gender differences in COPD, Kline-Leidy and Taver (1995) investigated physiological impairment, symptoms and psychosocial resources to compare functional performance profiles of men and women with COPD. Although women reported more functional difficulties than men across the majority of domains, the differences were found not to be statistically significant. Kline-Leidy and Traver (1995) propose that the instruments used do not take into account the possibility that men and women assign different weight, value, and meaning to various activities such as household chores. Others have suggested that women with COPD respond to, and cope differently from men (Barstow, 1974; Sexton and Munro, 1986; Janelli et al, 1991).

A study investigating women with COPD, found high levels of subjective stress and low life satisfaction as compared with women who had no chronic illness in a study using the subjective stress scale and life satisfaction index (Sexton and Munro, 1986). The women with COPD reported major problems of fatigue and breathlessness symptoms, restricted activity, loneliness and depression (Sexton and Munro, 1986). Leidy and Traver (1995) found that women living alone reported less functional difficulty across all categories except sleep and rest, despite having comparable lung function, symptom severity and psychosocial resources. The suggested reasons for

this difference were that women living with others may be confronted with additional activities that do not apply to women living alone, and/or that living with others may initiate earlier transfer of tasks resulting in physical de-conditioning (Leidy and Traver, 1995).

No statistically significant differences were found between men and women with COPD in a study using the JCS to investigate coping styles and coping style effectiveness (Frey, 2000). The women used confrontation, evasive, fatalistic, palliative and supportant coping styles more than the men, while the total group used the optimistic coping style most and found this style to be the most effective (Frey, 2000). Crockett et al, (2002) investigating the quality of life and living alone at the time of having home oxygen prescribed found poorer emotional functioning associated with shorter survival in female patients, but not in male patients. Living with a partner has been identified as beneficial for both men and women with COPD in terms of survival (Crockett et al, 2002).

### **2.13. Pulmonary rehabilitation for individuals with COPD**

Pulmonary rehabilitation has been defined as:

“A multidisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise physical and social performance and autonomy” (American Thoracic Society, 1999).

The principal goals of pulmonary rehabilitation are to reduce symptoms, increase physical and emotional participation in daily activities and to improve quality of life (GOLD Executive Committee, 2006). Patients at all stages of the disease are considered to benefit from exercise programs and education to increase exercise tolerance and reduce dyspnoea and fatigue (Berry et al, 1999), although there are some exceptions due to existing conditions such as having locomotive problems, cognitive impairment, angina or a recent myocardial infarction (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001; NCCC, 2004).

Pulmonary rehabilitation is seen as a means to break the cycle of inactivity and anxiety caused by dyspnoea and which leads to cardio-respiratory and muscular deconditioning, fatigue and further inactivity of patients with COPD (Lacasse *et al*, 1997). However although universally recommended by management guidelines for COPD, not all COPD patients in the UK have access to formal pulmonary rehabilitation services (BTS AND BLF, 2003). A BTS statement on pulmonary rehabilitation noted that rehabilitation for COPD in the UK has previously been poorer than in other countries and suggested historical reasons including: medical indifference to non-pharmacological management, lack of scientific evidence, poor funding, and ineffective consumer demand (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001). However according to the BTS statement, opinion is now beginning to change as strong scientific evidence recommends the application of pulmonary rehabilitation programs that include physical training, education, dietetics, occupational therapy, psychology and social support provided by a multidisciplinary team of health professionals (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001; NCCC, 2004; The Global Initiative for COPD, (GOLD Executive Committee, 2006).

The American Thoracic Society (1995) stated that almost any treatment given by well-trained health personnel would inevitably provide elements of psychosocial support and motivation and contribute beneficially towards the pulmonary rehabilitation of individuals with COPD.

Improvements in exercise tolerance following pulmonary rehabilitation have been demonstrated (Griffiths *et al*, 2000; Ries *et al*, 1995; Goldstein *et al*, 1994) in various domains of health related quality of life for patients with COPD (Benzo *et al*, 2000; Berry *et al*, 1999). Better results and longer sustained benefits have been linked with longer duration of pulmonary rehabilitation programme (Guell *et al*, 2000), irrespective of inpatient, outpatient or home setting (GOLD Executive Committee, 2006). Although reduced exacerbations have been found to be associated with a programme of pulmonary rehabilitation, the use of healthcare services has been identified as remaining the same as for COPD patient groups not receiving pulmonary rehabilitation (Guell *et al*, 2000; Lewis and Bell, 1995).

Exercise training and education including nutrition counselling have been found to improve individual skills, coping and health status which can in turn contribute towards improving exercise performance and lung function in patients with COPD (Celli, 1995; Mackay, 1996). Education within pulmonary rehabilitation is recommended to also encompass smoking cessation, patient management of stable symptoms and responses to acute exacerbations, and advice as when to seek professional help and information on end of life issues (GOLD Executive Committee, 2006).

For patients in acute respiratory failure, non-invasive mechanical ventilation has proved successful by improving severity of breathlessness and reducing mortality, but is not appropriate for all patients with COPD (Lightowler et al, 2003; Plant et al, 2000). Gift et al, (1992) found relaxation techniques effective in reducing dyspnoea and anxiety in patients with COPD. Investigating the affective response of dyspnoea during exercise training of patients with COPD, Carrieri-Kohlman et al, (2001) found decreases in dyspnoea-related anxiety after exercise training but not decreased shortness of breath, suggesting that factors other than disease severity influence individual perceptions of dyspnoea.

In a study investigating the effects of specialised community nursing care of patients recently discharged from hospital and those who received inpatient rehabilitation; Ketelaars et al, (1998) found no difference between the groups of COPD patients in terms of their coping, compliance with treatment or number of days in hospital over the duration of one year. However the authors noted that patients receiving specialised nursing care compared to ordinary nursing intervention were more satisfied with their care (Ketelaars et al, 1998).

#### **2.14. Intermediate care**

“Intermediate care is a treatment model which bridges the interface between hospital and community care” (BTS Guideline Development Group, 2007: 200). A type of intermediate care – hospital-at-home - for the treatment of COPD has been implemented throughout the UK, following a successful experiment where an outreach service of this kind was established in Scotland during the 1990’s (Gravil *et al*, 1998). Hospital-at-home (HaH) provides care for a limited period, and aims to



prevent unnecessary hospital admission and support early discharge from hospital (BTS Guideline Development Group, 2007). Soaring financial costs of hospital admissions have led to interest in comparing benefits, financial and patient outcomes, in hospital versus intermediate care for acute exacerbations of COPD (Ram et al, 2004). Siafakas et al, (1995) suggested that follow-up care in the community by nurses might allow earlier discharge of patients admitted with an exacerbation of COPD, without increasing readmission rates. The evidence for the benefits of intermediate care for COPD patients is however inconclusive with criteria varying according to geographical region (GOLD Executive Committee, 2006). A systematic review of trials on HaH schemes for patients with acute exacerbations of COPD found that mortality and readmission rates were not significantly different when HaH schemes were compared with inpatient care (Ram et al, 2004). The authors suggest that HaH can be safely implemented for selected patients with COPD exacerbations (Ram et al, 2004). In a Cochrane systematic review of four trials, Smith et al, (2001) found admission rates unaffected, reduced mortality only in less severe disease and improved quality of life for those with moderate disease but not for patients with severe COPD as a consequence of outreach nursing intervention. Irrespective of the unclear benefits of intermediate care, many patients have indicated that they would prefer to remain cared for in their own homes or receive early supported discharge from hospital where appropriate (BLF, 2005; DoH, 2006; Schofield et al, 2006; Fried et al, 1998). However contrary findings have been highlighted in a Cochrane review in which patients reported less satisfaction with the care received at home compared to inpatient care. Some patients have indicated that they feel more supported within the hospital environment, (Shepperd and Iliffe, 2005). Anxiety may explain patient preference to be admitted to hospital or to remain in hospital during an exacerbation of COPD (Ram et al, 2004).

## **2.15. Palliative needs for severe or end-stage COPD patients**

Despite recommendations that all end-stage COPD patients should have access to multi-disciplinary palliative care teams and hospice care, currently only a few do (NCCCC, 2004; Standing Medical Advisory Committee, 1992). The palliative care philosophy, which encompasses all aspects of the patient's well being including physical symptom relief, psychosocial and spiritual aspects of care to give comfort

and support when cure is no longer an option, aims to enhance quality of life (Twycross, 2003).

Since end-stage COPD has no cure (Connors et al, 1996), palliative care aims to manage symptoms and maintain quality of life (Siafakas et al, 1995). It is recognised that patients with advanced COPD have historically been a neglected patient care group. A growing body of research has highlighted this problem and identified the less known palliative needs and the inadequate service provision for end-stage COPD patients (Skilbeck et al, 1998; Gore et al, 2000; Edmonds et al, 2001; Guthrie et al, 2001; Elofsson and Ohlen, 2004; Seamark et al, 2004). A large study using secondary data from the Regional Study of Care for the Dying found palliative care services for non-malignant patients such as COPD to be sparse and patchy across the UK (Addington-Hall et al, 1998).

Studies comparing patients with terminal lung cancer and respiratory disease found comparable needs within the two groups of patients, but those diagnosed with cancer have received greater access to palliative care resources and services (Skilbeck et al, 1998; Gore et al, 2000; Edmonds et al, 2001; Addington-Hall et al, 1998). Since most terminally ill patients spend 90% of the last year of life at home (Blythe, 1990), then the emphasis is placed upon the primary healthcare team in the community setting to address the multiple and complex needs of chronic illness patients such as those with end-stage COPD (Oliver, 2001). However, patients with terminal COPD and their carers have reported high levels of uncontrolled physical symptoms including problems of breathlessness, pain, fatigue, sleep difficulties and thirst (Skilbeck et al, 1998; Elkington et al, 2004). Skilbeck et al, (1998) highlighted the fragmentary care and lack of a coherent process of ongoing supportive services for end-stage COPD patients within primary care. Medical care for patients with severe COPD has been frequently found to be re-active treatment aimed at managing the acute exacerbations and complications, rather than proactive preventative care to avoid symptom flare-up and to address patients' psychosocial needs (Skilbeck et al, 1998).

Gore et al, (2000) found most patients with severe COPD were generally satisfied with medical treatments that they had received, but identified that psychological problems had not been addressed and information needs were largely unmet. Poor self-rated quality of life has been found to be related significantly to social isolation,

emotional distress, high symptom load, low physical functioning/disability, and unrecognised psychological disorders such as anxiety and depression (Skilbeck et al, 1998; Gore et al, 2000).

The information needs of terminal patients have long been recognised within palliative care for cancer patients but studies have demonstrated that patients with end-stage COPD often have not had the opportunity to discuss prognosis, death and dying with healthcare professionals (Lynn et al, 2000; Fried et al, 2003; Addington-Hall et al, 1998). However, there are issues for the healthcare professionals in this area, as prognosis is unpredictable and often difficult to judge in COPD (Lynn et al, 1995, 2001; Edmonds et al, 2001; Freeborne et al, 2000). This may account for many general practitioners being reluctant to initiate end of life discussions and discuss prognosis with terminal COPD patients (Elkington et al, 2001). Despite these difficulties, in a survey (Gaber et al, 2004), 98% of 100 COPD patients said cardiopulmonary resuscitation and hospital ventilation should be raised with patients before these interventions are necessary with 48% wanting all treatments and 12% stating that they wanted none. The researchers concluded that discussion of sensitive end-of-life issues can be raised without causing distress as all patients in the study, stated satisfaction in the way they had been approached. The authors however noted that patient attitudes towards resuscitation, like prognosis itself, cannot be predicted from parameters of disease severity, age, sex, use of antidepressants, number of hospital admissions, on LTOT or quality of life scores (Gaber et al, 2004). A large American study investigating living and dying with COPD (SUPPORT), noted increased patient preferences for Do-Not-Resuscitate or for mechanical ventilation and a decrease in resuscitation orders as patients approached death (Lynn et al, 2000).

Research indicates that patients with COPD are more likely to die in hospital and without the presence of a relative compared with patients dying from cancer (Edmonds et al, 2001). Edmonds et al, (2001) found that over half the patients with severe COPD had worked it out for themselves that they were dying, unlike the cancer patients who were more likely to have been told by a doctor. Studies have revealed that some patients with terminal COPD wanted more information about their illness and its future course, whereas others preferred not to have further elaboration on what they already knew (Jones et al, 2004; Fried et al, 2003). Guthrie et al (2001) explored

patient views of living with severe COPD and noted how some patients openly discussed death and dying while others preferred not to discuss these sensitive issues.

Oliver (2001) suggests that patients with severe COPD are a vulnerable group characterised not only by poor symptom control but also low self-esteem and are generally disadvantaged within the doctor-patient relationship. A more balanced relationship is suggested, which would lead to improved exchange of information, shared decision-making and concordance with treatment. This in turn would enhance coping and quality of life (Oliver, 2001; Holman and Lorig, 2000).

The risk of dying with COPD is closely associated with significant co-morbidities, developing respiratory acidosis, and the need for ventilatory support within hospital intensive care units (Connors et al, 1996). The decision to initiate invasive mechanical ventilation is facilitated by the existence of patient advance directives or 'living wills', which specify patient wishes (GOLD Executive Committee, 2006). It is suggested that improved communication between patients and medical practitioners would enable the drawing up of 'advance directives' which would facilitate the carrying out of patient wishes when the patient's condition prevents communication or decision-making, so not relying upon care according to regional practice (Pritchard et al, 1998). Knauff et al, (2005) identified firstly, that not wanting to talk about dying, and secondly not knowing who their doctor would be at time of dying, were common barriers to discussing end-of-life issues by patients with COPD. However, finding that the views of older people about advance directives frequently changed following discussion and social interaction, Seymour et al, (2004) recommended that end-of-life planning should not be a single, final decision but an ongoing process of review with the family and their doctors.

## **2.16. Surgery for COPD patients**

Lung surgery has been suggested as a beneficial option for a selected few patients with COPD, who fulfil specific criteria, in order to improve lung function and exercise tolerance (Siafakas et al, 1995; ATS, 1995; BTS, 1997; GOLD Executive Committee, 2006; NCCC, 2004). Benditt and Albert (1997) reviewed the literature prior to December 1996 on surgical options for patients with emphysema noting the

diversity of techniques used and their varying success and suggested that much of the recent scientific data was prolific but incomplete. However, three types of surgical intervention are recognised as beneficial for a selected minority of COPD patients based upon physiological and functional criteria. These are bullectomy, lung volume reduction surgery (LVRS) and lung transplantation (Benditt and Albert, 1997).

Resection of a bulla, the removal of abnormally dilated airspaces in lung tissue has been found to reduce dyspnoea and improve lung function in a few selected patients (Mehran and Desiauriers, 1995).

Naunheim et al, (2000) found improved survival rate and health-related quality of life in patients who received lung volume reduction surgery compared to those receiving medical care. However, a second study found no evidence of improved survival, though it did find improvements in lung function, exercise tolerance and quality of life (Geddes, 2000). The National Emphysema Treatment Trial (NETT) Group (2006) found that lung volume reduction surgery increased the chance of improved exercise capacity but overall did not find improved survival over medical therapy. However, patients with predominantly upper-lobe emphysema and low base-line exercise capacity were found to have survival benefits and functional gains following lung volume reduction surgery (National Emphysema Treatment Trial Research Group, 2006).

Lung transplant in appropriately selected patients with advanced COPD has been shown to improve functional capacity and quality of life (Trulock, 1997). Lung resection or LVRS has been proposed as a bridge to lung transplantation either to reduce death rates for severe emphysema patients or to serve as an alternative for patients who are not suitable candidates for the more complex transplantation operation (Cooper et al, 1995a; 1995b). However, lung volume reduction surgery and lung transplant are not commonplace as they are costly surgical procedures and carry a high risk of post-operative pulmonary complications (GOLD Executive Committee, 2006).

## **2.17. Long Term Oxygen Therapy**

Long-term oxygen therapy (LTOT) has become a recommended therapy for chronic hypoxaemic patients with severe COPD since studies including two large multi-

centred randomised controlled trials published their findings. These studies showed that domiciliary oxygen inhaled for at least 15 hours a day improved physiological parameters and survival rates (NOTT, 1980; MRC, 1981; Cooper et al, 1987; Crockett et al, 2001). However, another study of elderly COPD patients on LTOT demonstrated that survival was poor; with outcomes independently influenced by malnutrition, dyspnoea, co-existence of malignancy and degree of airflow obstruction (Katsura et al, 2001). Other studies have demonstrated that fifteen hours per day on LTOT does not improve survival rate in COPD patients with moderate hypoxaemia, (Gorecka et al, 1997; Crockett et al, 2001), neither does nocturnal oxygen therapy on mild to moderate daytime hypoxic COPD patients (Fletcher et al, 1992; Chaout et al, 1999). Conflicting evidence has prompted a call for further research into the benefits of oxygen therapy for exercise related and nocturnal de-saturation (Zielinski, 1999).

Studies investigating the relationships between quality of life determinants and the expected benefits of LTOT for COPD patients have shown conflicting findings, despite standardisation prescription for recommended hypoxaemic COPD patients (Nocturnal Oxygen Therapy Trial (NOTT), 1980; British Medical Research Council (MRC), Working Party, 1981). Okubadejo et al (1996), and Ferreira et al, (2003) found no improvement in HRQOL in COPD patients on LTOT, raising the question of the cost benefit of LTOT for patients at the individual and political level. However other studies have reported improvements in quality of life and symptoms for hypoxaemic patients on home oxygen (Dilworth et al, 1990; NOTT, 1980).

Studies have found variation in patient assessment, prescribing, adherence to guidelines and patient follow-up for patients with COPD prescribed LTOT at home (Baudouin et al, 1990; Peckham et al, 1998; Waterhouse et al, 1994; Morrison et al, 1995; Guyatt et al, 2000; Ringbaek et al, 2001). Some COPD patients had home oxygen prescribed during hospital admission when their condition was unstable and were not routinely reassessed in the community due to poor communication between hospital specialist physicians and primary care professionals (Okubadejo et al, 1997; Restrict et al, 1993; Morrison et al, 1995).

Lack of patient monitoring following initial oxygen prescription allowed patients to continue with oxygen therapy even when inappropriate. Oba et al, (2000) estimated

that up to 60% of patients on LTOT could be discontinued if they were reassessed. The authors highlighted the financial implications of inappropriate prescribing on such a large scale (Oba et al, 2000).

Clinical audits carried out by nurse practitioners on COPD patients prescribed LTOT supported the findings of these studies, finding that patients were not always being assessed for oxygen during periods of disease stability. Additionally these patients were not being recalled for review or being referred to a respiratory specialist nurse. There was also a lack of patient knowledge and understanding of the aims of the treatment, and an incorrect use of oxygen equipment (Gibbons, 2002; Matthews et al, 2001; Rudkin, 1996).

Patient compliance of LTOT has also been found to vary greatly often according to whether it was the general practitioner or the consultant physician that initially prescribed the home oxygen, resulting in some patients not taking the recommended duration of daily oxygen therapy (Peckham, 1998; Pepin et al, 1996; Guyatt et al, 2000; Ringbaek et al, 2001; Gibbons, 2002; Matthews et al, 2001; Rudkin, 1996). Patient concordance has been associated with the patient receiving pre-treatment education and close monitoring following prescription (Atis et al, 2001; Waterhouse et al, 1994; Restrict et al, 1993; Peckham et al, 1998).

These nation-wide problems, together with the clients' views led to the first evidence-based recommendations for the use of oxygen therapy in the domiciliary setting for COPD and selected other patients (Royal College of Physicians, (RCP), 1999). The report set out seven areas of recommendation including patient criteria, suitable equipment, including ambulatory oxygen, further research, information to be given to patients about treatment and travel, safety measures in the home and education for health professionals (RCP, 1999).

Janssens and associates (1997) investigated health related quality of life domains in hypoxic COPD patients receiving home oxygen over one year and found that on average, quality of life was poor with high morbidity and mortality, high rates of emotional disorder and diminished physical mobility. The authors suggested that the use of pulmonary rehabilitation and portable oxygen would improve patients' quality

of life (Janssens et al, 1997). However, despite recommendations to prescribe ambulatory oxygen for hypoxic COPD patients, studies have been inconclusive as to its effectiveness (NCCCC, 2004; Ram and Wedzicha, 2003). COPD patients who do not qualify for LTOT but who demonstrate significant exertional desaturation, have demonstrated significant improvements in HRQOL on ambulatory oxygen but displayed a high level of poor tolerance with the portable devices (Eaton et al, 2002). One study suggests that the use of home oxygen does not limit independence in daily activities but due to the small size of the study sample findings are inconclusive (Okubadejo et al, 1997).

Qualitative studies have revealed conflicting patient views regarding the use of home oxygen (Elofsson and Ohlen, 2004; Ring and Danielson, 1997; Cornford, 2000). Ring and Danielson (1997) explored the experiences of living with LTOT in ten persons who were registered on the Swedish register to receive oxygen for sixteen hours a day. Four principal themes emerged from this phenomenological study; being restricted to time and room, an advantage for the body, living in one's own life rhythm and putting up with it to live (Ring and Danielson, 1997). Cornford, (2000) interviewed twenty-four patients receiving domiciliary oxygen to investigate what they thought about having oxygen therapy at home. Patient descriptions were thematically analysed into two contradictory views, oxygen as a means of maintaining independence and self-mastery or as oxygen therapy reducing independence by being restrictive and fearing dependency (Cornford, 2000). Consequently the author questioned the appropriateness of the prescription in terms of client suitability regardless of the medical criteria (Cornford, 2000).

## **2.18. Smoking and risk factors for COPD**

The development of COPD has been attributed to the interaction between host factors within the individual's body and environmental exposures such as occupational dusts, chemicals and air pollutants, but tobacco smoke accounts for an 80-90% increase in risk (GOLD Executive Committee, 2006; NCCCC, 2004; ATS, 1995). Cigarette and pipe smokers have a higher prevalence of lung function abnormalities, respiratory symptoms, more rapid decline in lung function (FEV1) and higher death rates than non-smokers (GOLD Executive Committee, 2006; ATS, 1995). However, not all smokers develop clinically significant COPD, suggesting that genetic factors play a



role in individual risk (GOLD Executive Committee, 2006). Passive exposure to tobacco smoke has been associated with reduced pulmonary function and airway hyperactivity (ATS, 1995).

Intense or prolonged exposure to occupational irritant dusts (e.g. mining) and chemicals (industrial sprays, fumes) has been found to cause COPD independent of smoking and to increase the risk of COPD in the presence of concurrent smoking (GOLD Executive Committee, 2006, ATS, 1995). Air pollution, especially indoor pollution from solid fuel for heating and cooking in poorly ventilated rooms also has been implicated as a risk factor in COPD, particularly in developing countries (GOLD Executive Committee, 2006; ATS, 1995; Tashkin et al, 1994). Less well known risk factors which may be interrelated have been implicated in COPD, including a history of childhood respiratory infection, low birth weight, and low socio-economic status (Prescott et al, 1999; Strachan, 1995).

Despite the known link between cigarette smoking and emphysema, there has been little mention of this in past research and government white papers. Previous research has focused predominantly upon on the hazards of tobacco smoking for diseases other than COPD, for example in The NHS Cancer Plan and The National Service Framework for Coronary Heart Disease (Dawber, 1980; DoH, 2000a; DoH, 2000b). However, since the government's first white paper on tobacco 'Smoking Kills' (DoH, 1998), guidelines from the National Institute for Clinical Excellence, (NICE), National Collaborating Centre for Chronic Conditions, (NCCCC, 2004) and the revised Quality and Outcomes Framework of the new GMS Contract (British Medical Association, 2006), have given COPD a raised priority profile. A report by the British Thoracic Society, 'The Burden of Lung Disease' shows that deaths from respiratory diseases in the UK are now greater than deaths for ischaemic heart disease (BTS, 2006).

Smoking cessation is considered one of the most important components of disease management regardless of age or disease severity, and is considered the most important strategy to affect outcome in patients at all stages of the disease (Fletcher et al, 1976; Cooper et al, 1987; Doll et al, 1994; US Public Health Service, 2000; BTS, 2001; NCCCC, 2004; BLF, 2005). Existing COPD guidelines emphasise smoking

cessation as a key priority to reduce the risk of developing COPD and to stop its progression (GOLD Executive Committee, 2006; NCCC, 2004; BTS, 1997; ATS, 1995, Siafakas et al, 1995, BLF, 2005). Although smoking rates fell substantially during the 1970's and early 1980's from 45% in 1974 to 35% in 1982, with men out-smoking women 51% to 41%, smoking cessation levels have since declined. The data also indicates an increased prevalence of smoking in young women in the 16-24 year old age group since the 1990's (General Household Survey, 2001).

Smoking cessation will not restore lung function but will slow down deterioration and deliver improved benefits from taking LTOT (Cooper, 1995). The report 'Smoking Kills' (DoH, 1998) suggested that 70% of smokers wanted to quit, but most will fail without self-motivation and professional support (West et al, 2001; West et al, 2000). Success rates of smoking cessation at three months have varied from 11% to 29% (Hughes et al, 1992; West et al, 2001) with many smokers attempting several times before maintaining abstinence (General Household Survey, 1997). Cohen et al (1987) found that less than 5% of patients who quit smoking voluntarily without some form of help maintain abstinence for one year. Despite general public awareness of the link between cigarettes and COPD, many people with severe COPD continue to smoke (Schofield et al, 2006). Physical addiction to the drug nicotine, the ritual associated with smoking habits, and psychological and emotional dependencies have been identified as contributing towards the difficulty in giving up smoking (Royal College of Physicians, 2000). It is suggested that just as the reasons for starting and continuing to smoke are multi-factorial then successful solutions to quit may also require multiple interventions including pharmaco-therapy and psychosocial strategies (ATS, 1995; RCP, 2000; West et al, 2001). Most guidelines for smoking cessation recommend encouragement and support with pharmaco-therapy to increase success rates of quitting (ATS, 1995; GOLD Executive Committee, 2006; NCCC, 2004; BLF, 2006; BTS, 2006). All forms of nicotine replacement therapy (NRT), gum, transdermal patch, nasal spray, inhaler, sublingual tablets or lozenge; which aim to replace the nicotine from cigarettes, and reduce withdrawal symptoms associated with smoking cessation have been proven to be up to twice as successful as attempts without pharmacotherapy (Silagy et al, 2004). Three large systematic Cochrane reviews of trials investigating smoking cessation found that pharmacotherapy (NRT or Bupropion) used individually or in combination with psychosocial intervention

(counselling, self-help materials, behavioural therapy) can significantly increase cessation rates (Ranney et al, 2006; van der Meer et al, 2000); particularly with prolonged, intensive behavioural support (Wagner et al, 2004). The use of Bupropion or a form of nicotine replacement therapy (NRT) together with intensive support has been found to increase smoking abstinence for over a year in approximately 20% of persons trying to quit smoking (Parrott et al, 1998). Using strategies of self-help interventions, group therapy, telephone counselling and exercise interventions for smoking cessation has been found to have limited effectiveness (Lancaster and Stead, 2005; Stead and Lancaster, 2003a; Stead and Lancaster, 2003b; Ussher et al, 2003). The use of hypnotherapy has provided conflicting results (Abbot et al, 2000), while no clear evidence is currently available for that of acupuncture (White et al, 2002).

National guidelines advocate that healthcare professionals should offer smoking cessation advice at every opportune patient visit. This is particularly advised for general practitioners, who are strategically placed to offer opportunistic advice to all smoking patients within primary care using a population-based approach (Fiore et al, 1998; Raw et al, 1999; GOLD Executive Committee, 2006). Brief, simple advice to quit smoking by a physician has a small effect on cessation rates, which has been shown to increase with intensity of intervention (Lancaster and Stead, 2004). However studies on GPs' views suggest that doctors generally prefer to assist those patients wanting to stop and are more likely to give smoking cessation advice on an individual-based approach to avoid possible negative responses and to preserve doctor-patient relationships (McEwen et al, 2001; Coleman et al, 2000). Nursing delivered smoking cessation interventions have proved most beneficial to hospitalised patients who have received more intensive intervention and follow-up after hospital discharge (Rigotti et al, 2002). Likewise, individual counselling from a trained therapist increases the likelihood of smoking abstinence. However, a Cochrane review failed to detect whether intensive counselling had a greater effect than a brief intervention (Lancaster and Stead, 2005). Most national and international guidelines for COPD management have adopted the work of Proshaska and Goldstein (1991) on which to base guidelines for smoking cessation ("The tobacco use and dependence clinical guideline panel, staff, and consortium representatives, 2000"; GOLD Executive Committee, 2006). Proshaska and Goldstein (1983, 1991) suggest that smoking cessation is not an abrupt event but a process of change that involves five

conceptual transitional stages from being a smoker to becoming a non-smoker, requiring support at each stage. Motivation and addiction have been identified elsewhere as the main factors that determine the difference between success and failure for smoking cessation (Pracy and Chevretton, 2000). The strategy recommends professional intervention using a five-step strategy of '5A's: Ask, Advise, Assess, Assist and Arrange to help patients who are willing to quit smoking (Proshaska and Goldstein, 1983,1991; GOLD Executive Committee, 2006; Raw et al, 1998).

## **2.19. Family carers and caring for individuals with COPD**

There is an abundant literature, both qualitative and quantitative, on the caring role and the impact of care giving by a family member for a chronically ill relative. Some of this literature includes caring for individuals with a respiratory condition but very few articles were found which focused specifically on caring for a person with COPD.

National statistics indicate that about seven million adults in the UK provided care for sick, disabled or elderly relatives in 2000, with women more likely to be carers than men, many of these carers were aged over 55 and in poor health themselves (ONS, 2000a; ONS, 2000b;ONS, 2000c). The report noted that women providing care were more likely to report mental health problems than men carers or women who were not carers (ONS, 2000c). Approximately a quarter of these carers were unable to take a break from caring, as they had no one else to transfer care to. A third of carers felt caring had an adverse effect on relationships, social life and their job if employed (ONS, 2000b).

A large study investigating informal carers in the general population analysed data from the British Household Panel Survey during the 1990's and found high levels of carer' psychological distress associated with, intensity of care, hours of care and during transitions of care of a family member (Hirst, 2005). Care giving within the same household was found to be four times as intensive as out of house care with more hours spent caring. Caring for a spouse or partner was found to be the most intensive care relationship for men and women alike except for mothers of a sick or disabled child. Caring for a friend or neighbour was seen as less demanding due to fewer caring hours involved (Hirst, 2005). Distress was found most pronounced at

time of start of the care role and when care-giving ends, with women at a higher risk of raised levels of distress than men (Hirst, 2005). The study findings identified care giving as a social determinant of health inequality and suggest that services should address the information and support needs of this high-risk group of carers (Hirst, 2005).

A psychosocial overview of the determinants of caregiver stress argues that stress is a consequence of a process comprising of a number of interrelated conditions including the socio-economic characteristics and resources of care-givers, and the stressors (problems, altered roles and reduced self-concepts) to which they are exposed (Pearlin et al, 1990). The mental health of family caregivers of frail elderly, demented or physically dependent persons is likely to be affected by the care-giving situation (Schulz et al, 1990).

Research has shown that spouse carers of men with COPD rated their health lower than a comparison spouse group of well men (Sexton and Munro, 1985), and a statistically significant relationship was found between carer mood, level of stress and social support as compared to a group of wives of well husbands in a study by Graydon and Ross, (1997).

Qualitative studies have highlighted how chronic illness not only has an impact upon the individual but also upon family members, in particular the spouse who has been identified as participating in different types of caring work (Anderson and Bury, 1988; Corbin and Strauss, 1984, 1988; Voysey, 1975). Multiple roles including the monitoring of symptoms, preventing and dealing with crises, carrying out treatment regimes, preventing or living in social isolation, modifying normal routines, dealing with role changes, grieving with losses associated with illness, maintaining hope despite uncertain prognosis and dealing with social stigma have all been identified as stressful aspects of the care-giving role (Strauss et al, 1984; Corbin and Strauss, 1984,1988; Miller, 1983; Sexton and Munro, 1985; Keele-Card et al, 1993; Bergs, 2002; Seamark et al, 2004).

As COPD progresses, sufferers become more breathless and exhausted on exertion, their level of mobility and functional capacity deteriorates, and they require increased assistance to carry out many activities of daily living (Leidy and Haase, 1996). One

study examining the impact of a husband's COPD illness on the spouse's life found that becoming a carer meant taking on new roles and responsibilities of being a decision-maker, errand-doer, finance manager and taking on minor DIY, with a resultant loss of time for her own leisure or social activities (Sexton and Munro, 1985). Investigating one area of the care-giving role, a qualitative study found that 67% of carers reporting at least one of four types of problems related to the management of patient's medication including: maintaining continuous supplies, assisting with administration, making clinical judgements and communicating with care recipient and health professionals (Smith et al, 2003).

A qualitative study using grounded theory (Corbin and Strauss 1984) found that some couples worked collaboratively through processes of negotiation and verbalising problems in order to manage the illness, whilst other couples experienced feelings of frustration, confusion, overburden or being worn-out as a consequence of their disharmony. Either way the chronic illness and the caring role has been conceptualised as a burden of unending work and care as both patient and spouse juggle illness, everyday and 'biographical' lines of work to manage the illness (Corbin and Strauss, 1988). The biggest concerns of carers have been articulated as lifestyle changes, social restrictions and worries concerning the husband's well-being, together with the uncertainty of the illness in terms of symptoms and prognosis (Sexton and Munro, 1985; Ross and Graydon, 1997).

Two small qualitative phenomenological studies noted that self perceived quality of life of the wife-carers was difficult to differentiate from that of their husbands, since their lives and identities become enmeshed as they jointly manage the impact of the illness on both their lives (Bergs, 2002; Seamark et al, 2004). Investigating the impact of social isolation due to COPD, Keele-Card et al, (1993) found although both spouse and husband with COPD experienced loneliness and depression. Spouse carers tended to be more lonely and less satisfied due to reduced social networks and relationships, and they perceived that they had less people to turn to for support. Despite feeling exhausted, mentally worn out and isolated, a quantitative study revealed that wife-carers felt they wanted to continue caring for their husbands despite the difficulties and lack of health care support received, as they felt it was their responsibility to remain with their husband until the end (Bergs, 2002). This perceived duty of care

reflects a societal-normative expectation for a healthy spouse to care for their ill partner (Revenson, 1994). Likewise Caron and Bowers, (2003) note that carers often express a need for support but demonstrate resistance in accepting outside help and under utilise formal support services. As the severity of the illness increases carers of relatives with end-stage COPD have been identified as potentially benefiting from palliative care support, but availability and provision of this service has been found 'patchy' across the UK (Skilbeck et al, 1998; Addington-Hall et al, 1998).

A systematic review of the literature investigating what support meant to family carers of an elderly person at home, found that the term support was perceived as: services, assistance, education, information, attitudes and lay or professional persons intervention for the benefit of the family care (Stoltz et al, 2004). The study revealed that family carers feared social isolation, wished to network in groups with peers either for social or for learning needs purposes (Stoltz et al, 2004). Respite care has been identified by some carers as being the greatest help to provide relief, so that the spouse can avoid burnout and continue caring long-term or free-up time for other activities (Ross and Graydon, 1997, Bergs, 2002; Stoltz et al, 2004). Caregiver mental health has been strongly associated with degree of freedom, as carers always need to be available. Emotional well being, including self-esteem is associated with the perceived level of skill and the ability to cope with the care situation (Cossette and Levesque, 1993). Cognitive impairment of the patient has been suggested as influencing family coping to a greater extent than disabling physical symptoms (Wicks, 1997). One study found patient social maladjustment represented by high levels of patient belligerence, verbal expansiveness, withdrawal and depression as reported by families caring for persons with COPD (Kline Leidy and Traver, 1996).

Family members, as the major providers of the informal care for ill and impaired persons living at home, have been found to be the main factor in preventing or delaying institutionalisation of the relative (Cain and Wicks, 2000; Emlett, 1996). Female carers prevent admission to a nursing home for twice as long as patients receiving care from a male care-giver (Jette et al, 1995). However, one study found that respite care for COPD patients was associated with a high level of psychotic medication use by their family carer, indicating high levels of mental distress in

situations where no regular formal care services were received (Cossette and Levesque, 1993).

It has been noted (Yohannes et al, 1998), that COPD patients receive the same types of social care services as elderly well persons. However, they receive fewer meals on wheels and district nurse visits, less community physiotherapy and have lower attendance at a day hospital, than comparable groups of disabled patients (Parkinson's, arthritis, stroke, amputees) living in the community, despite no significant differences in overall family support. Individuals with disabling COPD are likely to be of pension age and are entitled to health and social homecare support services, but have been found to have less contact with a district nurse or respiratory nurse specialist than cancer patients (Edmonds et al, 2001; Gore et al, 2000). Since family carers are implicated in the treatment and care management of the relative with COPD they need to be included and supported in the decision-making by health professionals (Kanervisto et al, 2003).

## **2.20. Conclusion.**

A comprehensive search and review of the literature to investigate the current state of knowledge of COPD was undertaken following the data analysis stage of this study. The search identified a number of professional, national, and international guidelines, which predominantly highlighted pharmacological recommendations, and to a lesser extent non-pharmacological interventions, for the management of the disease COPD. Numerous reviews and studies relating to one or more aspects of the respiratory illness were identified within both quantitative and qualitative studies. The previously low profile of COPD has recently become a subject of increased professional and policy interest, giving rise to a surge of COPD related research and resulting publications since the millennium.

However, the majority of research studies are quantitative in approach and investigate interventions, correlations and the impact of variants upon different aspects of COPD. In particular, research outcomes focus on the medical management of symptoms, smoking cessation rates, pulmonary rehabilitation indicators, functional status, coping mechanisms or patient quality of life.



Much of the literature however is both complex and confusing, as research findings are often contradictory, inconclusive, compounded by the application of differing conceptual definitions or use variable and/or unsuitable instruments to measure similar domains. Some studies have identified the use of unsuitable or generic instruments that are insufficiently sensitive to measure COPD disease-specific characteristics. Although some of the research findings are valid and useful to generalise and predict measurable variables and outcomes in larger clinical populations many quantitative studies were not large enough to be statistically representative of the COPD population. In addition, the isolation of various factors within the lives of COPD patients within a study can result in distorted or misrepresented findings and are often limited in explanatory power.

In tandem with the general focus on COPD as a chronic disease there has been a rise in the number of qualitative studies, indicating a recent increased interest in the patient's perspective of living with COPD. Studies using grounded theory or hermeneutic phenomenological approaches to study patients' experiences of COPD have revealed valuable context-related data that describes and explores in depth, various aspects of patients' lives. However some of these qualitative studies have been criticised for being too theoretical, forcing the data into pre-determined conceptual themes and omitting the physical corporeal components of the lived experience.

The literature search did not reveal any sociological studies that explored the patient and carer's experience of the illness trajectory of COPD. Based upon the philosophical foundation of symbolic interactionism, the present study sets out to gain an understanding of the holistic experience of living with COPD by exploring both patients' and carers' perspectives as they traverse the illness trajectory. This involved capturing individuals' disease-related experiences and their impact on the physical body, the self and on perceived self-identity along the illness trajectory. By exploring the illness experience in relation to the participants' life context, this study aims to gain further understanding of the complexities and contradictions of living with COPD.

### **3.0. Chapter 3: Methods**

#### **3.1. Introduction**

This methods chapter describes the empirical sociological approach and strategy employed by the researcher in order to study the research topic of living with COPD. A rationale for the chosen qualitative research approach and its theoretical underpinnings is given, together with a descriptive account of the natural history of the research study and the methods employed. The chapter also discusses how the data were analysed and highlights the issues of credibility and validity. Methodological choices, strengths, limitations and problems of the study are discussed throughout the chapter.

#### **3.2. The research problem**

The researcher found no published studies, which explored the illness trajectory of COPD. Since no formal literature was available it was assumed that little is known about the experience of living with COPD as considered from the insider's perspective; what is it like to have COPD or to be the carer of someone who has COPD?

#### **3.3. Aims of the study**

Based on the research problem identified above, the aims of this research study are as follows:

To reach an in-depth inductive understanding of what is like for the individual and their main family carer to live with the progressive illness termed chronic obstructive pulmonary disease.

To explore participants' experiences of living with COPD to illuminate the issues, problems or concerns associated with the illness and to understand how these individuals deal with the impact of the illness upon their lives.

In the light of the findings of the study, to consider whether and how these groups could benefit from changes to health and social care services, with particular focus upon the role of nursing interventions.

Thus the research problem translated broadly into two questions posed to the study participants: “Can you tell me about your COPD?” and “What is it like to live with COPD?”

### **3.4. Background history and political relevance to study**

COPD is a common, costly and preventable disease but is the fastest growing cause of death world-wide (Lopez et al, 2006). As tobacco- related deaths and disability are projected to increase significantly from the period 1990- 2020, then national and international policy responses to this public health challenge have been advocated (Murray and Lopez, 1997). In the UK hospitalisations due to COPD increased by 50% between 1990 and 2000. Bed days used for COPD were more than five times those used for asthma (Calverley, 2003). Hospital costs due to COPD in 2001-2002 amounted to £587 million (Calverley, 2003), with the annual cost per patient for treating COPD 2.5 times higher than for asthma patients (Calverley and Sondhi, 1998). The impact on the economy due to loss of productivity in terms of working days lost from sickness, the costs of sickness and invalidity benefit and work days lost to employers is considered significant (Calverley and Sondhi, 1998). COPD impacts upon the patient by leading to impairment or disability and reduced quality of life (GOLD Executive Committee, 2006), and represents a significant economic and social burden globally (Ramsey and Sullivan, 2003).

However, despite signs of a growing recognition of its prevalence, COPD is still a low priority, under-diagnosed, and poorly understood disease (BLF, 2003; Rennard et al, 2002; Shovelton, 2003). Although more recently a growing number of research projects aimed at understanding the disease mechanisms, the benefits of smoking cessation and pulmonary rehabilitation, and improved pharmacological treatments have emerged; fewer studies exist which explore the overall impact of the illness and health and psycho-social needs of the individual with COPD. Exceptions include a few studies that identify the needs of individuals with advanced COPD. These studies

note how COPD becomes a terminal illness warranting palliative care but highlight how patients with COPD often lack the same service provision as their cancer counterparts (Skilbeck et al, 1998; Guthrie et al, 2001; Claessens et al, 2000; Addington-Hall et al, 1998).

Murphy et al, (1998) suggest that qualitative research is valuable to understand the impact of service interventions and how and why they work or fail to work. Government policy now emphasises a move towards health services for chronic conditions provided in the community through primary care and self-management (DoH, 2006). However, although the government has highlighted the importance of the role of patients as experts in the management of their own illnesses (DoH, 2001), very few studies focus upon the client's perspective and their approaches to dealing with COPD or its prevention. This study aims to make a modest contribution towards filling this gap.

### **3.5. The researcher's background**

The researcher spent 5 years as a staff nurse on the medical unit of a local general hospital where patients with COPD were admitted, usually as a consequence of experiencing an acute exacerbation of symptoms. Contact with such patients sparked an interest in a poorly defined group of patients who were pharmacologically treated to overcome the acute episode of exaggerated symptoms and then discharged home, often with little or no follow-up or support. The researcher realised that many of these patients had only a vague understanding of their condition and often had unresolved issues associated with the illness. A change in job role in 2000 to become a district nursing sister brought the researcher into regular contact with patients in domiciliary settings. This change in role highlighted the same problems concerning patients with COPD but from the primary care perspective, and this reinforced interest in the subject.

### **3.6. Natural history of the study**

The idea of studying for a research degree came to me out of the blue on my graduation day for BSc (Hons) Nursing Studies, and followed a suggestion from my personal tutor at that time. She introduced me to a fellow lecturer who offered to

supervise me, should I decide to go ahead. Later that summer I contacted the university and enrolled as a part-time doctoral student the following spring. I had no hesitation in choosing the subject area, as I was keenly interested in respiratory-compromised individuals and wanted to know more about this ill-defined group of patients. However, progress in the following 12-18 months proved to be a slow for three reasons. Firstly, I had major concerns about how I would finance doctoral studies. Secondly, my supervisor went off on unexpected long-term sick-leave, and I was eventually allocated another supervisor who although more experienced had a background in sociology not nursing. Thirdly, I had expected to use and develop the research approach used in my first degree for this study but following discussion with other lecturers and further background reading decided on a change in approach from phenomenology to symbolic interactionism. This last change was largely bound up with my thinking about how I could study what was essentially a process of long term illness, and my eventual conclusion that interactionism provided a more convincing conceptual framework and useful precedents for this kind of research. During this time I also attended a research workshop at Sheffield University; and several student support sessions held out of hours at the University of Wales Swansea (UWS), and also completed a diploma module in Respiratory Health part-time at the UWS.

When I embarked on the study one of the first tasks was to prepare a proposal for ethical approval. This took some months but following a daunting but successful ethics research proposal meeting, I was at last able to start contacting various gatekeepers to gain access to potential participants. Also at this time I grasped an opportunity to change job, moving from acute care to primary care in the community. Although this was an area of work that I had been hoping to move into eventually it was ill-timed as far as the research was concerned. Working on the wards brought me into direct contact with greater numbers of potential participants than when I moved to community nursing. However, as an advantageous career move, this was an opportunity that I could not let pass by.

Regarding participants, I was finding that some end-stage COPD patients were too severely affected to take part in the study, and decided to extend recruitment for the study to include moderately-severely affected patients. Responses to the invitation letter from some patients were slow, as many who had agreed provisionally to be

interviewed when contacted on the ward had not replied to confirm. However, after a follow-up telephone call, most were only too happy to arrange a date for the interview. Of those who declined, all but a handful apologised and gave understandable reasons. However one lady who received a letter asking if she would be interested in being interviewed contacted her general practitioner to lodge a complaint, citing two reasons for her dissatisfaction. Firstly, she said that her confidentiality had been breached by the general practitioner in giving her name to an unknown person (me), and secondly stated that she did not realise that she suffered from COPD, and asked why if she had this illness was she not being treated for it. Thus the situation at the time became unpleasant not only for me but for the doctor, practice nurse and surgery as the patient threatened to take legal action. Following further discussions and apologies no action was taken, but several lessons were learnt from these events. Thereafter, all remaining (n= 27) patients identified as potential recruits were approached first by their general practitioner to inform the patient of the study and in order to gain consent to be approached by me. This arrangement provided additional safeguards for patient confidentiality and had the potential to increase patient confidence to take part in the study.

As the number of participants interviewed increased, I realised how few patients had live-in or next-of-kin carers. I had previously visualised interviewing patients and carers in similar numbers but this was not feasible. Some patients lived and coped alone, while others had social service carers who were allocated to help for just a short period; morning and evening, each day.

The interviews were conducted and transcribed and the main analytical themes were identified in the first two years of the study. At that juncture another career contingency intervened because I decided to take the following year out to complete a BSc (Hons) course in Community Nursing, which was needed for an upward career move. Hence the research study was put on hold for twelve months. Despite concerns at the time, this break had a hidden benefit; re-immersion into the data amounted to a fresh start, which revived enthusiasm and brought new ideas. I realised that I had previously 'gone native', in the sense of not distancing myself sufficiently from my NHS nursing role, and had missed or glossed over important themes arising in the data. Re-reading the transcripts, and re-transcribing unclear parts of recordings, led to

a new understanding of the scripts. Carrying out data analysis seemed to be a logical and systematic series of steps involving data reduction and construction but I was uncertain as to whether I was approaching the task appropriately. Few publications explained how to proceed and this was a time of uncertainty and delay again. However getting to grips with underlying theory and re-reading the transcripts taking on some ideas from narrative analysis helped me to make progress in writing up the data chapters, followed by the remaining sections of the thesis in steady succession.

### **3.7. Context and setting of the study**

The study was conducted within a Health Authority NHS Trust covering a geographical rural area of west Wales served by one general hospital, two smaller cottage hospitals, an acute psychiatric hospital and 18 GP Practices. The population density ranged from below national average in the north to a small area of higher than national average density (Dyfed-Powys Health Authority, 2002). Geographical access to health services is generally poorer than the Welsh average due the remote location of many inhabitants within the catchment area (Dyfed Powys County Report (2002). Within the year 2001-2, the three hospitals received 5,738 emergency inpatient stays for general medicine, which included COPD. Figures from the Compendium of Health Statistics for Dyfed Powys (2002) show lower numbers of death and mortality rates from COPD and allied causes within this region as compared to those of Wales as a whole. However, the Welsh Health Survey (1998) and National Assembly for Wales (1999) highlighted the health-related lifestyle measure such as smoking as an 'under performing' problem in this region which may indicate a future rise in COPD related morbidity and mortality rates.

### **3.8. Theoretical framework**

Most social science researchers recognise that the theoretical underpinnings of a research project need to be acknowledged in order to place the findings within a conceptual framework that will make sense of the acquired data (Silverman, 2000; May, 1999; Dingwall, 1997; Morse and Field, 1996). Theory has been defined as a systematic explanation of an event in which constructs and concepts are identified and relationships are proposed or predictions made (Morse and Field, 1996). Social theory

provides a framework for the interpretation of empirical data and a basis for critical reflection on the process of research itself (May, 1999). May (1999) states that the study of social theory and social research is a reflexive endeavour, each informing and modifying the other through reflection, experience and practice within a constant relationship. He emphasises: “the issue for us as researchers is not simply what we produce but how we produce it” (May, 1999:28).

As the study was being designed, the main theoretical choice made by the researcher was to opt for a qualitative, exploratory and inductive research strategy (Mason, 1996). This was largely dictated by the research question, but also by the researcher’s existing experience and skills acquired in an undergraduate project.

The philosophical background for this study is located within the epistemological framework of the interpretivist research tradition, which uses a qualitative and inductive approach to generate new data. Unlike a positivist, quantitative methodology which strives to maintain objectivity within the research process by using methods comparable to those of the natural sciences, the interpretivist approach recognises that interpretive cognitive processes are employed by both the researcher and informants (Murphy et al, 1998). Although not exclusively so, qualitative research is generally considered to be primarily an inductive approach aiming to generate emergent data rather than test hypotheses (Glaser and Strauss, 1967; Silverman, 2001; Hammersley, 1992). Understanding the phenomenon under study in the context of the setting or culture is considered a main distinguishing characteristic of qualitative as opposed to quantitative research. Unlike the latter, which is concerned with isolating variables to investigate causal relationships, qualitative research aims to achieve adequate description and understandings of social processes by examining social phenomena, their relationships and changes over time within their real world contexts (Lincoln and Guba, 1985; Silverman, 1985; Hammersley, 1992; Miles and Huberman, 1994; Stake, 1995).

A qualitative exploratory approach was employed in this study to ‘uncover’ and understand from the participant’s subjective perspective, aspects of living with COPD which would be difficult to ‘capture’ or ‘convey’ using quantitative methods (Conrad, 1990; Strauss and Corbin, 1990).



### **3.9. Historical background to interpretivist sociology**

Qualitative methods used in contemporary social research are largely derived from the development of British social anthropology since the end of World War 1, and work from the American neo-Chicagoan school of sociology since the 1960s (Murphy et al, 1998). The interpretivist or hermeneutic research tradition encompasses several theoretical approaches with a family resemblance including: phenomenology, ethnomethodology, existential sociology and symbolic interactionism. There has been a degree of confusion in nursing research whereby theoretical approaches (such as the above) are placed on the same level as methodological approaches (such as ethnography) or analytical approaches (such as grounded theory). Lowenberg, (1993) criticises current nursing research for fitting research into the methodological categories of phenomenology, grounded theory or ethnography. Lowenberg (1993) argues that interpretive research should be considered as being either phenomenological or symbolic interactionist, with the latter giving rise to ethnography. However, even Lowenberg is not always clear about how other micro-sociological theoretical approaches and grounded theory fit into the picture.

The design of this study is based upon the research tradition of symbolic interactionism, a theoretical perspective attributed mainly to George Herbert Mead, (1863-1931), and further developed by Herbert Blumer, (1937/1969). Most of Mead's work was conveyed orally, as he wrote and published very little in his lifetime (Giddens, 1992), but was carried on by Blumer who laid the foundations for contemporary symbolic interactionist theory (Blumer, 1937, 1969; Murphy et al, 1998). Mead had developed a social psychological theory of behaviour, which he contrasted with the dominant stimulus-response models employed in the Chicago psychology department. Mead and Blumer argued that human behaviour includes more than observable reactions to inputs, and instead they refocused attention on the way human action depends on the use of symbols and shared meanings, which are constructed and modified in an ongoing process of social interaction (Blumer, 1969). More recently this approach had been used in empirical studies by researchers such as Kathy Charmaz, (1983; 1987,1990,1995); Goffman, (1961, 1970); Norman Denzin, (1984, 2001); Catherine Kohler-Riessman, (1990,1993) and Gareth Williams, (1984).

### **3.10. Interpretivist research methodology**

This study takes on an interpretive symbolic interactionist approach, which seeks to gain insights and understanding into the meanings of the emergent data and aims to understand the interpretations of individuals, as they perceive themselves living with COPD. This approach aims to generate theory derived from data in contrast to imposing *a priori* categories upon the data, as may happen in quantitative research (Emerson, 1983). Inductive research starts with a collection of data and moves to a general conclusion, involving the derivation of general principles from a set of specific observations (Williams and May, 1996). As little is known about individuals long-term concerns in living with COPD, it is hoped that this approach will help to build new theory, which is ‘grounded’ in the data (Glaser and Strauss, 1967).

Issues of context, holism and process are considered an integral part of qualitative research (Bryman, 1988; Benner, 1994) and are therefore important considerations in this study. Contextualism is identified as understanding events and behaviour in their context and holism as approaching social entities as wholes to be explicated and understood in their entirety (Bryman, 1988). Process refers to the emergent and patterned nature of social interaction and meanings over time. This requires the researcher to adopt flexible research designs that can cope with unpredictability and capture data relevant to the study (Bryman, 1988; Hammersley, 1990; Guba and Lincoln, 1994).

Like other chronic illnesses, COPD is a socially and physically defined process, which creates a changing biographical and illness trajectory, and here too the researcher must employ a flexible approach to capture emergent data (Charmaz, 1983). Some researchers suggest that in studying participants’ perspectives, the researcher is inevitably imposing an interpretation influenced by his/her own social view of the world (Bryman, 1988; Hammersley, 1992). However, researcher reflexivity is considered an integral part of interpretivist inquiry, where sensitivity to the ways in which researcher and the research process have influenced the collected data is important in writing up the ‘findings’ (Mays and Pope, 2000). May, (1999: 14) emphasises: “Our sense of belonging to a society and the techniques used which we use for understanding are not impediments to our studies. The procedures through

which we understand and interpret our social world are now necessary conditions for us to undertake research...Contrary to positivism and empiricism, the social researcher now stands at the centre of the research process as a requirement of understanding social life”.

### **3.11. Insights from symbolic interactionism**

According to Blumer, (1969:47): ‘symbolic interactionism is a down-to-earth approach to the scientific study of human group life and human conduct. Its empirical world is the natural world of such group life and conduct. It lodges its problems in this natural world, conducts its studies in it and derives its interpretations from such naturalistic studies’. Symbolic interactionism has been described by other sociologists as usually focusing upon active and creative face-to-face interactions in order to understand, interpret and incorporate the views between individuals so engaging in symbolic communication or shared meanings (Giddens, 1992; Porter, 1998). Blumer proposed that symbolic interactionism rests on three simple premises, namely that: human beings act toward things on the basis of the meanings that the things have for them; the meaning of such things is derived or arises from the social interaction that one has with one’s fellows; and these meanings are handled in and modified through an interpretive process used by the person in dealing with the things he encounters (Blumer, 1969: 2). Blumer proposed that the framework for the study of symbolic interactionism is grounded in the ‘root images’ or basic ideas of human groups or societies, social interaction, objects, human beings as actors, human action and the interconnection of the lines of action. These root images represent the way in which symbolic interactionists view human society and conduct (Blumer, 1969: 6). The approach of symbolic interactionism recognises that individuals constantly interact through a process of ongoing designation and interpretation as they live out their lives. Hence symbolic interactionism was considered the most appropriate approach relevant to this study from which to ‘yield knowledge of the world of everyday experience of individuals as they meet the situations that arise in their worlds, past and present’ (Blumer, 1969:35).

### **3.12. The interview: patient narratives**

Within this interactionist approach the study used unstructured interviewing to elicit participant accounts, stories or narratives of living with COPD. Narrative has been defined as:

‘a discourse that consists of a sequence of temporally related events connected in a meaningful way for a particular audience in order to make sense of the world and/or people’s experiences in it’ (Hinchman and Hinchman, 1997: xvi).

Hyden (1997) suggests that narratives can be constructed by patients, carers or health professionals to convey, express or formulate their experience of the illness and may accomplish one or more of five purposes. These include: transforming illness events and constructing a world of illness; reconstructing one’s life-history in the event of a chronic illness; explaining and understanding the illness; asserting one’s identity; and transforming the illness from an individual to a collective phenomenon (Hyden, 1997).

Through narrative expression, people not only identify connections between their disease and causative factors but also reconstruct their story to depict how their lives and relationships to others have altered (Williams, 1984). The narrative allows the person to reconstruct a sense of order between physical body, self, and society in and to realign present, past and self with society (Williams, 1984) in the wake of biographical disruption imposed by the illness (Bury, 1982).

As a research methodology, analysis of narrative interviews is situated within the interpretive approach, has been hailed as a way of understanding the complex multi-layered experience of illness from the narrators’ viewpoint (Kelly and Field, 1996; Bury, 1991). This approach counter-acts the biases of the bio-medical, or the theoretical sociological models imposed upon research methodology (Bell, 2000; Bury, 2000; Frank, 1997). The making of narratives enables the patient as narrator to create his/her version of living with an illness, highlighting the moral dilemmas experienced and emphasising a sense of self-worth. It helps the patient to re-claim a sense of personal identity (Frank, 1997; Charmaz, 1987; 1994; 1995).

Thus narrative interviewing within illness research is as concerned with participant perceptions as with eliciting factual information (Miller, 2000; Mishler, 1990). It is not so much a route to constructing the factual circumstances of people's lives, but the meanings they attach to events and the kind of identity they seek to project.

Narrative analysis has been used increasingly in sociological studies as a method to gain knowledge and understanding of patients' experiences of chronic illness (Bell, 2000; Hyden, 1997; Gerhardt, 1990). As a recognised alternative strategy to grounded theory within interpretive research (Gerhardt, 1990), narrative research has been acknowledged as a powerful approach for exploring the experience of illness and suffering (Hyden, 1997).

Unlike the more traditional qualitative method of grounded theory, narrative analysis avoids the criticism of reductionism by not fragmenting data into discrete categories to be coded, but uses longer stretches of text to be interpreted into thematic units which are read in context and related to events and time frameworks introduced by the narrator (Lucas, 1997; Burnard, 1995; Riessman, 1990).

However an alternative qualitative approach, sitting between grounded theory and narrative analysis is analytic induction. Analytic induction allows patient narratives to be analysed by coding into emergent themes but always adhering/returning to the context from which it is derived to generate authentic meaning. Ensuring that all fragments of data are accounted for this method has the qualitative equivalent of statistical representativeness (Silverman, 2001). Unlike narrative analysis, analytic induction focuses more on why and how a phenomenon occurs and less about the construction of their interpretation.

### **3.13. Alternative approaches: why not phenomenology or grounded theory?**

Adopting a phenomenological approach to study persons' experiences of living with COPD seemed at first consideration an ideal philosophical basis for this study, in response to the question "what is it like to live with COPD?" However, further reading and reflection raised doubts about the way the original philosophical sources have been interpreted in nursing research and the adequacy of the associated research

methods that have been proposed (Paley, 1998). Phenomenology was founded as a philosophical perspective by the philosopher Edmund Husserl (1859-1938) to address the problem of Cartesian dualism, and the approach was developed by (among others) Heidegger, (1962); Dreyfus, (1987); Merleau-Ponty, (1962); Schutz, (1970); van Manen, (1990) and Benner (1984, 1985).

Dreyfus (1987) suggests that interpretive phenomenology is a way of understanding what it is like to be an embodied being who is self-interpreting, and what it means to be a particular human being in a particular place at a particular time in history. Taking up the approach of phenomenology researchers seek to understand the lived experience of individuals within their life-world (van Manen, 1990). In order to do so the approach of Husserlian phenomenology advocates the bracketing of the researcher's preconceptions in order to isolate and to avoid contamination of the data under investigation (Schutz, 1970). This approach has been criticized as an approach not unlike that of positivist science taking on a subject- object dualism involving data reductionism (Koch, 1995).

Some phenomenological researchers attempt something akin to Husserl's notion of the phenomenological reduction by seeking to strip away preconceptions and describe the essence of pure experience. However, it has been argued that the phenomenon always escapes because it is impossible to distinguish the level of pure experience from the many layerings of cultural knowledge and social expectations via which all of us make sense of our social worlds (Silverman, 2000). Other critics have pointed out that, in practice, much contemporary phenomenology becomes highly descriptive and does not generate theory in the way that approaches such as symbolic interactionism do (Field and Morse, 1996; Sorrell and Redmond, 1995; Baker et al, 1992).

The aim of this study is to explore and gain understanding of patients' perceptions of their illness experience, of how they feel and act as they do, as a consequence of the complex multi-factorial influences; personal and contextual, impacting upon their experience of living with COPD. The aim of this study is to understand the chronic illness experience as a dynamic process that changes continually according to context and time. As such current approaches influenced by phenomenology did not appear to fit well with the aims of this study.

The grounded theory approach has been categorised as one variant of sociological work influenced by symbolic interactionism as opposed to the distinct theoretical approach that it is sometimes said to be within nursing research (Lowenberg, 1993). There is some truth in this view since grounded theory research became widely disseminated as a consequence of the work and teachings of Strauss and Glaser (1967), who in Strauss' case at least had been brought up in the neo-Chicagoan tradition and was familiar with the interactionist approach, (Lowenberg, 1993; Field and Morse, 1996; Murphy et al, 1998). However, the originators of grounded theory stated clearly that it is an analytical approach that can be combined with a variety of theoretical frameworks and even with quantitative approaches (Glaser and Strauss 1967 – note *Discovery of Grounded Theory*), so this historic association with interactionism is not the whole story.

What is distinctive about the approach is not so much its underpinning theory of social interaction as its approach to generating knowledge. Thus Strauss and Corbin (1990:23) define grounded theory as theory that is derived from the study of the phenomena it represents. Grounded theory aims to generate theory from data, and because the theory is grounded in the emergent data the method is inductive as opposed to the deductive approach, which seeks to falsify an existing theory (Glaser and Strauss, 1967).

One of the main building blocks for generating theory is the identification of themes and sets of related categories, and the use of associated codes that can be used in analysis. Strauss and Corbin, (1990) describe how coding is a key part of a process of data analysis via which data are broken down, conceptualised and re-conceptualised, and put back together in order to generate theory from data. However, this fragmentation of data into categories and codes isolated from the social context from which they are derived did not seem to me to sit easily with a study that would focus mainly on patients' stories about their illnesses and would need to pay attention to the temporal sequencing and components of these stories. Thus I opted for a broader form of inductive analysis that did not involve the elaborate coding strategies characteristic especially of the later Strauss/Corbin approach to grounded theory.

A final possibility, also rejected, was to include an observational component in the study. Some qualitative researchers consider participant observation, or sociological ethnography, to be a preferable alternative to interviewing for understanding the insider's perspectives and practices (Denzin, 1970; Dingwall, 1997). Traditionally ethnography involved extended fieldwork of observation and interaction with individuals within the natural settings of their culture or sub-culture (Denzin, 1970; Dingwall, 1997). However, participant observation did not seem to fit well with the research question, which centred on the individual's interpretation, understanding or perceptions of living with COPD, as opposed to cultural understandings of COPD or interaction among sufferers and carers. Although the interviews were broadly ethnographic in character, the study focused on the individual level, exploring patients' and carers' perspectives and the meanings constructed over time and through interpersonal interactions. Persons living with COPD cannot be classified as a culture or subculture in so far as these individuals do not live within an isolated group who share common meanings as a consequence of learning or socialisation from other members of the same group. Observation, even participant observation, would not only be problematic in practical terms but often inappropriate because of privacy considerations. The focus of this study was to understand the participants' subjective experiences, feelings and actions/behaviour as a consequence of their own interpretations of living with COPD. Although the study revealed many similarities amongst participants, the aim of the study was not to learn about shared understandings within a cultural group, as in a typical ethnographic study, but to explore individual self-interpretations and understandings of living with COPD.

### **3.14. Issues of access, consent and confidentiality: the ethics committee, and organisational gatekeepers**

In order for this study to go ahead it required approval from the local Health Authority local research ethics committee (LREC). A research proposal was submitted to Dyfed Powys LREC in March 2000. As is usual the student was required to attend a committee meeting in person to answer questions. Subject to a few minor alterations in wording in the proposal, approval for the study was given to go ahead.



Following approval from the LREC, letters were sent out to main gatekeepers, first at the highest level of the relevant organisations, and then to staff closer to the clinical level. Thus the first stage was to contact the chief executive of the local NHS Trust hospital, director of medicine and director of nursing to request permission to proceed with the study. Following their agreement approaches were then made via letter to the hospital's consultant physician in respiratory medicine, senior ward sister of the medical ward, the respiratory specialist nurse and general practitioners from primary healthcare centres in the locality were then contacted via letter. The letters requested permission to approach potential participants and requested a list of suitable patients who were diagnosed with COPD, emphysema, chronic bronchitis or chronic asthma. Due to the researcher's status as a nurse employed within the hospital, it was possible to use opportunistic face-to-face contacts to discuss the study and what it would involve. All persons who were contacted agreed in writing to participate on the basis of the letter or in a few cases after further discussion.

## **Appendix 2: Patient information sheet and letters of ethical approval and consent to access**

Note: Submission to the Research Ethics committee and compilation of the patient letters was carried out prior to the change in regulations (March 2004).

### **3.15. Design and Methods**

#### **3.15.1. Case selection: sampling the targeted population**

Interviewing COPD sufferers and their carers was chosen as the most appropriate method to obtain relevant information for this study. Interviews enable participants to reveal what they think about the topic under study, how they evaluate their experiences and explain their behaviour (Murphy, et al, 1998). However, this raised the question of how to select participants. As the study aimed to find out information about living with COPD then it made sense to purposively /theoretically select individuals who had COPD to include an appropriate range of subjects. As Silverman (2001:250) states 'purposive sampling allows us to choose a case because it illustrates some feature or process in which we are interested'. Mason elaborates this point as follows: "theoretical sampling means selecting groups or categorises to study on the basis of their relevance to your research questions, your theoretical position ... and most importantly the explanation or account which you are developing. Theoretical sampling is concerned with constructing a sample "... which is meaningful

theoretically, because it builds in certain characteristics or criteria which help to develop and test your theory and explanation” (Mason, 1996: 93-4). Due to the flexibility of purposive / theoretical sampling, the researcher was able to add to the sample number during the research in order to expand upon emerging data concepts, and to seek out a small number of new deviant cases to test against provisional hypothesis arising from the data (Silverman, 2000).

### **3.15.2 Inclusion and exclusion criteria for sample selection**

Out of the population of named individuals with COPD proposed by gatekeepers, individuals were selected for invitation to participate in the study on the basis that health professionals knew them, or they were stated in patient medical records, to have COPD, emphysema, chronic bronchitis or chronic asthma. No ethnic minority subjects were included. All participants spoke English as a first language or were bilingual English/Welsh speakers. Participants’ ages ranged from 45 to 90 years, reflecting the typically late onset of COPD. Potential participants excluded from the study included patients who were known to have only mild COPD or clearly diagnosed asthma; or were currently suffering an acute exacerbation of severe COPD or experiencing severe effects of an acute concurrent illness. As a few general practitioners expressed reservations about suggesting spirometry to participants and the fact that these lung function measurements were superfluous to the focus of the study, the researcher decided against spirometry testing, informed participants and omitted this from further recruitment letters. Spirometry assists medical diagnosis and prediction of prognosis but cannot measure disability or quality of life (Simon et al, 2005).

**Extract of Summary table of participant characteristics (refer to Appendix 3 for the complete table)**

<b>Participant Code No.</b>	<b>Age</b>	<b>Gender</b>	<b>Family Situation</b>	<b>Prescribed Long-term oxygen therapy, (LTOT), or oxygen cylinders</b>	<b>MRC dyspnoea scale grade (NICE, 2004)</b>	<b>Carer Interviewed</b>
P1	76	M	LR	LTOT	5	C1
P2	45	M	LP	No oxygen	5	C2
P3	55	F	LP	No oxygen	4	
P4	69	F	LA	No oxygen	4	
P5	71	M	LA	No oxygen	5	

**Key:**

- LA - Living Alone
- LP - Living with Partner
- LR - Living with Relative
- LSH - Living in Supported Housing.

**Medical Research Council (MRC), Dyspnoea scale (National Institute for Clinical Excellence, (NICE), 2004).**

Grade: Degree of breathlessness related to activities

- 1 Not troubled by breathlessness except on strenuous exercise
- 2 Short of breath when hurrying or walking up slight hill
- 3 Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace
- 4 Stops for breath after walking about 100m or after a few minutes on level ground
- 5 Too breathless to leave house, or breathless when dressing or undressing

Note: The indication of medically prescribed oxygen therapy is used as a proxy of disease severity. However, medical prescribing for oxygen therapy was inconsistent prior to the implementation of the clinical guidelines for oxygen assessment (DoH, 2004b).

**3.15.3. Issues of authorisation, access, consent and confidentiality: the sampling procedure**

Some potential participants were contacted initially by the researcher via face-to-face contact, usually on the medical ward or in clinics, or by letter. Clear written and/or verbal information about the research was provided to patients together with a form, which required a signature of consent agreeing to take part in an interview. The researcher stressed at all times that the person was under no obligation to take part, but that if they did, all information would be confidential to researcher, who would

ensure that the participant's anonymity was preserved. Patients were given the letter and form to sign together with a stamped addressed envelope to return to the researcher. The vast majority of patients who were approached agreed to take part. However, a few declined on the grounds of not feeling up to it, family commitments, imminent hospital admission or in one case due to a recent bereavement. A couple of respondents had contacted their general practitioner to confirm the legitimacy of the study prior to consenting.

Participants were asked if they would mind if their carer were approached for an additional interview prior to any direct and separate approach to the carer. Similar issues of informed consent and confidentiality also applied to the family carer.

The researcher then phoned respondents to arrange a date, place and time for the interview. All but two interviews were carried out in the patients' homes; one was conducted on the hospital ward and the other at a GP surgery. All interviews were carried out during the researcher's free time and not during working hours on the ward to avoid a potential role conflict between employee and researcher (Field and Morse, 1996). The participant was reminded of the terms of informed consent and that he/she could terminate the interview at any time, being under no obligation to the researcher (Field and Morse, 1996).

#### **3.15.4. The data collection method: interviewing**

The qualitative unstructured interview was considered the most appropriate method to elicit participant views on living with COPD. The interviews conducted were non-standardised. No pre-set interview schedule was used because the researcher wished to allow participants to raise issues pertinent to them, in a sequence of their choosing (Denzin, 1970). However, despite the original intention to avoid a predetermined structure of any kind, the interviewer found participants needing to be coaxed into relaxing into the interview situation. Despite being asked to describe living with COPD in their own words, many participants had a pre-conceived idea that an interview equated with being asked set questions and consequently began the interview hesitantly. Silverman, (2001) suggests that open-ended non-directive interviewing can in itself impose certain constraints since interviewees are unsure of what is relevant to bring up in the interview. Therefore following preliminary social

pleasantries, the researcher found that the interviewing procedure benefited from beginning with a couple of prepared questions focusing upon demographic information in order to 'kick-start' the interview. After some non-directive questioning supported by probing to elaborate and clarify responses, participants became more relaxed and confident to open up and reveal thoughts and experiences of living with COPD within an unstructured style of interview (May, 1999).

As May (1999) points out, the researcher has a general aim in mind when conducting the focused interview but the participant is free to talk about the topic to achieve meaning rather than standardisation. Although this type of interview is sometimes referred to as in-depth interviewing because it provides detailed information about a specific subject (Britten, 1995), Gomm, (2004) prefers the term loosely structured interviewing. Gomm, (2004) points out that in-depth interviewing as used by psychoanalysts and the police rests on a differential power balance, which should not be present between researcher and study participant. Likewise Whyte, (1982) suggests that a genuine non-directive interviewing approach as used in Rogerian therapy is not appropriate for research purposes as it is "far from putting informants at their ease, it actually seems to stir anxieties"(Whyte, 1982: 111).

Other researchers have noted the importance of researcher and participant sharing certain characteristics or past experiences such as gender and knowledge of insider vocabulary. This approach may be taken in order to gain trust within the interview, to facilitate in depth, personal information to be disclosed (Anderson et al, 1990; Oakley, 1981). The unstructured non-directive interview depends on mutual co-operation between interviewer and interviewee, where topics related to the subject under scrutiny, are disclosed by the participant rather than the researcher (Gomm, 2004). Gomm, (2004) also argues that in a loosely structured interview the researcher will be hoping to cover a list of topics but the interview course will be respondent-led. Unstructured interviews enable the researcher to gain access to the respondent's feelings, thoughts and intentions in greater detail than would be acquired through structured questionnaires and allows respondents to uniquely portray their understanding of the world in their own words (Denzin, 1970).

The use of standardised questions in a standard order of questioning to reduce interviewer bias and increase reliability to isolate facts in positivist style would be a

highly flawed approach for this study (Silverman, 1985; Denzin, 1970). However, the researcher found that simple counting techniques, based upon common-sense categories arising from the empirical data, were useful in getting a feel for the data. Silverman (2000) points out that although the use of tabulations does not contribute in the final analysis or outcome of the study's findings, the construction of tabulated categories based on counting can give the reader a general sense of the direction of the data.

Due to the limited time available to the researcher as a part-time student (full time working nurse), the use of group interviewing to save time was considered. However, further reflection on this approach highlighted three main disadvantages. First for pragmatic reasons the taking of detailed notes and transcription of an audio recording would prove to be difficult as people often speak at the same time. Second, group dynamics may modify what some people say so that findings in this situation would differ from individual interview accounts and thirdly, some more extroverted participants might dominate quieter persons (Robson, 2001).

Telephone interviewing is a modern alternative method to face-to-face interviewing but was considered unsuitable for this study despite the advantages of savings on travel time and costs, high response rate, and lower interviewer effects (Denscombe, 1999; Silverman, 2000). The researcher considered that rapport would be difficult to establish in the telephone situation, particularly as the sample would consist mainly of elderly individuals who were likely to distrust a stranger asking questions over the 'phone. Also many individuals in this population group are likely to have a hearing impairment as well as being subject to episodes of breathlessness. Therefore telephone interviewing was considered inappropriate.

### **3.15.5. Interviewer as research instrument: skills needed for interviewing**

The qualitative interview is a flexible way of finding out information, which allows the interviewer to modify his/her line of enquiry or to follow up new leads. However, this flexibility requires certain skills and sensitivity on the part of the interviewer (Robson, 2001; Denscombe, 1999). Unlike the social survey or structured interview, the aim of the unstructured interview is to encourage in a non-directive way, the participant to talk openly and freely to disclose what they consider truthful

information (Robson, 2001; Gomm, 2004). By establishing rapport the interviewer hopes to build up a relationship of trust and empathy with the respondent (Gomm, 2004; Field and Morse, 1996).

Having paid attention to putting the participant at ease by reiterating their entitlement to stop or end the interview at any time for whatever reason, ensuring confidentiality and anonymity, explaining the aim and estimated time of interview, asking permission to use a tape-recorder and generally making small talk, then the researcher settled down to switch on and carry out the interview. Following these preliminaries, the unstructured interview typically started off with the researcher asking: “can you tell me what it is like having COPD?” Some interviewees at that point were already willing to talk at length, while others began with a hesitant silence. In this latter situation the researcher asked a few questions relating to basic demographical information, which usually resulted in respondents gaining confidence in subsequent answers. Where respondents were more forthcoming these basic demographic questions were fitted in later as and when the flow allowed. When silences or hesitations occurred, the researcher typically would use prompting phrases such as “is there anything else you can tell me about that?” or going back to “...did you say?” or, “what did you mean by that?”

As recommended in research methods books, the researcher found being an active listener, being attentive, not giving cues which lead respondents to respond in a particular way, tolerating pauses, being sensitive to participant’s feelings, using productive prompts, probes and checks, being non-judgemental and respectful towards the respondent enabled the interview to yield productive data (Denscombe, 1996; Robson, 2001). Learning to probe in a non-directional manner, not interrupting accidentally and allowing the informant to introduce unanticipated material were skills the researcher as a novice had to master quickly during the first few interview sessions (Whyte, 1982).

At first participants often seemed to want to talk about random non-illness related issues but the researcher eventually realised that these stories, accounts and unpredictable topics were all bound up and relevant to the subject under investigation, that is living with COPD. Some participants told their story in chronological order of significant events occurring in their lives often starting with the typical phrase ‘well

I've had it as long as I can remember...' Some plunged straight into telling about their most recent and dramatic breathlessness scare and emergency hospital admission while others tried to play down the constant limiting effects of the illness on their lives.

Many participants found talking for any length of time accentuated their breathing problems and they had to stop to regain breath or had to regulate the pace of their speech using utterances such as err between phrases and sentences. Hence the researcher decided after having transcribed a couple of interview transcripts that respondent utterances such as um, err etc. and lapses or silences within the interview data had a different (and reduced significance) in producing meaning than might in other contexts of interest to discourse analysts. In the researcher's view, these sounds or pauses within the telling of biographical accounts were generally simply due to the respondent being short of breath and hence were not recorded verbatim in the transcription.

Most interviews lasted approximately one hour; many participants were keen to carry on well after the audio-recorder had been turned off over a cup of tea while two interview sessions were ended within twenty minutes. One individual had a complaint against the hospital service and used the interview to vent her feelings despite the researcher encouraging her to talk about her illness. The second unsuccessful interview had to be ended prematurely, as the participant unknown to the researcher had recently suffered the bereavement of her son. The interviewing process had a renewed cathartic affect upon the participant. The researcher abandoned the interview and spent time counselling and consoling this lady.

#### **3.15.6. Researcher as research instrument: issues of subjectivity and bias**

It has been observed that the researcher in qualitative research is herself/himself the main research tool, and will have an influence upon the outcome of the interview data and affect research validity (Silverman, 2000). The researcher's socio-structural position, ascribed characteristics, gender, age social class may all influence the interview process and the content of the data (May, 1999; Guba and Lincoln, 1989). In contrast to quantitative research, where researcher objectivity is emphasised,



qualitative research relies upon researcher and respondent working together co-operatively. Effective interaction is considered important to establish rapport and empathy within the researcher/respondent relationship and get good data (Field and Morse, 1996; Denscombe, 1999; Melia, 1997; May, 1999).

Participants were informed that the researcher was a nurse, and indeed several individuals recognised the researcher from treatment settings, which seemed to put them at ease. Having a 'nurse' to talk to about sensitive or embarrassing issues related to their illness was perceived as okay, and among the comments received were: 'you nurses are used to seeing or doing this or that', and 'I can tell you 'cos you will understand...' Many participants voiced their opinions about the health care they had received (good and bad), and appeared to become more relaxed in talking about their healthcare experiences when the researcher could identify with the places or persons mentioned in the course of their story telling. However, as all except two interviews were conducted in patient's own homes, the researcher was careful to dress casually and adopt a friendly, equal power status. Although a non-judgmental and non-directive stance was necessary to avoid imposing the researcher's own assumptions upon the participant, the researcher felt that some personal involvement of showing emotion and responding to harrowing accounts with empathy was appropriate to maintain respondent trust and encourage the disclosure of further information (Britten, 1995; Anderson et al, 1990; Oakley, 1981).

Many participants asked questions of their own, sometimes about the outcome of the study but more usually about their own illness or the course of COPD in general. Enquiries such as how best to use their inhaler were discussed but more sensitive questions such as 'how long have I got?' were more difficult and dealt with in a sensitive but non-committal counselling manner, reflecting the question back to the participant and advising them to talk to their GP or hospital consultant.

### **3.15.7. Data retention**

All the participants of the study consented to having the interview audio tape-recorded, which was an essential back up for the researcher and a record of what was actually said to refer to at the various research analysis stages. In most cases, the researcher also made notes during the interview to highlight particular phrases used

by the participant as an aide memoir, to probe into glossed over issues later on in the interview. By appearing momentarily sidetracked in scribbling or jotting down in a notepad, the researcher found a useful aid for filling in the silences. Usually this did not interrupt the flow of the interview and allowed the participant time to elaborate on his or her story.

As each interview progressed the researcher started to get a feel for the general issues arising in the data and to develop hunches based upon the accumulative material. Unfortunately a couple of interviews lasted longer than the available audio tape (the researcher had only taken one spare cassette per participant). A few interviews were extremely difficult to hear clearly when played back later, and in another case the researcher had been oblivious to the fact that the participant's dog had knocked over the tape-recorder rendering the tape inaudible. Several participants only really started to reveal deeper thoughts and feelings after the recorder had been turned off at the close of the interview.

Although the researcher had originally asked to interview patient and carer separately, most participants took this to mean talking separately but in the same room. Therefore following the interviewing and escorting the researcher out of the house back to the car, out of ear-shot of the participant with COPD, the carer would often open up to reveal current problems and fears for the future. In these cases the researcher would make notes as soon as possible, trying to recapture what was said in the words used by the participant while these were still clear in the researcher's mind. In all cases, a brief summary was written, including demographic characteristics, general observations and key issues raised by the participant after each interview.

Transcription of recorded interview data was a lengthy and laborious process particularly when the sound quality was poor, sometimes taking up to ten hours per tape to complete. However, transcription proved a worthwhile activity as the content often revealed far more data than had been recorded in the field-notes.

Only one participant enquired about the eventual fate of the audio-tapes and no-one wanted their audio-tape returned.

### **3.15.8. Analysis of the data**

Most prominent qualitative researchers stress the importance of handling, analysing, interpreting, transforming or making sense of data as soon as any are gathered (Glaser and Strauss, 1967; Wolcott, 1990; Hammersley and Atkinson, 1995; Silverman, 2000). Hence, data collection and analysis are less like sequential stages and become an ongoing interactive iterative process (Glaser and Strauss, 1967). Thus Silverman (2000) has suggested how leads identified in the data early on can be developed and become as focus for enquiry as additional participants are interviewed (Silverman, 2000). However, due to the researcher's time out for the second-degree course, the process of data analysis was interrupted for a period after the interviews and transcriptions were completed. Returning fresh to the data provided a new start for the analysis proper (Silverman, 2000) and proved beneficial. It enabled the researcher to re-read the 'voluminous, unstructured and unwieldy' quantity of transcribed interviews, field notes and other sources of written information that had accumulated with renewed enthusiasm (Bryman and Burgess, 1994:216). The collection of interview transcripts containing detailed 'thick' description (Geertz, 1973; Denzin, 1989: 83) had almost amounted to a despairing 'data overload' (Miles and Huberman, 1994:2).

### **3.15.9. Analytic induction**

The use of thematic analysis, the search for and identification of common threads extending throughout the set of interview transcripts allowed concepts to be identified within the data (Field and Morse, 1996). These concepts or themes were examined for their substantive interest and relationships to each other, and also considered in relation to their context and the temporal stages of the COPD illness to tell a plausible story of living with COPD (Melia, 1997). Thematic analysis using the approach of analytic induction was employed to analyse the data.

Analytic induction is defined as an approach whereby:

“...the researcher seeks universal explanations of phenomena by pursuing the collection of data until no cases that are inconsistent with a hypothetical explanation (deviant or negative cases) of a phenomenon are found” (Bryman, 2001, p.389).

Analytic induction incorporates the methods of constant comparison, deviant-case analysis and comprehensive data treatment in order to draw valid conclusions about the data (Silverman, 2001). The constant comparative method involves a simple inspection and comparison of all the data fragments that arise in a single case (Glaser and Strauss, 1967). Each interview transcript was inspected for categories, and provisional hypotheses were formulated which were then compared and tested out by using these data categories in the analysis of subsequent transcripts. As pointed out by Silverman, this method involves a constant 'to and fro' between data segments and the interview transcript, so that eventually every part of the data collected from the interview is inspected and analysed in a 'comprehensive treatment' of the data (Silverman, 2001:236).

One way of improving confidence in the validity of the findings was to give special attention to negative or deviant cases that did not seem to fit with the working hypothesis at that time. If the comparative method is used systematically, deviant cases within the data are automatically identified, because discrepant data will come to the forefront of the researcher's attention. The emergent theory is modified or the working hypothesis is reformulated so that it can explain any incongruent findings. Originally formulated by Znaniecki (1963) and modified by others (Bloor, 1976; Strong, 1979), the method of analytic induction searches for and reviews negative/deviant cases which enable the researcher to refine theoretical statements by establishing their limits (Murphy et al, 1998).

In accordance with the approach of symbolic interactionism, understanding the data involved two main stages of inquiry; firstly 'exploration' followed by 'inspection' (Blumer, 1969:40). The exploration step involved getting familiar with the participant's world view of living with COPD, listening to their stories, observing them while they were telling these stories and forming descriptive accounts in order to 'develop and fill out as comprehensive and accurate a picture of the area under study as conditions allow' (Blumer, 1969:42). In other words it is necessary to understand the participants' sense of what was important to them (Charon, 2004). The second part of inquiry may be termed 'inspection', and involved further analysis by 'isolating important elements within the situation and describing the situation in relation to

those elements (Blumer, 1969). This involves forming descriptive statements about that element in a situation then applying that to other interactive situations (Charon, 2004). In this way significant concepts arising from examination of the transcripts were explored and further refined. Relationships between these concepts were also identified and given meaningful descriptions of their connections within their context.

Field notes and observations pertinent to each participant were examined and reflected upon as each corresponding interview transcript was explored. Each transcript was read line by line to identify and isolate specific phenomena or concept and these were coded by being written as a general heading on an index card. At this stage simple counting of specific phenomena seemed appropriate to get a general feel for the data. Importantly many sentences or paragraphs had multiple meanings or code categories. Each concept / category was isolated and written on an index card. As transcripts were examined it was noticed that many categories became quickly saturated, that is distinct patterns or trends existed in the data. The entries on each index card with a general category heading were then further scrutinized for links within the transcription data. The coded phenomena were re-examined, re-conceptualised and narrowed down (Silverman, 2000) to elicit further categories and links within the context from which they were derived to establish their relationships and the emerging temporal location of these concepts within the illness trajectory of living with COPD.

These methods together with the using of simple tabulations where appropriate were applied in order to avoid the criticism of having used anecdotal and unrepresentative data extracts (Silverman, 2001; Seale and Silverman, 1997). Overall, the researcher tried to follow Coffey and Atkinson's (1996) suggestion and engage in 'cautious analysis' based on the data. When in doubt the researcher tended to focus on the side of description as recommended by Wolcott, (1990).

**Appendix 4:** Example of coding of transcribed interview extract and a category card.

#### **3.15.10. Data analysis using a computer package**

Despite the claimed benefits of using computer-assisted analysis of qualitative data (CAQDAS) software packages such as NUD.IST, ETHNOGRAPH or ATLAS to

assist in the analysis of qualitative data (Tesch, 1991; Fielding and Lee, 1991; Kelle, 1995; Seale, 1998), none were employed in this study. The researcher took the view that use of such a programme might automate and speed up aspects of the traditional process of analysis but not change that process in any significant way. Due to the researcher's minimal level of computer competence and the shortage of time to learn how to use a software package, the researcher used traditional index cards for coding themes.

#### **3.15.11. Credibility of data: issues of validity, reliability and relevance**

The credibility of the study's findings cannot be assessed using the traditional criteria employed in quantitative research, but nevertheless need to be seen as rigorous and systematic if the study is to be of value. The standard criteria of validity, reliability and relevance are often discussed in relation to qualitative as well as quantitative research, but their applicability to the qualitative domain is controversial (Silverman, 1998; 2000, 2001; Seale and Silverman, 1997; Sandelowski, 1993; Riessman, 1993; Mishler, 1990; Kirk and Miller, 1986; Mays and Pope, 2000).

For many qualitative researchers, the problem of validity and reliability that research in this tradition is not setting out a singular truth that can be verified, but rather is putting forward one or more 'truths' as perceived and reconstructed by the narrator and reinterpreted by the listener or researcher (Riessman, 1993). Hammersley and Atkinson, (1995) suggest that a respondent's account is not simply a representation of the world but is a part of the world it describes, and is thus shaped by the contexts in which the account occurs. Narrative accounts are therefore context bound and socially constructed. Not only cannot such accounts be verified through member validation or triangulation but also these strategies would weaken claims to validity for a study using them (Bloor, 1983; Sandelowski, 1993; Silverman, 2001). The problem of taking the research back to the participants for verification is that this will typically produce another series of accounts produced in a different context and perhaps influenced by different emotions and biographical circumstances than the earlier ones (Bloor, 1983; Bryman, 1988). Hence participants were informed that no follow-up interview was necessary.

Triangulation, in the sense of data from multiple methods also offers no easy solution because different types of findings are often difficult to weigh against each other, and because demonstration of the factual inaccuracy of part of a respondent's account would not necessarily invalidate the subjective perspective being communicated in an interview. Particularly where a narrative research approach is being utilised, use of other methods will often add little to the first person account, which cannot be replicated by quantitative measurements (Hammersley and Atkinson, 1983).

Sandelowski (1993) expanding on Mishler's (1990) discussion of what constitutes validity in interpretist research argues that no general rules or standard procedures can be provided for the appraisal of validity. Stating that 'validation is less of a technical problem than a deeply theoretical one', Sandelowski (1993:2) suggests that trustworthiness rather than truth should be the goal in narrative research (see also: Riessman, 1993; Mishler, 1990). Many agree that the issue of trustworthiness can be best addressed by making the research process visible through detailed documentation of the procedures used and the data obtained (Kirk and Miller, 1986; Mishler, 1990; Seale and Silverman, 1997).

In keeping with this ethos, the researcher kept a dated diary of research activities (for example field notes and memos), including progress and setbacks, a list of relevant books read with useful extracts, supervisor's comments, and personal insights and decisions. This can be seen as a kind of audit trail (Rodgers and Cowles, 1993; Cryer, 1996). Care was taken to differentiate between the raw data of interview transcripts and descriptive field notes, and the memos and forms of interpretation created by the researcher (Miles and Huberman, 1984). The use of a tape-recorder for interviewing had the benefit of creating a semi-permanent record of the respondents' own words to which the researcher could return to when needed (Silverman, 2000; May, 1999).

Hence reliability can be judged through the documenting of the procedural steps undertaken within this study to demonstrate evidence of a consistent methodological approach to the study (Silverman, 2000; Field and Morse, 1996).

### **3.15.12. Claims about the data: representativeness, generalisability and relevance**

Assessing quality in qualitative research depends upon research validity and relevance (Mays and Pope, 2000). Relevant research is considered to be that which increases confidence in existing knowledge or adds to that knowledge, together with the extent to which it can be generalised beyond the setting in which it was generated (Mays and Pope, 2000; Mason, 1996). The author makes no claims to the representativeness of the present study beyond this group of sufferers, though it is hoped that future studies may shed light on whether similar findings apply elsewhere. Although random sampling was not used, efforts were made to ensure a degree of representativeness of study subjects of the local population of sufferers by using a theoretical sampling strategy, whereby the sample was selected according to pre-determined criteria (Glaser and Strauss, 1967; Seale and Silverman, 1997). Williams (1984: 176) points out that such research findings are not representative in a statistical sense but suggests that they help us to reach theoretical understandings of the experience of sufferers (Williams, 1984:176). The path towards assessing the generalisability of such theoretical findings is to do similar studies in other locations (replication) rather than to try to get complete population coverage. Detailed documentation of research procedure helps to assess the comparability of later studies and enables independent judgement upon whether the findings may apply in similar settings (Mays and Pope, 2000). If theories about the experience of sufferers hold across a number of studies confidence in those findings will increase. The individualised nature of a series of case studies does not mean they lack practical value. Qualitative research focusing on personal issues can and should be relevant to public concern, and contribute towards public understandings of these issues (Hammersley, 1990; Denzin, 2001; Dingwall, 1992).

The above carries an echo of C Wright Mill's (1959) classic distinction between private troubles and public issues, that has always had a resonance in symbolic interactionist writing, and should alert us to the pragmatic, reformist side of the interactionist tradition (Blumer, 1969; Charon, 2004). This study inspired by that perspective aims to add to the sociological knowledge and understanding of living with COPD. Within the symbolic interactionist approach, this study aims to provide insights into individual participants' perceptions of social reality by means of analysis



of detailed descriptive narrative accounts (Strauss and Corbin, 1990; Denzin, 1989). By exploring issues or concepts meaningful to COPD sufferers, the study aims to generate micro to mid-level theory of the illness trajectory of living with COPD. Based on the findings and wider social-health implications of the study, the researcher will go on to propose recommendations for patient care and further research.

## **4.0. Chapter 4: Living with COPD: The early days**

### **4.1. Introduction**

This chapter sets out to explore individuals' experiences of living with COPD during the early days of the illness, which raises several areas of significance related to the initial onset of COPD.

Firstly the chapter explores how individuals first come to realize that they have COPD; a progressively degenerative respiratory illness. Symptoms include increasing tiredness, irritant cough, phlegm production, wheezy chest and breathlessness. Due to the characteristic slow insidious onset of this disease, the individual is usually unaware of, or dismisses, early mild symptoms developing over several years until only then they become sufficiently problematic to seek out medical attention. Eventually individuals experience their first acute exacerbation of symptoms, which is characteristic of the illness COPD and often results emergency hospital admission for symptom control of the dyspnoea or difficulty in breathing.

Secondly, this chapter explores the issues around medical diagnosis and illness identification, following patient contact with the healthcare system and finds that explanations given to patients were often found to be ambiguous and not communicated clearly to the patient. Health professionals have traditionally used different criteria and medical terms to identify and categorise the subtly different conditions, which are encompassed under the umbrella term COPD. Professional ambiguity in terms of illness identification during this earlier stage of the disease was found to add to the confusion and uncertainty related to the illness experience of individuals with COPD.

Thirdly, an acute exacerbation of symptoms causing a life-crisis event is often perceived as the start of the illness and from that time on launches the patient into feelings of uncertainty, anxiety and questioning. The biographical disruptions experienced and impacting upon their lives, instigate a reassessment of self and identity as a consequence of knowing they have a chronic illness (Bury, 1982; Charmaz, 1995). Previously taken-for-granted assumptions about oneself are questioned in the light of knowing they have an illness.

Finally, the individual begins to question possible root causes for the illness and constructs lay explanations. The chapter explores the participants' health beliefs, attitudes and behaviours in relation to smoking and their perceived cause of their illness.

This chapter explores the early years of COPD, whereby the gradual progressive breathlessness is eventually interrupted by short crisis episodes of dyspnoea, from which recovery occurs but the individual experiences a slow but steady overall decline in health.

No previous studies were found which explored, in depth the subjective and holistic experience of participants' perceptions on first becoming aware of having the irreversible chronic condition of COPD.

#### **4.2. Biographical Interruptions and Disruption: Growing awareness of the bodily symptoms of breathlessness, cough, wheeze and phlegm**

Most individuals with COPD develop a dismissive stance or tolerance, over some years, towards the slow but gradual increase in symptom severity. As the disease progresses, the patient eventually comes to recognise his/her deteriorating state of health and impaired body functioning. The predominating symptoms of COPD are cough, sputum production, wheeze, breathlessness and/or dyspnoea (GOLD Executive Committee, 2006). However, a chronic cough often referred to by participants as their 'smokers cough' and the sputum production as 'that thick muck', often precede the more limiting and anxiety-inducing breathlessness characteristic of the later stages of the illness. The formal stages of the disease (GOLD Executive Committee, 2006) are discussed in the introduction.

Therefore, due to the slow progression of COPD pathophysiology, encroaching insidiously over many years, most individuals do not become aware of having a chronic condition until the disease is fairly advanced and lung function becomes noticeably impaired (Engstrom et al, 2001). At this time the characteristic symptoms of breathlessness, cough, phlegm and wheeze start to become more noticeable and encroach upon the basic activities of daily living. As one participant noted:

“(It develops) beyond a mild inconvenience” (P42/19).

### **4.3. The Insidious Onset**

#### **4.3.1. Always chesty as a child**

Some participants claimed that they had been ‘chesty’ since childhood, since when they had a predisposition towards chest problems. For these individuals, the experience of being short of breath (SOB) was commonplace and childhood asthma had developed into adult chronic asthma or COPD over the years. Typical comments included:

“I’ve always been since I was a child, coughing a lot of horrible old stuff up, you know – always coughing, coughing- cough and the horrible old stuff” (P11/402-3).

“ And having been born with a chest so they tell me, I was born with pneumonia and pleurisy- I’ve always had chest problems.” (P17/200-2).

“ Well I’ve had a bad chest – I’ve been asthmatic then since I was born, well since I was 7 years old anyway. So I missed a lot of school and I had to have the doctor out to me to get it better and it started then.”(P48/5-8).

#### **4.3.2. Been chesty for years**

Others stated that the problem started rather later, but still some time in the past. One man described how he had lived with frequent ‘chestiness’ since his time in the armed forces:

“When I was 18, I went into the RAF to do national service and I had my first chest problems when we were made to stand on the barracks square after a 3mile run. I picked up flu which turned out to be bronchitis... and that was my first – if you like indication of bronchitis and ever since, there was a weakness because whenever I had a cold it transferred straight into bronchitis... (P34/4-11).

Similarly, many participants declared having been chesty for years with a tendency for a common cold or flu like symptoms to develop into the characteristic reoccurring chesty symptoms of wheezing, phlegm and breathlessness. For many individuals being chesty was considered normal and was frequently ignored, played down or tolerated in the early years. As one man responded to the question of how did it start? He commented:

“I don’t know- no idea- it was just there” (P1/54-5).

A female participant noted:

“ I didn’t have any problems except I used to get bronchitis every winter.... wheezing and SOB ... I manage but it’s getting more difficult” (P4/25-7).

One man pondered:

“ When it started... I think it’s very difficult to determine. As I became older I became progressively more breathless- making anything like bending, stooping more difficult” (P28/4-8).

Another male participant recalled the mild symptoms he experienced during his years of employment, he commented:

“Well I’ve had it a long time, a number of years- approx 30 years. I found that I got a bit breathless doing things. I would be a bit more breathless than somebody else who was working with one would be. I mean it was minor really, it didn’t stop me doing anything but it gradually got a bit worse and really didn’t show itself until 3 to 4 years ago, not really bad”. (P49/4-13).

#### **4.3.3. Tolerating or ignoring mild symptoms**

Mild to moderate breathlessness tended to be largely ignored or tolerated as being inevitable, until progressively severe symptoms became a cause for concern and medical help is sought. The following interview extract provides an example:

“ Well as I said I was born with a chest, well I never had much to do with the lungs like but 12 years ago... I was sitting here one night and I had a bad chest- it had been coming on for a while, you could feel it and all of a sudden it went altogether, I couldn’t breathe - so they sent me to hospital...(P5/16-21).

Another woman noted:

“ It must have been 15years ago or more – the breathlessness just started you know, well I coped pretty well really...I sat down – if I became SOB. I sat down and waited for it to pass but eventually of course I had to go and see the Doctor” (P22/19, 37-8).

“Yes I mean I get the breathlessness and I use my nebuliser and [then] I’m fine but I’ve had two very bad attacks where the family have sent for the doctor but apart from that I cope very well” (P22/43-5).

Consequently, living with breathlessness was a familiar feature of their daily lives and only warranted medical intervention if the symptoms exacerbated sufficiently to become a cause for concern or alarm. An exacerbation of symptoms is characteristic of COPD and has been defined as: ‘a sustained worsening of the patient’s condition, from the stable state and beyond day to day variations, that is acute in onset and necessitates a change in regular medication in a patient with underlying COPD,’ (Rodriguez- Roisin, 2000).

Other studies have suggested that patients with COPD become accustomed to living with symptoms that tend to fluctuate and thus tend to under-report exacerbations to doctors until symptoms affect quality of life and become a cause of increased concern, anxiety or alarm (Seemungal et al, 1998; Okubadejo et al, 1997; Kessler et al, 2006).

#### **4.3.4. Part of the aging process**

For some participants becoming increasingly short of breath over the years was often considered a natural consequence of the aging process and therefore often ignored. One participant describing her chest symptoms said:

“It only came on after the years – it’s gradually come on and I suppose as you get older it gets worse (but) I seem to get this tightness more often”(P13/37-8).

A male participant commented:

“When it started I think it’s very difficult to determine, as I became older I became progressively more breathless making anything like bending, stooping more difficult. But this shortness of breath has crept up on me with age”(P28/4-6,41).

#### **4.4. Playing down the impact of symptoms on daily living**

Reduced walking distances, difficulty in managing stairs and needing to take one’s time to wash and dress were the most frequently noted affected activities of daily living. These ‘normal’ activities were the first to be noticed by participants as being affected by their increasing shortness of breath. Consequently, participants become aware of the need to take ‘planned actions’ to minimise their breathlessness and to employ exertion-saving strategies to manage the continuation of their daily activities. Generally participants strived to play down the symptoms and their impact on daily living to maintain a sense of normality. As one man commented:

“I go down to the doctor now and again but it hasn’t been bad enough to complain if you get me. You do what you can do... it depends on the day- it varies. You just take it easy or sometimes if it’s a day like today (mild) it suits me lovely and I keeps going so I won’t have much time to think about it. I ... it’s no good stopping and thinking about it” (P44/85-90).

However, since participants’ were unaware that early symptoms were attributed to a specific disease condition, many continued with their normal routines and activities, playing down the discomfort, managing the symptoms and adapting to the inconveniences. They often tried to mask symptoms and conform to social niceties in an attempt to maintain an appearance of normality. Some participants described how they were reluctant to see the doctor until symptoms became more pronounced. One man had noticed his health deteriorating and said:

“Well I couldn’t walk very far- I was getting out of breath (when first approached the GP) I couldn’t walk ahead without having to stop and get air in there then and that affected me for years ...”(P9/8-18).

Several respondents were reluctant to seek help until they felt it was justified, putting off going to the doctor in the hope that symptoms would resolve or resorting to over the counter remedies, before finally seeing a doctor. One woman delayed contacting her GP until she was convinced by her family it was the right thing to do. Feeling that her symptoms were not of significance, and unsure of how entitled she was to take up the doctor’s time or the response she would receive, she said:

“...If I get a bit of a cold it goes to my chest ... get breathless in between colds but I’m one of those who won’t go you see. I’ve got two sons and they tell me I should go to the doctor...before it gets you know.. But I think it’ll be better tomorrow - and I put it off and I always thought they’d think I was making a fuss over nothing generally.” (P13/34, 41-4).

However, despite experiencing substantial breathlessness, knowing that she had chronic asthma and having been prescribed steroids for years to control the symptoms, another woman claimed:

“I can’t say it’s changed my life in any ways, you know. I was running around doing this and that but I’ve always had to carry my inhaler with me. And I used to take steroids in the morning and then I wouldn’t stop all day and night sometimes. If I would feel short of breath, then I would take the Ventolin®” (P48/97-100).

However, further into the same interview she admitted:

“ If I was going out then somebody stopped to speak to me, I had to err I just wanted to sit down somewhere, it started then and working – on call, it caught me then ‘cos I was on my feet and I couldn’t stand and talk, so my chest would start off. But I can’t say it has stopped me doing anything anyway- not at all” (P48/180-3).

As for many of the study’s participants, the above woman was adamant that the shortness of breath did not affect her lifestyle and was reluctant to admit to being ill or disabled despite the limitations imposed by the difficulty in breathing. She was too busy to be ill. Participants frequently depicted themselves as being well and able to carry on managing an ordinary lifestyle despite the discomfort and inconvenience of the growing symptoms.

#### **4.5. Respiratory symptoms masked by more obvious illness symptoms**

Often, in the early days the symptoms of COPD; the phlegm, cough and increasing breathlessness on physical exertion are masked or over shadowed by more obvious symptoms of, or concerns about, an existing co-morbidity condition. Consequently, scant attention is given to the manageable breathlessness in the presence of more obvious debilitating symptoms. One participant told the following story of how her condition of emphysema was identified incidentally:

“Well about 8 years ago, I was diagnosed at hospital with arthritis and I went to see Dr. S. at Morriston and he – while checking me over diagnosed me with emphysema. I had suffered with my chest for years but no-one had ever said ...it really bothered me about 2 years ago when it started getting worse – before that I coped quite well- it didn’t really bother me and well of course your independence goes then.... I’ve always suffered from my chest- even as a child but they never made anything of it ” (P3/37-42,77-8).

Increasing shortness of breath due to poorly reversible airflow limitation is also associated with bronchiectasis, tuberculosis (TB) or asthma, conditions that frequently co-exist with COPD (GOLD Executive Committee, 2006). A few of the study participants were aware of previous diagnoses of TB or asthma but were not always informed of having COPD, until much later in the illness trajectory following a time of uncontrolled symptoms and medical interventions. One elderly man with severely advanced COPD said:



“About 5 or 6 years – perhaps a bit longer (been SOB) well I couldn’t walk very far- I was getting out of breath you see and I mentioned it to them and they think I’d got asthma but then he said it isn’t asthma he said it’s your heart – so- and then I had an x-ray and it confirmed that I had emphysema. I knew my chest used to get tight – I couldn’t walk ahead without having to stop and get air in... and that affected me for years, I just couldn’t get enough air in the lungs”(P9/6-18).

For others suffering from an existing co-morbidity, the symptoms of breathlessness are not easily ascribed to the respiratory illness, or compounded by another illness condition, only become noticeable at some significant point in time. One woman noted:

“ I never suffered with my chest see before I had a stroke, never, but I had bronchitis you know at intervals through the years but not – but I haven’t suffered with my chest as I have this time but I couldn’t breathe... since I had the stroke yes it has got worse – well I can’t walk very far with the breathing then...” (P15/8-26).

Another male participant was conscious of his heart problem contributing to the breathlessness, which in turn was compounded by the cycle of being overweight and not exercising. He noted:

“ I developed arrhythmias and with the arrhythmias came lack of exercise and came putting on too much weight altogether. I used to weigh 85kg and now I weigh err call it 100kg- now then I feel I find that I get breathless for two well three reasons really- the arrhythmia, emphysema and gross overweight- a mixture of these things and for example if I bend down when I straighten up I’m ‘puffy’ (P41/40-4).

The presence of another disease, particularly an acute illness, frequently takes treatment priority over a stable chronic condition such as COPD. This is illustrated by the following example of a participant who recalls how, following investigations, he was told he had:

“Emphysema, prostate cancer and anaemia all in one go, after which I went into hospital to sort out the prostate cancer and the anaemia” (P28/33-34).

Later he was discharged home, but with only a vague understanding of his emphysema and scanty instructions on how to use a nebuliser machine for therapy to relieve his breathless symptoms.

The condition COPD often co-exists with asthma, both of which exhibit similar clinical symptoms and are treated with similar pharmacological treatments (GOLD Executive Committee, 2006). However, asthma responds to medication by reverting back to a normal breathing pattern unlike for COPD. However as asthma and COPD are often con-comitant, then partial reversibility of airflow limitation is obtained following broncho-dilatory medication. Therefore breathless symptoms are controlled more readily in some patients as compared to others, demonstrated by one participant who now on prescribed medication, played down her manageable symptoms, commented:

“Of course when I was smoking my situation was a lot worse than it is now I’ve stopped. Oh I could hardly walk at all and I would get – walking up the slope up the pathway and I would get a panic attack because the breath wouldn’t come... and well it was pretty grim. And I gave up smoking... and now I lead a fairly normal life – apart from the breathing problems” (P36/14-23).

#### **4.6. Fluctuations of symptoms**

Fluctuations of symptoms, particularly during the earlier stages of the illness often masked the steady progression of the deteriorating condition until the symptoms could no longer be ignored or dismissed as insignificant. One woman described how the condition caught up with her:

“ When it started – err it came on very slow at first. I don’t know if you play bowls but when you’re walking across the green and all of a sudden – phew-you feel (SOB) and so you can’t get your breath. Doctor would know better than me ’cos when I started going to him um it’s a few years ago. I had my little car and didn’t do a lot of walking about so probably I wouldn’t have noticed it see if it was coming on but I can’t say I did but I found steps a trouble you know. Some days I think it’s getting worse and other days it varies”(P33/7-11, 18-20, 156).

One housebound participant on long-term oxygen therapy recalled:

“I wasn’t unduly worried at first you know, you put it down to cigarettes and working in that environment (smoky pub). I used to get colds like everybody else and once I was over the cold I’d be back to normal” (P51/21-3).

Fluctuating symptoms in terms of occurrence and degree of severity would occur unpredictably during the course of the day or on some days and not others. Circadian variation in symptoms was frequently identified as being more severe and limiting

towards the end of each day while daily variations were more frequently random and inexplicable. One retired male participant noted that the onset of breathlessness attacks was not always triggered by the activities predicted to cause breathlessness, but could be set off by unexpected causes, he commented:

“It’s not a straight line thing, in the sense that I can have good days and bad days but steps are a problem - yes it makes life difficult- movement will certainly trigger it ... Why? - I haven’t been able to identify” (P42/21-5, 29).

Another participant who had to take early retirement due to the illness, described her life:

“ It varies from day to day – some days you feel better than others, some days you can take your time and get things done - cleaning the house for instance- some of these things are just too much. You just can’t Hoover or mop out the kitchen floor or...” (P3/44-4).

#### **4.7. Plunged into crisis due to sudden exacerbation of symptoms**

A COPD exacerbation involves a sudden increase in breathlessness, more than daily variations, due to increased airflow obstruction. The increases breathlessness is accompanied by dyspnoea, increased sputum volume, purulence, wheezing, cough and possible sore throat, fever or fluid retention which can develop into pneumonia (Rodriguez-Roisin, 2000; GOLD Executive Committee, 2006; European Respiratory Society, 1995; Siafakas et al, 1995; NCCC, 2004).

For some participants, the realisation that they had a specific chronic condition was first confirmed at the time of experiencing an acute exacerbation of COPD. During this period of time, sometimes only over a few hours, there was a dramatic worsening of the symptoms, leading to self-referral to the general practitioner or contact with the emergency health services for hospital admission. Most participants vividly recall the distressing events of this time of crisis. This time of crisis marked a significant milestone when the individual became consciously aware and acknowledged having a respiratory condition, regardless of whether or not a formal medical diagnosis was made at the time. Paradoxically, although not all patients were aware of their medical diagnosis of COPD, most participants were aware of having a chest infection or

pneumonia, which compounded their chronic chest problem and led to an emergency hospital admission. One participant who at the time assumed he had asthma, recalled:

“Well on one occasion, I think you must differentiate, I had a very bad time at night and really felt ill- more than with the bouts I generally get....got worse and worse and suddenly I thought I’d better get somebody ... so I rang 999.. And it was pneumonia “ (P18/232-54).

Another male participant said:

“In December ’99 I was hyperventilating- I was bad then, I had no idea what it was but it turned out to be pneumonia... hospital... I was desperate for something ‘cos I didn’t know anything about the oxygen then...” (P26/117-123).

Participants described how they put off calling out the doctor in the hope that the breathlessness and other symptoms would eventually subside, not wanting to be seen as making unwarranted demands for medical attention. However, COPD exacerbations usually worsen unless treated with antibiotics and anti-inflammatory medication (GOLD Executive Committee, 2006). Hence, participants described how the delaying of seeking medical help precipitated a worsening condition necessitating urgent action of emergency hospital admission. The majority of participants describing exacerbations used the term:

“ I just couldn’t breathe”.

For example one woman described the events leading up to a hospital admission:

“It must be two years now when I was really poorly... and I wouldn’t let K. out of the house at all and I was so scared... we went to Norfolk ...and we had to call out a doctor because I couldn’t breathe... I was in my daughter’s in Weymouth and I was getting ready for bed, and my daughter’s got a shower and toilet out the back and she’s got the bathroom upstairs- so with four people going to bed and they all wanting to use the – so I said I’ll go out the back and I couldn’t come back – could I? I came back eventually trembling and making myself worse because you’re in a panic then and then the ambulance came and ooh the relief to have the oxygen. (P16/109-131).

Another participant described how his illness suddenly took hold:

“ I would be a bit breathless - I mean it was minor really, it didn’t stop me doing anything. But gradually it got a bit worse and really didn’t show itself until three or four years ago, not really bad. But then I had a chest infection and fluid on the lungs and then another chest infection on the top of that which became pneumonia. Well that’s what they told me and err it happened one

morning- about 5am I couldn't breathe anyway I got over that after a few minutes and ...then I felt it coming again. It was really, really bad. I wouldn't want to experience this again ... I was really panicking... they (ambulance crew) were trying to put an oxygen mask on me but of course as far as I was concerned it was constricting my airway- so I was fighting them and in sheer panic, it was sheer panic. It's an experience I don't recommend to anyone. I couldn't get my breath at all. I was living from one breath to the next breath sort of thing and you had the feeling – well you didn't have time for feelings, you were just struggling to breathe- from one breath to the next breath that's the only way to describe it. And I was hyperventilating wasn't I? Well you see I got confused because I don't know when I'm hyperventilating and when I'm not. I think I did at some time –again it's this panic thing you see. You get over it but you never really get over it- that feeling will never leave me, I know that...and I'm shaking like a leaf now. I try usually not to think about it” (P49/8-30, 188-192).

One woman who lives alone recalled:

“Well when I'm very breathless then I am frightened. You're gasping, trying to breathe and it makes you numb and gormless. That makes me sometimes frightened – one time I had an asthma attack that was not much different. I was with my daughter and we had dinner – well I could hardly eat dinner and when it was time to go home – my son in law said I'll get the car to take you home, well I got in the car and I said don't drive yet 'cos I was gasping. I just couldn't breathe, I thought the Lord was coming in on me and I was turning blue they said afterwards. Well instead of taking me home they drove me straight to the hospital and they gave me oxygen.”(P31/157-164).

At this point social inhibitions are forgotten and patients become desperate for treatment in order to ease the difficulty in breathing (Maslow, 1970). Playing down or dismissing the symptoms as insignificant is no longer an option as an exacerbation of symptoms raises feelings of urgency and alarm. Participants described how the difficulty in breathing or dyspnoea becomes the prime focus of the individual's attention and concern, where each inspired breath becomes a deliberate effort of energy-consuming hard work. As the breathing becomes increasingly more difficult with each breath, feelings of rising anxiety escalate into fear and panic. Hyperventilating or fast shallow breathing can cause hypoxaemia; a condition of reduced oxygen in the body, which can lead to mental confusion as illustrated in the above interview extracts (British Thoracic Society, 1997; American Thoracic Society, 1995).

#### **4.8. Medical diagnosis and patient understandings of the term COPD**

Sixty nine percent of participants interviewed were aware that their symptoms of SOB, phlegm, cough, wheeze and deterioration in general condition was attributed to having a respiratory condition medically diagnosed as emphysema, bronchial asthma or chronic bronchitis. Only a few of these participants recognised the term COPD and the majority did not recognise or realise that COPD was an umbrella term for each of these respiratory conditions. For example one man starts off to describe his condition:

“ I’ve got this thing COPD as they call it - what I thought was emphysema”  
(P50/6),

And another participant when asked what the doctors had diagnosed said:

“ Err emphysema I think, it was on the thing (discharge letter) from the hospital anyway...I can’t understand it anyway... err it says COAD”  
(P23/316-24).

Of those who were aware of the diagnostic terms used to describe their condition, most participants had little understanding of its pathophysiology, and had not realised that the illness would deteriorate progressively over the years. At the time of medical diagnosis, the slight breathlessness (particularly on exertion) was considered normal and therefore was largely accepted without realising the illness would gain momentum in symptom severity over time.

Other participants had lived with the knowledge of having emphysema/chronic bronchitis for years and therefore had not considered it significant, until the symptoms worsened and began to negatively impact on their lifestyle, or necessitated urgent medical attention. A participant recalls when he was first diagnosed:

“Oh 1993- that’s when I went for an X-ray and they confirmed that it was chronic bronchitis... but in those far off years I was able to do the garden, stop and start, I was able to walk and get around and go down and get shopping- by stop and start you know. I can’t do nothing like I used to be able to do you know. I used to drive ...I could go into town or do the garden. This year is the first year I haven’t had a go (in the garden)....” (P26/80-91).

The following report of a conversation between a participant (a retired accountant) and his wife portrays a lack of lay familiarity with medical terms, even within the same family. He said:

“ I don’t think anyone has ever given the technicalities of the condition. I have a vague idea what it is, from the doctor but we; I haven’t chased the doctors for a full explanation. In fact we’ve had precious little information, no one has expanded about it. Before I hadn’t even heard about emphysema”(P28/125-8)

At this point his wife interjected:

“Yes, we had- because your brother had emphysema and we knew about it then”. The husband replied: “Yes I knew he was breathless but I didn’t know it was called emphysema” (C/P28/ 129-130).

The above situation reflects the continuing low public knowledge of COPD as a widespread respiratory condition as noted in earlier studies (Williams, 1989, Williams and Bury, 1989).

#### **4.9. Patient uncertain of COPD diagnosis**

Many patients had been originally diagnosed as asthmatic, years ago, at an earlier stage of the illness, and were unaware that the symptoms they were now experiencing were due to the development of the illness COPD. These participants had assumed that they still had ‘straight forward asthma’. As one woman’s response suggests:

“It was just like a thick chest you know and I went to the doctor and he told me it was bronchial asthma- so that was a straightforward illness and I was on inhalers....”(P6/22-4).

It has been suggested that asthma; a well-known and treatable condition, particularly associated with younger age groups, has more favourable associations than that associated with the diagnosis of chronic bronchitis or emphysema, which conjures up images of old wheezy men coughing up and spitting phlegm (Williams and Bury, 1989). These patients presumed that they had asthma, as this was the term used at their first medical encounter years ago, and had not been informed of the subsequent revised clinical diagnosis of their condition. The following interview extract was taken from a participant who was a regular hospital inpatient due to severe COPD exacerbations, which were becoming increasingly more frequent and disabling and was totally unaware of his COPD diagnosis:

R: “ Well they called it asthma but err... that was about 5 years ago. When they were calling it asthma when I first went to him first and then they didn’t think it was asthma -it was dust and so fair enough but –

I- “And they haven’t called it anything else?”

R- “no, nothing” (P11/348-351).

For several others who assumed that their symptoms over the years had been attributed to asthma the diagnosis of COPD or emphysema came to light incidentally.

For example one man remembers:

“It was only – well it was the practice nurse it was, I think in the last couple of years she just sort of said to me one day here- that it was emphysema like – well we thought it was asthma like, you see well years ago you didn’t go to the doctor ...” (P5/388-399).

Other participants indicated that they didn’t like to ‘bother’ the doctor other than for urgent medical attention and consequently had not taken up the doctor’s time to discuss or ask for explanations of their illness. As a result some of these participants were unaware of having COPD and assumed their symptoms were attributed to having the more well known condition of asthma. One woman explained:

“ I didn’t know at first, I was short of breath and I went to the doctor’s and I thought it was just asthma – and they were treating me for asthma. And then it started to get worse and then they put me on the Ventolin® pump and then I started losing all the weight- lost a lot of weight- did tests with me...different tests... and then back the following week and then he said I had emphysema” (P24/5-13).

Another participant described how he felt that he had been misguided in his understanding of his respiratory condition, learning that he had emphysema not asthma as originally understood:

“ Well when I first had chest problems about 15 years ago they said it was bronchial asthma and over the years I’ve had different ‘medicants’ and I find no ‘medicants’ are helping although they have altered the types... so anyhow well this one time I said I’ve got this bronchial asthma business err... ‘You haven’t got that he said, you’ve got emphysema’ – just like that! That must have been about 10 years ago I suppose about 5 or 6 years after I’d been going up there. He told me in the beginning that I had bronchial asthma and then you know only by talking by chance... and that’s what I’d been telling everyone I had, so you know- but the last 8-9 years it’s been emphysema like” (P18/165-199).



#### **4.10. Professional inconsistency in diagnosis**

Historically, COPD has generally been considered to be of limited professional interest and to have a low medical priority. Variable clinical symptoms of COPD have caused difficulties in standardising a medical diagnosis and staging identification of the disease. This, has in part been due to: (a) COPD symptoms being not overtly obvious until the disease is moderately advanced, so allowing COPD in the earlier stages to remain undiagnosed (Soriano et al, 2000); (b) functional performance or health related quality of life of individuals with COPD only weakly predictive of disease severity (Leidy, 1995; Leidy and Haase, 1996; Engstrom et al, 1996) and (c) the frequent existence of con-commitant pathological conditions such as asthma, which display similar clinical symptoms (GOLD Executive Committee, 2006). Consequently over the years, inconsistencies in medical detection, classification and differential diagnosis have resulted in frequent mis- or under-diagnosis and subsequent under treatment of COPD (van Schayck et al, 2002, Siafakas et al, 1995; Rennard et al, 2002). Prior to the implementation of the new General Medical Service contract for COPD (BMA, 2004), the identification of this respiratory condition was based upon patient history, clinical signs and symptoms, ad hoc, without the confirmation of spirometry and given a variety of terminology.

This general uncertainty and low public awareness of the disease COPD, together with the historical lack of professional interest has led to uncertainties and vagueness about the condition of COPD (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001). Consequently, the under diagnosis and treatment of this chronic condition, has contributed to COPD being a socially ill-defined disease.

#### **4.11. Uncertain illness identity**

The participants of this study were not subjected to a consistent methodological procedure to identify their illness, which is consistent with the above evidence. Many of the study's participants had not been given a name for their illness and in some cases it was referred to in their medical file by the generic term 'respiratory disease'. This situation reflects the inconsistencies in detection, identification and the ambiguity of diagnosis made by different physicians even in one small geographical

area. Consequently, the majority of participants of this study experienced multiple uncertainties about their health status and health-related quality of life in relation to the respiratory illness. These illness related uncertainties included: time of commencement, cause, predicted illness trajectory and its impact on future lifestyle and prognosis.

The interview narratives indicate that during the earlier stages of the disease, the participants were uncertain as to whether they should consider themselves ill or not, as they reflected upon their previously taken for granted health status and self-identity. Participants recognised that they had a health ‘trouble’; a chest complaint with unpredictable respiratory symptoms, but were unable to identify with COPD as an established ‘respectable’ disease with a recognised pathway, as it has only recently been partially socially established and categorised (Turner, 1992). Thus, during the early years, symptoms were frequently ignored, tolerated, or dismissed as a smoker’s cough, and were often unrecognised as being attributed to a specific respiratory disease; an illness associated with smoking.

The study revealed how participants continued to manage their lifestyle routines in order to maintain a sense of normality and perceived social identity despite encroaching symptoms causing personal discomfort and limitations in their daily lives. Illness identification was seen as a significant point in biographical time at which many participants started to take an active interest in their illness. At this time patients often sought out medical assistance to manage their health and/or in the attempt to avoid experiencing a repeated exacerbation or breathless attack.

#### **4.12. Patients’ responses to the diagnosis of COPD**

The study showed that medical diagnosis occurred at different stages along the illness trajectory, which meant symptoms varied in severity at the time of illness identification for each participant. Consequently, participants responded differently on receiving the diagnosis due to perceived limitations imposed by the illness and the severity of disease (Corbin and Strauss, 1987). Medical identification of COPD surprised some participants but confirmed suspicions for others. Being medically defined as having emphysema/COPD justified the increasing daily limitations experienced as a consequence of the increasing debilitating symptoms. Identification

of a specific condition and confirming that it was not cancer was considered a relief to some participants; whilst for others it confirmed fears and induced emotional feelings. Some participants admitted responsibility for causing their illness using the term 'self-inflicted' and revealing feelings of guilt, self-directed anger and frustration. As one man said when responding to the question of how he felt knowing he had COPD:

“ Pissed off! I know it's a self –inflicted injury but I'm still pissed off. And yes it has affected a lot of activities and I don't want to think about it – anything involving any heavy physical exertion now- now is getting extraordinary difficult so I don't even bother to think about it” (P42/101-4).

Another woman confessed to feeling guilty that she still smoked said:

“ Oh I wish I didn't smoke at all –I'm not at all proud of myself – I wish I'd never started ..... I'm trying to discourage him (grandson) 'cos he doesn't want to end up like me. Yes, I'm quite ashamed of myself for smoking” (P30/175-9).

However another respondent described the relief felt when she was diagnosed and prescribed an inhaler to ease the symptoms at that time. The physical relief of controlling symptoms mirrored her psychological relief at being able to carry on working. She said:

“ It was confirmed in 1981 that it was emphysema, they put me on an inhaler... they were surprised that I found a relief- obviously before that, I didn't know that I had it properly you know. And I was struggling but when I had that – it was great the relief, I found I could do a lot more than I had been doing previously but having said that over the years you learn to cope even though it gradually gets worse and worse to where I can't do much”(P7/5-10).

For some participants, increasing symptoms and a clear diagnosis imposed early retirement, despite taking regular medication. Participants' responses varied, for some who were advised to take early retirement, diagnosis was seen as a relief; an acknowledgement of the limitations imposed by a defined illness and a legitimate reason to stop working. One participant said:

“Well ... I was 63 and Dr. D. he said to me your chest is not all that clever... and he said how's it going and I said well I'm gasping a bit err SOB- well I wasn't too bad at the time but he said I think you should retire... it was retiring time, you know and so Dr. G. was my doctor and I said to her and she said quite right retire- you retire if you can and then I finished” (P38/4-10).

For others, giving up work was perceived as the only practical option, but one that entailed emotional upheaval and loss of lifestyle and self-identity. One woman described the emotional upheaval of having to give up work saying:

“Well my life has changed completely - I had a home, two children, I had my mother here, I had to look after her- there was never enough hours in the day and then after my Mum died, then all this sort of came on me and then it gradually got worse and worse and with the rheumatoid I couldn’t cope. It was unsafe then and I just had to finish work- and of course I loved my work” (P3/174-181).

Another participant forced to take early retirement due to his breathing problems recalled:

“Well it started- it must have been over 20 years ago- while I was still in work and it was not chronic but at the same time you knew that you were on the path with what was happening to me. So I carried on work and then in 1988- I was on sick for 18 months and I made a decision to retire because I knew I couldn’t carry out my work”(P18/5-11).

For these individuals, the identification of chronic bronchitis or emphysema was welcomed. It legitimised the release of the individual from employment, which due to the breathlessness and fatigue was becoming too demanding. Medical advice to take early retirement often restored a degree of dignity as some participants felt they were letting down work colleagues in not being able to fulfil duties. However, several participants, all male, described how they changed their ‘line of work’ to take up more sedentary work rather than retiring from working altogether. Reluctant to surrender to the label of being ill, they persevered in less physically demanding work: doing office work for a family business, working from home while spouse worked full time, taking up part-time consultancy work or undertaking local voluntary work (P17, P14, P21, P34, P42, P44, P50, P53).

#### **4.12.1. Diagnosis of COPD as a relief**

For some participants becoming aware of their medical diagnosis of COPD/emphysema/chronic asthma, was a sense of (false) relief, in that their illness was not a more feared condition such as cancer or heart disease. For example, one man said:

“Well years ago you didn’t go to the doctor- I think when it first came to light was when I was in the army and went for a medical and they didn’t tell you what was wrong like but they were keeping an eye – and then when I saw Dr. D. here one day and I said was it a bad heart? He said no, nothing like that, it was your lungs he said- there’s no elasticity in them - so that’s why you get a bit short winded then like you know”(P5/399-405).

The relief that the illness was not identified as heart disease, was evident in the above participant’s comment as he recalled a conversation he had at the hospital:

“Well I talked to the lady there and I said I’d been heavy smoking and they knew I had emphysema but was there anything else? And the answer was – well there was nothing else” (P41/30-7).

A male participant said:

“ Well I was determined (to give up smoking) because Dad had cancer see and err he was ill for a long time, poor old boy and he was working down the colliery like and I think he had a touch of the coal-dust”(P9/115-120).

#### **4.12.2.        Diagnosis of COPD: confirmation of having a medically defined condition**

For those participants who had seen a parent suffer and die from emphysema, the diagnosis of COPD confirmed their own suspicions that they had the same illness as they were experiencing similar symptoms and smoked like their parent had. However, these participants comforted themselves with the reassurance that modern medicine was more available and effective to control symptoms, than it had been a generation ago. Thus one woman said:

“Well I think watching my Dad with that, and then being told you’ve got it yourself. You think of all the things he couldn’t do and I just thought well - I shall want (this?) and I won’t want this... I know the medication has changed dramatically since he died. Well you know, I don’t suffer in that respect like he did- but you have your limitations” (P4/145-9).

Others realising that they were treading the same path as their parent, had given up smoking in an attempt to reduce the risk of ending up the same way. One female participant commented:

“Well I was a heavy smoker of course, that caused all the problems and my mother also had emphysema also through smoking and she had a massive heart attack and died suddenly - just like that- ‘cos of the breathing problems

you see. When I was smoking my situation was a lot worse than it is now” (P36/5-12).

#### **4.13. Health-beliefs and the perceived cause of illness**

The medical diagnosis of COPD marked a specific point in biographical time along the participants’ illness trajectory. Participants became aware of a changing self, due to growing symptoms becoming ‘more than a mild inconvenience’. The smoker’s morning cough and phlegm, breathlessness, wheeze and tiredness on exertion of simple routine daily activities start to become issues of needing to reconcile bodily comfort with practicality and social dignity. The symptoms were described as increasingly problematic; intrusive on well-being and becoming socially visible, so warranting both personal and professional attention. Consequently, during this time the majority of participants had reflected on their altering health status and were searching for reasons for the cause of their illness.

#### **4.14. Participants’ perceptions of the cause of COPD: the smoking issue**

This study highlighted a division between lay reasoning and scientific medical research findings on the causal link between smoking and COPD. Despite extensive government health promotion, media campaigns and advertising coverage over the last decade to promote smoking cessation, the use of widespread information and slogans such as ‘smoking kills’, ‘smoking is harmful to health’ based upon research evidence; only 19 of 53 study participants stated that they unreservedly believed that smoking was the most possible cause for their COPD illness. A further seventeen (n=17) participants considered smoking to be a contributory factor, but not the root cause of their COPD. However, all except five (n=5) of the study participants had by the time of interview finally given up smoking.

##### **4.14.1. Why start smoking?**

The most quoted reason (n=12) for men starting to smoke was due to free or cheap issue rations during their time in the forces. As one man said:

“Because we were encouraged to - now I’ve got a cutting in my wallet- here it is- you take 200 cartons + 11lb tin tobacco- 16oz- that’s a lot of tobacco. I don’t say I smoked it all but it was free. Well all the other kids were doing it and in

those days it was a common thing. And you see others doing it now.”(P26/147-158).

Fourteen women admitted to smoking because it was an enjoyable habit and the thing to be seen doing. As one woman pointed out:

“Well it was fashionable: when I started smoking you were the odd one out if you weren’t smoking”(P16/235-6).

A male participant said:

“ I started when I must have been fourteen or fifteen, it was the thing to do, the grown up thing, it was thought strange if you didn’t smoke” (P53/22-4).

Several men recalled that they had been encouraged to join a male family member or colleagues in having a smoke. Both male and female participants had started to smoke out ‘of curiosity’ and it had become a ‘habit’ (P9, P19, P36, P38, P45, P44, P7, P8, P15). Continuing to smoke despite repeated attempts to quit was attributed to being unable to break the habit, submitting to cravings or starting again during times of emotional stress as smoking provided a psychological comfort (P33, P42, P5, P46, P21).

#### **4.14.2. Reasons for quitting smoking**

A few participants told of their self-directed personal decision to quit smoking, as the sensible thing to do. These participants with self-directed motivation appeared to demonstrate having the least problems in giving up and staying off cigarettes. For example one woman said:

“ I haven’t smoked now for 3-4 years, I was on about 6-10 cigarettes a day but once this asthma started I thought right- that’s it! And I tried to stop my next door neighbour – she would come round and say have a cigarette but no- you can smell it on your clothes, in your hair and that- I’ve gone off it!” (P6/183-7).

One participant tells of how his increasing breathless and coughing was affecting his work and how he decided to quit smoking:

“I was in the mess room most of the time – there were two flights of stairs and by the time I got up there I would cough and blow something awful and all that nonsense and I thought something’s got to happen here. If I had messages to another part of the ship I used to send someone else - the lad to go down because I couldn’t get up or down those flights without starting off the bouts

of coughing, so I thought well- I didn't take my cigarettes to work. I thought that's it 'clean yourself up boy' and from then on I didn't bother – no trouble at all..." (P18/99-112).

However, while others acknowledged 'it's self-inflicted' they had nevertheless taken positive action to 'quit smoking while ahead' (P51, P16, P34). One woman reflected:

"I don't think I would be here today if I was still smoking- I was so frightened- yes I wish If I'd known what was in front of me I would have given up smoking donkey's years ago- I would never have started (P16/213,225-6).

#### **4.14.3. Professional advice to quit**

Many participants eventually ceased smoking due to receiving, often blunt, advice from a health professional. For many, this advice coincided with increased patient – doctor contact for the treatment of growing symptoms, and reinforced a patient desire to quit anyway, knowing that to give up smoking was commonsense. The following narrative typifies many participants' descriptions for giving up smoking, as one woman recalled:

"Well it started about 13 years ago – I went up to go and see my doctor because I had this cold on the chest again and she told me you must give up cigarettes and I wouldn't be able to walk and in a few years time you won't be here. So then I gave up them up and then a few years after I couldn't walk up to the village with it. It was not easy - I'd been smoking since I was 27 and I was 57, well I done it like you know, I was determined you know" (P31/5-9,13-15).

A male respondent described how after numerous hospital admissions and numerous occasions of being advised to give up smoking he finally quit:

"The last time I was in hospital there was a male nurse- I've got a high opinion of him- we'd discuss ailments and he told me about the lungs... and told me about smoking and the effect it's got on you... and I thought about his words for a long time and that time I was in there – I said I'm stopping smoking... I had an interest in medicine and what have you so putting one and one together- I think that's why I stopped smoking. After stopping smoking what I do find is that drugs respond far quicker than if you're a smoker. " (P21/99-127).

Several participants remembered blunt advice from doctors as the reason they stopped smoking, but this study is not able to differentiate between taking advice to quit smoking in order to reduce symptom severity or due to the patient feeling intimidated



by medical authoritarianism! (P4, P23, P28, P31, P44, P53). One participant quoted his hospital physician who said:

“Every cigarette is a nail in the coffin” (P53/38).

Some participants acknowledged smoking as the most likely cause of their COPD. However, the study group was diverse, displaying a range of attitudes about themselves and their previous and current inability to cease their smoking behaviour. Some described how they had ignored earlier symptoms, the smoker’s cough and early morning accumulation of phlegm. Over the years they then realised that they should attempt to give up smoking but had been repeatedly unsuccessful, until eventually they experienced an alarming and distressing breathless situation. As the illness trajectory runs its course, the increased severity of symptoms often jolted patients into re-evaluating the impact of their lifestyle upon their lives. The study revealed that the majority of participants eventually ceased smoking due to fears of increasing symptom severity and/or a fear of mortality. One woman recalled:

“I was a heavy smoker then I bout of pleurisy and then I had the bronchitis ... at the time it was worse than it had been so I said I better quit smoking then while I’m ahead then because I felt so poorly at the time.... I think I first realised I was in trouble was two years ago when I’d been on Ventolin® for about four years... ‘cos I was having all these chest infections... well you get to the point where you know that if you don’t give up smoking then you’re not going to be here any longer.” (P16/9-14,166-8).

Another participant describes how his craving for tobacco even drove him to smoke in the hospital toilet after being on continuous oxygen and between puffs of his inhaler! However, having decided to finally quit he recalls telling his daughter to take his tobacco home and said:

“I never looked back. It was never a problem, from only being able to go six hours without it ... well I think I realised that my number was coming up very fast and my breathing was so hard and I could physically tell when I went into hospital because I had to open up my lungs to be able to smoke and I realised that as soon as I had 2-3 puffs again I couldn’t breath and so I to take more puffs of the inhaler. And that suddenly makes you say it’s the cigarettes, it’s the tobacco doing it- never mind what people tell you. That’s meaningless- people can tell you all the time. But it was the very fact that the crunch had come and I realised that something had to be done. Fear is involved but I can say at the same time... it wasn’t until I realised then I wouldn’t survive if I didn’t stop. Something has to trigger you....” (P20/314-349).

Some participants, all of who were men, suggested that the increasing financial cost of cigarettes was a major contributory reason for giving up smoking (P1, P41, P34, P50, P28).

#### **4.14.4. Strategies employed to quit smoking**

A conscious decision 'not to smoke', from a particular point in time, was the most common, but not the only tactic identified to cease smoking. A female participant described how she reduced the number of cigarettes over time using them as a night-time treat. She said:

“What I did – for a month I had a cigarette last thing at night and I looked forward to that cigarette, and at the end of that month I just stopped ...and I was smoking since I was a teenager well I couldn't smoke now if I tried...” (P29/124-130).

For other participants hospitalisation was the trigger for giving up. Rules prohibiting smoking on the wards created a window of opportunity for quitting once and for all that some accepted. For example one woman said:

“I stopped when I went in with the stroke- I didn't think about it after- no habit, no craving- just as if I hadn't been a smoker... and I've never wanted to pick up a cigarette again “ (P15/72-4).

Others gave up not entirely through their own endeavours but largely owing to strong family support, one woman describes her craving:

“I find it hard- he (husband) wouldn't buy any and I wouldn't be able to go out... and I used to say go and buy some and he would say -no don't be daft! - I'd say just go up and buy me a packet just to calm me down and he'd say no I'm not going to buy you one. I couldn't go up see, I couldn't go out there, I was stuck here 'cos I could only just make it to the car- four steps down to the car” (P24/143-170).

One man knowing the damage smoking was doing tried cutting down the number smoked before actually quitting. He noted how the craving was easier to get over than the habit of smoking (P53/26-36). A few participants, aware of their inability to stop smoking, had resorted to alternative therapies. For example one woman said:

“I did try – I had hypnosis to give up and it worked for a few weeks and then it went off. I tried acupuncture but that didn't work at all- it hardly stopped me at all.” (P7/16-20).

Other participants had tried Zyban® with different results, for some it had made smoking cessation bearable as highlighted by the comments:

“Well with Zyban® it is possible- Zyban® is wonderful”(P42/45)

“It was hard to get off it but I had patches. I found it was the only way to get off it” (P50/44-5).

However, other participants had experienced a severe reaction to the drug. One woman who was a current smoker said|:

“I even tried acupuncture but that was no good. Then I tried the patches and well I was allergic to those and the lozenges I had- well I was so ill... I tried the patches and I had such a severe reaction it was as if I had been burnt on my arm” (P52/27-9,102).

Interestingly, of the participants who tried alternative smoking cessation therapies, three were current smokers, and two had experienced adverse reactions.

#### **4.14.5. Confusion over conflicting health messages for smoking cessation**

Contradictory medical advice and poor role-modelling behaviour by health professionals, particularly by doctors, further compounded the patients' confusion in identifying the cause for their COPD illness and its symptoms. Of the five current smokers in the study; the father of one was a GP who himself smoked, two participants highlighted how health professionals continue to smoke despite giving out smoking cessation advice to patients, and the remaining two considered it too late to give up smoking. This professional behaviour conflicts with the health messages of health promotion and causes ambiguity and uncertainty for patients being given the advice to give up smoking. One participant during her time in hospital noted:

“I was in the side ward, the first time and I was on the oxygen then, three times now I think I've been rushed in and they thought I wouldn't make it to tell the tale. But as the doctor said, you're a fighter. And I said yes, but honestly I had a bed by the window and I could see the doctors coming off duty and they all have fags in their mouths and they've lectured me but...you know. I did but it didn't make me feel (convinced). Well- if they can smoke, I'll smoke. But it amused me that to think that they've been lecturing me and then they were all lighting up cigarettes...” (P30/189-199).

The second participant also noted how she confronted her GP saying:

“Now Dr. L. I’ve seen him smoking and I said to him one day, Dr. L how can you preach one thing when here you are doing the same. And he admitted that he found it very difficult to give up and if he finds it hard then – you know!” (P52/35-8).

One man found himself still breathless and generally tired despite taking medical advice twelve months earlier to give up smoking. Not understanding his condition of COPD, he had unrealistic expectations to return to his previous health status. However, this had not happened, his condition was not improving despite having quit smoking and he was sinking fast into disillusionment. (P50).

#### **4.15. Perceived causes for COPD other than smoking**

Approximately 30% of the study’s participants described how they considered smoking over a period of time probably contributed to their ill health causing the symptoms of cough, phlegm production, wheeze and general unthriftiness, but remained reluctant to admit to smoking as being the root cause. For example, one man when asked if he considered a link between smoking and his emphysema replied:

“No I don’t think so because I had no symptoms for years when I was smoking” (P28/72).

Another participant who was housebound due to his illness said:

“I haven’t smoked for seven years – oh this chest well I realised it myself, well it wasn’t doing me any good and my son (non-smoker) said to me- you’re bloody smoking Dad and so I stopped. Well I can’t say that it’s helped me but I wouldn’t know – well it wouldn’t do me any harm in stopping”(P38/16-20).

The interviews revealed how participants often searched for meaningful explanations other than the smoking to explain why they had contracted this illness. One participant, an electrician and an ex-smoker, and his wife, in the course of the interview listed three different possible causes for his chronic asthma. The wife explained:

“Weren’t it pleurisy? When we first moved in here... and you thought perhaps that started it off” (C2/8,11).

Later on the participant suggested that the breathlessness and wheeze was allergy induced, and said:

“We thought it was the dog” (P2/85)

And then giving a third reason for the illness he said:

“They think what started it was- pulling a mate off a live cable at work- yeah the shock of that. And he’s back in work now- fully fit!”(P2/ 185-9)

His wife added that her husband did return to work, to which the participant noted:

“ Yeah. About three months afterwards - and they reckon that’s what the build up was- when I wasn’t supported” (P2/192-4).

The medical diagnosis of the above participant has since been confirmed as COPD.

Another participant considered the cause of his COPD to be:

“Fifty percent smoking and fifty percent from being in the building business, I think it’s a combination of things” (P53/12,20).

He described how he encountered asbestosis, chemicals and considerable amount of dust routinely in his job as a builder.

Participants cited varied and sometimes multi-causal reasons for the cause of COPD, including: a coal fire, which caused coughing (P12, P13), specific life-crisis events such as a ship-wreck (P44), or prolonged anaesthesia for a surgical operation (P46, P31). Of those participants who did not see smoking as the cause of COPD, approximately 20% considered their respiratory condition to be inherited. Another sizeable group attributed their COPD to previous occupational, industrial or farm pollutants including dusts, chemicals or fumes.

#### **4.15.1. COPD considered to be hereditary**

Some participants who had seen their parents living with a respiratory illness recognised the same symptoms in themselves. Despite paying lip service to smoking as the cause of COPD, many still felt that it was latent within them or was a familial disease, passed from one family member to another. For example, one woman stated:

“I didn’t have any problems except I used to get bronchitis every winter and then I got married in 1983, of course this was a second marriage and he died in the November of 1983 and we were only married a fortnight and he was told that he had malignant melanoma, and the shock of that brought it all out. But my father he died when he was 41 of asthma/ emphysema/ TB, so I think it was just sitting there waiting for something to happen. That’s what I always think.... Although they say it’s not hereditary, I don’t know.” (P4/4-10).

Another participant, a retired chemist, recalled:

“I think it’s in the family- hereditary- my father was in his eighties when he died but his breathing wasn’t clever...” P32/71-6).

A female respondent implied that asthma was not only in the family but was gender related. She noted that despite some of the male members of the family having smoked they were not diagnosed with COPD, unlike some of the female members who had COPD but did not smoke. She commented:

“Well all the girls and it’s a big family- twelve of us and seven girls have all got asthma- not the boys just the girls- yes and mum had asthma see”(P24/134-8).

#### **4.15.2. Occupational, industrial or farm pollutants considered as cause of COPD**

Other participants revealed how they had endured occupational hazards such as industrial or farm dusts, chemicals, paint, sprays or fumes during their time during the war years or in employment. One man who had been in the merchant navy described a typical scenario during his years aboard ship, he recalled:

“I remember up in Canada -they were loading raw asbestos fibre. We were taking it to Australia you know. And then grain on different ships and coal, things like that. It didn’t bother me then you know. So no, I didn’t take any notice of anything like that at the time.... So it could be – I don’t know. One time I fell into the grain” (P37/95-107).

Another participant who was a farmer who also cited grain as a probable cause of respiratory problems commented:

“Another thing that didn’t help me was the handling of moist grain ... I think handling the grain to feed to the cattle in winter was - had a detrimental effect on me yes... or another thing that might have started it off was when I was in the navy- you see you’d be – there’d be aircraft engines running and things like that and I used to do a lot of testing on aircraft, I suppose you’d be in the fumes or whatever. I used to try and get out but you’d be in it without realising sometimes” (P39/133-143).

One participant considered a particular event as the start of his illness. He recalled:

“I can remember we was home, we were strong then you see then at the time and a neighbour said- oh I’ve got some hay to sell so after milking that night I went right! Tractor and trailer to fetch a load of hay. Well the hay had all

mildew and nobody helped me to load it. So I thought oh I'm not going home without it. So that night when I went home I didn't want supper and that was the start of it- yes it could be, that is when I would say it started" (P11/392-400).

Other participants attributed their chest condition to passive smoking and having worked in smoky environments including social clubs, pubs, bar or work office.

One man remembered:

"We took over the Bell hotel in C. and my wife was running that, I'd serve in the bar and I don't think that done me any good with the smoke- 'cos I'd go out in the weekend (into the bar) and we used to have a television there in the bar and that would be yellow (from the smoke)" (P5/509-16).

Another female participant recalled:

"I had my own pub for a lot of years and everyone would be smoking and you'd go in and there'd be a blue screen of smoke so I'm sure it's related" (P52/52-6).

So despite public and professional acceptance that smoking is strongly linked with illnesses such as respiratory disease, lung cancer and heart disease, a significant proportion of the participants suggested alternative causative factors for their COPD.

#### **4.16. Chapter summary**

This chapter describes the circumstances in which individuals first come to realise that they have a respiratory condition and explores participants' responses to this knowledge.

Participants described noticing minor fluctuating symptoms but during this early stage they dismissed these symptoms as normal. Several reasons were expressed: the experience of mild symptoms for years, symptoms attributed to smokers cough, and or they assumed that the symptoms were part of the normal aging process and therefore were inevitable. In addition, many of the study's participants felt they were unjustified in taking up their general practitioner's time to discuss these mild symptoms, which were generally unproblematic. Hence the early symptoms are accommodated and incorporated into normal lifestyle as the individuals prevent their symptoms from intruding upon the normal routines of daily life.

Typically then, individuals presented themselves to their GP late into their illness when the symptoms had become established, moderately severe and starting to impact on daily living, prompting the individual to seek medical advice. Others vividly recall emergency admission for a sudden breathless attack or an 'acute exacerbation of symptoms'. It is at this time individuals realise that the breathlessness and other symptoms are disease related and start to reflect about the illness and its growing impact on daily life.

Despite receiving medical intervention for problematic symptoms some participants were unaware of having a specific disease and many did not recognise the term COPD. A medical diagnosis given by doctors was revealed as frequently being unclear, undefined, mis-diagnosed or simply lacking. Of those participants who were familiar with the term COPD or emphysema, not all were able to explain what it was and often assumed it to be a treatable condition. The terms asthma, bronchitis or emphysema were generally better-recognised terms and some participants were aware of existing co-morbidities. Participants highlighted the lack of COPD related information from both primary and secondary care medical staff, often gaining knowledge about their illness from nursing staff.

Finding out that their illness was COPD was received with varied responses including; relief that the breathlessness was not heart or cancer related, feeling the benefit of taking newly prescribed medication, feeling legitimised to take early retirement, and experiencing feelings of loss due to the implied consequences of the illness.

Illness identification raised questions as to the cause of their disease. Nearly all the participants offered meaningful reasons or causes for their illness, with only less than half of the participants freely acknowledging smoking tobacco as the root cause for their COPD. Although recognising the accepted evidence for the causal link between smoking and ill health, a sizable number of the participants did not accept the relationship in their particular case. Those participants who accepted smoking as the cause of their COPD, expressed feelings of remorse, embarrassment and guilt for not giving up smoking sooner. Many participants identified polluted air encountered in occupational environments during their years of employment as possible causes of the



illness. Other participants believed factors, such as hereditary transmission or experiencing a life-threatening crisis in the past, were responsible for having COPD.

This chapter reveals the general uncertainty surrounding the illness COPD as perceived by the participants. This uncertainty included a lack of information about diagnosis, ambiguity as to extent of illness severity and illness trajectory and a vagueness about how and when to access healthcare. Reflecting this uncertainty, diagnosis was received by most participants at this time along the illness trajectory without undue alarm or concern for the future.

The next chapter expands on how participants come to terms with the progressively deteriorating illness, which can no longer be ignored, and how participants physically manage the impact of the symptoms of daily living.

## **5.0. Chapter 5: Living with COPD: Adjusting to changes in self and lifestyle**

### **5.1. Introduction**

This chapter explores how individuals with COPD learn to adapt to the changes imposed by the illness on self and consequently upon the individual's lifestyle. The chapter explores several themes arising from the participant narratives as listed below.

Firstly, participants realise that the growing symptoms of COPD have started to limit or restrict ordinary activities of daily living. As the symptoms of COPD become increasingly intrusive and restrictive upon their ordinary daily functioning, individuals with COPD realise that previous strategies used to manage the disease and its symptoms to 'get by' are becoming less effective. As a consequence, individuals learn to manage the progressive symptoms by devising strategies to minimise the impact of the disease and to maintain a sense of social normality. Eventually normality, as previously known, breaks down and individuals realise that they are becoming a changed person, a person who is incongruent with previous self-identity.

Secondly, some individuals become more knowledgeable about their prescribed pharmacological therapy and begin to adapt regimes and doses in accordance with perceived benefits. Other participants are unable to use inhaler devices effectively or become confused with multiple medications and different sources of advice. Hence, issues are raised in relation to patient compliance with medical advice.

Thirdly, participants often demonstrate recognition of the factors, which compromise the management of their symptoms. As the illness becomes more intrusive upon daily life, participants frequently demonstrated carrying out active measures in the attempt to take control over their lives, such as seeking out information, altering medication and planning ahead to avoid undue breathlessness and exertion.

Finally, this chapter explores the relationships between individuals with COPD and their family members and healthcare professionals. Relationships are found to become particularly significant for individuals with COPD as the illness progresses and negatively impacts on daily life. Participants' perceived level of support and

understanding of the experience of living with COPD by family members and healthcare professionals is explored.

Previous studies both quantitative and descriptive, have found that functional status and health-related-quality-of-life of individuals with COPD is only loosely associated with disease severity and is largely attributed to non-clinical, psychological factors such as emotional well-being, personal outlook and self-esteem (Prigatano et al, 1984; Kinsman et al, 1993; Schrier et al, 1990; McSweeney et al, 1982; Guyatt et al, 1985,1987; Wijkstra et al, 1994; Ketelaars et al, 1996). The level of individual coping with COPD has been suggested as being influenced by the availability and mobilisation of psychosocial assets, which include individual, interpersonal, and socio-cultural resources (Czajkowski and McSweeney, 1996; Dudley, 1980).

This chapter explores individuals' subjective perceptions and experiences of adapting and adjusting to the changes in self and lifestyle brought about by their illness COPD.

## **5.2. Learning to recognise and manage the increasing symptoms of COPD**

On reflection, participants retrospectively realise that they were able to differentiate between the earlier stages of the disease and subsequent later eras. Participants compared former self in terms of physical well being and functioning with the present increasingly disabled self. This comparison of self was often highlighted by the growing severity of symptoms illustrating significant changes in their general physical well being and growing limitations impacting on their lifestyle. As a consequence many participants verbalised or implied that they increasingly experienced a reduced quality of life. The increased breathlessness was often attributed to the other inherent symptoms characteristic of COPD, the persistent cough and phlegm production. Participants frequently described how their unrelenting bouts of coughing, particularly early morning coughing often referred to as their smoker's cough, would result in loss of breath and gasping for air. A typical comment was:

“ I do have this smoker's cough every morning which until I clear my throat in the morning I feel pretty rough. I have to cough and cough until it's cleared you know” (P52/67-9).

The bouts of coughing were sometimes attributed to the sensation of an irritation in or a tightening up of the throat or more frequently was in response to phlegm production. Participants frequently described how in the attempt to dislodge thick phlegm or mucous from the back of the throat they would repeatedly cough until successful. Sometimes this plug of mucous would be difficult to move and would result in a choking sensation, resulting in a fear or panic of not being able to get one's breath. One man commented:

“Well if I start to cough, I've got- there's no air in there and I'm struggling to get air in the lungs.... and some days you've got a tight chest and I don't know if it's the phlegm or not but whatever you do it won't break... (P9/32,143-5).

Consequently a cycle of coughing (in the attempt to dislodge the tenacious phlegm from the back of the throat) would result in an episode of exaggerated and uncontrollable breathlessness, which in turn evoked feelings of anxiety, fear and social consciousness.

COPD slowly but gradually affects the entire body over time but symptoms fluctuate and influence the general level of well being of the individual at any point along the illness trajectory. Cyanosis (a common indicator of poor peripheral circulation in COPD due to low levels of blood oxygen) was often observed by the patient and the family. For example one woman commented:

“ Sometimes I feel worse than other times. My sister tells me that I go an awful colour ... she'll say yes you've gone a funny colour again” (P36/29,293).

Another participant noted:

“ Sometimes I notice that my nails have gone a blue colour and, I take a look in the mirror and see that my ear's blue” (P9/81-3).

Developing hypoxaemia can however, result in more serious consequences such as the patient becoming disorientated and confused, and can lead to possible failing consciousness. Several participants described incidents of the patient's altered cognitive functioning, which had resulted in emergency hospital admission (P23, P35). The wife of one participant described her husband during such an episode:

“ You (he) black out- oh yes you lose your eyesight- you just go- oh I don’t know- you can tell when you look at him- he doesn’t know anybody or anything and he doesn’t know where he is. His eyes are glazed over. He gets disorientated” (P35/365-75).

Another participant described how severe bouts of coughing would result in difficulty in breathing and feelings of panic and recalls:

“ When you get into a pickle- I’d grab at the oxygen, the first couple of minutes trying to breathe like taking great gulps- but sometimes I’d get the mask and sit here gasping and almost gaga ‘cos I’d have the mask in my hand and not be able to get it- hold it up to my face- not realising... (P18/45-8).

Even eating and sleeping become problematic as the symptoms of COPD worsen. Many participants disclosed that they had lost weight due to having a poor appetite and eating considerably less than in the past as they often: ‘just don’t feel like it’. Reduced dietary intake was of major concern for the spouse of one participant who commented:

“But his appetite has gone and he does seem physically incapable of eating... even though I’m giving him smaller portions... but he eats frighteningly little- I don’t know if it’s the stomach rejecting more or the physical effort of eating- too much effort like walking perhaps? ...the doctors say ‘oh don’t be ridiculous it can’t be that but I don’t know what else it can be due to...” (C/P46/ 2535, 258-260).

Typical comments made by participants include:

“ I can’t- if someone would show me how to eat and breathe at the same time I would be home and dry” (P4/77).

One participant who was severely affected by his illness said:

“Most of the time I waste it- I don’t want it- I have a spoonful and that’s about it... I don’t want any more- just can’t push it down. I’ve got the feeling that you’re full to the top of your throat.” (P9/194-7).

Many participants highlighted the actions of chewing and swallowing as requiring a conscious effort, which, resulted in a choking feeling, sometimes causing facial flushes and body sweating. Dry crumbly foods and nuts were often identified as being avoided to prevent irritation and coughing while participants identified cravings for vinegary, piquant foods and fizzy drinks. Some participants claimed that the sharp taste of the latter cuts through and helps to clear the thick phlegm, which lodges at the

back of the throat. In contrast to the participants who had lost weight, others pointed out how they had gained excess weight, becoming obese due to reduced exercise tolerance or to the side effect of having taken long-term corticosteroid medication. Consequently for these participants, gaining weight had compounded their problem of becoming short of breath on the slightest exertion.

### **5.3. Pharmacological regimes employed to manage the symptoms**

As with other chronic illnesses, participants revealed that living with COPD entails establishing daily routines, which revolve around taking medications. As the symptoms grow increasingly severe and irreversible, so treatment doses are increased and become more frequent. During the early days patients are initially prescribed inhalers, known as ‘puffers’ to relieve feelings of chest tightness or breathlessness, on demanding exertion, to use as required. As the disease progresses and the symptoms of breathlessness worsen, inhaled therapy via inhalers or a nebuliser is recommended routinely for several times a day. Some patients with severe COPD fulfil the medical criteria for prescribed home long-term oxygen therapy (LTOT), prescribed for 15+ hours out of every 24 hours. Consequently some patients perceive themselves literally tied to the home.

In accordance with published guidelines on pharmacological management of stable COPD, all the study participants used bronchodilator pressurised metered dose inhalers (pMDI); the most commonly used being the short acting B<sub>2</sub>-agonist Salbutamol, known by its brand name as Ventolin® and by patients as their ‘reliever’ inhaler. Other pMDIs prescribed included anti-cholinergics e.g. Ipratropium bromide and more recently the longer acting Tiotropium, known by its brand name Spiriva®. In addition participants were prescribed inhaled gluco-corticosteroids e.g. Beclamethasone, Budesonide or Fluticasone while some participants had been issued with combination drug inhalers e.g. Fomoterol with Budsonide or Salmeterol with Fluticasone. Various designs of pMDI were used, partly due to the introduction of CFC-free equivalents and including breath activated metered dose inhalers and dry powder inhalers. Some participants regularly or intermittently took systemic oral gluco-corticosteroids e.g. Prednisolone or Methylprednisolone, while a minority had been prescribed Methylxanthines e.g. Aminophylline or Theophylline. Approximately 58% (n=29) of the participants were issued with a nebuliser machine to inhale

vaporised bronchodilator and gluco-corticosteroids medication, and approx. 38% (n=14) of participants received home oxygen therapy via a concentrator or oxygen cylinders. At the time of interviewing no participants were prescribed anti-mucolytics. Some had received a Pneumovax® while nearly all participants had received the annual influenza vaccine.

### **5.3.1. Perceived efficacy of prescribed medication**

Over time participants formed an individual evaluation of the efficacy of their prescribed drugs, and in some cases this had influenced the degree of compliance in taking their medication as recommended. Participants revealed considerable differences in perceived benefits from the medication. Of those participants issued with a hospital-loaned nebuliser machine for use at home, the majority rated its effectiveness higher than that of a pMDI. For example one participant noted:

“ I take the nebuliser 4 times a day- Atrovent® and Ventolin®. The inhaler they took off me in hospital but I don’t really miss them but the nebuliser I do feel a difference- I can feel it going down into my chest” (P27/87-9).

One male participant who was virtually housebound due to his disabling breathlessness stated:

“The machine now- I’ve just been on it and it’ll last me now until the middle of the afternoon and that’s pretty good. I’m quite happy with that- I couldn’t do without it. There’s no doubt I’d be stuck without it- I really would be, whereas those things (inhalers) I’d be using these every ten minutes sort of thing” (P35/56-11).

Another male participant, a widower who lived alone commented:

“ ...and nebs yes- I don’t think I’d be any good without it well you know it helps you like- that practice nurse advised me to get that and it made a big difference- a bigger difference than inhalers- yes I think so” (P39/34-57).

But as one man pointed out:

“ ...Yeah they help a lot- they help at the time and when you’re really gasping- after a while you go right down and they help you to get up for a while- make the breathing a bit easier but they don’t last very long” (P1/35-8).

Several participants commented on how their bodies would alert them to disruptions in their usual medication routine as one woman explained:

“ I know when it’s getting near to the time to take them (nebs). I get err not stressed but agitated to have it and for about half an hour afterwards. Like if I go to the hairdressers... and I’m late back then I know without looking at my watch” (P51/53-60).

Another participant who lived a ten-minute car ride away from her son’s house commented:

“ Well I don’t find it much good really but then if I’m late – like if I’ve been over to my son’s for the afternoon and I’m late back- I’m gasping then so perhaps it is doing something” (P31/72-5).

The nebuliser is an electrically powered device, which vaporises the same drug as administered from inhalers i.e. bronchodilators and gluco-corticosteroids, but nebulised medication is delivered to the patient through a facial mask and connection of tubing, thereby facilitating the inhalation of the drug. The administration of nebulised therapy, unlike the pMDI does not require the co-ordination of breathing and pump mechanism and maybe therefore an easier method of self-administrating medication particularly when experiencing distressing breathlessness. However, not all participants preferred the nebuliser to inhalers as the following two extracts illustrate. One woman stated:

“ I have got a nebuliser at home but I can’t get on with it...it affects my throat-the Ventolin® and Atrovent® but it makes my throat very sore and to be honest with you I don’t think it makes an awful lot of difference to my breathing...” (P4/39-53).

Another participant noted:

“...It just makes me blow up – my throat and chest. When I take the nebuliser I sometimes have to switch off while I have the coughing then calm down letting the ‘bloatedness’ subside before I continue...because when you start to cough you can’t stop for a while and you can’t get your breath and it catches the back of the throat. Sometimes the medication does make it better but sometimes it makes it worse” (P18/61-73).

The administration of inhaled medication has been demonstrated to be equally efficacious by the pMDI (with or without spacer device) and nebuliser delivery appliances, provided the correct technique is used (Dolovich et al, 2005). However,



many participants revealed how they were unable to perform the correct inhaler technique so reducing the administered amount of drug. Most participants had been provided with a Volumatic® spacer, which facilitates use of the inhaler by attachment onto the device enabling better drug delivery. As one man pointed out:

“ [I take] Combivent® inhaler and because I find it easier I’ve got the thing to adapt on – because you don’t have time to get it accurately and I find it difficult- as the nurse down in the hospital said – my technique was inadequate so the spacer makes it easier- without it I can’t inhale properly- and it makes it a lot easier” (P42/68-72).

Several participants commented on how they didn’t really feel the benefits of taking their inhalers but were afraid to discontinue taking them in case their symptoms escalated. For example one comment was:

“ I take it morning, night and midday- I don’t carry it around with me lately because it doesn’t seem any damned good- how much it’s doing I don’t know but I daren’t stop in case it is” (P14/118).

Another man stated:

“In my opinion the inhalers aren’t worth the cost of them- they’re not worth having, I’ve never got relief from an inhaler. I’ve had them all- I’ve religiously done them...I don’t think after ‘ah that’s better’- I’ve never felt that yet- never... but the nebuliser is a different kettle of fish- you can actually feel that open you up... well opening something up and you can feel the benefit with the nebuliser.” (P17/259-267).

Many participants could differentiate between types of inhaler, being able to identify, which they perceived as the most beneficial in managing their breathlessness. Being able to feel the physical sensation of the medication at the back of the throat was highlighted as an indication of satisfaction that they had received the inhaled drug. For example one woman noted:

“ If ever I can’t feel the stuff going down then I don’t think I’ve had any- you wonder how much of it remains in the spacer and you don’t get – it’s only a psychological thing – you think you haven’t taken it” (P36/145-150).

One woman articulated this typical misconception:

“ The Ventolin®- they’ve now changed it – it’s still Ventolin® but a different inhaler because of changing from the CFC’s. So I’ve got another type of

inhaler now but it's not as nice as the old one. With the old type I used to be able to feel it in the back of the throat after taking a dose but now I don't know if I've taken it properly you know - enough. You don't know whether it's working properly. The old one you could tell when you'd inhaled it" (P52/82-6).

The experience of the aerosol spray hitting the back of the throat known as the 'cold Freon effect' is incorrectly perceived by patients as being effective but as the drug deposits at the back of the throat less actually reaches the lungs (Osman and Hyland, 2005).

Despite being considered less effective than nebulised therapy by some, most participants emphasised their reassurance in having an inhaler readily at hand, particularly when out of the house or between nebuliser times. Typical comments included:

"The inhaler is convenient if you're not at home and you can take a couple of puffs then..." (P21/46).

"I keep that in my handbag and always take it with me- I like to be prepared" (P31/180).

"... It's always in my pocket" (P51/49).

Clinical effectiveness was occasionally traded-off for discretion or convenience so that inhaled therapy was not always taken as frequently as prescribed so avoiding the use of inhalers or a nebuliser when in company. Pointing out the benefit of not using his spacer aid as recommended one man said:

"I do carry my inhaler in my pocket and obviously you can't carry on of those things (spacer) around with you so I'm finding that my technique is improving" (P42/73-4).

As with the nebulised therapy, conflicting opinions were obtained from participants as to the benefits of receiving home oxygen therapy. For some participants knowing the oxygen was close at hand was a reassurance as the following extracts indicate. One man noted:

"The oxygen I think so (in favour over pMDI or nebulised therapy) that's what I always dive for..." (P26/244).

Another housebound participant commented:

“ The oxygen- oh yes (couldn’t do without), I was up to 10 that’s why I’ve got two machines. They wouldn’t let me go home until I had two machines put in” (P38/137).

One man stated:

“ I would rather have the oxygen than not- ‘cos it calms me down, because I do – well you do think it’s your last gasp.” (P18/52-3).

A female participant who was still moderately independent but prescribed the oxygen therapy for her severe disease commented:

“ (Oxygen) doesn’t make any difference to my breathing what so ever but it just makes me feel better” (P29/105).

However other participants thought otherwise, for example:

“ The nebuliser I couldn’t do without you see, the oxygen – really you don’t feel it do you? I mean I’m sat down- you don’t feel the oxygen do you? But with the nebuliser I couldn’t do without that” (P30/41-3).

One woman commented:

“ I’ve had the oxygen for a couple of years now- well I must say I don’t feel as if I feel the benefit of it if I’m short of breath not like the nebs. I do get relief from the nebulisers... maybe it’s doing me good but you can’t feel it you know” (P51/95-8).

Some participants spoke of their confusion regarding the inconsistencies in prescribed medication and inhaled therapies, for example one woman stated:

“Well I was in hospital on two occasions with the asthma and on one occasion they put me on oxygen and it was marvellous-oh it cured me completely but when I was in hospital the second time the specialist wouldn’t let use it- I don’t know why and I haven’t had it since.” (P22/67-8).

### **5.3.2. Perceived side effects of the prescribed medication**

Becoming over-weight was a side effect of the prescribed medication taken for COPD referred to by some participants. They pointed out that a combination of giving up smoking, being unable to exercise due to breathlessness and experiencing false hunger due to the steroids, made weight loss difficult and weight gain easy. As one participant pointed out, repeating a comment made by his respiratory physician:

“ As DJJ says – it’s one or the other- it’s life or death again- that’s what it amounts to” (P21/225-7).

The symptoms of sore throat, dry mouth, husky voice, bleeding, scabbed nares, oral thrush, and mouth ulcers were identified as being the result of taking inhaled medication and long-term oxygen therapy via nasal cannulae. Osteoporosis, broken ribs as a result of violent coughing, fractures, bruising and paper-thin skin were given as being the direct side effects of taking long-term steroids.

Urinary incontinence due to diuretics, tremors and shaking due to B2-agonists, impaired eyesight from nebuliser spray, allergic reaction to antibiotics and adverse reactions to nicotine replacement therapy were other highlighted consequences of taking pharmacological treatments for COPD.

### **5.3.3. Patient compliance and participation in healthcare**

As the symptoms become more uncomfortable and intrusive, participants described how the quest to control symptoms became increasingly important to them. Consequently most participants revealed their willingness to adhere to professional advice concerning therapeutic monitoring and treatment regimes in order to control their symptoms. Many participants described a routine of taking tablets, inhalers or nebulised therapy to coincide with meal-times, pre or post prandial, a system devised to avoid forgetting to take medication. As one typical participant said:

“I take it (nebuliser) as soon as I get up in the morning, teatime, lunch time and just before I go to bed- four times” (P30/60).

Another participant highlighted his strict adherence to professional advice:

“So I’m on blood pressure tablets and a water tablet which I’ve got to take religiously everyday and I’m alright as long as I do... I’ve just had the flu jab and the pneumonia vac - we have that every year (P34/49,233).

Several participants describe entering an agreement with their general practitioner whereby they were issued a course of steroid or antibiotic tablets to be kept in reserve and to be taken at the patient’s discretion, only in the event of the acute onset of symptoms. These patients described how they have a cooperative relationship with their GP, who relies upon their commonsense understanding of his or her own

condition. These selected patients are thus empowered to monitor and treat themselves within medical guidelines.

Carrying out and recording twice daily peak expiratory flow rates (PEFR) known as 'peak flows' as advised by the general practitioner, respiratory specialist nurse, practice nurse or hospital staff were often performed and noted meticulously in the early days as also was ambulatory exercise and controlled breathing exercises as advised by hospital physiotherapists. However, over time many participants admitted that due to various reasons they no longer complied with the professional advice given to them.

#### **5.3.4. Adapting therapeutic regimes to suit self and medical non-compliance**

Some participants revealed fears of becoming too dependent upon pharmacological treatments and tried to wean themselves off or reduce their inhaled therapy to a minimum. A few others had initially refused to accept the installation of oxygen concentrators in the home when advised by their consultant physician. For example one man said:

“Well that’s what they said I’ve got to have (oxygen concentrator) but there’s no way on earth I’m going to do it ... well because I’ll be thinking I’ll just be like some of them I’ve seen, there’s no way err - I want to beat it” (P17/363-5).

Other participants considered taking more than their recommended therapeutic dose as being beneficial for example one woman disclosed:

“If I’m feeling chesty then I’ll double up on the inhalers” (P29/157).

Other participants displayed non-compliance to medical advice due to a lack of patient knowledge and understanding of their illness. They were confused by conflicting or confusing monitoring or treatment information given by more than one health professional. One woman noted:

“When I go into hospital DJJ says antibiotics aren’t going to do you any good and when I come out my GP puts me on antibiotics so what do you do? You

can't win. He says do the exercises the physio tells you but I don't know if they help - the chest is still there (P31/ 44-51).

From the accounts given in the interviews, the monitoring of peak expiratory flow rate (PEFR) was eventually abandoned by the majority of study participants. As one man noted:

“I stopped taking records because nobody at the hospital was interested ... it's a waste of time me recording 'cos it's not helping me” (P17/319-322).

Another participant also not understanding the benefits of maintaining a PEFR record claimed:

“I stopped keeping a peak flow record- it never goes above 350 so what's the point?” (P37/14-15).

Deviation from professional advice or non-compliance, as perceived by healthcare professionals, has been portrayed as a means by which patients take control of their situation by making alternative decisions, particularly when they perceive no benefit from the medical treatment or advice (Conrad, 1987; Peynot et al, 1997). However, for some individuals, non-compliance arose as a consequence of experiencing functional difficulties in following treatment regimes. A common problem was that of not being able to handle or to co-ordinate the use of the inhaler effectively. As one woman said:

“I've got a spacer, cos ... hopeless –couldn't get it in- just couldn't manage. You're supposed to breathe and pump them and I just couldn't manage it at all!” (P15/42-4).

However, for others, taking an inhaler to relieve breathlessness was often considered impossible because of being short of breath and thus being physically unable to activate the device.

Professional advice to increase exercise tolerance by increasing mobility or by physically attending hospital or surgery appointments were claimed by some participants as being unreasonable expectations placed on patients by health professionals; due to their disability as a consequence of the breathlessness and its related fatigue.

#### **5.4. Strategies used to ‘get by’ to manage the impact of breathlessness on lifestyle**

As the illness progresses the breathlessness and accompanying symptoms become increasingly pronounced causing some discomfort, and a degree of disability and inconvenience. Physical exertion reminds the individual of the disease’s presence as any moderately strenuous exertion, ambulation or movement induces a state of increased breathlessness. Generally the greater the exertion the more breathlessness is experienced, until the later stages of the illness when shortness of breath is experienced even at rest.

Participants spoke of the strategies they employed to avoid or to minimise the experience of being unduly breathless. Strategies used included slowing down body movements and simplifying activities to avoid increasing the breathlessness. Short-term action plans or coping strategies were put into operation in order to maintain a degree of control over the symptoms, to maintain a level of functional independence and ultimately to maintain a sense of self-respect. These short-term tactics become routine and established into daily practice thus ‘normalising’ the impact of the symptoms on lifestyle. Over time individuals with progressive COPD symptoms adapt to the demands of the illness by learning to ‘take their time’ and to think ahead in the planning and execution of pragmatic tactics to conserve energy and breath. As one woman who lived alone said:

“ I know if I take it slowly I can walk around town on the flat” (P4/94).

Another participant, a grandfather commenting from experience pointed out:

“You mustn’t rush ... if you go that little bit faster- if I’m messing about with the kids ... and I’m out of breath then, it’s the least thing but you mustn’t push that bit (more) - (P11/61-3).

Not surprisingly the most frequently quoted phrases were the need to: ‘stop and rest’, ‘stop and sit’, ‘stop and get one’s breath back’; strategies to avoid or minimize excessive breathlessness, before continuing the arduous journey of getting from one

room to another or the carrying out of a simple daily activity. One man who was virtually house bound due to the restrictions of his illness commented:

“Well you get about but wherever I’m going I have to stop half-way like to get my breath, some days I go to the toilet and I sit up here and sit upright ‘till I get my breath back” (P23/283-5).

Tactics of ‘stopping and starting again’ were perceived not only as useful but frequently essential for participants to carry on with their lifestyle. ‘Stop and start’ were often translated into stages of pre-planned activity as depicted in the following extracts. A male participant who lived on the same street as the church stated:

“The only place I walk to is the Catholic Church...walk down there ...and walking back up then, I’ve got to use the bus shelter. I sit there a while ... for about 15mins, I’m alright then –it’s halfway you see” (P8/38-43).

Another man describes how he managed at home prior to his recent lung operation:

“I just couldn’t breathe. If I sat still I wasn’t too bad but I don’t think I could walk from here to the kitchen, I was gasping for breath. I’d go upstairs and I’d get to the first landing- there’s a stool on the first landing for me to sit down and get my breath back...life was a misery” (P20/174-8).

The use of aids such as a walking sticks, mobility-frames or supermarket trolleys not only facilitated movement and provided a physical support but also acted as a social prop; as a leaning place to stop and regain breathing. These practical short-term strategies then become incorporated into daily routines. ‘Taking one’s time’ was referred to as limiting activities, which can range along a continuum from deliberate body manoeuvring at the bedside to carrying out more energetic pursuits outside the house. However, for the majority of participants, significantly disabling symptoms dictated slowing down the pace of movements associated with carrying out simple basic activities of daily living within the home. Mobility and movement of any kind becoming limited, consciously slowed down and paced out, as one female married participant pointed out:

“When I get up in the morning and when I go to the bathroom I’m quite exhausted then, after that ...sometimes I’ve got to sit down and get myself round and [I have to] go back to bed sometimes” (P15/95-7).

Another married woman stated:

“Dressing has to be done slowly, everything has to be done slowly” (P51/72).



So ‘knowing your limitations’ and ‘pacing yourself’ become major factors in managing essential daily activities and accepting the changes imposed by the illness.

As one man stated:

“...On the whole you get to know what you can do, well you’ve got to. You’ve got to pace yourself too” (P44/41-2).

Another woman commented:

“Well the thing is you can’t hurry, you’ve got to take your time and another thing is, what I’ve found is I think – can do things and I can only do it partly, (then) sit down and then try again...” (P19/5-7).

Knowing one’s own limitations often necessitated delegating tasks to others, relying on others to help out or resorting to novel practical strategies to overcome the restrictions imposed by becoming increasingly short of breath. For example, one man described how he coped from getting up in the morning to getting ready for bed at night:

“It took me about twenty minutes to get dressed and that was only my shirt and trousers and I was gasping then you see and I’ve got to stand and hold myself forward sort of thing” and “once I get upstairs I’ve got to sit on the bed and wait, cos I can’t breathe and then I gradually work myself down...”(P5/99-100,271-3).

The above patient even admitted to sometimes sleeping downstairs in a chair in order to avoid the necessity of tackling the problem of getting up the stairs. Participants demonstrated that they had learnt to adapt to the increasing limitations imposed by the steady deterioration in their general condition and increased symptoms, although this did not necessarily imply an easier lifestyle. One woman noted:

“I’ve had to stop wearing skirts because I can’t get – can’t get tights on. It’s such a struggle and I loose breath in the shower. I stopped having baths, I had that taken out and a big shower put in cos I couldn’t get in and out of the bath- it took all the breath I had away. And the shower was lovely but now I’m finding that even- that I’m gasping now... it’s just that I’m aware it’s getting worse and it’s when I get into bed at night, which never used to be- this is in the last few weeks – losing my breath in the shower and getting undressed takes forever now- it takes ages”(P4/31-5,209-11).

Simple tasks such as dressing become a significant daily activity, which often requires planning and strategy. For example, as one participant stated:

“ Just getting dressed or undressed takes me forever – I put my knickers on and something like that and I’m leaning over the bed and waiting until I can breathe again before I can get on with something else - in stages.”(P7/162-5).

A 65-year-old man described how:

“ I find difficulty sometimes in the bath. I get up, run the bath, sit down and by the time I’ve leaned over to test the water and clambered in I’ve got to sit quietly to get my breath back before I can start to wash...” (P34/189-91).

As symptoms worsen over time, participants admit to not being able to do the things they used to do. Housework or household related activities involving lifting, stretching or swinging arm action such as hanging out washing and vacuuming were frequently mentioned activities, which had become more difficult or impossible. These household chores were only tackled by employing step-by-step tactics or by reluctant delegation to others. Participants frequently spoke of simple established routines, which involved a particular member of the family or neighbour or carer in carrying out certain activities. Barstow, (1974: 141) noted in an earlier study that patients with COPD use coping strategies such as simplification of activities and resting pauses in order to ‘plan ahead to maximize economy of effort.’

## **5.5. Recognition of trigger factors**

Having lived several years with the steady progressive symptoms of COPD, participants often could confidently identify factors, which would trigger an acute increase or fluctuation in symptoms, the breathlessness, cough, wheeze and sputum purulence and production. However, a distinction was noted between a pathological infective exacerbation of COPD and a temporary “flare up” of symptoms due to physical, emotional or allergenic factors. Having the common cold was noted by participants as nearly always ‘going to one’s chest’; an indication of respiratory infection needing medical intervention. In a few cases participants reported how they had become seriously ill when their chest infection had developed into pneumonia. Consequently most participants had been eager to receive annual influenza and pneumonia vaccinations and pointed out how they avoided social contact with

individuals if they were potential sources of infection, to reduce the risk of developing a respiratory tract infection.

In contrast to the symptoms characteristic of an infective exacerbation of COPD, which would last as long as the duration of the respiratory tract infection, the increased symptoms of a simple flare up would generally subside within minutes or hours of the trigger factor being removed. In contrast the former condition would be characterised by copious amounts of purulent sputum as well as increased breathlessness, dyspnoea, cough and wheeze; the latter condition would principally exaggerate the individual's breathing pattern resulting in increased breathlessness. Trigger factors identified as causing increased breathlessness included physical movements, ergonomics, changes in the weather, atmospheric allergens and emotional upheaval. Mobility, walking more than a specified safe distance, bending, lifting, stretching, rushing, lying flat in bed, and talking were activities highlighted as triggering off an increase in breathlessness, coughing or wheeze. For example one man stated:

“I've only got to turn over in bed and that can start it of” (P2/87).

Most participants identified changes in the weather as affecting their respiratory symptoms. Damp, cold, wet or very hot weather would trigger off symptoms, but most participants identified windy weather as being the most feared as depicted by these extracts:

“ If there is a terrific wind – there's no way I can go out 'cos I'd be gasping for breath” (P34/113)

“ I can't walk against the wind- wind pressure suffocates you” (P17/409).

Several participants identified enclosed spaces such as small rooms with the door closed, being in crowds out shopping on the street or being in a room packed full of people, particularly if in warm or smoky atmospheres as causing feelings of claustrophobia. These environments were avoided wherever possible, to prevent triggering off coughing bouts and becoming increasingly short of breath. One woman disclosed:

“ If there’s a crowd and I feel hemmed in – I don’t like enclosed anything, I have to have my bedroom door open and I feel as if I need air. I have a little fan in my bedroom and summer time I have the window open and the door because – well I feel as if I don’t get enough air” (P36/377-80).

Bathrooms and shower-cubicles, especially when steamed up with hot water, were identified as causing undue alarm as a consequence of loosing one’s breath and thus causing panic. Other factors attributed to setting off increased symptoms included polluted air (urban environment), air conditioning on public transport or, coming into contact with allergens such as perfume, polish, or sprays. Emotional upheaval or stress, such as feeling angry, upset or anxious were considered contributing factors in triggering off symptoms of increased SOB, cough and wheeze which sometimes resulted in experiencing a panic attack.

#### **5.6. Factors which compromise the management of symptoms**

Over time patients become accustomed to their condition and in due course learn how to maintain a status quo by avoiding factors, which are likely to trigger an exacerbation of symptoms. Participants had however become aware of factors, which they were often unable to modify resulting in the compromise of symptom management. These factors included the co-existence of another illness condition, undesirable side-effects of their medication, dependency or reliance upon others as carers neglecting to attend to needs, a lack of knowledge/understanding or confusion over therapy regimes leading to lack of compliance to medication, inability to quit smoking, and the acquisition of a hospital infection.

The most commonly cited co-existing conditions of the participants with COPD were asthma, rheumatoid arthritis, osteoporosis, cardiovascular disease and diabetes. Consequently mobility was found to be restricted not only by exertion induced breathlessness but also by pain and limited range of movement due to muscular-skeletal impairment or in the case of cardiovascular disease due to exercise related anxiety. One woman noted:

“Of course having the osteoporosis doesn’t help- what with the steroids you take to help the breathing... and everything (steroids) aggravates the osteoporosis (P4/135-8).

Another participant explained how sleeping was a problem due to pain of the arthritis and the breathlessness of the COPD:

“ It’s a crampy feeling when I’m sitting for long... I lie flat for the spine that’s the only way I can get comfortable- I’ve got a backrest- so I sleep with a backrest and pillows on one side- that’s the only way I can get comfortable – as I said to my husband I can’t win- with my back and my lungs – you’ve got to laugh about it!” (P43/179-81).

A well known side effect of taking long term cortico-steroid treatment is weight gain which was only too apparent for one participant who described its counter effect:

“ Dr. J. has told me to lose weight ... and I said it’s nearly impossible because of the steroids and he quite agreed with me, and walking... well everywhere I go I use the car ...” (P8/35-41).

Another noted:

“ It’s a vicious circle then ‘cos you put on the weight then- and so you’re a bit breathless because you’ve got this extra weight to carry ...” (P16/68).

For one woman being overweight was not only a health problem but also an issue of altered self-identity as she stated tearfully:

“I’m on steroids 5mg a day...but the trouble is I’ve put on a stone and it’s all around here- my middle and I feel heavy and it weighs me down and that makes me breathless...and I feel as if I can’t breathe literally” (P27/89-93).

Several participants described adverse allergic reactions to medication. Notable was one man who reacted badly to antibiotics and consequently lived in fear of catching a respiratory infection. For a few participants, being unable to give up smoking was acknowledged as a major factor in compromising the management of their COPD and its symptoms. One woman who has since quit smoking remembered:

“ When I was smoking my first excuse was - well I need a cigarette to help clear my chest ... what rubbish!”(P36/42).

For others who were attempting to give up smoking, COPD management was compromised when they experienced severe reactions to nicotine replacement therapy so resorting back to cigarette smoking. One participant’s wife described how:

“He had a terrible reaction (to Zyban®); he was very very shaky and very dizzy and all he wanted to do was to lie down and to be left alone” (P46/46-50).

A frequently quoted problem was that of being confused with different tablets and inhalers and not knowing what to take and when. Repeat prescriptions were often issued as a job lot irrespective of the patient need on ordering ‘more tablets’. Changes in brand name for a generic drug and differences in tablet strength confused many patients as to what they are actually meant to take. The issuing of more medication from the hospital on discharge, noting the differences in drug, packaging, or dosage further compounded the confusion. Many participants had since benefited from local pharmacies issuing tablets in made-up ‘dosette boxes’ which clearly identified which tablets should be taken at any particular time of day, each day. As one man commented:

“...And the tablets now they - they’re in a box so I don’t get mixed up” (P38/203).

Poor inhaler technique, a lack of understanding/knowledge and confusion over medication dosages and regimes had lead to a lack of compliance with prescribed medication for some participants at some stage during their illness.

Other participants had commented on how they were unsure of how to deal with their oxygen supply if it failed to work properly or, how to change the connection from the concentrator to cylinder in the event of a power cut. One man had suffered hypoxaemia and an incident of reduced consciousness due to a failed oxygen supply arising from an undetected split in the oxygen tubing, whilst another woman had gone without oxygen for 24 hours because she was afraid to “tamper” with the concentrator to replace a connection after accidentally removing the tubing. Neither participant had thought to contact the oxygen company help-line despite advice and leaflets given to patients from the supplier.

An additional factor for compromised management of COPD symptoms is hospital-acquired infections. A small number of participants described how during hospital admission for an exacerbation of COPD, they had acquired the superbug MRSA, (methicillin-resistant streptococcus aureus), urinary tract infections, infected pressure

sores and pneumonia .One disillusioned participant described how he acquired MRSA and pneumonia followed by a blood clot during his hospital admission He claimed:

“I was cough, cough and he would insist – the doctor- that I go into hospital for the antibiotics and all the usual ... and I came out worse than when I went in” (P35/19-20,122).

Another participant who had experienced complications arising from a hospital acquired infection, which had led to a lengthy inpatient stay, also commented:

“ I wish I hadn’t gone in the first place- ‘cos I had all these problems after” (P48/111).

### **5.7. Adjusting and coming to terms with changes in self and lifestyle**

Symptoms may worsen noticeably within weeks or months of medical diagnosis but usually take up to a few years before symptoms become problematic and impact upon daily living. As the illness progressed individuals with COPD start to acknowledge that they have an irreversible degenerative condition. Previous successful coping strategies devised to deal with the inconvenience of symptoms and related problems become less effective with disease severity. Participants reveal how maintaining one’s previous sense of normality and self-identity becomes more difficult to preserve. Covering up, pacing, knowing one’s limitations become inadequate and participants describe how they reassess their lives in the light of their deteriorating condition. The intrusive impact of symptoms not only evokes a reappraisal of self-concept and identity due to their physical body changes and failing body performance but also raises questions about the uncertain course and nature of the future illness trajectory of their illness COPD.

Adapting professional advice and medical regimes to suit self, seeking further knowledge to increase understanding of illness and treatments, planning ahead to minimise functional problems and adjusting to altered relationships were issues revealed by participants in their quest for maintaining some control over their lives and giving meaning to their altered life course as individuals deal with the uncertainty of the illness progression.

## 5.8. Planning ahead

Participants describe how they steadily lose freedom of mobility as a consequence of avoidance or restricting activities, which cause exertion-induced SOB. As activities are curtailed and body movements are limited, participants reveal how they become physically less able and look for means by which they can retain an element of self-reliance as well as boosting self-confidence. Forward planning strategies or longer term planning and organisation to avoid potential breathless episodes and incompetent functioning take on an importance hitherto not considered. Forward planning issues included a range of considerations from simple immediate actions during the day to longer-term planning over the forthcoming years. Simple strategies included ensuring readily availability and easy access to an inhaler at all times. This was highlighted as a routine ritual enacted out by most participants particularly when leaving the house. As one participant said after recalling a frightening incident where she had been caught out without her inhaler:

“So I’m wary now, the inhaler is always kept within easy reach because once I’ve got that I’m ok- I suppose I’m reassured- I know if I can take the inhaler I’ll be ok” (P52/111-3).

Some participants had obtained or even specifically purchased equipment such as dehumidifiers or wheelchairs, whilst others had taken comfort in installing nebuliser machines at various locations or ensuring ready availability of backup oxygen cylinders in the home and car. Many participants, as they came to terms with the progressive worsening of their condition, made plans for house renovations or alterations in order to accommodate their reduced physical functioning. As one man stated:

“We’re going to change over the heating now because my wife can hardly do that (coal) and I can’t do it so now it’s to oil” (P49/292-3).

In response to growing breathlessness and related problems directly linked to the reduced physical functions such as mobility, washing and dressing, other participants described their plans for major home modifications such as: installing a downstairs toilet and bathroom, converting a downstairs room into a bedroom, changing the bath unit for a shower cubicle, installing hand-rails within the home or applying for a stair lift. Some participants had realised the significance and severity of their illness when first diagnosed and had planned for the years ahead by moving house, often to a



bungalow or granny flat. Others moved in with a family member, or moved closer to a family member or to a less isolated location. One participant described how:

“Up to 6 years ago we had a flat upstairs at my daughter’s house and there were stairs and they were getting too much and that’s why we came here (bungalow)- it’s easy to cope with”(P29/180-2).

However, planning ahead was not only a means to overcome exertion-induced breathless but was exercised in order to have a degree of control over social circumstances to avoid being rushed, flustered or caught unawares, situations which were perceived to aggravate symptoms. For example, one man was concerned about council plans to make alterations to his house to convert the down stairs room into a bedsit. He said:

“But I still want a little room where you go and be private you know if you gets visitors. If the grandchildren comes and all and you want to be alone- you can go and get out of the way like – ‘cos if a crowd gets in the room, I can’t breathe then.” (P5/206-210).

One woman told of how she made sure she was prepared in the event of an acute exacerbation of her COPD:

“ I keep that (inhaler) in my handbag and always take it with me. I like to be prepared like when- I’ve been to hospital several times now and I’ve been so breathless that I can hardly talk and it’s all such a rush and I’m SOB and can’t tell them (ambulance crew) where my nightie is ...so now I have a bag ready to go into hospital so I don’t have to try to explain where everything is when I can’t breathe...” (P31/79-84).

Another participant noted:

“Space and calmness is very important to me you know, in shops where there are a lot of people... I don’t like a sudden influx of people unexpectedly calling in on me. I like things to be prepared and to know what’s going to happen” (P36/238-9,243).

Other participants planned ahead by phoning the surgery requesting to speak to the GP in order to avoid having to make an appointment and attend surgery. This strategy would avoid having to wait in a crowded and /or hot waiting room, which may trigger off coughing and breathlessness. Participants were anxious to prevent symptom flare

up in order to avoid the physical distress as well as the social embarrassment of drawing attention to oneself in a public place.

### **5.9. Seeking further knowledge/information/advice**

Many participants sought knowledge, information or advice additional to that routinely given by health professionals. This included asking the GP to refer to a 'specialist' when symptoms appeared not to be improving under current treatment or seeking out information on COPD from the Internet or trying alternative and complementary therapies in response to media advertising. One man disclosed:

“ I was reading up a while ago about this Russian who says we in the western world take too much oxygen. I read up on the subject like and about four years ago it must have been- went without oxygen for two years. But now out of the two choices I would rather have the oxygen than not- cos it calms me down...” (P18/49-52).

Another man who would be still leading a physically active life if it were not because of his rapidly deteriorating condition; challenged his consultant physician about having lung reduction surgery. This articulate patient was fully informed about COPD and the options for its management as a result of self-education through access to relevant Internet sites on the disease. After several consultations with the local hospital consultant and doctors from the Royal Brompton Hospital, the patient succeeded in obtaining lung volume reduction surgery to improve his lung function and hence his quality of life.

Other participants compared and contrasted themselves with others; neighbours, family members or people that they knew that had COPD. This often confused them when their treatment or medical advice appeared to be different and conflicting despite appearing to have similar symptoms. For example one woman noted:

“I wondered if I needed oxygen but the respiratory nurse said no. There's somebody over the street on oxygen and they're on it night and day- I wouldn't like to have to do that.” (P31/96-8).

The researcher found that patients frequently used the interview time opportunistically to question and obtain snippets of information about COPD; the most commonly asked question being: “will it get worse?” As the symptoms increase in severity and

duration so does the individual's uncertainty about the nature and course of their illness. A few other participants however, were less curious about the outcome of their illness, these described how they had cared for or seen a parent or family member with the same condition as they had now themselves. As one woman pointed out:

“Well probably- I shall die of it I expect-or of heart failure - the same as my mother did drinking a cup of tea” (P29/165-6).

As for individuals with other chronic illnesses, many of the participants of this study experienced uncertainty about their illness and questioned the course and nature of the illness trajectory. In trying to re-establish a sense of control and balance over their lives many participants sought out further information to help explain or inform decision-making concerning their illness; to give it meaning and continuity despite the disruptions and changes the illness brings (Corbin and Strauss, 1987).

#### **5.10. Adjusting to relationship changes and altered family roles**

As the symptoms of COPD progressively and increasingly intrude into their daily lives, relationships and social roles alter between individuals with COPD and others. Participants become more dependent upon significant others to take on not only menial household chores but also often individualised daily personal care. Frequently participants described how they had to adjust to the change in their family role from being the physically able-bodied provider or carer, of the past, to becoming the increasingly dependent cared-for family member. One housebound widower reflected on how now his daughter has to do everything for him, even lifting of his legs onto a stool when sitting out of bed, compared to previously when he had been a full time carer for his wife. As he stated:

“I packed up work early- before retirement to look after her (wife) – she had Alzheimer's... it's hard”(P1/90-102).

Another participant was trying to come to terms with having to relinquish her hands-on caring role for her daughter who was now in a nursing home due to the progression of her own illness. She commented:

“She phones me every day but I haven’t seen her for a while – cos she’s got MS – and I’m fed up now and again- depressed like- I don’t know – it could be the worry of my daughter” (P6/190).

The participants often reinforce this increasing reality of ‘being dependent’ on others, allowing themselves to slip into a submissive role, as they let family members (usually adult children) take on the organisation of their living arrangements. Adult children realising the growing restrictions imposed by the illness often set about to instigate practical arrangements to ensure patient safety and welfare for example house adaptations or renovations, social services homecare and meals-on-wheels. However the individuals themselves did not always welcome these arrangements. For example one man felt pressurised into having his cottage renovated to provide a downstairs bedroom and bathroom. This he had agreed to in principle but was afraid that as a consequence of these renovations he would lose his backdoor and a downstairs room which he valued as an ‘escape hole’ when the grandchildren visited. He said:

“ And they wanted to put the bed over here and put a toilet in there but I said that’s going to be... if they’re going to block the door off there, well... so I wasn’t very keen and told them I wasn’t very keen on that but whether they will or not I don’t know.... no well if they blocked my back wall up and that door there and I liked going out there.”(P5/136-162).

Well-meaning actions of health professionals and family members were not always appreciated as participants felt an accelerated loss of independence and decision-making autonomy. One woman complained that although her children were very good she wished they would let her do something when they visited. She said:

“I find the children have to do a lot more than I would wish. I still want to be independent and as I say when my daughter comes down she won’t let me do a thing and it irritates! I know she wants to be helpful but I would rather be doing for myself” (P22/ 151-4).

Many participants claimed that they considered themselves very fortunate to have a supportive caring family and/or plenty of good friends and neighbours to provide assistance when needed. They were confident in the knowledge that they would not be neglected. Married couples of the study (n=29) generally assumed the role of carer for the ill spouse, particularly caring for a husband with COPD was perceived as merely an extension of the traditional wife’s role, as one wife carer said:

“Oh yes (family/friends available to help) but I don’t actually need it- I can manage with him on my own. I done it all these years- haven’t I? It’s 57 years now we’ve been married” (P23/245-6).

However, of the wife carers (n=8) and husband carers (n=21), not all spouses were able to take on the formal role of carer due to frailty or illness. One married couple were separated with the wife having to reside in a nursing home. Conversely, some male participants with COPD expressed remorse or guilt that they were now unable to continue to do their share of the household duties and tasks done previously, such as window cleaning, car washing or heavier gardening. This was especially noted where the spouse also had some ill health. For example one man commented:

“It upsets me because it’s something I know I should be doing, the man of the house should be doing and it’s made worse by the fact that having dislocated her left arm a year ago which hasn’t set properly and now she’s trying to do things with one hand which she shouldn’t do you know” (P34/206-9).

Another man expressed his gratitude towards his sons-in-law who he would rather ask for help than burden his frail wife (P18).

During the earlier days of living with COPD, symptoms could be managed and restricted activities could be overcome to some degree. Subtle or gradual changes in family roles and relationships were not always expressed as unfavourable as one wife laughingly pointed out following her husband’s early retirement due to his respiratory condition:

“Before the stroke ...back in those days we couldn’t go anywhere or do anything but we muddled through didn’t we? And he did the cooking and I did the cleaning and we had a really good life didn’t we? (P2/158-61).

However, as in the above case, for many patients, as the illness progresses the onset of another morbidity occurring often compounds the problems of living with COPD. Participants with COPD revealed how family members, usually the spouse or adult children not only took over practical arrangements to facilitate daily living but also became guardians or mediators of health care. Most participants revealed overtly or implicitly how they relied increasingly upon their main family carer not only for practical assistance but also to re-enforce professional advice and to provide

reassurance and moral support. Typical comments referring to inhaled medication include:

“ ‘He tells me I’m not using it right”(P15/48)

“I take them as often as my wife makes me!” (P28/88).

Participants described previous events in which they would turn first to family members when noticing deterioration in their health before contacting the GP or dialling 999. Wanting a second opinion and delegating the responsibility for decision-making to the relative was an action strategy often revealed by the participants. It has been suggested that gaining family support and legitimisation prior to seeking medical help may reflect the participants’ uncertainty about the illness course and their perceived relationship with their doctor (Oliver, 2001).

Some participants described how they developed a special relationship with a specific family member. This family member was able to provide continued sensitive support through times when they, the participants, experienced raised anxiety and fear due to exacerbated symptoms. Although family, friends and neighbours were often referred to as being very good, helpful etc., some participants identified a significant person with whom they had developed an intensely dependent relationship, someone who could empathise with and be present during times of fear and panic. (P7, P24, P49, P16).

#### **5.11. Adjusting to relationships with healthcare professionals**

As the illness progressed, the participants with COPD (as for individuals with other chronic conditions), tended to develop close patient relationships with the healthcare professionals they encountered. In the early days, most patients commenced on an inhaler prescribed by the GP to ease the occasional exertion induced breathlessness. Over time this bronchodilator becomes inadequate in controlling symptoms and the individual makes further visits to the surgery to see the GP, practice nurse or to the hospital consultant physician and respiratory specialist nurse, (for lung function tests and alterations in pharmacological treatment). However, participants described their relationship(s) with individual healthcare professionals either, as being supportive and

helpful or, unsupportive and unsatisfactory. Participants distinguished between those healthcare individuals in whom they had faith and those that they did not.

#### **5.12. Feeling supported and having faith in healthcare professionals**

Paramedical staff, physiotherapists and pharmacists were among those individuals identified by participants as healthcare professionals, other than the doctors and nurses, who through their relationship with the patient, had inspired a sense of faith and confidence. The following examples typifies this sense of being supported:

... “It was in hospital that did me- I couldn’t get out of bed or in, so I had a few gadgets from the hospital and physiotherapy- that Marie-Ann she was wonderful. She was really wonderful and she said –well there’s a difference Floss she said- when you came in I could hardly walk...” (P6/100-3).

“But it was Chris at the chemist that helped me and in fact it was Chris at the chemist who ... and she said well we’ve got one here (nebuliser) if you want to try it, then you get your own. That’s what she did...and then I tried the Ventolin® and that wasn’t very good – it was no different and I told Chris and she said try the Atrovent® she said- and I did and it was (better). So it was due to her that and ...it was Chris the chemist again wasn’t it. And Chris suggested that it could be a reaction to the tablets – she said I’ll ring through to the doctors.” (P7/199-205,247-50).

Participants described how since being diagnosed with COPD they had increasingly come into contact with their general practitioner, practice nurses, hospital doctors, nursing ward staff and the respiratory nurse specialist. Effective symptom control, achieved through receiving useful advice and appropriate medication from healthcare professionals was valued. However, participants highlighted the importance of the healthcare staffs’ personal social attributes, in addition to their professional competencies; being approachable, friendly and taking their time to listen and to explain were identified as important as their medical judgements. These healthcare professionals were those in whom participants could place their trust and have faith.

One woman commented:

“They’ve been really good- sorting out stuff that really suited me. I can’t fault this surgery. I’ve had really good attention from the GP and practice nurse. They give you the support you need; you can come in and talk about anything. I mean I can remember years ago how doctors used to be like gods and you weren’t allowed to speak to them...you used to just answer their questions:

‘yes’, ‘no’, and however they got a diagnosis out of that, I’ll never know”(P4/270-7).

A few participants described how they had an agreement with the surgery that they would phone at a particular time to speak directly to the doctor in order to avoid not only making the exhausting trip to the surgery but also having to wait there which invariably started off bouts of coughing. Not only having time to talk and being understood in terms of the condition but making a house visit when requested was highly valued by participants. Several participants emphasised that they were conscious of only calling out the doctor as a last resort as one woman said:

“...They’ve never refused to come out. I think they know that I don’t like asking so when I do they know, you know- I need them” (P31/174-5).

Another woman who attended a different surgery revealed:

“Our doctors are very consistent; they come out to the house once a week so I don’t have to go down the surgery for an appointment- they are ...(very good)”(P27/138-41).

Being approachable, showing interest and reliability in responding to house-calls were GP’s characteristics said by participants to boost confidence and provide patient support, particularly when needed at times of an exacerbation of symptoms, acute breathlessness and raised anxiety levels. One man spoke of his local GPs:

“Wonderful, they are good- the doctors- you pick the phone up and ask the doctor to come out and see you and they’ll be here then either before surgery or after surgery then” (P23/298-30).

His wife added: “I think he feels safer then”(C13/302).

### **5.13. Feeling unsupported by healthcare professionals**

However, not all participants could speak favourably of their doctors. Problems were described that had resulted from the implementation of new systems, such as: having on-call doctors out at night instead of their own local GP, the rapid turnover of doctors, the closure of small local surgeries, long waiting times for appointments or, difficulties in getting through by phone to make appointments. One woman stated:

“ Well we haven’t got a GP now, we’ve got locums.... He was very nice.... but then again I won’t see him again... and there’s talk of closing the centre



down. It's such a nice clinic.... it's like home from home. Would have to go to C. which is overstretched at the moment and it's no good me ringing up, booking up and having to sit in a surgery with other people coughing and so on. No (here) I book up and be first in ... so there's no waiting about- I go straight in and straight out- so it's ideal"(P3/255-279).

Likewise in the hospital, the frequent turnover of hospital doctors instigated for some participants a perception of lack of continuity of care. As one man observed:

"There's always a different one when you go up to the hospital there with DJJ. ...and he goes through the same old routine...and I still walk out with the same problems and the same 'medicants'." (P18/168-74).

Others recalled horror stories of their hospital encounters and of acquiring iatrogenic diseases such as MRSA and *Clostridium difficile* and claimed they were reluctant now to ever be readmitted to hospital if their COPD should warrant admission. as many participants admitted to a lack of faith in healthcare professionals as felt well supported. Several participants' recalled how a hospital doctor had informed them of their medical diagnosis in an abrupt and blunt manner and did not give any further advice or information at that particular consultation. As one participant recalled after a period of illness, uncertainty and undergoing a series of tests:

"And then he said I had emphysema... and then we asked if there was anything he could do and he said no. So I didn't go back then did I? 'Cos there was no point..."(P24/12-5).

For some participants a lack of faith in professional judgement was based upon acquired information (Internet, reading up or experience of another family member with same diagnosis but a different doctor and treatments) and past personal experiences of their own illness. These participants challenged professional judgements, calling upon their own lay version of what medication and therapy they considered best for themselves. The following extract is a typical example:

"He put me on six steroids a day and antibiotics for a week but well I think if he had put me on them a bit longer – 'cos I always- and they dropped them off you see from six a day instead of gradually dropping them off ...well I wasn't too bad when I was taking them but after I stopped taking them I started going downhill. You see but I'm sure if he put me on for a bit longer and gradually took them off I would respond to that. I always do.... Then perhaps I wouldn't have gone to hospital – but who knows?" (P13/57-65).

Many participants who revealed feeling unsupported by healthcare staff attributed this to a lack of understanding or empathy by doctors or nurses for patients experiencing breathlessness and dyspnoea, and the fear and anxiety that this breathlessness causes. Experiencing claustrophobia, feeling rushed or being perceived as making unnecessary fuss in taking one's time over carrying out simple movements were highlighted as examples of not being understood by healthcare professionals, particularly ward staff. One woman described an incident where she claimed the ward nurses showed little compassion for her exertion-induced breathlessness that led to fear of dyspnoea, she commented:

“They all say- the nurses on the ordinary wards don't understand emphysema - they really don't and it's upsetting for us because we need to be understood...” (P7/264-5).

One participant hospitalised and bed-bound at the time of interview described how the nursing staff did not realise the significance of his having access to a drink:

“ Some days you know you've got a tight chest and I don't know if it's the phlegm or not but whatever you do it won't break...I can keep on coughing day in and day out and it still won't budge. It's worse than ever. If the chest is bad then I usually ask them (nurses) for a cup of tea which helps but – then somebody told me I'd have to wait, they're too busy ah well you've got to accept that” (P9/143-9).

#### **5.14. Chapter summary**

This chapter explored participants' experiences of living with COPD as the disease and symptoms encroach and become a constant feature of daily life. The chapter identifies the adaptive physical and psychological strategies by which participants strived to play down the breathlessness and other symptoms, by incorporating necessary changes into daily routines in order to 'normalise' the consequences of the illness. Hence outwardly individuals at this stage appear largely unaffected by the illness and retain their appearance of social normality. Therefore for most of the time during this phase of the illness trajectory, participant self-identity was perceived as susceptible to the consequences of the illness but remained largely unchanged. The participants considered themselves only properly 'ill' during acute exacerbations of the illness but these fluctuations were overcome and normal level of functioning was resumed.

A constant feature of daily life was the employment of pragmatic strategies to slow down movement and ambulation, described by participants as ‘taking one’s time’, ‘stopping and start again’ and ‘knowing one’s limitations’ in striving to minimize exertion and avoid undue breathlessness and conserve energy.

The chapter highlights how participants learn to recognise and deal with, although not always successfully, their increasing breathlessness and other COPD related symptoms. Factors identified which compromise symptom management included accommodating con-comitant conditions, side effects of medication, and a lack of patient understanding about the benefits or knowledge of the correct administration of inhaled therapies. Simple activities such as shopping, socialising and eating were highlighted as requiring planning and care so as to not trigger off coughing bouts and breathlessness in public. Participants described a variety of factors which they perceived as triggering off a breathless attack but could differentiate between short lived ‘flare-ups’ and the more serious and longer lasting infective exacerbation.

This chapter explored the ways in which participants take control of their lives in the acknowledgement of having a degenerative illness. Typical examples included planning ahead as in, installing household modifications to make life easier, moving house to a bungalow or nearer to family or to seek out further COPD related information.

The chapter highlights how the relationship between the individual with COPD and healthcare practitioners becomes increasingly important for the physical and psychological management of the illness. During this stage of the illness the participants were noted to have increased contact with their doctor to monitor the symptoms and efficacy of the medication. Most participants had experienced an admission to hospital following an acute exacerbation of symptoms.

Exploration of the participants’ experiences of adapting to the illness COPD identified medication and related issues a recurring theme. Over time many participants had developed personal beliefs about the perceived benefits, efficacy and side-effects of their prescribed treatment which led to varying degrees of patient concordance with their medically prescribed therapy. Some participants were keen to demonstrate strict

adherence to professional advice and medication (even when perceived as not effective), while others described how they often adapted advice and pharmacological therapies to suit themselves having weighed up perceived benefits. Others challenged practitioners' opinions, having acquired further knowledge and understanding of their condition from personal past experiences or from other sources.

During this time patient- practitioner relationships developed and participants highlighted how healthcare practitioners and social services influence the quality of life for individuals with COPD. Participants revealed how they felt supported by some healthcare professionals while losing faith in others. Healthcare professionals, who were perceived as approachable to discuss problems, those who gave advice/treatment that proved beneficial or who were consistently available were attributes valued by participants.

The next chapter explores how individuals with advanced COPD struggle with the progressive illness and the changes in identity occurring as individuals become increasingly dependent upon others due to the continuous and unrelenting breathlessness and fatigue experienced.

## **6.0. Chapter 6: Living with COPD: The daily struggle**

### **6.1. Introduction**

This chapter explores the progressive impact of COPD upon the individuals' day-to-day lives. In their daily struggle, patients with advanced COPD strive to control the physical symptoms of SOB, dyspnoea and fatigue, and this becomes a major daily occupation. Lifestyle changes are imposed by necessity and convenience, and the individual experiences further 'biographical disruptions' in order to accommodate increasingly disruptive symptoms (Bury, 1982). The limitations imposed by the debilitating physical symptoms of COPD not only impair physical functioning but also have a negative impact upon the individual's social, psychological and emotional well-being. Consequently, daily living becomes a physical and a mental struggle in striving to retain a level of independence and self-respect. Life becomes a daily struggle dealing with both functional difficulties and emotional psychological upheavals.

As individuals with COPD realize at this stage of the illness that the disease is not going to improve they display varying attitudes and coping behaviours in order to come to terms with their degenerative condition. Hence this chapter explores participants' attitudes and feelings as they become increasingly dependent and reliant upon family, friends and neighbours. Participants' attitudes are influenced by how they perceive themselves as they become functionally disabled and dependent upon others. Increasingly, reliance for practical help in the home falls on the carer, spouse, family member or social services' home help, while increased support is frequently sought from specific health care professionals for advice, information and reassurance. Relationships and societal roles are further explored in this chapter with emphasis upon interactions and levels of understanding between the patient, family and healthcare practitioners.

Finally this chapter explores how the participants struggle to come to terms with the perception of a changed self in terms of a disabled body and an altered self-identity. At this time the illness constantly reminds individuals of their altered bodies and as a consequence their altered selves. The participants recount social and psychological losses due to the ever-growing restrictions and limitations imposed by the illness. Consequently

self-identity is reappraised and seen to be affected by the availability of resources, social support and individuals' sense of self-worth. Charmaz (1987) describes individuals who have a chronic illness, as 'aspiring to a reconstructed or preferred identity', within an identity hierarchy, in order to give meaning to their altered circumstances that arise from their long-term illness. The chapter explores how participants with progressive COPD struggle to manage the disabling symptoms and maintain self-esteem despite the cumulative life-losses and perceptions of an altered self within society.

Previous studies investigate various aspects of coping and quality of life of patients with advanced COPD, emphysema or chronic bronchitis; but few explore the patient's self-told experience of managing and coming to terms with this disabling illness.

## **6.2. Recognition of one's deteriorating condition over time**

As the COPD severity progressively limits most activities, and makes carrying out even the most basic of essential daily activities increasingly arduous, some patients described their daily struggle using retrospective language. Extract examples include:

"Whatever you were doing, you got out of breath and you had to stop like, and you couldn't work in a confined space - like you couldn't work in a shed..." (P44/26-7).

"In those far off years I was able to do the garden, by stop and start. I was able to walk and get round and go down and get shopping- by stopping and starting you know. Same old story - stop and start all the damned while!" (P26/83-5).

"I knew my chest used to get tight - I couldn't walk ahead without having to stop and get air in there, then; and that affected me for years" (P9/13-4)

"It must have been about 5 or 6 years ago I noticed ...'cos then I could walk. I'd have a little rest like, but I'd be alright and go on but then... Now, I can only walk short distances"(P43/172-4).

"Dressing has to be done slowly; everything has to be done so slowly and getting upstairs. You'd laugh because I go on my hands and knees, and when I get half-way I have to stop to get my breath back. I've been doing that for a couple of years now" (P51/ 73-4).

The capacity for walking becomes limited to attempting only short distances, for example along a street, but, in most cases, individuals are limited to walking a few paces from room to room. Self-management strategies are devised and employed to enable a degree of ambulation, despite being short of breath. Making sense of their altered health status and changed identity, some participants revealed their disillusionment and /or despondency with their general situation. Other participants, who had reasonable understanding of their disease, knowing that they had incurable irreversible lung damage, experienced despondency. One man, who had perceived a progressive deterioration in himself, noted:

“But the short straw is that over the last two years – I know myself- physically – I’ve deteriorated to such a state that it now, it does surprise me. .... I’ve put this to my own doctor that – well they seem to think that there’s nothing else better they can do about it ... that it’s just due to my deterioration, rather than a lack of proper medical care (P18/16-8,33-5).

Another man stated helplessly:

“ There’s not a lot they can do – not really” (P5/60).

For some COPD patients, former self-help strategies to cope with the struggle of performing activities with breathlessness become obsolete, as they succumb to almost total dependency on others for care. One despondent man described his helplessness as his condition had deteriorated further during his current hospital admission:

“I need a hand to get into bed and I need a hand in getting out of bed. I’ve got to be helped to be dressed, washed, undressed; and I get help to sit up in bed- I’ve got to be lifted” (by hoist) (P8/38/40).

### **6.3. Struggling with the physical symptoms of COPD**

The majority of COPD patients who were interviewed spoke of their unrelenting tiredness, which accompanied their breathlessness. This tiredness was described as daily fatigue or exhaustion, experienced after any physical exertion, regardless of the time span or how simple the activity. In general, simple tasks were described as ‘taking longer to do than they used to’ and ‘becoming hard work’. Most patients described being conscious of

their tiredness from first thing in the morning, even before venturing out of bed. One recently discharged participant described how she felt in hospital:

“And you get out of bed and right- now you’ve got to put on your slippers and then you’ve got your housecoat to put on, and by the time you’re ready you’ve done a day’s work - you’re exhausted” (P7/323-325).

Getting up, washed and dressed is a daily struggle. Many patients used analogies to illustrate how they felt after carrying out simple activities, such as simply walking to another room or to the bathroom.

“[It’s a] feeling of absolute tiredness- don’t feel as if you’ve got the strength to walk... It’s a loss of movement of your arms and legs, you’re so tired, as though you’ve climbed Mount Everest” (P17/154-5).

“To go to the toilet now ... When I get back here I feel like I’ve been out digging the garden or something all day- exhausted” (P26/6,10-11).

“ Every time I go from here (bedroom) out to the back through the kitchen it’s like half a mile!” (P48/227-228).

The majority of participants considered that they experienced poor quality sleep, periodically interrupted by wakefulness, breathlessness, coughing or the need to visit the toilet. This contributed to daytime fatigue and daytime sleeping. One man commented:

“When I’m feeling rough, I get so tired, tired – very, very tired, and I can’t sleep very well. But that’s the only bit of comfort, no matter how tired, is to go to bed and you’ll be just lying there ...It’s so much better than just sitting there. And I do wake up some mornings – wake up more tired than when I went to bed ... But I don’t sleep a lot.” (P11 / 22-24, 37-39).

Other participants observed:

“ Well, some days I just sit down and want to go to sleep and some days I’ve got up and had my breakfast and I’ll sit down and just go off to sleep” (P13/243-4).

Another participant explained his continual tiredness:

“Sleeping is a problem. Now, I’m going to sleep, and [I] put my head down, and after half an hour I’ll get these coughing bouts, and I cough for a while then get back to sleep, and then [I’m] up coughing again. I wish I could have a good night’s sleep. About three thirty in the afternoon, I’ll be watching television and



I'll be nodding off, or I'll be reading or something and the same - 'cos I don't get enough sleep, I suppose. It's when I'm lying down to sleep or if I walk down to... then I'll have a good coughing fit" (P8/142-149).

One woman commented:

"Tiredness- oh my God – in the mornings it takes me till dinnertime to wake up, and I've said to a few people, 'why am I so tired?' " (P30/233-4).

It later transpired that this woman was prescribed sleeping tablets and antidepressant medication, which could account for the morning drowsiness, and worsen respiratory function. Research evidence suggests that up to 40% of elderly persons with COPD suffer with major depression (Yohannes et al, 1998, 2000) and a possible 25% experience mild depression (Yohannes et al, 2003). Participants' accounts of tiredness fulfil the definition of chronic fatigue as:

"A subjective, unpleasant symptom incorporating total body feelings, ranging from tiredness to exhaustion, creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity" (Ream and Richardson, 1999: 527).

These findings are also consistent with studies revealing that fatigue is a complex phenomenon commonly encountered in patients with COPD (Small and Lamb, 1999: Graydon and Ross, 1995).

#### **6.4. Getting mentally prepared for the physical struggle ahead**

Getting mentally prepared to tackle the struggle of activities of daily living often involves summoning energy and physically forcing oneself to get moving. Participants with advanced COPD often implied that they had to think ahead and plan strategies to conserve energy and avoid excessive breathlessness. Each body movement or activity, however simple, becomes a weary struggle for patients with severe COPD symptoms. Since each activity requires increased oxygen intake, the individual becomes increasingly hypoxic, due to compromised lung capacity. Muscle tissue is obliged to metabolise anaerobically, releasing lactic acid. This, together with hypoxia, intensifies

breathlessness, and contributes to general fatigue. Consequently, the patient learns to conserve breath and energy by preparing mentally prior to mobilising or performing any activity. This not only involves thinking strategically in terms of practical solutions to minimise disruption to breathing patterns, but also in terms of acquisition of the psychological and emotional ‘readiness’ needed to tackle the expected activity. Describing how she feels before getting out of bed in the morning, one woman who lived alone said:

“I’m just tired. I lay there and I think ‘Oh well lets go’. .... another little fight you know...” (P4/128).

Along the same theme, other participants commented:

“Now, well I have to pluck up courage before starting... ” (P18/144).

“ You have to control yourself and think ...I have to really think about it, you know, if I’m going to do anything that I know is going to be hard; I’m on the oxygen a few minutes before hand ... Going to the toilet even used to be a struggle – a heck of a struggle - but I’ve got over that a bit. But I have some oxygen before I go” (P49/162-5).

For some patients with severe COPD, preparing oneself to minimise breathlessness involves thinking about what one is going to say before speaking, and keeping words and sentences simple and concise in order to be readily understood, thereby minimising the amount of energy and breath used in verbal communication. One woman explained:

“You don’t talk ‘cos it takes up too much energy ... We do have to think of what we’re saying so that we don’t have to say it a long way round; to say it so it uses less energy - to think it through first.... more so in hospital. If it’s your family they know and wait and you can say ‘eh wait’, but you can’t say it to staff- you understand, so we’ll think about it first” (P7/270-5).

## **6.5. The struggle to reconcile ‘self’ with having an incurable degenerative condition**

This study highlighted how patients suffering from severe COPD respond with different degrees of awareness and acceptance. At this advanced stage of the illness, even the most stoic of patients could not deny the presence of the relentless illness and its related

symptoms, which had worsened over the years and impacted increasingly upon daily activities. Referring to the shortness of breath and exhaustion following any simple activity, one man pointed out:

“It’s in everything I do, no matter how small” (P26/9-11).

And another who was still able to mobilise independently said:

“It’s harder for me to get about... it takes more breath out of me and (takes) breath away quicker than it used to” (P2/249).

Patients with COPD acknowledge, to varying degrees, that they had a progressively deteriorating illness. Some participants portrayed a mental struggle reconciling with, or coming to terms with, an incurable chronic illness. Patient attitudes ranged from a ‘fighting spirit and reluctance to surrender independence’, a situation of ‘compromise’ to that of a ‘passive resigned acceptance’. Bury, (1982) suggests that different styles of response are influenced by the symbolic meanings and social practices inherent in the patient’s cultural background.

For members of a generation greatly influenced by the principle of the Protestant ‘work ethic’ (Weber, 1976), being chronically ill, unemployable and dependent upon others for care conflicts with deep seated cultural norms and values, which uphold moral prestige in being seen to strive for independence and health (Giddens, 1992). Also, the prospect of being labelled chronically ill indicates being redundant from previous roles, which further undermines the patient’s self-esteem and is indicative of an affliction of possible life-long discomfort and suffering due to the illness (Blaxter, 1990). Consequently, patient responses to increasing severity of symptoms, and the resultant further negative impact upon lifestyle, cause varying degrees of mental conflict and turmoil. As the physical symptoms of breathlessness, dyspnoea, fatigue and reduced ambulation become increasingly pronounced; individuals often demonstrated psycho-social and emotional responses, reflecting a mental struggle in striving to accept their illness.

Some participants presented themselves as ‘fighting it’, adopting a positive approach in acknowledging the presence of the illness and doing what they could to slow down the

disease's progressive deterioration. These individuals faced the changes imposed on their lifestyles and adapted accordingly. They displayed their sense of self-worth, and a positive approach to life, maintaining a sense of self-respect despite negative consequences of the illness. Several participants spoke of fighting the illness in terms of being reluctant to surrender independence, to ask for support or to accept help in their struggle with the illness. Other participants were found to harbour feelings of compromise towards their illness, articulating that they hoped it would remain at the same degree of severity and not get any worse in the future. A few participants held unrealistic expectations, hoping that their condition would actually improve. Some participants spoke about how they ought to try to be optimistic about their condition and situation but confessed that they felt 'distressed,' 'down,' 'fed-up' or 'in low spirits.' Although most participants were preoccupied with managing current symptoms and problems, they often expressed feelings of uncertainty about the actual future course of the illness.

#### **6.6. Struggling to be positive**

Patients endeavouring to manage and come to terms with their illness revealed different characteristics from those who found coping difficult. They described a striving to retain and maintain independence, playing down the symptoms and their impact on daily living, understanding the disease and maintaining feelings of self-worth. Striving to maintain one's independence implied minimising one's dependency on others, being physically and socially free to fulfil freedom of choice and ultimately retaining one's perceived sense of self-respect. Changes in daily living strategies and routines were perceived as necessary in order to retain a degree of independence. Many participants perceived themselves as 'fighting it' by trying to help oneself, thereby not succumbing to helplessness and total dependency. Being seen as 'trying to help one's self' was perceived as a moral trait, upholding a perception of self-worth and gaining societal approval. For example one woman said:

"I won't give in, I always find something to do.... knitting... I persevere... sit down for a while and then start again. I don't give in..." (P13/87,256-263).

And another man whose wife was also disabled stated:

“... We’re just soldiering on the best we can.... You can’t start stopping in (house), you’d be an invalid see... and the dog’s got to go out for a walk” (P14/177).

Struggling to maintain normality, and possibly out of a sense of duty towards his wife, one participant commented:

“ As for affecting lifestyle- well the wife says not to go shopping with her to save getting so breathless... But, I feel if I can’t do it, then there’s not much point in me being here so I carry on. Well I’m not going to just sit here doing nothing. Wednesday is our day out. I can sit in the car and if I get SOB [*sic*]. I’ll sit there and compose myself into a rhythm of breathing and perhaps take a whiff of the turbo-haler Ventolin® ...”(P18/151-6).

Playing down symptoms and their impact on daily living emerged as a frequent theme for patients trying to normalise and incorporate necessary changes into the routine of daily life in order to manage and cope, without causing a dramatic domestic upheaval. However, worsening symptoms impose greater restrictions upon mobility, with some activities becoming too demanding. One woman described how she maintained her role as housewife, despite symptoms preventing her doing everything herself:

“ I know if I don’t do anything, and if I just sit down all day, I’m worse. But, if I keep going, you know... I try to do my breathing exercises if I remember. If I’m really bad then I have to go back to bed and then if I feel I need the oxygen... but I still manage to keep the house, you know. I don’t go up step-ladders or nothing like that; but my husband – he does all the shopping and he takes clothes out to the line.”(P43/113-4, 174-5).

Many COPD patients are reluctant to seek help until they feel justified. Delaying going to the doctor’s in the hope that symptoms will resolve, or resorting to using over the counter remedies, are frequent strategies prior to seeking medical attention. One woman summed up this approach:

“I’m one of those who won’t go, you see. I’ve got two sons and they tell me I should go to the doctor before it gets worse, but I think it’d be better tomorrow and put it off. I always thought they’d think I was making such a fuss over nothing... generally ... I wouldn’t say it’s caused any problems really ‘cos as I say, I don’t give in – I carry on, but if I’ve got to then that’s it. While I can do it,

I'm going to do it, and when I can't do it, I'll ask for someone to do it. (P13/41-4, 93-8).

Some participants acknowledged that they had a chronic illness, but, as part of their coping style, displayed an attitude of 'compromise' in that, if the symptoms remained at the same level, they could accept the fact that they now had an incurable illness. However, these attitudes may reflect living through 'remission-time', without a recent acute exacerbation to remind them of the ongoing degenerative nature of their illness. As the following extracts imply:

"I feel OK most of the time, if I can just keep it down you know, if I can get along as I am now, and not get any worse" (P31/98-9).

"I realise that... the breathlessness and the emphysema is [*sic*] probably with me for the rest of my days. It's not going to be cured, but there is little point in worrying about it.... I don't feel it's getting any worse, so I'm not unduly concerned about it. (P28/119-22).

"Your life has changed through it you know. You've got to go on the way you can now. I can't go rushing and doing things now... just as long as I can keep it tidy (under control)..." (P19/226).

For one woman, the compromise was that she had given up smoking after years of heavy consumption and had 'traded in' her habit for extra life years:

"I feel that I've reached a point now where the worst is over, because I gave up smoking and I've reached a very comfortable type of existence. I don't think I'm going to ever get any better than I am, but I'm happy with the way I am" (P36/339-44).

## **6.7. Acceptance**

For others, acknowledgement of having a chronic illness was balanced by the thought that there were others who fared worse in this life, either people observed locally or whose plight was advertised in the media. These individuals had accepted the illness for what it was. Two respondents described how their Christian faith helped them deal with their illness. One of these, an educated man, described his approach:

"Well, it's not going to get any better, that's the nature of it, it's a progressive thing, but I'm a positive sort of person and I don't even think about it. I'm also a Christian and I tend to believe there's no need for me to worry about it. Maybe

it's just a fatalistic point of view ... but I'm quite happy.... One of the things I've learnt in the last ten years. There's no more can be done for me- so what do you do other than medicate? ..." (P20/234-246).

Unable to come to terms with the changed 'self', some patients cling to unrealistic hopes of returning to their former health status. For example, one man, whose medical prognosis was poor and was virtually bed-bound, and had recently been hospitalised for several months, due to advanced COPD and complicating conditions, proclaimed:

"I really need a portable one (oxygen cylinder) to get out- perhaps not at the moment of course, but in the summer, if the weather was nice in the spring or summer, and I could get out into the car and trot off for a couple of hours. I only get around this room really... just the house at the moment, but it will pick up, it'll get better in the spring..." (P35/81,355).

Later, out of earshot, his wife claimed that his GP. had predicted that her husband had only a few weeks to live. Articulating unrealistic expectations may represent an attitude of denial of the severity of the illness by the patient. Denial has been identified as a cognitive coping mechanism by which chronically ill people attempt to normalise their lives and avoid acknowledging and dealing with the fact that they are seriously ill (Royer, 1998).

#### **6.8. The downward struggle: resigned acceptance**

For some patients with COPD, the continuous daily struggle to manage symptoms and to get through the day becomes arduous and this becomes reflected in their moods and feelings. Such patients find it difficult to accept the prognosis of progressive deterioration and increasing debilitation, despite acknowledging that COPD is incurable. Often they have unrealistic hopes for improvement in health. They fear further loss of independence, deny the need for care support or long term oxygen therapy (LTOT), are unable to make suitable adaptive plans for the future, and generally display loss of self-esteem and self-worth. One man fatalistically said:

"It's something you learn to live with... you have no choice. You've got to - got the problem - and got to live with that problem and there's no escape. There's no drug, as yet, that is a cure for it"(P21/139-41).

For another participant, the struggle continued; she complied rigidly with the medical advice in the hope of overcoming her difficulties. However, feelings of hopelessness surfaced as she tearfully said:

“ I do everything that I’m told to do. I try to be positive - I mean you have to be don’t you? But every so often, I get down. I’ve never been a person to sit down, but you’ve got to keep trying. I’m never going to give up.” (P27/108).

Another woman stated dejectedly:

“Well, I’ve got to accept it... what else can you do? I have a good cry sometimes and I do feel it being alone you know. ... I know it’s bound to get worse, ...each time I have bronchitis (exacerbation) and am ill with it, it takes longer to get over it” (P31/101-3).

One man summed up his situation:

“I do miss, to take charge and do things for myself ... the mundane everyday things. I’m not in charge of myself now - only to a certain extent because there’s an automatic reliance on somebody else. It encroaches on your normal way of life...I’ve been battling with it up to now, but I’ve come to terms with it. That’s how it is now; it’s no good looking at it any other way. I think you’re on the slippery slope, and therefore you get up and do what you can at the time...” (P18/157-163, 327-9).

For some patients, having long-term home oxygen therapy signified the seriousness of their condition. They were reluctant to accept medical advice to have an oxygen concentrator installed in the home. As one man said:

“ Dr. J. said three years ago, you’ll have to have oxygen in the house, and I said to him- ‘no thanks- that’s another nail in the coffin!’. That’s how I answered. But now I’ve decided if he wants it, if I need oxygen, I’ll have it. For the simple reason it can be overnight, and perhaps if you have oxygen, it’s safe so [*sic*]. I’ll have the oxygen because I’m not bound to use it” (P11/286-291).

The above patient’s deterioration had initiated feelings of vulnerability, prompting a change of heart. He now felt that he would be reassured by having oxygen in the home – for a ‘just-in-case’ scenario.

Not realising that oxygen therapy is non-addictive, fear of dependency on oxygen was a concern for some patients; they were reluctant to use it more than they felt necessary.



This behaviour was in spite of medical advice and prescription by their local Consultant Physician to take the oxygen for a minimum of fifteen to sixteen hours every twenty-four hour period, as recommended (Royal College of Physicians, 1999). Long-term oxygen therapy is indicated to improve survival rate in a selected group of COPD patients with severe hypoxaemia but few co-morbidities (NOTT, 1980; Crockett et al, 2003).

Some patients realised that COPD is usually a self-inflicted illness (caused by smoking and/or occupational exposures –see chapter 1), which carries stigma and elements of recrimination, embarrassment, guilt and feelings of self-directed anger. One man describes his feelings:

“ Well, I try not to let it affect me (low mood), but I do sometimes - sometimes at the end of the day, you know. I just want to sit down, take no notice or interest or anything, you see. And you wake up - you’ve got to be more positive about it all ‘cos it’s ... err ... the way I look at it, it’s self-inflicted anyhow, so I thought – well I’ve done it, so I’ve got to do something about it as well as the medical profession, they can only go so far” (P18/256-261).

One woman felt shame at not only having smoked, but at continuing to do so despite desperately wanting to quit, she said:

“I can’t blame anyone but myself, because I do feel it’s self-inflicted, as I have smoked for years, although asthma and bronchitis do run in the family. I know I will get no sympathy from the doctor. I remember when I was in the surgery waiting one time and the nurse brought in the notes and I saw written right across the page- ‘must stop smoking’. Every doctor I have seen over the years has said to stop smoking, but I have found it very difficult. But thinking about it, I’m sure I’m slowly pushing myself to the grave” (P52/6-7,13-17).

## **6.9. Struggling to control emotions**

Shortness of breath gets to the stage where even ruffled emotions will cause an exacerbation of breathlessness. Therefore, feelings of anger, frustration and emotional upsets are worked through or “calmed down” in order to prevent acute episodes of distressing breathlessness and/or panic attacks brought on by dyspnoea. One woman described:

“If I go too much or get too flustered up then I get a terrible job of breathing then.... (recalls an incident). I had to calm down – it was just coming out of the house –it’s an awful feeling. I keep saying to myself ‘for goodness sake just steady up now and ease down a bit” (P6/88-93).

Another man said:

“It is quite frightening, and I’ll tell you what makes you SOB- you’ve got to try and keep cool, but if you go into a temper- well ... you can feel it coming on and if you flare up into a temper... Well, you have to cool off slowly and that’s it” (P11/411-6). He goes on to describe his frustrations/irritation at not being understood: “if you’re trying to tell somebody something and he can’t see through that straight away –oh you know” (P11/438-9).

Participants described how a problem encountered, however slight, can cause increased difficulty in breathing, as the following two extracts highlight. A house-bound male participant stated:

“... One thing I don’t like is quarrelling- a quarrel in the family... now that brings it on... makes the breathing worse. You get into arguments with the grandchildren sometimes – ‘cos they might cry and then that doesn’t do me any good. That’s what I feel. I don’t want to know any problems now – I don’t want to be burdened with anything” (P26 / 210-216).

A female participant commented:

“...I don’t cry, but I’ve been so worked up just lately- over my toe and it’s been – it’s really dragged me down and I cried. You know that frightened the life out of me, ‘cos I was absolutely gasping for breath .... I didn’t know how to handle it. I got into a situation myself that I didn’t know how to handle it, so I make sure I don’t cry now, I mean sort of ... err ... not just tears and that, but sobbing ... everything got on top of me” (P4/112-7).

Such examples reinforce the observation of Dudley et al, (1973), that many patients disabled with severe COPD live in “emotional straitjackets”. Patients become too afraid to allow expression of the emotions of anger, depression or elation for fear of triggering a flare-up of symptoms.

## **6.10 Struggling for mutual understanding with healthcare practitioners**

At this difficult phase in their illness, some patients with advanced COPD revealed that relationships with healthcare personnel were not always as helpful and supportive as they

would have wished. Some participants described experiences of confusion or felt unsupported. These feelings appeared to be largely due to ineffective systems in the local health service or general practitioner surgery. However, a number of experiences were the result of poor communication or a lack of understanding on behalf of specific healthcare professionals. Two reoccurring themes were revealed (a) feeling confused about medication or treatment regimens and (b) a lack of empathy for the experience of dyspnoea and breathlessness.

Frequently, patients struggled to make sense of medical advice as it was ambiguous, had not been sufficiently explained, or the patient had received conflicting advice. Patient confusion over medical regimens led to non-compliance, despite intentions to follow professional advice. One of the most common problems was not knowing 'which inhaler to take when', particularly following hospital discharge, when several new 'to-take-homes' (TTHs) medicines were inadvertently added to the medication previously prescribed by the GP. Frequently, these patients had not been told to discard the old medication and to take only the reviewed medication, as prescribed by the hospital physician. Another area of confusion was whether to continue to monitor and record peak flow levels as previously advised by healthcare practitioners. As one patient said:

"I stopped taking records because nobody at the hospital was interested... and it's a waste of time me recording 'cos it's not helping me" (P17/319-22).

This patient had noted that although the consultant had recommended peak flow monitoring, his GP wasn't interested in peak flow measurements.

The second major concern, highlighted by many participants, was the lack of understanding by nurses and doctors about the patient's fears and anxieties in relation to their acute breathing difficulties during exacerbations. This situation was particularly significant during hospital admissions, when patients' established routines and strategies to avoid undue breathlessness could not be pursued in a different environment. Several (n=11) patients talked about their fears of being left in enclosed spaces, for example in ward toilets or in the shower, and how ward staff were not aware of patients' experiences

or how claustrophobia and panic caused increased breathlessness, as one participant said:

“I had to ask the nurse to wheel me to the toilet. Well, she said, ‘just ring when you’re ready and I’ll come and get you’. Well I rang and waited.... it seemed like ages. And I was getting panicky by then, so I called out and the cleaner came and helped me... I felt such a nuisance.”(P52/179-187).

Not only were participants distressed in these situations, as they provoked the onset of escalating symptoms, but they also felt a sense of guilt and frustration for needing assistance. A few patients describing previous bad experiences in hospital were reluctant to be re-admitted in the event of future acute exacerbations. They struggled to maintain a stable level of being and had become adept at knowing how to draw on resources to manage their symptoms at home. As one woman said:

“Well I don’t think he can do a lot for me anyway, and I’ve come to the routine now of knowing what to do you know... And like it is now, as long as I am quiet, then it doesn’t bother me much” (P48/150-152).

However, one woman who lived alone described how she felt prior to imminent hospital discharge. She had been recently admitted due to a sudden attack of breathlessness, which had shaken her badly. The participant described how the nurse had implied that she no longer required treatment in hospital, and was expected to go home. She recalled:

“I didn’t want to go home, because I was frightened...I was scared, I wanted help. I mean I was frightened, there’s no two ways about it. I was scared, and it was out of character as well” (P4/249-259).

A few patients talked of feeling unsupported by their doctors, who conveyed disinterest or had said they were unable to do any more for the patient. Some participants were told by their consultant that there was little more that could be done to improve their condition. For one woman this abrupt disclosure led to her avoidance of healthcare for nearly four years and feeling abandoned and unsupported. She describes the appointment:

“ He said I had emphysema...three or four years ago wasn’t it? And then we asked if there was anything he could do, and he said, ‘no’. So I didn’t bother going back then, did I? Just ‘cos there was no point going back and fore to the hospital, if there was nothing to do. So anyway, I left it at that, and last year,

wasn't it, I started getting...err ... going downhill and we called the doctor and [he] rushed me in [to hospital]. And then Dr. J. (Consultant) said then that there was something we could do - he said we could do a transplant" (P24/13-20).

One man describes how, at each visit, his GP advised him to exercise more, but did not appear to understand the extent of the patient's effort and anxiety induced by the increased breathlessness on exertion. The doctor had either not explained the benefits of rehabilitation or facilitated the patient's understanding of the benefits of rehabilitation. There was a lack of mutual understanding, leading to non-compliance by the patient. He said:

"The doctor was saying to me to try to walk about a bit more, but I said the point is, if I get up and walk over there to the bathroom, then when I get there I'll have to sit on the bed and then... I'll be absolutely gasping for breath and it'll be quite a while before I can come out again.-Well to me, that's no point - 'cos I'll be sitting there for about half an hour or more with the oxygen" (P38/ 230-5).

However, the majority of incidences reported by patients describing feelings of being unsupported involved the healthcare system itself rather than individual professionals. Closure of a local satellite clinic was one example, which made visiting the doctor more difficult, due to increased travelling and waiting in a more crowded waiting room. Long waiting times to book a GP appointment, long waiting times at the practice, or not seeing their named GP as frequently as they would like were further criticisms of the health service. One man noted:

" There's always a different one when you go up to the hospital there... And I say you're asking me all the same questions as the guy before and the guy before that. And I said I still walk out with the same problems and the same medicines...but it does annoy me a bit" (P18/168-72).

The recent changes in GP contracts (2004) and implementation of twenty-four hour cover by a GP co-operative were causes of concern and anxiety for many participants. It was generally assumed that response times by emergency staff, such as paramedics would increase. Having been admitted to hospital recently for co-morbid heart problems, one participant described the delays in getting attention:

"I got somebody out to me. I mean, but what I find is when you phone the doctor-

well he's full and you're put through to so on, and then they put you through to so and so. But before, you got the doctor you knew-especially at night. Now, you call the doctor now and you're through to (town) –well if you want a doctor then they've got to come all the way from (town). On-call see, I think is a bad thing now, if ever anything should happen then. And we've got five or six doctors in this surgery. You would think one of them could do an on-call now... I mean I had a good doctor come out, he was very good to me, but that's what I say. You see, it takes so long- whereas if you're really ill it takes too long for a doctor to come you know. I think the system is a waste of time myself" (P12/144-156).

#### **6.11. Increasing reliance on a family member**

As symptoms of COPD become more pronounced, reliance for help and support was increasingly sought from family members, neighbours and friends, home-help carers or outside agencies. Frequently, participants identified one particular person as being invaluable in helping them maintain a sense of security. Despite realising the need for increased help and support for activities of daily living, the majority of patients struggled to retain an element of independence.

The majority of participants (n= 37) identified a family member without whom they would not be able to manage. Patients described a range of daily activities as requiring assistance, from daily washing and dressing, preparing meals, or to being taken to the local supermarket to do the weekly shop. Typically, spouses and daughters were most frequently noted as helping with showering and personal hygiene needs, whilst husbands, sons and sons-in-law were called upon for heavier tasks or for sorting out arrangements. For two male participants, family support included taking over and running the farm by the rest of the family. Delegation of more strenuous activities was a management strategy employed to retain usual routines and to maintain independence in the family home for as long as possible. One woman pointed out:

“ My niece comes every Tuesday and cleans over for me ... I do all the small wash, 'cos I could never do the sheets... (P19/20).

Coming to terms with having a chronic and incurable illness appears easier for those individuals who currently have the resources to enable them to manage their lives: a conscientious carer or a supportive family member. Patients revealed feeling reassured

that family were 'there' if needed, but were also keen to demonstrate their struggle for independence for as long as possible. One woman who lived alone said:

"I've four sons and they're very good, but they've got their families and their jobs you know, so they're very busy, and I don't like to keep on to them, I know they don't mind but..." (P31/105-7).

Many of the patients who had become housebound due to the overwhelming symptoms said they were learning to live with it, although frustration or anger surfaced at times. One man described his situation:

"Oh I sit here and I can see things what need doing, and I can't do them myself. I have to ask my daughter to pass me this or that ... and it hurts, you know. I try, I'm going to start going to the outside toilet without the oxygen, 'cos in hospital... they were encouraging that" (P26/93-6).

Other patients disclosed their almost total dependency on a significant family member, who not only assisted with basic activities of daily living but whose presence was of paramount importance, particularly in helping the participant to overcome breathing difficulties and avoid panic attacks during times of exacerbated symptoms. One man who had been rushed to hospital as an emergency admission, with pneumonia and respiratory failure, spoke about those who helped him most at that time, including his GP. However he emphasised:

"Really and truthfully, well my wife is the biggest help...well by being there... there's no other way of saying it... Being there, how can you put that into words? Supportive (?)... more than that- it's more intense than that." (P49/57-63).

Another patient describes the intimate and trusting relationship built up between herself and one of her daughters, she recalled:

"Because when I had that chest infection 8 years ago, and I was brought back onto the ward, the oxygen I was getting wasn't high enough and I was struggling and J. stayed with me through the night. She was awake at the side of me and she would say, 'right, come on mum- we'll breathe together slowly', and anytime I thought I wasn't doing alright I would look at J., and she would say 'come on mum'. And so, I think from that...it's only J. that can sort of calm me down, which she does, the other daughter isn't as good is she? It isn't that she isn't as good but we've just got used to each other" (P7/137-148).

Another woman described how she relied on her husband to give her confidence to overcome her fear of breathlessness and feelings of panic. She said:

“Well I just can’t breathe, and then the more I fight it, the worse it gets, so err...he’s got to calm me down; it’s terrible- I’m all shaky and I feels like I’m going to pass out” (P24/104-5).

#### **6.12. Increased reliance on neighbours and friends**

Apart from running errands or helping out with the odd domestic task, neighbours and friends were often referred to as sources of valuable support particularly for participants living alone. Neighbours, friends, people across the road were identified as individuals who were perceived by participants as providing support in the form of being reassuringly around if needed in times of difficulty, or who would ‘pop’ in on a regular basis just to check on participants. One man, not long bereaved, described his anxiety of being alone with the symptoms of breathlessness and revealed the reassurance felt by regular contact with his neighbours checking on him, He said:

“I was wondering about winter coming on anyway... a combination of the worrying about it plus the cold weather...I try not (to worry) but I think it’s in the back of your mind, like you know. I wasn’t so bad when there was someone here with me- it wasn’t so bad then. It’s being on your own see. A bloke up the road here, his daughter comes down nearly every day to see if I’m alright. I’m on the phone like, and then my daughter comes down.... So they’re all pretty good really” (P5/327-38).

Having good ‘understanding’ neighbours and regular social contact was considered important to single people and married couples alike. One married woman confined to the house due to her dyspnoea and locomotive problems, missing the company of her friends stated:

“The neighbours are very nice. The one opposite, P., she’s said to ring whatever time of day or night if I need anything, you know. Nothing is too much trouble, they’re lovely neighbours” (P27/152-4),

The wife of one participant said:



“Family and all the people down the bottom (neighbours) are great, and they know if anybody’s got a cold, then they don’t come near” (P35/582).

However, others were anxious not to become dependent upon neighbours and reluctant to ask for help. One participant described:

“ We wrote to the council asking to see if we could have a ramp up them steps- to get a wheelchair down there. ... It’s not very nice having to ask for help, ‘cos the last time I had to go into Morriston (hospital), I had to leave at 7.00 am ‘cos I had to be there for nine. And so we had to knock early and ask next door neighbour to help get/ lift the wheelchair down the steps... I know they don’t mind, but I don’t like relying on other people to help like”(P24/291-300).

However, social contacts decline for some participants as one woman noted:

“I’ve got a friend- lives across the street - who comes over, but I find not like she used to. We were always over at hers or here for coffee or whatever, but I don’t see a lot of her now. I don’t blame her, I suppose, what with the breathlessness- I don’t know” (P31/144-6).

Another couple planned on moving house as they had no neighbours where they currently lived as the surrounding houses were unoccupied. They felt isolated and possibly vulnerable, living in a country village where half the houses were seasonal holiday cottages, empty of occupants for a large part of the year. The participant reflected:

“From November ...we don’t see anybody, and I think we need to be nearer civilisation ... because the village is empty” (P34/217-223).

### **6.13. Seeking support from agencies and other sources**

As individuals acknowledge and accept their condition as a degenerative chronic illness, many seek out further information, support and advice from alternative sources in addition to ongoing professional medical and social homecare services. A minority of participants (n=5 of 53) were financially able to procure private services: cleaner, gardener or DIY and house maintenance. This allowed them to remain living alone at home. Two male participants mentioned having to pay for car maintenance instead of being able to carry out repairs as they previously did. Voluntary organisations, notably ‘Country Cars’ and ‘Age Concern’ were highlighted by participants as being particularly helpful and supportive in meeting needs and addressing problems. A few (n=4) patients

used the voluntary service Country Cars, a volunteer taxi service to take patients to hospital for clinic appointments or to take shopping and help carry groceries). Several participants mentioned having applied to the council for a stair-lift to make life easier. Another patient described how Age Concern had been instrumental in providing advice for financial benefits and grants to update the house heating system.

Some participants found that, as patients with COPD, they had difficulty in obtaining disability benefits or were not classified as urgent cases for aids and equipment. Unlike other illnesses, such as cancer or stroke, COPD was perceived as a vaguely defined illness, with low priority for provision of aids and equipment. For example, one man described how he had applied to the council for a stair-lift and was told that, despite his extreme breathlessness, he was not a priority case. He said:

“ So I put down what I thought, and a letter a month ago said: “your condition has been noted as ‘medium’”. Well I thought, ‘bloody hell’, he hasn’t got my lungs then. So then I rationalised more and thought some people have got no legs or things like that “ (P18/284-6).

Another participant described how he had difficulty in obtaining Attendance Allowance until the voluntary charity Age Concern stepped in to help, he said:

“I can’t get a car allowance now because I’m over 65. ... The only thing you get is this attendance allowance, but that wasn’t easy to get. ... We fought them six months to get that.. Well twelve months, and we fought them and they wouldn’t listen, they didn’t want to know. But we received a lot of help didn’t we? From various agencies err ... Age Concern and those sort of people – they helped us an awful lot. They were very good. They virtually did it for us, but I must say it was very stressful, because these people are a law unto themselves. We had to appeal and so on...”(P49/330-343).

Realising their inability to mobilise without aids, participants voiced their frustration at having to rely upon aids and equipment, such as handrails and wheelchair ramps, to make life easier.

Participants contacted and used several agencies. This included joining: an anxiety management group and seeking advice and information from an engineer specialising in oxygen delivery systems. Some patients were reassured by having Piper® lifeline

systems installed. These linked their phones to the local ambulance station. However, most patients indicated that they were reluctant to use the systems and would struggle to cope and manage unless absolutely necessary. For example one man recalled a recent incident:

“Last night I got stuck on the stairs going up. I was there for 10 minutes and couldn’t move, and I was debating whether to press my buzzer (indicating pendant to interviewer). So I haven’t used it like, but it’s there if I’m stuck you know. ... I was debating whether it would come back (breath) – it goes and then it comes back, but it’s taking longer and longer to come back.”(P5/222-231).

#### **6.14. Struggling with feelings of loss**

As the symptoms of COPD increase in severity, patients with COPD increasingly lose independence, requiring assistance by others to carry on living at home. All participants revealed feelings of loss of one kind or another. These included loss of freedom to pursue previous activities, such as going for walks, playing bowls, driving and reduced psychosocial well being. For some, the lifestyle restrictions imposed by their limiting symptoms were accepted unquestioningly, as participants implied that this was part of being older. However, others struggled to accept the lifestyle losses caused by the progressive impact of COPD. Many participants described their struggle to preserve feelings of self-worth, confidence, and personal fulfilment as they experienced increasing loss of physical independence and social and recreational pursuits.

#### **6.15. Struggling to preserve self-esteem and respect**

Loss of independence and reliance on others to assist with carrying out activities of daily living and domestic chores revealed a sense of lost self-respect. Being unable to perform tasks traditionally ascribed to gendered roles often evoked perceptions of reduced self-worth or self-esteem and even guilt. For example, one man disclosed:

“The wife has to do all the gardening, and that, psychologically, doesn’t do me any good. It upsets me because it’s something I know I should be doing, the man of the house should be doing. And it’s made worse by the fact that having dislocated her left arm, she’s doing things that she shouldn’t do you know” (P34/205-9).

Another participant who was severely restricted by her breathlessness commented:

“And you get so frustrated. The other day I tried to iron but he wouldn’t let me, he got mad with me, and it’s hard just sitting there and letting him do it, when you’re used to doing it...” (P24/372-4).

For others, the impact of increased breathlessness challenged the maintenance of family roles and self-esteem, and reduced social interactions: for example, not being able to interact playfully with the grandchildren, walk the family dog or maintain previous levels of social contact with neighbours and friends. Feelings of threatened self-worth were implied by some male participants who had to employ a handyman, or tradesperson, for general house maintenance or had to take the car to a garage for repairs, when previously they would have carried out simple jobs themselves. Needing to employ others not only challenged one’s sense of self-respect but also caused financial concerns. One man who had to take early retirement from a job he enjoyed pointed out:

“I had to give up work you see. I’ve worked all my life like... I still do Country Cars (local voluntary transport service) for something to do, but you can’t do anything heavy – you’ve got to have somebody else to do things like the car or the tractor like (repairs) (P44/97,101,151-2).

By helping out as a volunteer, the above participant compensated for the loss of previous employment and maintained in his eyes a useful (although limited) role in the community.

#### **6.16. Loss of self-confidence**

As symptoms of COPD worsened, many participants experienced a loss of self-confidence. One woman described how she carefully considered making the walk to the corner shop, which was less than one hundred metres away. She recalled previous instances of becoming overwhelmed with breathing difficulties:

“ You’re loosing your independence. You get to the point when you don’t like to walk up the hill on your own, because you don’t know what you’ll be like by the time you get to the top” (P16/248-50).

Two male participants used the example of their fear of having a puncture while out driving, Others explained how they avoided large gatherings or social events which

exacerbated the SOB in full and instigated embarrassing uncontrollable coughing bouts, (P39/P6/P19).

#### **6.17. Reduced social life: loss of personal fulfilment**

All the participants spoke of the changes in their lives, which necessitated having to rely on others to assist with some or all daily activities. These lifestyle changes included: social activities, social outings and leisure pursuits, which had become reduced, limited or no longer viable. Consequently, participants with progressive COPD struggled to retain an interactive social life, as many only had their carer or family members to talk to for days, sometimes weeks, on end. Several participants with severe COPD were completely housebound (n=11), while the majority of participants only ventured out of the house accompanied, were able to walk short distances only (a matter of metres in some cases) and transported to destination by car.

Most participants acknowledged that their 'dancing days' were over, not only due to the impact of their illness but because of their advancing years. However, many participants portrayed a real sense of loss, as they spoke of how they missed doing certain activities. Feelings of loss were linked with a sense of being restricted by the illness. For some individuals, these feelings were considered inevitable under the circumstances, and they resigned themselves to living within the constraints of the illness. As one severely affected farmer said:

“ I enjoyed going out ... but if you go somewhere and there's smoking, I can't go, so it makes it awkward you see. I used to go down the pub and play darts but that's out of the question. ... There's no point in worrying about it. You get- I get - down in the dumps sometimes, but ... err ... you might as well die with a smile on your face as not. ... I used to enjoy the farm sales... Like there was a sale down (here) two or three years ago. I went to that sale, but I was ill for days then – so I just stay at home and don't go out. It wasn't worth risking it, no. Ah there's lots of things- just can't do it... I don't think of going- it isn't worth it. What's the point in going and then suffering after?”(P11/130-150).

For some, social embarrassment was as much a deterrent to mixing socially as the suffering. A warm, crowded or smoky environment was often cited as triggering protracted coughing and wheezing episodes, which would lead to acute shortness of

breath and/or difficulty in breathing. Such an incident in public would be an unwanted focus of attention and embarrassment. Other reasons for withdrawing from social activities included: not wanting to let team-members down by being unable to keep up the pace of the activity (e.g. playing bowls) not eating out due to being unable to eat at same pace as others; being unable to walk to or get up steps and stairs in a friend's house; being unable to sing in church or talk with friends without coughing; being no longer able to walk, but unable to afford a taxi to one's destination.

Attending church services or functions, going shopping or walking with family or friends were highlighted by some participants as activities they missed most, as they were now too breathless or physically weak to walk any distance. Others were too afraid to venture out alone, in case of experiencing a paralysing attack of breathlessness. Participants who talked about their reduced social engagements frequently expressed feelings of increased social isolation. For example one wheelchair bound lady despondently commented:

“Life is non-existent - all I do is sit in the chair. I miss going for walks, coach rides. I used to go places with friends, but I can't now; but walking I especially miss dreadfully. The shopping trips, down to the coast, picnics... I used to go with a few friends. Because he likes to go and play golf, and we would go off somewhere for the day. In fact they've gone off today, and I couldn't go” (P27/57-9,126-8).

Another woman who missed the freedom of the outdoor life said:

“ I do get depressed sometimes about it. ... When I go into the garden and can't do a lot, and when my friends go out for walks, and I can't go with them, I find that depressing. I just like being outside; this is why I'm so resentful about the walking - that really bugs me and gets me angry. But there we are - it's as much for me to do the knitting you know (P36/84,381-3).

On the same theme, a man sums up the words of other participants when he notes:

“ It's very depressing to know you're never going to be able to do these things again...” (P49/97-8).

Feeling socially isolated was compounded for some participants by having lost a spouse. Several participants mentioned their loneliness due to increased social isolation following the death of a spouse. One housebound widower commented:

“[It’s] horrible (stuck in house) – well, at times I get a bit depressed yes. Because you’re on your own; and you sit here, and as I put it, you look at the four walls... depressed and confined to this space - it shortens your life altogether....” (P38/208-9, 267).

Another man explained:

“It’d got a lot worse, so I’m frightened to go out; well I can’t go out - I’ve only got to go to the door and I’m out of breath. ... I used to take the wife out in the car for a run, ‘cos she was in a nursing home ... As soon as she finished (? died), I stopped doing that, and I don’t know – I seemed to get worse after that... Oh you get fed up when you can’t do these things and you remember what you could do.”(P5/27,113-241).

### **6.18 The struggle for self-identity**

As dependency upon others increases, patients find their previously ‘taken-for-granted’ social roles changing within the family and society in general. Retirement (early or otherwise), role reversal with the spouse, or increased dependency upon adult children or family members due to the restricting symptoms of COPD lead to altered roles and responsibilities within the family and community. When COPD symptoms become severe, patients lose their independence, and become increasingly reliant on significant others for help and support.

As a consequence of altered physical functioning, patients with COPD perceive themselves differently, their sense of self-identity changes, and with that their sense of self-worth and personal dignity is challenged.

Just under half of the participants (n=22 of 53) had taken early retirement due to respiratory ill-health, of whom four self-employed farmers had relinquished control and running of the business to other family members. The other participants had reached retirement age before the symptoms of COPD became a dominant factor in their lives. Having acknowledged their increased dependency on others, some participants had concerns for their carer, particularly if the carer was an aging spouse. Participant concerns included: fear of being a burden, anxiety about not being able to take care of

another vulnerable family member, health of the spouse or carer, awareness of the spouse's imposed social isolation and being unable to care for and/or play with the grandchildren.

Frequently role reversal of traditional roles between husband and wife was experienced as a difficult transition evoking responses of mixed feelings and emotions. Participants reported not only feelings of loss but also emotions of guilt, frustration, embarrassment and helplessness. For others, having a capable, caring and dependable spouse or family member on whom to rely was a source of good fortune, frequently described in terms of: "I'm lucky to have...".

Struggling to maintain a sense of self-worth and respect, many participants strived to display actions of reciprocity within the family. For some men this was illustrated by helping to prepare meals as the wife worked fulltime. One woman who had become housebound and was desperately missing social outings nevertheless 'allowed' her husband to go out three times a week to play golf with his friends. This was seen as a subtle way of showing appreciation for being looked after the rest of the time. A poignant example of reciprocal action between a participant and her temporary carer, who was an intensive care nurse, was illustrated by disclosure of her decision to finally quit smoking after years of failing to do so. She said:

"There was one chap, one nurse, I can see him now, saying about smoking and the damage it does. I understand that, from his point of view, that he was doing his best to save my life and I wasn't doing anything to help myself. They were so caring, so when I came out (of intensive care) there's no way I could smoke again, because I would be stamping them in the face, if I put another cigarette in my mouth - so I have never smoked again since and I wouldn't" (P7/27-30, 38-40).

#### **6.18. Clinging to one's past self-identity**

As the COPD progressed, most participants were anxious not to allow their former self to be forgotten in terms of their physical abilities and independence as a capable individual. During the interview they described their former selves and their lives in order to portray their qualities and capabilities before being limited by their illness. Adjusting



psychologically to the limitations imposed by the symptoms of COPD, most participants were eager to represent themselves and remind others of their previous identity of being fit and able-bodied. Making known to others the person they once were appeared to be a psychological strategy to retain an element of self-respect and self-esteem. Many of the male participants recalled past life events or incidents in which they had been involved, highlighting that they had been in the armed forces during the Second World War. They compared their former and present selves, which they depicted as weak, vulnerable, disabled and dependent on others. Some male participants emphasised their previous physical fitness, pointing out how physically demanding their work had been and how, in comparison all their muscles had now wasted leaving them weak and vulnerable. One man claimed that from seeing his doctor for the first time:

“ From that moment onwards, life changed for me, as always being an active man seven days a week, 135 hours a week in my heyday – (from) hard physical labour to none. ...The muscles have gone ...I was boxing until I was 58 and I boxed all round the world. I’ve never met my equal in strength for my age; I don’t want to be ill, well maybe that I am now. Know that I am ill, ‘cos I just have to accept it. I can’t do nothing now...I feel disarmed, my strength, my punch and power is no use to me .... The muscles have gone and I’ve lost three stone since Christmas” (P17/16-7,178-81,276-88).

Several participants, mainly women, told of how they themselves had been the main carer for a family member. Now it was their turn to be the dependent cared-for-relative. Other women described how they had been busy wives or mothers who took a pride in their housework and had the energy to hold down a full time job in addition to managing the house and bringing up children. As one woman said:

“I was on the go all day”(P48).

A few participants described their past; as physically competent sports persons contrasting their former selves with their current physical disabilities (P33, P46). These stories recounted by participants are consistent with the ‘salvaged identity’ concept described by Charmaz, (1987). Charmaz (1987) suggested that chronically ill persons struggle to retain a sense of control and self-worth, as their illness puts into question, undermines, alters or negates previous self-identity. Chronically ill persons perceive a

loss of former self due to changes in body appearance and functional performance. This often leads to a restricted lifestyle, social isolation, being discredited and feeling a burden to others (Charmaz, 1983). By way of retaining a sense of self-identity and worth, chronically ill individuals develop 'preferred and hierarchical identities' to which they aspire. Individuals who cling to a past (salvaged) identity based upon a valued attribute or activity or present a positive aspect of self, in spite of becoming physically impaired and dependent, are attempting to define self as positive and worthwhile despite reduced ability to function (Charmaz, 1987).

## **6.20. Chapter summary**

This chapter explored the participant's experience of living with severe COPD and highlighted several issues relating to the changes imposed by the worsening symptoms.

The debilitating impact of the breathlessness and/or dyspnoea and chronic fatigue increasingly change not only the participant's lifestyle but also the individual's sense of self. At this advanced stage of the illness, living with COPD is revealed as a daily struggle due to the unremitting presence of breathlessness and its physical and psychosocial impact on the individual. Many individuals with severe COPD become immobile and dependent upon others to assist with personal needs such as dressing and getting to the toilet; while others struggle to maintain independence but are severely limited in physical capacity.

COPD reduces physical mobility, partly by physical impairment of oxygen transfer and muscle wasting, and partly by the increasing anxiety or fear of provoking heightened difficulty in breathing. The struggle to maintain a stable breathing pattern frequently results in a positive feedback cycle or vicious circle: reducing movement to reduce risk of dyspnoea causing muscle deterioration. For many patients, leading a more sedentary lifestyle to reduce the risk of inducing further breathlessness compounded the deterioration in their illness.

As participants described the functional limitations in their lives at this time, they emphasised their psycho-social and emotional health status. Participants revealed their attitudes towards their illness; some adopting a fighting spirit in order to do what they could to modify the disease, while others were reluctant to acknowledge the illness's ongoing deterioration and to accept support. Despite the increased contact and interaction with healthcare professionals at this biographical time, many participants continued to reveal their uncertainty about the illness course and expected future outcomes. In addition, participants identified a continuing lack of understanding of illness management such as the benefit of taking long-term home oxygen therapy for the time duration medically prescribed. Inadequate support and monitoring within primary care is likely to account for the participants' general lack of medical knowledge and understanding of the management of their illness.

The chapter highlighted how participants with severe COPD experience multiple losses in their lives. Due to being breathless on exertion and physically weak, participants identified not only the loss of independent daily functioning but also the loss of previous social and leisure pursuits and hence the loss of personal fulfilment. As the participants became less physically independent and more dependent upon others, they experienced feelings of reduced self-reliance and self-worth. However the participants often demonstrated resilient self-management strategies, functional and emotional, enabling them to retain an element of independence and hence self-esteem. Needing to feel in control of their lifestyle and avoiding unexpected situations, which may cause unpredicted symptoms were highlighted as important considerations by some participants. Family relationships were highlighted as becoming of increasing importance as the disease severity and loss of independence increased. Good relationships between family and participant were valued as boosting patient confidence and self-esteem.

A principal theme that emerged from the chapter was the lack of understanding for the illness and its consequences on the lives of the patient by the general public and in particular by healthcare professionals. Participants identified how they encountered difficulty in obtaining aids and equipment as a priority case from the council or health

and social service loan departments, due to a lack of understanding of the severity and disabling nature of their illness COPD.

Other individuals highlighted the lack of understanding or empathy shown by some healthcare practitioners for the exhausting and/or distressing symptoms experienced by patients with severe COPD. The chapter revealed how participants' perceived lack of understanding by others further reduced their self-confidence and morale. The widespread lack of knowledge and understanding about COPD appeared to perpetuate the lack of legitimisation for COPD as a medically defined illness. Consequently, at times participants felt embarrassed, guilty or stigmatised for not coping with the illness according to social or health professional expectations.

At this advanced stage of the disease, it was noted that individuals with COPD significantly reappraise their sense of self and identity. Notably, unlike other illnesses, where losses associated with chronic illness and an altered self-concept usually occur at the time of diagnosis and identification (Charmaz, 1983; Corbin and Strauss, 1987), this study identified that reassessment of self-image and identity became significant only when strategies to play down and minimize the consequences of the illness could no longer be 'normalised' into daily living. In the early days, participants frequently received a vague, uncertain diagnosis, which reflected the onset and nature of the disease, and its slow onset of symptoms, as described in chapter 4. Later on along the illness pathway pronouncement of an identifiable condition came as no great surprise, as individuals had been living with its consequences for some time before the diagnosis. In a few cases, participants had never received a diagnosis, or were unaware of having been given one. Therefore in most cases, self-concept was not influenced at the time of medical diagnosis of chronic bronchitis/emphysema/COPD, but was reappraised later when the symptoms dictate changes in self and lifestyle. The participants did not perceive conflicts between the self, body and identity until these later stages of the illness.

The next chapter explores how patients with severe and terminal COPD face the future,

living with illness-related uncertainties and the fears of experiencing severe breathing difficulties or not being able to breathe at all.

## **7.0. Chapter 7: Living with severe and terminal COPD: Fears and facing the future**

### **7.1. Introduction**

This chapter extends the discussion of the previous chapter by further exploring the experience of living with severe and terminal COPD. Prognosis of COPD is notoriously difficult to predict which makes the illness trajectory of terminal COPD difficult to define. However, within this uncertain biographical timeframe the chapter explores the issues and concerns raised by the participants who experience severe symptoms of COPD during the later stages of the illness.

As the severity of symptoms increases, individuals begin to realise that they have a progressive irreversible, degenerative condition, which is becoming difficult to manage. This engenders multiple fears. Although participants have become accustomed to a steady deterioration in their physical condition, they begin to experience new uncertainties in their lives and gradually adopt different approaches when facing their undefined futures. Struggling with practical strategies to overcome mobility and lifestyle restrictions becomes secondary to more urgent new concerns, anxieties and fears. As symptoms escalate, from being intrusive to becoming overwhelmingly problematic, most participants with advanced COPD, as those with any chronic illness not only experience extreme physical disability but also are also more likely to suffer psychological disorder and emotional distress (Morse, 2001; Ohman et al, 2003).

Firstly, the experience of being severely breathless or dyspnoeic is explored; how the participants deal psychologically with this distressing symptom, which often escalates into feelings of fear and panic.

Secondly, the chapter explores how participants who are severely compromised by the debilitating illness perceive themselves as vulnerable members of society who become more dependent upon carers and local services for their daily well being. Participant concerns and feelings are explored which arise from the struggle for social respectability and legitimacy.

Thirdly, the chapter explores the participants' emotional health, the feelings of helplessness and mood states arising from the increased loss of independence due to the limiting impact of the illness symptoms and the subsequent lifestyle losses.

Fourthly, the chapter explores the perceptions of a few selected participants with severe COPD, who through a paradoxical twist of fate are offered the chance of an improved quality of life and possible extended life through having elective lung surgery. No previous studies were found reporting the subjective experience of patients undergoing lung surgery for COPD/ emphysema.

Finally, the chapter explores participants' attitudes and behaviours relating to their unpredictable future, including end-of-life issues, death and dying.

Professional interest in palliative care for patients diagnosed with non-malignant diseases has resulted in several studies that have investigated the needs of individuals with end-stage or terminal COPD. These studies have identified significant unmet physical and psychosocial patient' needs (Addington-Hall et al, 1998; Skilbeck et al, 1998; Gore et al, 2000; Rhodes, 1999; Goodridge, 2006). Due to the unpredictability of the COPD illness trajectory, which is an overall steady decline, judging life expectancy and making end-of-life plans are considered to be more difficult than for other illnesses such as cancer. This unpredictable course of the illness has been given as the explanation for the lack of palliative care provided for this particular group of patients (Murtagh et al, 2004; Teno et al, 2001).

## **7.2. Fear of physical symptoms: the fear of not being able to breathe or get one's breath**

The advanced progression of COPD manifests itself by inflicting the ill person with the ever-present and increasingly severe symptoms of breathlessness, dyspnoea, fatigue and general bodily deterioration. Participants described the progressive degeneration of their condition as being increasingly interrupted with sudden acute episodes of breathlessness. Sometimes, these episodes could be predicted by changes in symptoms, for example, increased purulent sputum, but frequently episodes of

acute breathlessness would occur spontaneously for no apparent reason and with no forewarning.

The main daily focus for participants with advanced COPD was to get through the day without causing unnecessary breathlessness or dyspnoea. Individuals with severe advanced COPD remained in their homes for most of their lives; some were chair or bed-bound. For these individuals, even simple body movements had the potential to increase breathlessness to unmanageable levels. Consequently, in addition to the ordeal of struggling through each day, participants disclosed how they lived in fear of a potential sudden acute episode of urgent and terrifying dyspnoea. Sudden episodes of breathlessness are frequently caused by factors such as the accumulation of phlegm at the back of the throat, strenuous body movement or anxiety. However, severe attacks of breathlessness are also caused by a bacterial or viral infection, causing an acute exacerbation of symptoms. Onset of breathlessness can be rapid; within a couple of hours, and often requires prompt admission to hospital for intensive treatment with intravenous antibiotics and corticosteroid medication. Many participants described how they lived with the daily recurrence of frightening episodes of breathing difficulties, caused either by pathological, physical or psychological triggers. These could result in hyperventilation and panic attacks. For example one woman described:

“I just cough and cough until I can get the lump- the phlegm up.... And when I can’t, I cough and cough and panic a bit... the more I think of it the worse I get, so I don’t think of it” (P24/268-273.)

Another woman commented:

“Well, when I’m very breathless, then I am frightened. You’re gasping, trying to breathe and it makes you numb and gormless. That makes me sometimes frightened... I do panic, you know. The kids don’t think so, but I do. I feel pins and needles in my hands and I think here we go again” (P31/157-8, 168-9).

### **7.3. Previous frightening experience of breathlessness**

The overwhelming majority of participants recalled at least one previous specific terrifying incident of acute exacerbation of COPD, caused by an infection, resulting in unusual breathing difficulties. Participants lived in constant fear of further episodes. They described these events as terrifying or frightening and feared that they were



facing death. One participant, who had recently undergone lung reduction surgery, described how he felt during these attacks of breathlessness occurring prior to his lung surgery:

“ If I suddenly lost my breath, it could be absolutely terrifying. The number of times when I’d thought my last moment had come, and I’ve thought – this time my breath isn’t going to come back” (P20/262-4).

Another man vividly remembers being admitted to hospital as an emergency, with hypoxaemia and cardiopulmonary complications. He recalled:

“ I wouldn’t want to experience it again... I was panicking. Oh yeah too damned right- they were trying to put an oxygen mask on me, but of course, as far as I was concerned, it was restricting my airway - so I was fighting them and in sheer panic, it was sheer panic. It’s an experience I wouldn’t recommend to anyone. I couldn’t get my breath at all. I was living from one breath to the next breath, sort of thing, and you had the feeling – well you didn’t have time for feelings - you were just struggling to breathe- from one breath to the next breath that’s the only way to describe it” (P49/20, 22-3).

He went on to say, how sometimes, almost twelve months later, when he thought about the incident or when he found himself in certain circumstances, such as taking a shower, the mental reliving of the event might trigger a repeat episode of fear and panic. Even talking about it caused an emotional response as the researcher noticed when he said:

“I was hyperventing – wasn’t I hyperventing? Well you see I got confused because I don’t know when I’m hyperventing and when I’m not ... again it’s this panic thing you see. You get over it but you never really get over it – that feeling will never leave me. I know that. That will never leave me... and I’m shaking like a leaf now. ... I try usually not to think about it ...”(P49/188-194).

Another participant, who had since moved to a town house with easy access, described how previously she would start to panic while still sitting on the bus returning home, as she anticipated the breathlessness that would be caused by the physical exertion of walking up her garden path to the house. She said:

“Oh, I could hardly walk at all and I would get- walking up the slope up the pathway - and I would get a panic attack because the breath wouldn’t come... and err well it was pretty grim... the panic attacks were terrible. If I had to do a certain thing like, if I was going somewhere and I knew there was a hill

involved, I would start to get a panic attack, even thinking about it” (P36/14-16, 218-221).

However, for other participants the cause of the sudden onset of acute breathing difficulties and panic attacks was often unidentified, as one severely ill 59-year-old woman commented:

“ I just can’t breathe and sometimes when I wake up, I don’t know. I was terrible when I first came out of hospital wasn’t I? I first thought I wasn’t breathing proper- I was terrible wasn’t I? I’m not so bad now but I could be sitting here one minute and I just can’t breathe- it just comes on me so quick. I don’t know what it is. They just come on now and again. I had one this morning, didn’t I? I was sitting here one minute and the next minute I said to him, I can’t breathe... it takes me ages to relax.... Well I just can’t breathe and then the more I fight it the worse it gets, so he’s got to calm me down.... terrible ... I’m all shaky and I feels [sic] like I’m going to pass out” (P24/80-106).

#### **7.4. Fearing it’s going to be the last breath**

The breathlessness would become so severe and laboured at times that participants frequently described incidents where they thought they were taking their last breath. One man commented:

“ It does make you think - wonder where the next breath is coming from” (P26/326).

Another participant said:

“Oh, it’s a terrible feeling. It’s the most frightening thing I’ve ever experienced. .... I was so frightened. Oh, it was terrible. Looking back on it, it was terrible- oh dear yes, yes. I don’t think I could go through that again...you get very frightened ... you can’t breathe properly. And I very often think, oh my God, it’s my last, you know...” (P16/ 117, 214-5).

One woman recalled how she used to feel when walking up an incline, which would precipitate breathing difficulties:

“ I really felt as though – oh my God, I can’t breathe, you know- no oxygen- it was terrible. It really was an awful feeling and you felt as if you were never going to do another breath. You do, but you don’t think you’re going to- and you come out all hot and sweaty” (P36/228-231).

## **7.5. Learning to overcome and endure the fear of breathlessness**

Over a period of time individuals living with severe COPD, realise that they can and do survive episodes of frightening breathing difficulties, gulping and gasping for air, despite feeling that they are dying at the time. However, despite learning to get through these terrifying episodes of dyspnoea, participants realise that the disease is now unrelenting and unlikely to improve. One woman said:

“And although I know what’s wrong with me and I know that I’ll get it (breath), it doesn’t stop the panic. You still panic ‘cos you can’t breathe properly. ... Well, I know that it’s not going to get better than it is ... because I’ve got lung damage. Well it’s not going to repair. I mean I’m 69 –last week, so I think I know I’m not going to improve, but if I can stay as I am, I shan’t be complaining” (P16/260-306).

As one man said:

“Well, you do think it’s your last gasp, but then you learn to ignore this side of things ... and you’re there gasping - just waiting for the body to right itself - there’s nothing else you can do. You try not to over-breathe. I used to start breathing in large gulps, to try and get the air down, but that doesn’t help. You have to do gentle breathing. You get to the stage where you’re unable to do something sometimes - you don’t talk about it - you haven’t even got the breath for it, you know. And I think here goes – we’ll calm in a few (minutes)” (P18/52-254).

Another participant described his fear of exertion-induced breathlessness, brought on even by movements such as getting himself out of a chair and standing up. In an attempt to overcome his fear and the impact of the breathlessness, he demonstrated how he had taken on board breathing exercises as advised by hospital physiotherapists in order to calm down. He said:

“I’ve made an appointment for the 18<sup>th</sup> - but it’s scary- I’m scared to death of moving, and fear... It does make you wonder where the next breath is coming from. Yes, I find it worse than pain ...”

He goes on to recount his experience at the dentist:

“I’d rather that (The dentist) than this ... well, the pain is not so frightening, is it? ‘Cos it’s like you’re being strangled – like somebody with fingers round your neck and you’re fighting them off... It’s not so bad as it was. I’ve learnt to deep-breathe, like this ... controlled breathing they call it” (P26/25-6,326-342).

Despite all COPD inpatients having access to a hospital physiotherapist for information and education on breathing exercises to control dyspnoea, only three study participants mentioned the carrying out of these exercises as recommended.

#### **7.6. Needing to feel in control to avoid undue breathlessness**

Although participants learned to tolerate breathlessness, the fear of uncontrolled situations, leading to increased difficulty in breathing, was a concern of many participants. As one house-bound man commented:

“Well, over the years you get used to it, see. I don’t panic like I used to, but it doesn’t take much to put you in a flap, like. If something out of the ordinary ... err ... say now, if there was a power cut, I’ve got to get from here to the bedroom and there’s oxygen bottles there, but I’m not sure how to connect them up see. My son he’d do it but he’s not here all the time. .... Oh yes, it doesn’t take long to get in a flap you know.” (P38/245-9,258).

One housebound woman whose bedroom had been moved downstairs removing the need to negotiate stairs said:

“I used to wake up gasping when I was very bad.... well you panic, don’t you? The best thing is to keep cool and try not to panic and breathe and take deep breaths- that’s what I used to do. ... Frightened yes, like because if I went upstairs I couldn’t come down, if I didn’t take my inhaler with me, and then I wouldn’t be able to go upstairs or down... But now I’ve got it around me so I can get hold of it, or if I go anywhere I take it with me of course so I can ...(participant points to lifeline pendant which can be used in an emergency)” (P48/196-224).

Anxiety and emotional stress was frequently implicated as causing increased breathlessness as another female participant commented:

“ I get very breathless. Now I’m alright (sitting down). I’ll go up the stairs but by the time I go up, of course I’m very short of breath [sic]. But I have good days and I have bad days, and, of course, as the doctor says and my daughter says – I panic – like if I’ve got to go somewhere or do something out of the ordinary. When I feel I need some air I start panicking then. If, as far as the chestiness goes, how can I say - oh if I have to rush you know, or if the family gets on my nerves sometimes, or if I get worked up about something or somebody, if they say don’t do this and don’t do that... But I do panic sometimes. The doctor said when you start to panic, then take a deep breath but you feel like it’s closing in on your neck.” (P43/30-3,120-6).

Some participants feared unusual or unplanned events occurring which could trigger unpredictable episodes of coughing and breathing difficulties. Typical comments include:

“... if visitors come anytime I can panic” (P6/250);

“ I don’t like a sudden influx of people unexpectedly calling in on me. I like things to be prepared and to know what’s going to happen” (P36/242-4);

“ I panic like if I’ve got to go somewhere or do something out of the ordinary (P36/33).

Participants implied that they like to be in control of their circumstances, so that they could control their symptoms. Unplanned or unexpected events risked triggering exacerbations of breathlessness, as individuals experienced unpredicted emotions or performed unplanned or rushed activities. It was unclear whether the anxiety triggered the breathlessness or vice versa. However, both symptoms were linked with unplanned events.

#### **7.7. The breathlessness – anxiety - panic cycle**

Feeling out of control in one’s immediate situation was likely to precipitate a cycle of anxiety, breathlessness and panic. This could be due to physical symptoms, such as failure to dislodge a plug of mucous from the throat, a prolonged bout of coughing and choking, or an episode of intractable breathlessness. Alternatively, psychosocial factors could initiate feelings of anxiety, causing increased breathlessness and possible panic.

For example, one man described how he lived with the fear of not being able to answer his door to callers in time:

“Lately when I’m waking up, when I sit up, I can’t breathe then. I’ve got to have some Ventolin® then, and sit there for about 5 min or so, then I starts [sic] to get dressed, and I’ve got to put my shirt on and I’ve got to sit then again, and it all takes time like, see. And what I find is say, if I’m getting dressed like that then, and someone knocks at the door, I panic then. I can’t then. I’ve got no chance of getting down the stairs then- I’ve tried not to- and I’ve tried telling like you- explaining to people, but I still worry about it like.”(P5/282-290).

Another participant who had moderate to severe COPD described her experience of a previous event, whereby she had felt out of control. She recalled:

“ I was driving to the hospital ... and as I was driving, I could feel my throat getting tight and I reached for my bag, which was on the passenger seat, to rummage in to find the inhaler, and I couldn't find it, and I could feel myself starting to get panicky and breathless. Well, I had to pull over and stop, and open the window to get some air, I was telling myself to breathe calmly, you know. It was quite frightening and yet I was perfectly normal when I set out. So I'm wary now, the inhaler is always kept within easy reach because once I've got that I'm ok – I suppose I'm reassured- I know if I can take the inhaler I'll be ok” (P52/107-113).

One man unsure whether to contact his GP about the increasing number of breathless episodes stated:

“ I was anxious about it you know- do I need to get help? ...and that sort of thing. I had one or two of those breathing attacks. I get over them once I sit down for a while you know. And a lot of my problem is probably being anxious” (P50/157-9).

## **7.8. Feeling vulnerable:**

### **7.8.1. Fears due to feeling vulnerable**

Individuals with advanced COPD often lose muscle tone, have corticosteroid-induced osteoporosis, and generally become physically frail. Due to loss of body strength and the reduction in physical endurance required to carry out normal daily activities, individuals with advanced COPD felt physically vulnerable. Individuals with severe breathlessness or dyspnoea often reduced their mobility and movement, due to a fear of inducing further breathlessness. Over time, the reduced level of exercise resulted in muscle wasting, reduced lung function and general body weakness. As a consequence, individuals become more dependent upon others, not only to carry out domestic chores, such as preparing meals and shopping, but also to assist with personal activities, such as washing and dressing. A few participants, who were in the terminal stages of their illness, required assistance to transfer themselves from bed to chair or commode, as they were physically weak, physically unsteady on their feet and experiencing extreme breathlessness, even while resting. One severely ill hospitalised participant (P9) required assistance to move position while resting in bed, as he was unable to move unaided. Movement of body position was carried out in stages, to avoid causing excessive dyspnoea, and subsequent distress. To minimize breathlessness, talking was limited to phrases or essential words to convey meanings. The above participant had a very poor prognosis. His condition illustrates the final,

terminal stage of COPD. Although most of the other participants had not yet reached this final stage of the illness, many expressed feelings of vulnerability, due to becoming increasingly frail and dependent upon others.

Becoming dependent upon others and losing one's independence raised concerns, fears and anxieties about being a burden on others. Participants expressed how these experiences of helplessness and feeling powerless to help themselves had left them feeling hopeless and vulnerable. Altered self-conceptions then impacted negatively upon feelings of self-esteem and self-worth.

### **7.8.2. Feeling vulnerable due to changes in the local health service**

This study was conducted during a time when several small satellite general practitioner surgery clinics were closed down, and a centrally based out-of-hours doctors' on-call system was being established. Also at this time, a few well-known local doctors either changed surgery location or retired. Several participants verbalised concerns about these changes in the delivery of their local healthcare services; some participants expressed apprehension and fears related to these changes, highlighting their feelings of uncertainty and vulnerability at the anticipated changes. One man recalled an incident where he called out his doctor:

“... But what I found is when you phone for the doctor - well he's full and you're put through to so and so, and then they put you through to so and so and ... before you got the doctor you knew. Especially at night now, you call the doctor now and you're through to (town). Well, if you want a doctor then, they've got to come all the way from (town). On-call see- I think it's a bad thing. Now if ever anything should happen then – and we've got five or six doctors in this surgery - you would think one of them could do an on-call now. Yes, I think so anyway. I mean I had a good doctor come out. He was very good to me, but that's what I say, you see, it takes so long. Whereas if you're really ill it takes too long for a doctor to come you know. I think the system is a waste of time myself” (P12/144-156).

Another concerned participant highlighted:

“Well we haven't got a GP now- we got locums... but there again this is his last week. He was very nice... but then again I won't see him again. .... And there's talk of closing down the centre here, but I don't know... And it's such a nice clinic, you can see the doctor, you can have injections, see the chiropodist, have blood tests and it's like a home from home, it's always been.... (would have to go) to C(surgery) which is overstretched at the moment. And, I mean it's no good me ringing up, booking up and having to sit

in a surgery with other people coughing and so on. (here) there's no waiting about- I go straight in and straight out – so it's ideal ...”(P3/255-277).

Many participants did not understand the new health service changes or systems and voiced concerns about the quality of available healthcare. This often related to: the lack of continuity of healthcare, not being able to see their own GP, or having to be seen in hospital by a locum or registrar instead of their named consultant. Several participants felt aggrieved by what they perceived as a lack of professional interest in individual patients. One man heatedly commented:

“So you know, they've no interest in you at all...I haven't seen my doctor since December- only others you see, well I've got to the stage where I don't care if I don't see the b----- you know.” (P14/103,130),

Previous bad experiences with healthcare services compounded feelings of vulnerability for a few participants. Most particularly, participants wished to avoid further unpleasant medical procedures and nosocomial MRSA infections. A few participants said they would be very reluctant to go into hospital again regardless of their doctor's recommendations (P35; P27; P48).

### **7.8.3. Feeling vulnerable: lack of empathy from others regarding dyspnoea and panicking**

For an individual with severe COPD, becoming short of breath can easily escalate into a frightening situation of breathing difficulties and feelings of panic. Participants familiar with such a scenario say they gasp, cough and splutter as they try to regain a steady breathing pattern. Contrary to some participants' accounts of feeling breathlessness (n=43), other participants (n=10) deny onlookers' observations that they panic. One bed-bound man tried to explain:

“And then they call it panic attacks, and I say I'm not panicking, it's just I can't get air in my lungs and I'll be like ...” (makes groaning noise to ease the discomfort) (P9/268-70).

Another man contracted himself by saying:

“No it doesn't frighten me. But mind you, I do get frightened, 'cos when I'm breathing heavy [sic] and I'm getting a panic attack on, well the consultant says but ... err ... I don't know how he means - it's when you're breathing heavy, then what are you to do when you can't get the air?”



His wife added:

“ Well all the doctors that come here said to me- he’s panicking- he’s panicking too much because he’s breathing heavy and when I tell him that, he says ‘I’m not’. ‘Yes you are’, I says. I knows [sic] that myself, he’s panicking, you know. I think he is.”

The participant retorted: “Well what are you to do? Breathe - how?”(P23/327-335).

Another participant recounted a previous conversation she had had with the consultant:

“[You feel] frightened (couldn’t breathe) and, as he said, when you’re like that you’re gasping for breath, he said, but your lungs are full - you want to get rid of it not try to draw it in but you think you want to draw it in see, ... it’s a terrible feeling” (P16/115-7).

Although these participants often felt a sense of panic when they were breathless, they did not want to be perceived by others as panicking. They tried to give rational explanations for their behaviour, attempting to regain a sense of social acceptability and self-respect.

## **7.9. Losing self-confidence**

Concerns over the uncertain illness course and its future and fearing for compromised physical safety contribute towards participants losing their self-confidence. For several participants, losing self-confidence was due to losing their physical strength, fitness and ability to be self-reliant and independent. As one male participant, a retired builder said:

“ I still want to go out, I still want to work, I still take an active interest in the garden, but I can’t do it- I’m gasping- terrible. I feel disarmed, my strength, my punch and power is no use to me – I’m washed out. Whereas I could hold my head up and couldn’t give a damn about nobody, but nowadays I’m looking at the adversities ..... anything energetic now... I’ve no faith in my legs- I can feel them, they’re gone... the muscles have gone...” (P17/278-287).

He went on to say how he had imagined having a puncture while out driving:

“ And what a panic! And the thought - I’d have to get out and jack it up. I wouldn’t be able to do it, and I got frightened. If I break down I’ve had it, but I’ve got all the tools in the back. ... But there’d be no one to help me. But I do get panicky now. I think one day I won’t be able to bend. I won’t be able to

get under the wheel, and I won't be strong enough to push the gear – oh dear!”(P17/420-6).

For another man, getting the car out of the garage to drive less than a mile down the road was the only solution to his immobility problem, caused by breathlessness. As he said:

“ I can't walk from here to the garden shed. I do feel guilty to have to get the car out to go down the village but as long as I can use the car - but it has come to the stage where I'm not as confident a driver as I used to be. Put it this way, I don't drive for pleasure. Because of the breathlessness - it takes away one's confidence um, I suppose it makes you feel vulnerable.” (P28/47-54).

However, for other participants, going out of the house, let alone driving, had become impossible as one severely disabled man pointed out:

“ This last three months.... I'd been going out in the car like. I've now all of a sudden – with the winter coming on- it'd got a lot worse- I'm frightened to go out... Well, I can't go out. I've only got to go to the door and I'm out of breath...” (P5/26-9).

#### **7.10. Fear of being alone**

Many participants revealed their anxiety of being breathless was compounded by being left on their own. Being alone accentuated their feelings of vulnerability. For some 'being alone' meant living alone. For example, the above participant describes why he is worried about his condition:

“ It's probably that the winter's coming on... I was worrying about the winter coming on... It's in the back of your mind like, you know... I wasn't so bad when there was someone here with me (wife) - it wasn't so bad then. It's being on your own” (P5/327-335).

Another female participant said:

“ Well you've got to accept it- what else can you do? I have a good cry sometimes and I do feel it, being alone you know. And I do still miss my husband although it's been three years now”(P31/101-3).

For other participants, their fear of being alone was even more intense, as revealed by the following extracts. One married woman highlighted her worst experiences of living with the COPD saying:

“Oh, to be alone - oh yeah, see. If I don’t feel well, and like he says he’s going out in the car, I says no! No you’re not going out there, and he knows something’s wrong then. So he says, ‘come with me’, or if he’s got to go to the doctor or whatever, the woman next door comes in. I don’t want to be alone ‘cos I’d be frightened I’d pass out and no-one would be here, you know.”

She described a past incident in which her husband had returned home to find her collapsed on the floor in a hypoxic state of extreme breathlessness and mental confusion saying:

“That time I passed out- I can remember buzzing in my head.... and I was arguing, saying, ‘no, no- I’m not going (to hospital)’” (P24/276-285).

Another participant described how she felt during a period of exacerbated symptoms, which marked the onset of the illness’s severity, she recalled:

“ And I wouldn’t let Ken go out of the house at all...and I was so scared.... frightened” (P16/111-2).

A recently widowed man tried to rationalise his fears:

“ I am most practical and self-disciplined, but I feel like as though I want to run- I want to run away from it. I’d get what I call now anxiety. I’m dead frightened of what I know won’t happen anyway. I mustn’t worry about my feelings or else I wouldn’t live alone otherwise” (P17/342-5).

Some individuals turned to specific people as ‘confidence boosters’. They trusted these people, usually a close relative: a spouse, daughter, son, or a specific healthcare worker to help them deal with their lives; they had promoted feelings of confidence and well-being. Following hospital discharge from the intensive care unit, one woman described how she was coping, by staying at the house of one of her daughters. She said:

“...So I stayed at Jane’s so she could watch me all the time ...and it’s only Jane that can sort of help me calm down, which she does- the other daughter isn’t so good. Well, it isn’t that she isn’t as good, but we’ve just got used to each other”(P7/131, 145-8)..

Her daughter added:

“ It’s just that I know what mum is thinking – she’s only got to look at me a certain way.”(C3/151).

### 7.11. Fear of being without a confidence booster

Many participants admitted to relying increasingly on someone or something to provide practical and/or moral support to overcome their growing helplessness and vulnerability. Participants considered that not only being alone, but also being without a specific confidence booster was a cause for alarm. One man who had been recently widowed described how he felt frightened by his symptoms and indicated that having a light switch and oxygen within easy access, boosted his confidence. He described his situation at night, saying:

“And then I don’t sleep, I’m sitting at this table, I reckon every two hours ... I wake up suffocating and once I wake up I want to stay awake...I have a cup of tea ‘cos my mouth is so dry ‘cos I’m breathing through the mouth.... I get panicky in the pitch black now, and once I couldn’t find the oxygen, but I’ve got it established now.... So I’ve got it there at hand, so I can pick it up, and I’ve got the other one (oxygen mask ready connected up to oxygen supply) in the other room” (P17/342-356).

Many participants valued emergency phone alarm pendants; they knew that help was at hand in times of crisis, because using their alarms would alert the local ambulance service. The above participant described how he felt supported by the ‘Lifeline’ service to allay his constant anxiety and fear of not being able to breathe. He said:

“And now – well I couldn’t be catered after better, ‘cos I’ve got my punch bag and my button, and when I press that button it’s only minutes, and I’m talking about those ambulance people - lifeline - yes. That’s absolutely essential. I couldn’t go anywhere without that... it’s the biggest comfort I’ve got- it’s like having a mum around you. It doesn’t matter how dark it is - those ambulance boys are sitting there – oh it’s wonderful, plus the speed in which they get to you” (P17/447-456).

Several participants highlighted the importance of having their inhalers, nebulisers or oxygen supplies close at hand at all times, in case of an unexpected need for additional pharmacological support. For some individuals, being without their oxygen supply, even for a few minutes, would cause alarm, as one woman described:

“I’m on it (oxygen) twenty-four hours, constantly and there’s a portable for the car, but I haven’t used that one much. Yes, constantly- the only time it comes off is when I’m dressing and I whip off my nightie and panic to get it back on. It’s all a bit of a rush, so as to not be without it for long... I have tried without, but I don’t know if it’s partly psychological, but there is a difference” (P27/76-84).

### **7.12. Fear of dependency on therapy**

A few other participants voiced concerns that they would become dependent on their medication; oxygen therapy was the most frequently mentioned. As one participant described following hospital discharge to home, he attempted to wean himself from his twenty-four hours a day oxygen therapy. He said:

“I’m trying to start going to the outside toilet without oxygen ‘cos in hospital when you went they were encouraging that. I done it once last night, but I weren’t there long. I couldn’t get back to this (oxygen) quick enough ...”  
(P26/ 95-7).

Oxygen therapy is not addictive, and can only improve life expectancy in those patients for whom it has been appropriately prescribed (Nocturnal Oxygen Therapy Trial Group, 1980; Medical Research Council Working Group, 1981; Crockett et al, 2001). This is a frequent misunderstanding by patients who are prescribed long-term oxygen therapy. One male participant who took early retirement commented about his medication, he said:

“If I’ve forgotten the inhaler, I do feel uncomfortable, so it is a habit, I realise that if I stand still I get my breath back and then I carry on. The Ventolin® does help, it calms everything down and helps with the throatiness, and the wheeziness goes but I don’t like to taking it too often. I don’t want to get reliant on it- I daren’t do” (P53/76-8,86-90).

### **7.13. Fear of losing social respectability and personal dignity**

As symptoms become more severe and pronounced, individuals with COPD frequently have not only retired from employment, and resigned from participation in leisure and sporting pursuits, but also become increasingly self-conscious in public about their wheezing and laboured breathing. As one male participant noted:

“Well, I do feel conscious of being breathless. I am conscious of puffing - particularly to anyone who doesn’t know my history and they must wonder what is the matter with me” (P28/115-7).

Out-door activities, or the use of public transport, which had previously become curtailed, are eventually permanently given up, as even the tactics of self-pacing and energy saving are inadequate for continued independent mobility. Consequently, several participants had resorted to wheelchair use, each having a different attitude

towards this aid. Although the use of wheelchairs enabled these participants to maintain a degree of mobility and social integration, some were concerned about their image or identity as invalids. Most participants who used wheelchairs described their initial apprehension. For example, one younger woman recalled:

“ Well two year(s) ago, I didn’t get out of bed. Then the specialist nurse got me a wheelchair, so I started to go out. Then he (husband) could take me out in the wheelchair. Before, I wouldn’t have one- I said, ‘no - it’s stupid to have to be pushed in a wheelchair’”(P24/ 73-35).

Most participants’ attitudes towards being seen in a wheelchair were shaped by a resignation to its practicality, and by other people’s responses to being seen in a wheelchair. One woman described overcoming initial feelings of self-consciousness and embarrassment due to a positive encounter with a previous acquaintance. She said:

“Anyway, the other week I went to Tesco with my sister, and she got me a chair and took me round and that didn’t bother me, until I met somebody that I knew. And it was one of the lads that used to play bowls with me, and I did feel a little bit embarrassed, but he didn’t seem to think anything of it so – but you do get a bit embarrassed” (P33/137-40).

Over-coming the self-consciousness associated with being in a wheelchair was promoted by being surrounded and supported by member of the extended family, who made light of the situation. As one man said:

“...It’s alright I suppose, I’d put up with it. If you want to get out, you have to put up with a wheelchair... I wouldn’t grumble. Luckily, one of my daughters is full of the joys of spring, and she’d push and shove and laugh about anything, it’s all a big joke sort of thing” (P35/255-262).

For others it was a means of not being left out of social and family outings. The wheelchair was a source of liberation and enhanced self-esteem. It compared favourably with former experiences of self-consciousness in public places, struggling to walk, while impeded by breathlessness. As one woman said:

“If you’re walking slow [sic] in the rain, when everyone’s hurrying, and they look at you as if to say, ‘what are you doing, you fool!’ ... It’s just the things you remember, and they stick in your mind, not that I walk now, I use a wheelchair now... And I don’t mind at all, cos otherwise I would be stuck, you see. I wouldn’t be able to do a lot of things” (P7/ 223-5,230-7).

However not all participants had come to terms with using a wheelchair. Another female participant claimed:

“ I go in the wheelchair, which I hate.... You feel that people are looking at you, and especially children. I know they don't mean anything, but somehow you know and people talk over your head. They'll talk straight to my husband and ignore me.” (P27/65-9).

For other participants, being self-consciousness about using a wheelchair resonated more deeply than an awareness of being seen as disabled. It confirmed a change in self-identity, which was difficult for some individuals to accept initially. As one participant said:

“I don't know yet, because I have never tried a wheelchair – part of me rebels. I don't want to be in a wheelchair, and part of me feels it would be nice to go any distance ... but I don't like the thought of it, to be honest. But it'll have to come to it, I know that ...but it's certainly worrying - having to cope with it. I don't fancy being in a blasted wheelchair. I will though, but I want to see myself as being fit and active...”(P49/311-322).

Several participants pointed out how they felt uncomfortable when in a crowd of people, socialising or speaking on the telephone, due to bouts of uncontrollable coughing. Troublesome symptoms included laboured, exaggerated, heavy breathing, bouts of prolonged coughing, due to accumulation of phlegm, persistent cough, due to a dry throat, brought on by inhaled medications or oxygen therapy, and a wheezing chest. These symptoms contributed towards many participants' self-consciousness and fears of not conforming to socially acceptable norms while in public places. Previous experience of similar embarrassing episodes influenced many individuals' decisions to withdraw from social activities, such as church services, committee meetings or larger family gatherings. One woman spoke of her embarrassment:

“And if I'm in church...when you keep on cough, cough, cough and you've got to - the more you try and stop it, the more it goes on...” (P13/182-4).

Another participant pointed out:

“ I used to sing in the chapel in the choir, but I daren't sing because I start coughing straight away. I'm not just coughing, a bit of chest coughing, but you're heaving from the bottom- a real bad cough you know” (P14/113-6).

For those severely disabled participants who were totally dependent upon others for personal care, social respectability and personal dignity was further compromised as a

consequence of the illness. One man, who received visits from a home-carer four times a day, appeared self-conscious, and apologised for her regularly needing to remove and wash a bowl that he used for expectorating thick sputum every day (P38).

In addition to COPD symptoms, the side effects of medications taken to control the disease often impacted upon individuals' functioning and psychological well being. Participants indicated that side effects of prescribed medications caused physical and/or social problems and self-consciousness. Common issues included: antibiotics prescribed for infective exacerbations of COPD resulted in oral fungal infections; long-term corticosteroids caused fragile, aged and bruised skin and/or weight gain; bronchodilators induced limb tremors when inhaled regularly; diuretics, to reduce body fluid volume and improve pulmonary function, necessitated frequent and urgent visits to the toilet. For example, one woman had recently been discharged from hospital following admission for an infective exacerbation of COPD and pneumonia. She said:

"I'm on (cortico-) steroids ... But the trouble is, I've put a stone on ... It weighs me down, and that makes me breathless... And my ankles were all swollen...(Take) Frusemide ... I had reduced sodium levels and the dietician brought me supplementary drinks to push up the sodium, but I couldn't chew, I had thrush in my mouth – it was all sore and my tongue was black - oh I was a mess" (P27/89-100).

Another participant demonstrated the side effect of his broncho-dilatory medication:

"Oh, I shake very badly, very badly – sometimes you look as if you're having a seizure - it shakes terrible (holds out his hand)" (P49/95-6).

#### **7.14. Fear of being perceived as a fraud: struggling for legitimacy**

Often the symptoms of even moderately severe COPD lay dormant until triggered by movement or some other factor. Therefore, many individuals sitting quietly may avoid undue breathlessness, wheeze or coughing, and may deceptively assume an appearance of being 'normal'. Participants revealed how they feared movement and exacerbation of symptoms. But also, because outwardly they were not visibly disabled, they feared that healthcare professionals, and the general public perceived them as fraudulent.



One man, a farmer, described how, on a previous hospital admission, a junior doctor had told him, ‘there was no need for you to be in here’ and a physiotherapist had said, ‘oh you can go’, implying his condition did not warrant hospitalisation. He commented:

“But when they turn round and say there’s nothing wrong with you, that’s one of the things that really hurts me. You could turn and say to me now there’s nothing wrong, and there’s nothing wrong at this very minute but if I was to run out of the kitchen you would see” (P11/258-267).

He went on to say:

“You’ve got to treat it like a lazy man you know, there’s so many things out there on the yard (to do) and they (farm workers) must think – look he must be lazy- but you mustn’t push yourself that bit.” (P11/354-5).

One woman was particularly distressed about how she thought she appeared in public while out in her wheelchair with her husband, she explained:

“We changed it from one with small wheels to one with large wheels so I can help get it up over the ridges at the curb, otherwise I had to stand up and my husband would lift the chair over and I would get back in. But then I would notice people looking at me as if to say, ‘well if she can stand, why is she in a wheelchair?’, and that made me feel well, uncomfortable” (P27/70-4).

Even family members sometimes don’t realise the degree of disability caused by the illness. One participant and his wife who had two teenage children pointed out:

“The children find that hard, don’t they? When you’re sitting there and you say you’re tired and they say, ‘well you haven’t done nothing [sic]’, they don’t realise how hard it is to breathe. It’s hard. He says to me... ‘I don’t know why I’m so tired I’ve done nothing’, but I say, ‘look how much effort it takes to breathe’”(P+C/257-62).

#### **7.15. Feeling down and depressed: fluctuating feelings**

As the symptoms become increasingly severe, curtailing daily activity and limiting physical independence, most participants experienced negative feelings, induced by their situation. These included anger, remorse, frustration, emotional turmoil and depression. For some, their condition was not an issue but just a reality of their daily lives. As one man said, despite intermittent coughing throughout the interview:

“You don’t think. If you think of your illness, the worry of it will kill you before the disease does! If I feel a bit tight chested, then I go down and see the doctor. You know you’ve got an illness. There’s no good in worrying about it!”(P44/175-8).

However, most participants acknowledged that from time to time they experienced feelings of low mood or depression, and these feelings were never far away. ‘Feeling down’ was attributed to several factors including: the fatigue and general loss of vitality associated with the illness, fears and energy expended on breathlessness and striving to avoid loosing one’s breath, the loss of independence and spontaneity in pursuing previous lifestyles and activities, perceived change in self-identity, an uncertainty as to future living arrangements, and the suspected shortened life-expectancy. Just as participants often made light of or played down the impact of physical symptoms, then so too did they play down their feelings of gloom and depression. Most individuals talked about feeling down at times, but then made comments, which attempted to display a stoical or moral attitude. The following extracts were spoken by participants who were married and able to get out of the house, but who still experienced low feelings periodically.

“Yes, I get days when I feel down, but you just have to try and pull yourself out of it.... Frustrated - very frustrated - angry yes- but you look around you and probably somebody else is saying the same about something, so there’s really no point in - well you know” (P3/93-110).

“I get down in the dumps sometimes, but you might as well die with a smile on your face as not. I always say look on the bright side - but you can’t always” (P11/ 138-140).

Similar feelings were expressed by the participants who were house-bound due to their COPD. One woman commented:

“Yes, the breathing is getting me down. I do get down from time to time.... Life is non-existent - all I do is sit in the chair. I miss going for walks...I try to be positive, I mean, you have to be, don’t you? But every so often I get down. I’ve never been a person to sit? ...down, but you’ve got to keep trying. I’m never going to give up”(P27/18,57,111-3).

Another participant stated:

“I’m not going to be an invalid, I’m going to keep going as long as I can. But no, it does make me very depressed – we’re lucky though - we’ve just managed to get the allowance, the attendance allowance.”(P49/274-77).

Despite experiencing intermittent low moods, most individuals drew strength from having a supportive spouse or family to compensate for the negative aspects of the illness. This sentiment is captured in the following comment:

“It does get frustrating, and sometimes I do get down- not often – but I do, and I think, ‘oh dear, why me?’ I’ve got to say that I am so fortunate in having a supportive family” (P7/164-6).

A minority of participants reported more persistent and severe low mood states. They revealed feeling helplessness and experiencing a lack of motivation, as they existed from day to day. Aware of the limited pharmacological treatment for their advanced disease, these individuals felt they had nothing to look forward to. Three of these hinted at having had suicidal thoughts. One man, who was married and worked in a family business, appeared to be clinically depressed saying:

“ I’ve been feeling down, very, very down. There’s no doubt...you know, I get up in the morning, and want to get on with something, but... I couldn’t care less. I couldn’t care if I live or die, to be honest with you.” (P45/211-13).

Another male participant disclosed:

“Well, I do try and not let it affect me that way, but I do sometimes- sometimes at the end of the day, you know. I just want to sit down and take no notice or interest in anything...and you wake up and... you’ve got to be more positive about it all....I did.... a few years back, but I gave that up, that was too defeatist, that was how I looked at that so, no – I had too much going for me to think along those lines – not to dwell on it” (P18/256-268).

Other (n=10) participants had recently lost a spouse, and now living alone, they felt despondent and lonely. One woman commented:

“... There’s nothing else they can do about it anyway... Well, I’ve got to accept it- what else can you do? I have a good cry sometimes, and I do feel it, being alone, you know.... Well I do feel upset sometimes ’cos it’s always there, and it’s not going to go away, so I have to accept it and do my best” (P31/72,101-2,180-1).

One housebound man said:

“ Well at times I get a bit depressed yes, because you’re on your own, and you sit there, and as I put it, you look at the four walls. There’s the telly, but I’ve gone off telly, strange as it may seem...Depressed and confined to this space - it shortens your life altogether... I don’t know really” (P38/210-13,267-8).

Another participant disclosed:

“Well I gets a bit down hearted, ... well actually, a lot of the time because...’

He went on to explain that following hospital discharge, he would probably go into a different nursing home from that of his wife. As well as his deteriorating condition, the pain and fear of breathlessness, he was also worried about the financial arrangements.

He explained further:

“... We’ve been 49 years married now, and I haven’t seen her now for ...err 19 weeks. How am I going to manage? ‘Cos if I walk from the bedroom to the bathroom, I would cough straight away, you know... you get so stressful that you’re at the verge of breaking down... you get to that stage when you want to end it all....” (P9/241-292).

However, most participants experienced continuous fluctuations, between feeling down, and more positive mood states. Participants frequently used the phrase of having ‘good days and bad days’ reminiscent of work on chronic illness by Charmaz, (1980).

#### **7.16. Fears for the future: uncertainties and decision-making**

Most participants expressed concerns for the future regarding living arrangements. Due to the uncertain future course and nature of their illnesses, many participants (and their carers) felt uncertain about how they would manage if their level of functioning deteriorated further. Less than 50% of participants with COPD lived with a family member, or received daily visits from formal carers (social service home-carers). Of the other participants, some admitted to having given thought to how they might manage in the future, if their condition continued to deteriorate. When asked by the researcher ‘what would you do in the future should your condition worsen?’, participants’ responses differed.

Due to their growing acknowledgement of the reality of their degenerative illness and its impact upon effective and safe functioning within the home, some participants had changed their living arrangements or were currently investigating options. In view of their deteriorating condition over the last few years, five participants and spouses/partners had either moved from a house to a bungalow, into a granny flat adjacent to their family or into a residential home. Most had stayed in their own home, including sheltered accommodation, but had installed aids, such as rails or a stair-lift (n=48). A few participants recognised that it was likely that, in their words: ‘they would end up in old peoples’/nursing homes’. Others vowed that they would not go into a nursing home, come what may! However, the latter group all had family, whom they felt they could rely on to provide the care they required and were already fully dependent upon this family support. A few participants voiced strong opinions against going into a care home. For example, one man, who had extensive family support responded:

“Oh no- I’d jump off the bloody roof before I’d go into a nursing home- no-way! (P35/400).

A widowed participant who had virtually no family and was equally opposed to going into a nursing home, however realised:

“I try not to think about it (the future) because- especially as I’m on my own, I think I know that I shall end up in a home...” (P4/214-5).

She admitted that going into a home would be her greatest fear saying:

“ Losing your independence ... and I hate being told what to do. I’ve been alone for a very long time... and become very selfish I suppose... and I would hate to be spoken down to, as if you’re an absolute idiot... and shouted at you as if you’re deaf.” (P4/230-241).

However, for a minority of participants, those living alone or living with equally frail/disabled spouses, going into a residential or nursing home seemed the only ‘safe’ solution. A typical case involved a participant who had been interviewed on a hospital ward during an admission for an exacerbation of his end-stage COPD symptoms. Already, his wife had spent the last few months in a nursing home, and when asked about plans for the future he replied:

“ Well yes I have- err well no I haven’t. I’ve got my wife in Park House, and so I’ve got to decide one way or another, before long, what I’ve got to do. Can I manage at home? If not, I’ll have to go to an old people’s home. I think it’s going to end up like that now....” (P9/231-5).

When asked if he could reside in the same home as his wife he was doubtful replying:

“Well I could if I would get in there with her... We’ve been married 49 years now, and I haven’t seen her now for err nineteen weeks....No, I don’t know when they’ll get room” (P9/240-245).

More than one participant noted how they might lose out financially if they moved into a care- home. As one man pointed out:

“ I don’t want to go into a home if I can help it, you know, but- ‘cos you loose everything if you go into a home like. They take the house and all you know- that’s the bit I’ve got against it. Well, I think now, if the children should have that now, you know. ... I wouldn’t worry so much then, no, no I think I wouldn’t worry about it (P5/437-449).

Some participants considered that their illness had stabilised and were in denial; regarding the possibility that their condition would deteriorate any further. Despite their severely disabling condition, these people had not given serious consideration to the idea of moving into a residential or nursing home. When asked to give their views on the subject, most participants expressed the hope that their condition would not worsen, beyond its present state, and assumed that they would continue to manage, despite being already disabled.

#### **7.17. Fear of surgery**

Lung surgery is an option for a selected minority of patients with severe COPD. Elective surgery had been suggested to four of the study’s participants, one of who had already received lung volume reduction surgery a couple of months prior to the interview. The other three participants were waiting for further discussion with their physician. However, already fearful of the unpredictable natural course of their disease, these individuals experienced further anxieties and uncertainties about being offered elective surgery. They were identified as being potentially eligible for surgical intervention by certain physiological criteria; either for lung volume reduction surgery or for lung transplantation. This surgery had the potential to improve their quality of life (Naunheim et al, 2006; Hosenpud et al, 1998; GOLD Executive Summary, 2006).

However, for these selected individuals, the potential benefits of surgery had to outweigh concerns regarding the risk of the operation. Ultimately, the final decision rested with the patient, and deliberation over this dilemma created further anxiety, uncertainty and fear. Three potential participants expressed a desire for further information about the procedure itself, the chances of success and information on others who had undergone similar surgery. The fourth patient had devolved decision-making to the consultant physician, content to comply with his considered 'superior' knowledge and judgement. In stark contrast, the one participant who had previously undergone lung volume reduction surgery received the intervention largely as a consequence of his persistent and active campaign for surgery. He had become well informed through his own endeavours to access relevant information about lung surgery and then lobbied for surgical intervention. Although realising the risks, his main concern was not that of surviving the operation, but to get it done and to determine how successful the benefits would be post-operatively. As he said:

“ I was very, very fortunate at my age to be offered the opportunity to have the operation...It is a very dangerous operation, because, apparently, they shut down the one lung that they're going to work on, and you're breathing with the other one. Now if that's a damaged lung anyway, this is where the risks are. ....But... They say that within five years I should be in the same situation as I was before I had the operation. But when I went up the last time he said to me. 'Look you have levelled out, you're not improving any further'. I said, 'well, how long should you improve before you level out?' He said: 'up to three years'. So that's the down side, as I'm concerned. I suppose I've levelled out too soon. I should be getting more improvement, and I've noticed it” (P20/104-120).

The other three candidates expressed varying degrees of concern and anxiety about undergoing lung surgery. The one woman, confident in handing over the decision-making to her consultant, expressed the least anxiety, as she said:

“ Dr. J. is at the moment talking about surgery-so- yes 'because of my age', and well I think he said to my husband either a transplant or what they call a section, where they take part of the lung. I don't know but this is what he felt, well he's mulling it over...well it's a big thing but there again if it gives me ... I think it would be worth it – oh yes definitely. ... If Dr. J. can help me, all well and good, you know. As I say, I'll leave it in his hands, he's the man who knows- I've a lot of faith in him. I mean he knows better than I do – you know- how I cope, and whichever way he decides ...as he says he may decide not to, he's just mulling it over...” (P3/ 11-23,324-330)

However for the other two participants the prospect of lung surgery for their emphysema invoked feelings of considerable anxiety, apprehension and fear. During their conversation about lung surgery both participants talked about other individuals who had previously undergone similar operations with differing outcomes. When asked how she felt about waiting for a transplant and carrying a bleeper, one participant responded:

“ A bit nervous yes- because I went down there (Papworth Hospital), and spoke to one girl- she’s the same age as me- she was. She had hers and she was showing me the scar and that, and I had to go and see the surgeon to see what he said about me. And then, when I got back up to the ward, I thought it was a bit strange like- the curtains were pulled across and it was all quiet- well she’d died. So that threw me a bit. It did frighten me then ...”(P24/48-56).

“... And after I got back I found that she’d gone...and I was panicking like hell- so I don’t know if I want it or not.... One day she was there and the same day she died. I mean... and I don’t know that the drugs were working properly. Well once you’ve got that bleeper you’ve got to go, if you get that call. You can’t say I don’t want to go now ‘cos it’s not fair on other people... I don’t know really what (to do)...”(P24/428-438).

The other participant was also nervous about having lung surgery as he had seen his own father have lung surgery, but his fears were reduced by currently knowing someone who had undergone a similar operation, his response was:

“ Well to be honest with you, having my lung out ... I’m a bit worried, you see Dr. J. told me that I haven’t got cancer. My father died of cancer and my father did have his lung out, but that’s going back about 30 or 40 years ago and things have improved since then, so. And I know a person who’s had his lung out and he’s been much better afterwards. He didn’t have the same complaint as I did though. He’s much better and he’s in a choir and no problem.” (P8/194-205).

Displaying concerns about the actual procedure, he continued asking:

“Well my dad had it round his back, round here and in front... they still break the ribs though? (P8/215-18).

In fact participants have some reason to be apprehensive about consenting to surgery for emphysema due to the high- risks associated with the procedure and reported previously poor outcomes (Benditt and Albert, 1997). However, more recent studies have shown increased survival and quality of life for selected COPD patients, meeting specific criteria for lung volume reduction surgery (Naunheim et al, 2006) and



improved quality of life and functional capacity following lung transplantation (Hosenpud et al, 1998).

#### **7.18. Facing the Future: Fear of fatality**

By the time participants had survived at least one respiratory crisis, and were living with chronic breathlessness on a day-to-day basis, most had realised that their prognosis was fairly poor in terms of duration of lifespan. Added to the increasing severity of COPD symptoms, many of these individuals experienced the complications and discomfort of one or more concomitant diseases, such as cardiovascular disease or osteo/ rheumatoid arthritis. Others considered ageing as another reason for their condition not improving. Although a few participants mentioned having talked about their prognosis with a healthcare professional, only one woman disclosed that her GP had brought up the subject of dying. She said:

“ No, Dr. M. was suggesting.... are you prepared for eventually it's going to happen... it's because I've been seven years on a nebuliser now. I can't go on much longer and she wanted to talk about death but we didn't want to...”  
(P51/234-6).

During the course of the interviews, participants often raised issues relating to their future. Their attitudes towards dying were perceived by the researcher as ranging from denial, through avoidance to acceptance. Although nearly all participants admitted that their symptoms were worsening, and as one man acknowledged:

“You're on the slippery slope” (P18/328).

The majority claimed that they did not want to think or talk about 'the future' in terms of death and dying, although the subject was often implied. For example, one woman broke down in tears when talking about the wedding plans for her daughter. She said:

“You don't plan - you don't, not with this. And with the emphysema, it's a matter of as long as your heart can hold out. You don't plan, but you take each day as it comes. If you think now J. is getting married next year ... And I will go with her, want to look at dresses and so on, but I don't want to look for myself...not yet, not yet, maybe next year; but this is what you do, you don't plan. You just say if I do reach that time, thank God, then so be it.” (P7/335-340).

She went on to talk about the family and grandchildren she has and ended the subject saying:

“So I think lovely, well done... right, now we’ll change the subject” (P7/344).

However, this subject appeared to be at the back of many participants’ minds as they described seeing fellow patients die on hospital wards, and commented on family members or friends dying from respiratory-related illnesses (P5; P11; P36; P38; P17).

One man disclosed his fear of dying:

“It’s scary- I’m scared to death of moving and fear- yeah and by night - well some nights I’ve... well I’ve felt quite strange - err lack confidence, thinking this is the end. I do really. mmm ... It’s very difficult (P26/24-7).

However, a few other participants discussed their impending mortality freely and openly, for example one woman commented:

“ I shall probably die of it – or die of heart failure – the same as my mother did sitting having a cup of tea... no it doesn’t worry me, no” (P29/165-171).

A male participant commented:

“ I’ve accepted the fact it will get worse gradually- I’m accepting it but she’s not (wife), I know my energy levels are dropping... that’s the way- I will die that way” (P53/158-164).

One participant had ensured that all his funeral arrangements were in place and had instructed his wife exactly where he was to be buried. His wife recalled a time when she had called out the doctor:

“She (the doctor) said, ‘don’t worry’, and he said, ‘well when my number’s on the wall, I’ll be gone’ ... that’s him, he takes everything as it comes, if he were to go tomorrow, he doesn’t care you know...” (P+C 23 /254-264).

Further dialogue revealed that this participant feared dyspnoea more than dying. Another house-bound man talked of the will he was having drawn up so he:

“...Could stop worrying- just in case”(P35/4-48).

“ I’m 71 so it’s not going to get any better is it? No, we’ve never bothered about talking about this place –making a will- if you like, but we’re doing it this week aren’t we? So you can tell how serious it is. Yeah ... I’ve known about it for sometime but you kind of put it out of mind you think – next year ... so yes we’ve taken the bull by the horns haven’t we?”P35/389-95).

However, when asked about the future, the majority of participants talked about how they could see degenerative changes in themselves, but skirted the subjects of death and dying. For many, daily living had become a struggle and required stamina to continue. One participant summed up what others implied stating:

“You have to push yourself on, what else can you do?”

And many noted that: ‘Nothing else can be done’ in terms of medication. As one man said:

“That down side of it does get me now and again, but it’s no good dwelling on it like, you know. I drive myself on...” (P18/306-8).

Awareness of the limitations of medications for symptom control, together with realisation of deteriorating physical function, caused distress and low mood and /or depression in many participants. One man with end-stage COPD, who had suffered increasingly over the years said:

“You get to that stage when you want to end it all. You get a lot of time to think ...and then they (carers) say get up and do a bit of walking, but you can’t get the air. And what with the hiatus hernia and rupture, it just takes your breath away.... Some days are better than others.... and it’s always there... (P9/294-9).

Being unable to plan ahead, and living from day-to-day appeared to be a means of coping or enduring for many participants who chose not to confront the reality of their situation, and hovered between hope and despair. The following extracts are typical comments made by participants who had previously led busy lives but now strived to get through each day without aggravating their symptoms. A married man living on the family farm commented:

“No, well what can you do? Nothing. I do what I can, and that’s it, you know. You’ve got to sort to live every day as it comes. Yes, it’s no good saying I’m going to do this and I’m going to do that next week. Lets get today over first”(P11/447-450).

A widow living alone remarked:

“There’s nothing they can do about it anyway. If I can just keep it down, you know, if I can get along as I am now and not get any worse. No you can’t plan ahead- you have to take each day as it comes. You get a good day and then a not so good day...” (P31/72,98-9,153-4).

A married woman who had to take early retirement said:

“As I say, just go from day to day, ‘cos some days you’re good and some days you’re bad- you can’t –so planning is out of the question.... But I just try and pull myself. Yes, I get days when I feel down, but you just have to try and pull yourself out of it. I don’t think about the future, because I think it would depress me ..... I just live day by day” (P3/87-95).

Despite a general vague awareness of having a poor prognosis, some participants commented that they deal with problems in the future, when and if they arose. Not wanting to face up to the fact that their life expectancy was now coming to an end, these participants frequently changed the topic of conversation within the interview as they preferred not to pursue thinking or talking about the future in terms of dying and death. (P7, P41; P42; P47).

Of the fifty-three participants with COPD who were included in this study from August 2000 to June 2002, nineteen (n=19) had died by the summer 2007, six (n=6) of whom had died within twelve months of being interviewed for the study. A further six (n=6) had moved out of the locality and could not be accounted for.

## **7.19. Chapter Summary**

This chapter explored participants’ experiences of living with advanced COPD and highlighted the issues and concerns related to the illness severity during the later stages of the illness trajectory. Central to the experience of living with severe COPD is the fear of not being able to breathe during times of accentuated breathing difficulties. The chapter highlighted the continuing anxiety felt by individuals as they lived in apprehension of future episodes of dyspnoea and exacerbation of symptoms. Participants recounted how anxiety related to acute breathing problems often led to panic attacks, which caused further difficulty in breathing. Consequently, the immediate focus of living for participants with severe COPD was seen as striving to keep their breathing pattern under control, and avoiding any situation or activity which could undermine symptom control. However, participants learned over time to tolerate the fear and to endure the duration of the dyspnoeic attacks, resorting to self-management strategies sitting quietly and using self-taught or physiotherapist recommended breathing techniques to calm down.

The chapter revealed the participant's perceived heightened vulnerability owing to their physical frailness and consequent dependency upon others to ensure their ongoing well-being. Dependency upon others, for example, needing assistance: to alter body position to facilitate breathing, to transfer from chair to toilet, with personal hygiene, and disposal of expectorated sputum, exposed activities which were previously private or concealed from public view. Becoming physically dependent upon others was seen to impact upon psychological well being, evoking feelings of inadequacy, frustration, and increased vulnerability. Individuals perceived themselves as becoming increasingly incapacitated and helpless, despite being observed by others as physically intact, consequently the participants feared losing dignity and social respect. They feared being seen by others as fraudulent and not being entitled to the disability role imposed upon them by their impairment.

Stemming from this perspective the participants articulated a fear of being alone, fears of being without a perceived 'confidence-booster' such as an inhaler or easy access to the oxygen supply or fear of being in a situation unmanageable as a consequence of their physical frailty.

An unexpected issue raised by a few of the study's participants, was the opportunity to undergo elective lung surgery. The possibility of having lung volume reduction surgery created additional fears and uncertainties as well as optimism and hope for an improved quality of life for this minority group.

However, for the majority of participants, despite a recognition of their steady decline in physical health, they revealed continuing uncertainties in the knowledge of the future nature and duration of what Glaser and Strauss, (1968) term a 'non-scheduled status passage' illness. Living with perpetual uncertainty and unpredictable exacerbations of the illness course influenced the mental health of the participants. Many participants of the study revealed experiencing periods of low mood or negative mental state, which were perceived as associated with increased symptom severity and feelings of hopelessness and helplessness. Others displayed an acceptance or 'awareness' of their illness and recognised that their downward path was inevitable (Glaser and Strauss, 1968). In addition, participants experienced multiple lifestyle

losses promoting feelings of anger, denial, compromise, resignation or acceptance towards their illness not unlike Kubler-Ross's (1969) conceptual stages of dying.

Some participants were keen to discuss arrangements they had made for the future, such moving to a nursing home or even planning their own funeral, in the acknowledgement of their terminal decline, whereas the majority said that they didn't want to think ahead or make plans for the future. A few individuals portrayed an unrealistic optimism, hoping that their condition would remain at its present level or even improve. Mishel (1991) suggests that uncertainty in chronic illness can have positive effects by allowing the patient to retain hope in the face of adversity. It is suggested that these attitudes reflect the inadequate knowledge and understanding by patients, as for health professionals, of the predicted illness trajectory of COPD.

In conclusion, from this chapter, it is suggested that the experience of living with end-stage COPD raises as many uncertainties as living with COPD during the early days.

## **8.0. Chapter 8: Living with COPD: The carer's experience**

### **8.1. Introduction:**

This chapter set out to explore the experience of living with COPD as perceived by the family carer. All the informal carers in this study were family members: the patient's spouse, partner or adult child, who either lived in the same household or separately in the local neighbourhood.

The carer's subjective experience of caring was explored to gain insights and understanding of the practical and emotional issues inherent within the coping- caring role of the family carer for a person with COPD. The role of the family member in caring for a relative with COPD was perceived as evolving over time to encompass multiple roles and responsibilities, in order to accommodate the increasing care needs of the COPD relative. The degree of involvement of the carer reflected the severity of the ill relative's functional disablement imposed by the physical symptoms and the perceived psychosocial impact on the relative's well being.

This chapter describes and explores carers' experiences of living with a family member who has COPD. It is suggested that a study of the experience of living with COPD is incomplete without the exploration of the carer's perspective, whose day-to-day living is also affected by the impact of the illness. This chapter aims to enhance the understanding of the specific issues and concerns inherent in family caring for a relative with COPD.

Participants described the carer's role as being a multifaceted role, evolving over time to require the carrying out of task orientated care, as well as employing psychological strategies to meet the relative's emotional care-needs. This chapter explores how the steady unrelenting progression of the illness COPD impacts simultaneously upon the family carer and ill-relative imposing lifestyle changes and altered psychosocial well being of the carer as well as the patient.

Analysis of the carer's experience identified concerns and issues focused around both the self and the ill relative within three conceptual stages of the illness trajectory. Due to the insidious disease onset, the frequent complications of co-existing morbidities and the differences in perceived coping by carer and patient, the conceptual stages of

caring that emerged from the interviews are non-uniform, and vary from individual to individual. The stages of the caring role by a family member for a relative with COPD were defined as: (a) the transition from a caring relative to becoming a care-giving relative, (b) caring through a crisis, and (c) becoming a full-time carer.

## **8.2. The transition from caring relative to care-giver relative**

### **8.2.1. Overview:**

Of the 16 carers interviewed in this study, eleven (n=11) were wives, two (n=2) were husbands and three (n=3) participants were daughters of the interviewed patients with COPD.

Just as the symptoms of COPD insidiously creep up on the patient, so the role of carer is gradually imposed upon the family member. All but one of the spouse carers in this study were aged over 70 years and, although all were mobile, some carers had health problems of their own. The transition from the role of supportive relative to that of full-time carer developed in tandem with the worsening symptoms. As the COPD symptoms imposed growing restrictions on physical activity for the individual, the relative not only increasingly relieved them of previously assumed roles, for example the more tiring household chores, but also started to provide personal care such as assistance with washing and dressing for the ill-relative. In addition many carer participants recounted how they and their ill relative over time had become more knowledgeable about the disease and the management of the symptoms. Employing task-orientated care, devising practical strategies and making lifestyle alterations to address patient needs and facilitate daily living were common to all carers as they underwent the transition from being a sympathetic family member to main carer. As a consequence, the carer as well as the relative had changes imposed upon their former lifestyle in order to accommodate and manage the illness, while striving to maintain a sense of everyday normality. Participants revealed how caring becomes a multifaceted role, bringing new responsibilities including anticipatory, preventative, supervisory, and protective aspects, as well as the more visible task-orientated instrumental care-giving (Bowers, 1987).



### 8.2.2. Caring through the earlier stages of the illness

During the earlier stages of the illness, often spanning many years before symptoms became severely disabling, family members did not consider themselves to be carers but perceived themselves as merely enacting out caring practices assumed and embedded within a caring family relationship. Carers' accounts of living with a family member with COPD during the earlier stage of the illness reflected similar issues raised by the ill relative. The mild to moderate symptoms of COPD including the early morning cough, the wheeze and SOB on exertion, the unpredictable breathlessness brought on by specific trigger factors initially were tolerated or modified by the individual often needing minimal or no assistance from the relative. Thus the initial role of the carer was generally perceived by both ill-relative and carer-relative as merely being that of a helping hand, or being a concerned supportive family member who helped avoid, subdue or alleviate the nuisance of undue breathlessness, bouts of coughing and general fatigue.

Pearlin et al, (1990) makes a distinction between '*affective caring*', defined as one's commitment to the welfare of another and '*care-giving*', defined as the '*behavioural*' expression of this commitment. Gregory, (2005) discusses '*caring about*' another as a welcome option for all family members while '*caring for*' another to ensure continued health is a unpaid responsibility, done routinely out of love, duty and obligation. This study illustrated how, over time the family relationship between spouse or adult child developed from '*caring about*' to include '*caring for*' the relative with COPD. Living with the breathlessness was a taken for granted aspect of normal life for patient and carer. The COPD symptoms often had ill defined beginnings, as the mild symptoms went largely unnoticed, until they became distressingly problematic during later stages of the illness. As the following comments by carers illustrate:

"He's always had a bad chest ever since I can remember.... but in the last two to three years it's deteriorated and he's been more aware that he's got it like. (...) He was a bit breathless on a bad day- never been able to run or anything like that.... but it has deteriorated a lot, he is very breathless now" (C6/4, 12-13,23-5).

"Well it's always been there but it was something we'd always grown up with. When she actually went into hospital with the chest infection in the

intensive care unit three years ago, I suppose it got worse since then really, but gradually over the years it's got worse and worse" (C3/80-3).

Both parents of one carer participant had suffered from a chronic illness but the parent who had Alzheimer's' disease had received more attention due to the greater caring demands imposed compared with those of the parent with COPD. The daughter carer said:

"Err I've got to think about this...but maybe we're talking of ten, ten to fifteen years ago, ... we've had a lot of problems with my parents so it's hard to remember what and when everything happened..." (C1/92-104)

Participants revealed how the progressive symptoms of COPD became increasingly intrusive upon the routines of daily living, and disrupted the lives of both sufferer and the relative. However participants were usually unable to identify a precise time along the illness course when caring '*about*' the relative became an identifiable role of caring '*for*' the relative. Changes in physical health of the ill relative were sometimes first noticed or remembered when thinking back to specific events or dates; going on a specific holiday, having to give up a leisure or sporting pursuit, death of the spouse or recalling when they were unable to play with grandchildren, were identified as times when patient and family carer recalled a deterioration in patient health and showing signs of needing specific assistance. For example one wife participant recalled:

"...You had a very, very bad spell when we were on holiday three years ago. We were in Weston-Super-Mare and it was very windy ...and you couldn't walk. He was in a very bad way and it went on for days and you could only walk a few yards.... all the time there you would walk a few yards and sit down, visit somewhere and sit down.... He didn't want to go to the doctor because he felt all right when he came home." "I think you had one or two attacks really when you were confined to bed and then he went to see the doctor and it was finally diagnosed as emphysema" (C8/9-16,24-30).

A wife carer described her initial awareness of something amiss:

"Well he'd been coughing a lot and then when he started to get breathless and we liked to dance and we'd get half way round and he'd say he couldn't- that's when I first noticed it and then of course it got worse and worse" (C5/42-4).

One daughter remembered:

"He's always had a bad chest since I can remember...(but) he deteriorated I think when mother died three years ago- that's when I feel he went down hill" (C6/4-8).

Another daughter participant also associated her father's decline in health and well-being with bereavement saying:

"My mother had Alzheimer's ... so she went into a nursing home in 1992 and she died in '95. I suppose we – between 92-3 saw a deterioration- Dad was living on his own - yes - that was the big turn I think"(C1/111-5).

As discussed in chapter 4, the impact of COPD on the individual during the earlier stages of the illness was often masked or overlooked by more obvious problems associated with a co-existing morbidity. In addition, often the patient and family were uncertain of a clear diagnosis of COPD until respiratory symptoms had become sufficiently severe or distressing to warrant seeking professional advice.

Family carers were often more focused upon the relative's other health problems and the impact of their daily lives of the symptoms associated with co-existent morbidity.

As one carer participant said:

"Well he's had several strokes as well and then one day at the hospital then he said he had this...and that affected his walking and then of course a year ago he was back and fore up to the doctor you know for his chest. Well I must say his chest hasn't been very good... we discovered it when we found out about his strokes you know.... well they didn't seem to say much – he was on the (inhalers) he's using them quite a bit now. No, no they haven't given it a name ..." (C4/7-36).

Hence, carer concerns during the earlier stage of COPD often focused upon practical tasks that were deemed necessary, and were often caused by the patient's other health problems. For example, the above spouse went on to describe the problems caused by the strokes her husband had suffered, causing incontinence and partial immobility. These were considered more pressing concerns than his breathlessness. However, several participant carers noted, in retrospect, the increasing frequency of influenza or chest infections experienced by the relative. As one spouse noted:

" Yes I can remember - back – what nine years ago- her having a bad chest with flu or chest infection and going back and fore to the doctors for antibiotics and it was always there. Lots of phlegm and it wouldn't come up properly and she would spend a lot of time in bed" (C14/2346-9).

Another husband carer said:

“About two or three years ago – I was annoyed – the first time she went into hospital because she was on antibiotics all the time. I thought they’d gone on long enough doing nothing about it. So I told Dr. C. it was about time something was done. I was worried because she was deteriorating in front of our eyes really” (C7/13-6).

Looking back upon the earlier stages of the relative’s illness, family carers not only remembered becoming concerned about the increased prevalence of respiratory symptoms but also noticed the relative’s weight loss, decreased appetite, poor night-time sleep or changes in their skin colour.

### **8.3. Empathy and collaboration in care**

Earlier concerns of the family carer about the ill relative focused mainly on the relatives’ physical well being and how to avoid undue breathlessness. Participant carers suggested that being sympathetic, and understanding the ill relatives’ need to avoid exaggerated physical exertion, were important to prevent symptom exacerbation. Hence family carers remembered slowing down joint activities such as walking together, or taking on the heavier domestic chores, in order to avoid or reduce coughing bouts, a wheezy chest, breathlessness or general fatigue in the relative with COPD. Hence, caring from the earlier stages of the illness involved being sensitive and displaying empathy to avoid the exacerbation of breathless symptoms, as well as the increasing amount of instrumental care. Allowing time for the relative to mobilise or carry out an activity was considered vitally important, as one participant daughter pointed out:

“And we just have to take it very slowly- don’t we? ... can’t be *rushed*...” (C1/36-8).

Another carer participant noted:

“He’s always grunting while he walks and that gets on my nerves because that’s horrible to listen to all the time. But on the other hand I’m basically sympathetic to him...” (C9/132-3).

A wife carer commented:

“ It doesn’t really affect me much- I give in to him I suppose but you actually walk slower with him and I’m always a bit in front, as I said. And you look back to see if he’s still there but then I’m walking slower now.” (C5/9-11).

Being there, looking out for, checking up on the relative, were expressions used by the participant carers to ensure the welfare of their ill relative, for example, a carer wife disclosed:

“When he goes up the stairs he stops you know, he goes up so many stairs then stops, then goes up a few more and then I’m waiting there behind or if he goes in the shower... we leave the door open”(C5/38-40),

Another wife carer said:

“We’ve got used to it and well you do things automatically now... but if I see him out the back and coughing and he wants anything – I get in there first and get it – or get the boys to come over to help out which I do do- but no I don’t jump in and stop him, but I keep an eye on him” (C5/48-50).

One participant described how she looks out for her husband when out in social gatherings. She said:

“ He can’t cope where there are a lot of people- so he doesn’t go and if we do go out somewhere I need to watch then because he’ll get breathless. It happened a couple of weeks ago – Christmas - we went to a party and he disappeared and ...he said we’ve got to go – it makes him very tired and he gets fairly flaked out the next day” (C11/14-8).

During this phase of the illness, which often spanned many years, participants had not considered themselves to be carers but described how they had learnt to assist the relative by being sensitive to needs, recognising signs of deterioration and knowing how to help. Kramer, (1993) suggests that care-givers who are able to empathise with the feelings and experiences of the ill relative are more likely to find useful strategies for coping with the illness as well as deriving greater satisfaction from the caring role.

All but two of the carer participants in this study conveyed positive feelings about their caring role. Relatives of individuals with COPD who worked collaboratively together to manage the impact of the illness were those who had become sensitive to clues, indicating the relative’s moods, needs and wants. Studies by Corbin and Strauss, (1984; 1988), investigating coping with chronic illness, found enhanced coping in relationships where spouses worked collaboratively, had come to terms with the illness and acknowledged limitations imposed by the illness. Participant carers talked about the mundane domestic tasks and interactions carried out to ensure relative well-being, to maintain a sense of normality or continuity in their lives while accommodating to the changes inflicted by the illness. Managing the growing symptoms of COPD and dealing with their limiting influence on daily living had

become a shared way of life, involving working in partnership to overcome problems arising from the disease. Over the years these patients and spouses had absorbed into their joint lifestyle the necessary changes to accommodate the illness and its symptoms, so that managing the illness had become part of both their normal lives. For example, the wife of one man with advanced COPD remarked:

“You know – he has sleepless nights so I have sleepless nights. I mean last night – I get up every night at least once but last night it was three times. But it’s always between one and three times... even if it’s only to check on him.” (C16/479-81).

Although all participant carers considered caring for their relative a taken-for-granted duty by virtue of their kinship, most spouses displayed a more collaborative, partnership-in-care approach, whereby they shared the responsibilities and impact of the illness on their lives.

#### **8.4. Taking on multiple roles and responsibilities**

Carers pointed out how over time they had taken on extra domestic responsibilities relieving the burden from the ill relative. Participants were unable to pinpoint an exact time or date but mentioned a vaguely remembered era of beginnings of taking over the heavier household tasks: shopping, errands or gardening chores previously undertaken by the relative with COPD. As the COPD symptoms progressed and enforced physical disability, family carers expanded their role of providing domestic care to also include personal care for the ill relative. As Schumacher, (1995) pointed out, “taking on the care-giving role involves changes in established patterns of behaviour and expectations and often the acquisition of new knowledge and skills”. Participants described much of their caring role as providing hands on care to assist with basic activities of daily living. However, analysis of the descriptions revealed in addition to instrumental care other forms of tacit caring.

Carers described how much of their caring involved having to think or plan ahead to ensure the well-being and safety of their ill-relative. These caring activities were often not tangible or visible but considered as important as the provision of observable task orientated instrumental care. Often carers actively monitored their ill relative’s activities to avoid further illness-related problems from occurring. For example, one spouse participant said:

“ I like to see him down in the chair before I go out you know. If I go shopping and all, I’m happier that he’s downstairs ...” (C4/177-8).

A daughter carer was anxious about her father’s imminent hospital discharge having previously experienced acute breathing problems commented:

“... And I said to the nurse - I hope he’ll be a bit better and more mobile before he comes home because if he falls – he’s tall but he’s lost his strength and if he were to fall I’d never pick him up ....I want him to be able to walk from here to the sink and be able to make himself a cup of tea - not be totally dependent on me” (C6/72-4,84-5).

Another spouse carer commented:

“And the other thing is I don’t want him to drive anymore... I don’t think it’s a sensible thing to do” (C9/225-7).

### **8.5. Lifestyle changes**

Taking on the caring role for some participants had involved a major upheaval and changes in their own lives, while other participants had unquestioningly incorporated caring for the close family relative into their normal lifestyle. Three daughter carer participants had each made considerable lifestyle changes to ensure the well being of their parent. As one daughter recalled:

“Dad used to live in warden-assisted flat in Sussex and it became increasingly difficult for him to manage. We realised that he couldn’t stay on his own for much longer, so once we got the opportunity to take early retirement we decided to move to a nicer location and bring Dad with us - and look after him myself” (C1/ 3-13).

Another daughter carer also felt responsible for her father who lived down the road from her and her family. She said:

“My husband is on shift work and so he’s not always here and so it’s a case of going over there (to the father’s house) first thing in the morning, doing his shopping or whatever, seeing to him, getting his dinner and then back here and then back over there then. (...). Since my mother died, I’ve done all the washing and cleaning the house and things. It’s only now he’s been so dependent on me - now I do all the cleaning, but I find it’s more and more now” (C6/132-5,155-7).

The third daughter who had taken her mother in to her own home considered the upheaval in her life and pointed out:

“I would love to go back to work but you know... you’re expected to take the first two years of a child’s life and teach it and nurture it and that’s the same with my mum now.... it’s a role reversal isn’t it? (C3/142-6).

Having to take on a transfer of role was mentioned also by spouse carers, as one wife commented:

“(I feel) upset – put it that way – living with him for more than fifty years. He’s always done all the money, done everything. He’s made the decisions, done everything and now it’s all gone. So we talk about it and I’ve got to go and do it...I have to take over” (C16/ 425-7).

However, for many spouses caring for their ill partner and ‘the taking on’ of daily domestic tasks was an assumed part of their relationship and warranted no particular explanation. For example one husband carer commented:

“ No, it hasn’t affected me really, because I don’t go out much anyway and haven’t gone out much without her – except for the golf” (C9/19-20).

Another spouse carer remarked:

“When he were first out of work and ill and I thought, my God what would I do with him home all day –you’ve got your own routine haven’t you? But then...back in those days we muddled through didn’t we? ...and he did the cooking like and I did the cleaning and we had a really good life didn’t we?” (C2/155-161).

## **8.6. Learning to manage the illness**

Learning to detect signs of early symptom exacerbation, the avoidance of trigger factors, and management of appropriate medication or treatment therapy had become second nature for both carer and ill-relative. Attendance for appointments at the hospital clinic and local general practitioner surgery were generally commonplace for the family carer as well as the relative. Over time carers had become more knowledgeable about monitoring and managing the symptoms of their relative’s disease, particularly to avoid a crisis. One wife participant described learning from past experiences of episodes of severe breathing difficulties, which had led to hospital admission. She said:

“But we know you better now, don’t we? I know now to – whatever his peak flows are - to have his steroids and his nebuliser. You know when you can see



an attack - well not so much of an attack 'cos we've stopped the attacks coming now - it's just when he gets really err I don't know, low or ...picks up an infection and then he ends up in hospital then (...) On a good day he has the nebuliser when he gets up and just before he going to bed and manages the rest of the day then.. His peak flows are up to 240 at best, 240-250 when it's that he can go for weeks and weeks and then wham all of a sudden it drops- and in the summer it's worse than the winter, definitely" (C2/21-9, 64-7).

Another wife participant expressed her confidence in recognising when to call out the doctor due to worsening symptoms in her husband. She commented:

"At the moment he coughs a lot because he's just had a chest infection and he's just recovered from the chest infection and about ten days ago he finished the antibiotics and he's still got a cough but I mean, I think other people worry about it more than I do because over the years - and other people say 'oh his chest is rattling' and I say well yes it just does but there comes a time when we both know it's time to get a doctor you know" (C10/37-42).

Bowers, (1987) identifies activities of management, arranging, checking on and setting up as 'supervisory' care. Carer participants from this study described how they would remind or reinforce medical advice and treatment regimes to the relative to ensure that therapy was taken as prescribed. As one daughter explained:

"I think he thinks I nag a lot.... it's 'don't cross your legs, put your feet up, don't forget your tablets, don't forget your nebuliser...'. He has nebuliser 4 times a day; then at a separate time he has saline nebs 4 times a day. He has tablets 3 times a day, oxygen for 16 hours err he's got to keep his legs up because he has fluid retention and he's on diuretics...and it's backwards and forwards back to the loo all morning ...so he's quite busy doing nothing aren't you?" (C1/19-6).

Thus caring becomes a daily routine of ensuring the welfare of the ill-relative by anticipating and preventing setbacks caused by potential increased breathlessness, and by the provision of instrumental and supervisory hands-on care to manage and monitor the illness impact on daily living. Thus, living with COPD becomes the focus of living for both the ill-relative and carer as daily activities and lifestyle revolve around the illness. However, at some point along the illness trajectory, living with the steady but manageable decline in the relative's health is described by participants as being abruptly interrupted by the sudden onset of dramatic changes in the ill-relative's breathing. This period in time becomes a time of crisis.

### **8.7. Caring through crisis**

As carers described caring for their relative with COPD, eleven of the sixteen (n=11/16) participants recalled the ordeal when the relative experienced a sudden onset of exacerbated symptoms, which necessitated urgent hospital admission. Details of this specific event were recalled in vivid clarity and perceived by carers as being a significant landmark in the course of the illness. Participants described how the gradual progressive disease with the hitherto tolerated symptoms had suddenly developed into a state of unmanageable and exaggerated breathing difficulties. These acute episodes of breathing problems were usually the result of a chest infection, which further impaired breathing and triggered an acute and severe exacerbation of COPD symptoms.

Exploring the narratives revealed several themes. Firstly, the crisis event had precipitated the relative into the care-giving role of advocacy, where participants realised that they were responsible for ensuring their relative's welfare during the crisis incident and beyond. Secondly the incident confirmed that the relative had a defined and known illness, which legitimised their disabled behaviour and warranted professional medical and social care. Carers revealed how they had learnt from this event to try to avoid future distressing episodes. Thirdly, carer participants revealed their feelings and emotions experienced at the time of the crisis and how their lives had been affected by this crisis event.

### **8.8. Caring as a responsibility of advocacy for ill-relative**

Participants described their feelings of distress at the onset and during the acute episode of exacerbated symptoms experienced by the relative with COPD. An acute exacerbation of COPD symptoms, particularly an infective exacerbation, can cause breathing problems in just a few hours (Rodriguez-Roisin, 2000). Carers described how the rapid onset of unfamiliar and severe symptoms, which did not respond to usual medication, gave rise to alarm and anxiety in both the ill relative and the carer. One wife carer recalled:

“At about 3.30am he said I don't feel at all well- I can't breathe and at 5.30am I got up and made a cup of tea and I was worried that he was in a bad state.... So he then at 5.30 was in a terrible state and then I realised he was sweating – perspiration was coming from his forehead – his arms err everywhere and I

thought this is not right he's going to have a heart attack if I don't be careful. So of course I rang for an ambulance. By the time they got here he was in a terrible state and it really was quite sudden and I tore out of the house because he didn't want to be alone because he was very ill and panicking and when I got to the hospital they said he was in heart failure.... it really was a very upsetting time" (C12/13-4,19-25,29).

Although not the first crisis episode for another participant carer, she recalls a particularly stressful time when her husband was discharged home and re-admitted to hospital the same day. She described the situation saying:

"Well this last time he was breathing heavy so I said I don't like the look of it so I phoned the doctor and the doctor came - Dr. M. - she came up and she said 'oh he's got to go in' she said. But he couldn't speak; he couldn't move he couldn't do nothing. I had to pick his legs up and put them back on the bed- he couldn't - he was completely gone. .. he was home a couple of hours from the hospital and I thought oh God no, I hope he's not going to have another... so I thought I better get the doctor in and I thought I need to because he's gone before like that ...and all of a sudden ... It was petrifying, I was petrified". "(Felt) terrible - I didn't know where to run - no, the doctor came then and err she said he got to go in" (C13/30-41,72).

Some family carers were concerned for the welfare of their relative, even when under medical care as a hospital inpatient. For example, one daughter carer felt that hospital staff did not provide optimal care for her mother and was reluctant to hand over care to the ward nurses. She commented:

"I don't think that some of them know what they're doing.... and basically why I stay is because they don't fully understand Mum's needs... Just being able to breathe with her - when she was in hospital ok I could co-ordinate that with her, when she was in intensive care she found it very, very hard to breathe and - but sometimes I would come up on the ward and they hadn't put the oxygen up enough- they didn't give her enough oxygen and she was frightened and she was thinking every breath she was taking was her last then, and I was sat straddled on the bed with her, face to face. I sat on the bed literally like this - her breathing in and out with me all night we did that 'cos I didn't know what else to do until she was sleeping..." (C3/ 39,85-92).

A husband carer also had concerns about his wife's fear of breathing difficulties and the lack of general understanding by others of her fear of the sensation of dyspnoea. Ward staff dismissed his concerns as he relinquished his wife into their care. He recalled:

“ Well when we went into hospital and told the doctor there she panics - gets a panic attack like when she gets breathless ...and they said ‘oh no- no she’ll be all right’...”(C14/385).

Relative carers felt responsible for seeking and accepting professional help but also felt a responsibility to remain present with the relative during the time the relative was under the care of healthcare professionals.

### **8.9. Feeling powerless and frightened**

Carers described how they felt powerless to do anything during such an episode of severe breathing difficulties especially when the usual medication proved to be ineffective. Carers expressed feelings of inadequacy during an acute exacerbation of symptoms using words such as feeling ‘*useless*’, ‘*helpless*’ or ‘*powerless*’. During these episodes of breathing difficulties the use of inhalers to improve dyspnoea was impossible and even the inhalation of nebulised therapy via a facemask or an oral mouthpiece sometimes proved too difficult to manage. Consequently, the individual with breathing difficulties would end up gasping for breath; panicking, hyperventilating and sometimes becoming temporarily disorientated, a situation, which was emotionally distressing for family members. One participant carer explained: “He gasps, he doesn’t think he can get enough breath in ...” (C6/41).

During these acute attacks of exacerbated symptoms carers admitted to being alarmed and frightened by the relatives sudden change in condition but at the same time felt responsible for initiating professional help while outwardly trying to appear calm in front of the relative. As one daughter commented:

“ Well I tend not to panic in front of him but think oh God breathe properly you know and you don’t know what to do like...when he starts yes, I think oh God no” (C6/ 46-9).

One acute event was still vivid in the mind of another wife carer even twelve months later, she recalled:

“I would never want to see anyone in that state ever again. I hope I never see him like that ever again, I would hope never again. His eyes were protruding he was well, in a terrible state and I know the ambulance people tried their best with him. It wasn’t easy, he couldn’t bear the doors to be shut in the

ambulance because he was claustrophobic and the – not breathing...”(C12/84-8).

As illustrated by the above extract, many carers feared a repeat acute crisis episode, as one participant commented:

“They were bad attacks. I don’t want another one, no-way. They were really ...(frightening)” (C16/532).

#### **8.10. Providing emotional support**

Despite feeling powerless to help the relative overcome the breathlessness, carers emphasised the importance of maintaining their presence with the ill-relative during these crisis episodes. They didn’t want to leave the relative alone with strangers even if these strangers were health professionals, such as ambulance crew or hospital staff, and felt that they were needed to provide emotional comfort and support. As one wife said:

“I mean there are times when it’s a bit frightening and he can’t breathe and I’ve got to help him sort of thing. But I can’t breathe for him so there’s not a lot I can do when he gets like that, I just stand there and be there ...”(C16/474-476).

Some carers described how living with a relative with COPD, they had acquired a heightened recognition, understanding and interpretation of their relative’s physical and emotional needs. As a consequence of this empathetic relationship between themselves and the relative, carers assumed a responsibility not only to provide practical care but also to provide emotional support and encouragement through these distressing times of crisis. A daughter carer described one such relationship between herself and her mother. She said:

“...I think that’s just because I’m so attached to Mum I know that it is only me that can calm her down, there’s an awful lot of responsibility on me with her being...I know there’s my sister and you know but they don’t have done as much in the way of caring as I have done...I’ve been the sole carer really...“( )” and I didn’t leave her while she was in hospital because of the panic attacks. So I was with her all the time she was there, day and night...(she) never needed me like she needs me now...”(C3/9-13,18-25,156).

Although family caregivers sought professional medical care for their acutely ill relative to bring the exacerbated symptoms under control, they were often reluctant to leave the relative alone in hospital. Carers considered themselves to have a better

understanding than health professionals about their relative's fear of not being able to breathe and realised the importance relatives placed on them to be present to translate the ill-relative's needs, wishes or preferences to health professional staff and to provide moral support and confidence. However, the carers themselves often experienced fear of the breathlessness attacks and were eager to receive professional support and advice for symptom management during an exacerbation.

#### **8.11. Becoming a full time carer**

As the patient's illness progresses and symptoms become unrelentingly severe, the role of the family relative becomes that of full time carer. Some family caregivers noticed that a crisis event precipitating emergency hospital admission marked the time when they became full time carers for their relative. However, this was not always the case and some ill-relatives would experience one or more crisis events up to several years before becoming totally dependent on others to provide care. Exploration of the full time caring experience revealed considerable physical and emotional demands upon the carer. The carer often had to surrender ambitions, lifestyle and risk own ill-health in order to take on the full time care of their relative with COPD.

#### **8.12. The physical exhaustion**

As severe breathlessness and fatigue restrict the patient's general freedom of movement, so the care-giver described catering for and often assisting with even the most basic activities of daily living such as helping in and out of bed; assisting to dress and undress, and helping to transfer from bed, chair or toilet. Carers revealed spending their entire day assisting the patient with basic needs as well as maintaining the day-to-day living within the household, by doing most of the housework, shopping and meal preparation. As the symptoms of COPD usually become debilitating in the latter decades of life many spouse carers were elderly and frequently also were frail or had impaired health themselves. Consequently some carers reported feeling physically exhausted, as one elderly wife participant typically exclaimed: "[I'm] worn out sometimes!"(C4/7)

Another wife carer described how she and her husband had established a routine of care to suit them both. This included wound care for weeping oedematous legs; a complication of cardiopulmonary impaired functioning. She explained:

“And now we do his legs at bed time ‘cos I can do them when he gets on the bed, ‘cos it was taking it out of me as well as him.” (C16/535-6).

However, other participants glossed over the hardships of carrying out necessary physical tasks as being an assumed responsibility by being the healthy relative, as one husband carer participant said:

“ Nothing has changed much for me – well I do all the housework, cooking, cleaning and I do the garden which B- used to do but otherwise it hasn’t really. I haven’t really thought about it. I mean you learn to live with it and I don’t let things get on top of me” (C7/ 5-6,22-3).

Another participant said of her severely disabled housebound husband:

“Oh yes, (family help out) yes but I don’t really need it- I can manage with him on my own. I’ve done it all these years – haven’t I? It’s 57 years now we’ve been married”(C13/245-6).

Most carer participants expressed more concerns over having to ‘look out’ for their relative than the actual carrying out of physical tasks demanded of the caring role.

Several had installed alarm systems for the patient relative so that they could be contacted via a bell in times of need so avoiding over-exertion and exacerbation of breathless symptoms. One participant explained:

“We worry about him at night but he’s got a bell in his room which rings upstairs. He can use if he gets into difficulty. But as much as you do - but that works quite well - but as careful as you are... I think at night, I think I am not going to hear him but we always do hear don’t we? I mean he doesn’t bother us unless he really has to... and whenever err if I get up to the loo, I, we, either of us always come and check....” (C1/ 43-4, 56, 153-157).

Many COPD sufferers, despite being inflicted with debilitating symptoms still strove to be as independent as possible, particularly when knowing that their spouse had their own health problems. As the wife carer of one such patient said:

“ Well I just make sure he’s alright - okay in the bath for example but it doesn’t make much difference to me at all. We’ve got used to it and well you do things automatically now... but if I see him out the back and coughing and he wants anything- I get in there first and get it – or get the boys to come over and help out which I do do... but no I don’t jump in and stop him but I keep an eye on him” (C5/ 32-3,46-50).

Respondents highlighted that having a supportive network of extended family and friends who helped out with domestic chores or provided transport for shopping or hospital appointments as a valuable asset. One wife carer recalled:

“ And the doctor said would we be alright- would we manage? And we said yes, we will manage yes definitely. Because as long as I can do it I will do it and then we’ve got the children. We are lucky, we are lucky that we’ve got a family that will rally round”(C16/402-4).

For others, family relatives lived away, so the burden of caring rested with the spouse. Only two of the sixteen carers in the study were currently receiving formal homecare input on a regular basis, as they considered that they could cope without outside help. However, one couple had received homecare in helping to wash and dress following hospital discharge but had subsequently dispensed with the service despite struggling to cope. The wife carer explained:

“But then the social services came in hospital and they asked could they get someone in to shower him and you know to help me. But quite honestly they couldn’t because we couldn’t always err if someone was coming we couldn’t always be ready... so really we couldn’t take advantage – I couldn’t take advantage of the services that were available to us largely due to the fact you know, the nervous anxiety and of course the fact that he was claustrophobic- all these sort of little things you know. They all add up together and it really was a very stressful time all round (C12/ 50-8).

A study exploring care-giving elsewhere also found that some family carers decline available care services despite the obvious benefits so as to preserve the family relationship and the ill relative’s sense of self (Caron and Bowers, 2003).

### **8.13. No time for self**

Of the carers, all three of the daughter carers were among those who expressed a need to have some free time from caring for themselves. Although happy to resume the care-giving role, some carer-givers felt not only were they physically exhausted but also they had little or no social life. As one daughter carer said:

“I know it’s a responsibility but it’s something I’ve just accepted and I just do it naturally and I don’t feel it’s any burden. It’s like instead of considering my daughter now, I used to consider her before anything else – it’s not a matter of considering a child any more, it’s about considering my Mum...no I never leave her (alone), no I wouldn’t go out and leave her, I’m not far away she wouldn’t feel safe you know. (C3/120-3,135-8).



The above participant was also planning her wedding, which had to fit around her mother's condition, she went on to say:

“And I don't have the freedom - for the honeymoon now - I can't go abroad, no way we were going to the Cotswolds so I could get home if... And I suppose we've got to make hay while the sun shines - while Mum's good. So the wedding is very organised, it had to be...it's a matter of right! These next few weeks I'll do this, this and this 'cos everything came to a standstill for a few weeks while she was in hospital and now it's go again while she's good in case she goes in again - everything comes second - takes a backseat” (C3/202-5, 274-8).

Another participant disclosed feeling exhausted because she felt the responsibility of caring for the relative had fallen to her, despite having other family members living nearby whom she felt were incompetent or rarely offered to help out. She said:

“ I don't know how I would manage a weeks holiday, I really don't... and I'm rushing there and rushing back here all the time. And sometimes I think oh God, you know – if somebody would give me a break. You know even with dad in hospital I went down every day. I feel I like to be there 'cos like the other day my brother went down and he phoned back and he said your sister wants to see you and I said what does she want to see me about? Oh she needs to speak to you ... she had told him but he couldn't remember what it was so you'll have to ask her- well why me? You ask! You know I get cross with him. I've got to cope with everything - I feel, well - trapped sometimes- I just want to get out”(C6 / 330-344).

However, some spouse carers coped by taking regular time out to pursue a social outing or an activity, which they considered their entitled time. One husband participant said:

“ I play golf three times a week to escape to male company because all B's friends are female and they tend to come down to the house because she can't go out, which is fine but then I go golfing...” (C7/ 7-9).

Another participant, an elderly wife, talked about how she coped with the constant strain of caring. She said:

“ I do get days when – there are days when you get down- can't continue you know, but I overcome.... I overcome. I go for a walk and every Thursday morning now - oh I've been doing that for years, I meet friends and go and have a coffee on the old bridge. Oh it's lovely and one table looks out and there's ducks and geese down there. Do you know, I find the water so soothing. I could sit and look at that water and the ducks going down - it's

only the simple things that relaxes you, you know. I go down and get a little bit of shopping- my friend drives me down and drives me back- oh I'm blessed with lovely friends" (C4/ 255-266).

Two of the daughter carers mentioned how they had thought of taking up available services to give them some time and also peace of mind. One participant had applied for meals on wheels provided by local social services for her father and the other participant was hoping for assistance from the voluntary agency, Age Concern. She explained:

"Perhaps we might get someone to sit in – for a couple of hours...as we've got to go to...I can't be away more than an hour without worrying!" (C1/174-7).

Of the thirteen spouse care participants, only one received formal homecare assistance provided daily by social services, and this same wife carer had also made use of available respite care in a local residential home, twice for one week in the previous year. (C10/45).

While loss of personal time was a concern for daughter carers, loss of social pursuits was of more concern to most spouse carers. Many of the spouse carers led close and shared lives with their COPD partners, which involved a sharing of the changes in social activities for the carer as well as the ill partner. Other studies have found that carers who reported better quality of marital relationships before the onset of illness have less depression, remain centrally involved in providing care and derive more satisfaction from the care-giving relationship (Kramer, 1993; Knop et al, 1998). However, comparing quality of marital relationships pre and post onset of the illness was beyond the scope of this study.

#### **8.14. Carer's loss of social activities**

Even for carers whose ill spouse was still able to mobilise slowly and get out of the house, social activities became curtailed or non-existent. The activity most commonly missed by carers was articulated as being able to go out together, going on walks or on shopping trips with friends. One carer remembered when her husband first took early retirement in the earlier stages of the illness. She said:

“I do miss that part when we used to go out and about- and he was my friend then - he was home then and we went everywhere together you know and you do miss. Well I’ve started going out and about a bit with my friends but it’s not the same as when you’re a couple is it? You know- I went out with my best friend ....oh weeks and weeks ago and it - it upset me it’s the only time I can honestly put my hand on my heart and say it got to me – you know” (C2/166-76).

Another participant carer reflected:

“ ... We used to walk a lot you know, the coastal path we’d walk for miles. Drop the car off and go – it was wonderful” (C12/195-7).

Several carers mentioned the importance of preventing their ill spouses from catching a simple cold to avoid developing a more serious chest infection. One participant illustrated how self- imposed responsible behaviour to safeguard the spouse’s well being had impacted upon her lifestyle. She commented:

“Our social life comes to an end in the winter. We can’t go into restaurants, we can’t go into pubs and we have to say to friends please don’t come near us... I mean last Christmas we were asked out quite a bit and you know if people have a cold then you have to say no - so I mean our friends understand but most people don’t. So it’s really affected the things I do because if I’ve gone out with a group of people – even if it’s lunchtime - there’s always someone sniffing and you don’t want to bring it home. But it does mean life has sort of closed in on us more - we’re not up and about and around as we would like ” (C15/ 77-86,237).

Some carers talked of missing out on holidays. For example a carer wife disclosed:

“ What I miss is going on holiday- going abroad. He doesn’t trust himself because he can’t carry – he couldn’t manage the cases or the carousel you see and sometimes...err... the last time we went, we went to the carousel to get the cases and my daughter said I’ll get them but no - he insisted on getting them but it was too much.” (C5/20-4).

For two couples, aware of their advancing years and the spouses’ illness, a last trip abroad to see their families had been contemplated. However, a lack of information and confidence had so far prevented them from tackling the venture. One of the carers voiced concerns about the complexity of arrangements that would be needed said:

“We were thinking of going abroad but what about his breathing? Would flying make it worse, you know? Is it advisable with his respiratory condition? I don’t know if you can take aerosols on the plane. But I have wondered about any limitations to flying because I asked the doctor and they didn’t seem to know... and that’s another thing if we do go anywhere I’ve got to try and

arrange like if there was a wheelchair. But for certain circumstances like going into hospital for appointments I've got to get a wheelchair for him because he can't walk those stairs, and at the airport it's the same now..."(C9/220-236).

#### **8.15. Positive aspects of the caring role**

For most participants, caring for a relative with advanced COPD was a physically and emotionally demanding role, but one, which fulfilled a satisfying sense of duty and responsibility, felt by the carer. Participants expressed satisfaction in seeing their ill relative content to enjoy the little things in life, such as, having grandchildren to visit, being able to sit in the car on short shopping trips, or to sit out in the garden on a warm day. As one spouse participant pointed out:

" Well he goes out there sometimes you know, when it's a nice day - the pipe (oxygen tubing) goes through the window there see and he can sit outside there in a chair and watch everybody go up and down. It's nice to see him go out mind..." (C13/269-71).

Despite the considerable effort of caring, most carer participants talked about the personal reward of managing the illness and symptoms to ensure that the relative was sufficiently comfortable to have a reasonable quality of life. One daughter participant summed up her situation:

"...Like I say if it were somebody else – somebody I wasn't so close to and loved so much I could detach from them but I can't. But the good times make up for the bad times which is good you know. (...) Yes I wish I could put breath into her body. I mean we're so very close and living with somebody, I mean all the time (caring) so to see her on a good day well she's laughing and joking and she's full of it with the children, you know and all that. And then to see her down, she does go down, is heart wrenching (...) As I say the good times outweigh the bad times, but the bad times have been nearer together. But as long as I can make her happy - that's what I try to do and I don't want to have any regrets with her or Dad and I want to say well - I've tried to do my best. Like take her down to the beach once a week if she wants and so on. I just want to go to my grave knowing I've done my best" (C3/29-31; 172-5; 374-8).

However, not all carer participants expressed such selfless sentiments, a couple of participants did not comment on the positive side of caring for their spouses and one spouse displayed hostility towards her husband, condemning him for continuing to smoke despite medical advice to give up smoking.

### 8.16. Playing down the effort of caring

Although carers often felt physically and mentally exhausted, socially isolated and having little time for self, they tended to play down the effort of caring, particularly in front of the relative. Caring for a relative with COPD was perceived as a greater burden for some carers than others. Younger carer age, appropriate housing adaptations and having extended family and friend networks were significant factors perceived as facilitating the caring role. As one participant commented:

“He’s really easy to look after you know - but we’ve had everything installed you know to make things possible. He’s got a walk-in shower and a disabled loo with all the rails and hand rests he needs, err electric chair, electric bed - you name it we’ve got it all. So we manage and just have to take it very slowly don’t we?” (C1 / 29-36).

Comments made by other carers included:

“ We don’t make a big issue of it, we just got on with it, you know we’ve never made a big point of it have we? (C2/ 137-140)

“ I know that it is only me that can calm her down, there’s an awful lot of responsibility on me ...but... I’ve been the sole carer really - I wouldn’t have it any other way” (C3/8-15).

Most participants were keen to demonstrate that they were managing with the extra workload and responsibilities despite new difficulties encountered. Due to the disabling nature of the illness, carers had to carry out most of the household chores as well as helping the ill relative with many basic daily needs. Despite many spouse caregivers being elderly they displayed fortitude and resilience in coping, taking on board the growing demands of the carer role. For example, an elderly wife carer was delighted when her son bought her a washing machine. She said:

“Of course I had to wash everything by hand, right up to Christmas time...and the youngsters today - that’s the first thing they have, oh no, it’s a boon, it’s a real boon! [and jokingly went on to say] yes and I’m head cook and bottle washer! But as I said - carers have holidays but I don’t!” (C4/75-81,198).

She described how she helps to wash and dress her husband, do all the housework and shopping, mostly without help, but when asked how her life had been affected by her husband’s illness, she have a reply typical of many carers: “Well it affects J’s life more than me” (C4/232).

Other similar comments, which played down the effort of being a carer, included:

“It doesn’t really affect me much” (C5/9).

“I haven’t really thought about it .I mean you learn to live with it ...”(C7/22-3).

“I don’t really need it (help) - I can manage with him on my own, I done it all these years...” (C13/245-6) and “no I don’t find any problems, I’m coping at the moment” (C16/472).

Despite feeling exhausted due to the demands of being the main family carer for her father, one participant commented:

“Yes we’ll cope. I’ve never thought we won’t cope however bad he gets. No I promised my mother that I’d never put him in a home”(C6/225-6).

Juggling family commitments with caring tasks, she strived to play down her hectic life in front of her father. She said:

“I never show to Dad but I never said you know -I can’t do it tomorrow or...” (C6/332).

#### **8.17. Giving legitimacy to the relative’s disability**

Family caregivers often felt the necessity to defend the relative’s inability to participate in ordinary activities. As participants noted, individuals with COPD often appear to the casual observer to be unaffected by the illness while resting or sitting down, since the symptoms temporarily becomes controlled and less noticeable. One wife carer commented:

“You watch him now and you get the impression he’s all right but sometimes his breathing is terrible and laboured like this (demonstrates) and he can’t breathe” C9/108-110).

Another participant commented:

“ The children find that hard don’t they...when you’re sitting there and you say you’re tired and they say, well you haven’t done nothing. They don’t realise how hard it is to breathe. It’s hard he says to me. I don’t know why I’m so tired, I’ve done nothing. But I say, but look how much effort it takes to breathe...we do take it for granted” (C2/257-262).

A wife carer excused her husband from helping her in the house as he did in the past said:

“There isn’t anything he can do to help. The only thing he will do ... he will come out into the kitchen and chop up the vegetables and things like that for me. Even that makes him tired. When he’s eaten his food he comes to sit down and he’ll probably go to sleep. And when he sits down he’s quite exhausted when he’s eaten his food, whereas normally he would have helped me clear the table and wash up. No, almost everything I have to do” (C12/150-160).

Putting up with withdrawn moods or irritating habits are similarly excused as part of the carer’s understanding of the impact of the illness or the prescribed medication on the relative. The spouse quoted on page 239 complaining about her husband’s “grunting” is one example. Another participant talked of the effects of the medication on the ill relative, said:

“He was (in an anxious mood) when he was first on them, it was like a Jeckyl and Hyde personality – until he got used to them and I’d just give him a wide berth then. When he had a strop on I just left him alone. I’d go out for a walk and come back and he’d be fine. I knew he couldn’t help it, it was just ... but over the years you got all right – haven’t you?” (C2/73-7).

#### **8.18. Boosting ill -relative morale and self-esteem**

During the course of the interview many carers sought to include the ill relative in the conversation at intervals, often mentioning a positive characteristic of the relative; something having value or merit, which could be seen to counterbalance their growing disability and dependency on family carers. Most participant carers displayed care in the way they spoke of their care-giving role so as to shield the relative from feeling a burden. It seemed to the researcher that participants displayed a positive attitude in front of the ill relative mainly to avoid feelings of guilt, low mood and depression. Sometimes previous patient identity was highlighted to boost patient morale and self-esteem. For example, one wife carer after giving a detailed account of the caring tasks of looking after her disabled and dependent husband went on to announce:

“He was a Royal Marine Commando.... I was telling nurse that you were a Royal Marine Commando. He was at Monte Casino and now it comes to this. He was very agile” (C4/200-207).

Some carers boosted their ill-relative’s morale by repeating encouraging comments made by doctors on patient progress back to ‘normal’ after experiencing episodes of acute exacerbated symptoms. A typical comment was:

“I think his GP is amazed at how he has progressed ... but we do have little bouts sometimes...” (C12/64-5).

Another said:

“Mind you he’s completely different this week to last week, ‘cos the nurse came and she said goodness what a difference” (C16/4512).

Other participants made light of the effort of caring for the relative while trying to boost lowered self-esteem and feeling down due to their increasing dependency upon family members. For example one daughter carer said:

“And if dad wasn’t so cheerful we wouldn’t be able to cope- he’s really easy to look after you know - but we’ve had everything installed you know to make things possible” (C1/28-31).

However, even those carer participants who spoke of their caring experiences in the absence of their ill-relative were keen to promote the relative’s positive characteristics. For example despite the fear of leaving her father alone for long, one daughter carer said:

“He’s good ... he knows when to take his nebuliser and his tablets and he writes everything down - he knows exactly what’s what. He can tell you exactly what he’s supposed to have and things. I mean some of them on the ward don’t know what time of day it is” (C6/99-104).

Caregivers made the effort of boosting the morale of the ill-relative in order to bolster their failing self-esteem. Carers strived to promote the psychological well-being and a positive outlook of their ill-relative.

### **8.19. Carer concerns over the uncertainty of the illness trajectory**

Just as the illness had vague and ill-defined beginnings, so the course of the illness trajectory was perceived as uncertain and unpredictable, including during the terminal stage. Although most carers felt they were currently managing to care adequately for their ill relative with COPD, many were uncertain as to how the illness would manifest itself in the terminal stage, what care-changes would be needed and whether they would be able to continue caring for the relative.



In addition to the carer's management of the steady progressive deterioration in the relative's health, most carers had to contend with the relative experiencing at least one sudden and unexpected crisis episode during the course of the illness. Some participants recall recurrent crisis episodes where the relative was repeatedly admitted to hospital for emergency treatment and then discharged back home when breathing was stabilised. Hence participant carers noted that the course of the illness was visibly degenerative but was unpredictable as to the frequency, nature and duration of acute episodes of severely increased breathing problems. Some participants described how their relative had nearly died during such an episode and expressed their anxiety about witnessing a repeat event. One daughter carer considered the toll of each acute episode on her mother's general well being, she explained:

“...And we thought she was on her way out at the time and she's picked up quite well since then but then it is hard to accept sometimes, each time it's taking a bit more away from her, and each time she's losing the fight – this time we had to fight for her ... and each time she goes in – I don't ever say it to her now but it always stays in my mind, she – I don't want but I dread the day.... if anything happens but I can cope with this but ...I'm afraid of hospital, I'm afraid she won't come out ... I think she's losing the strength inside of her –her physical strength- each time it's taking a bit more out of her and a bit more away from her.” (C3/20-3, 297-99, 326-9).

Each crisis event imposed increased impairment, disability and dependency of the ill relative upon family carers. Some participants expressed concern that they would be unable to cope adequately for the relative following future crisis events and further deterioration of the relative. For example, one carer was anxious that her father could regain a degree of independence in basic daily activities before being discharged home from hospital as quoted on p.242. However the hospital was eager for prompt discharge.

Other participants expressed concern over their lack of knowledge of the illness in terms of its progressive nature and how they would cope with the relative in the future. As one spouse reflected:

“Well I think it may- it will get worse and that is what worries me is that smoking probably won't help...but it's the fear that he might need help if he gets worse you know. Well he doesn't like to think about these things but I'm the exact opposite – if it's going to get worse then I'd like to know what's in store err oxygen and [inaudible]” C12/146-50).

Feeling unsupported by health professionals compounded their concern as the above participant continued:

“ The specialist said – quite frankly if you continue smoking we’ll have nothing to do with it you know. There is nothing they can do” (C12/153-5).

#### **8.20. Carer concerns over own health**

Carer anxiety about how they would manage caring for their relative in the future, was an issue of particular concern for some spouses who were elderly, becoming increasingly frail or had their own health problems. Some carers had concerns about practical issues, such as questioning whether they had the strength to assist the relative with basic care needs and activities within the home and to manage the daily household chores single-handedly. One spouse carer who had her own health problems to deal with commented:

“But no it was a terrible time for him and it did affect me an awful lot. However when he came home I sort of – I found it quite hard to help him really because – in as much as - not doing things for him but I found that err the moment he got into a breathless state it would affect me.... and then I would start getting irregular heart beats and things were happening to me. I’ve had a couple of blips since then and I think it’s only because of the stressful situation...I’m hoping to keep well enough to look after him, that’s all that worries me” I just hope that I’m going to be well enough and be able to keep well enough to help him. That’s all I hope I can help him fully with everything – do everything – do everything I can to help him. I do fear – it does worry me that I’ll not be able to keep my health....to keep him going that’s all that concerns me. As long as I can keep well then ok” (C12/169-173). (C12 /29-48,92,180).

This respondent went on to talk specifically about the wheelchair:

“Whether I’ll find it too much to do - to push it, pull it or whatever.... and I’ll have to load it, get it into the car and out again so I’m hoping it won’t be terribly heavy” (C12 /215-221).

Many carer participants feared having future health problems, which would prevent them from caring for their ill spouse. Another wife carer said:

“ I’ll cross that bridge when I get there – I’ll worry myself sick if I look that far ahead. I went to Arthritis group.... And they were talking about err you know - how we dealt with everything. We had to explain fear. Well I said my only fear was if I became crippled, who would look after J.? - That was my fear that, it wasn’t about myself... You know” (C4/293-300).

The above participant also disclosed having kept worries from her husband, about her current health prior to visiting the doctor. She said:

“Yes I was (scared) ... but I kept it to myself as well I didn’t want nobody to confide in and well they couldn’t do nothing if I did“ (C4/214-221).

Other participants made light of the effect of the caring responsibilities and duties on their health in front of their ill relative. For example, one wife participant described how she constantly gets up to check on her husband through the night. She said:

“You know he has sleepless nights so I have sleepless nights. I mean last night I get up every night at least once but last night it was three times. But it’s always between one and three times even if it’s only to check on him...the good thing about it is you lose weight!

Participants, both patients and carers described how during times of hospitalisation, the patient is regularly visited, sometimes daily, or perhaps more than once a day by relatives. For many families living in the rural locality this means travelling up to twenty-five miles or more to visit the hospital. For elderly spouses or busy families this journey becomes an arduous daily task and a financial drain. However, most carers were keen to emphasise that they would not miss visiting their relative although they expressed appreciation of car-lift offers from friends instead of having to catch the bus. One elderly wife carer commented laughingly:

“Well I lost two stone when he went in - I was going back and fore for sixty one days and I lost two stone!” (C16/481-487).

### **8.21. The carer’s thoughts about smoking**

Of the sixteen carers interviewed, three (n=3) participants, one spouse and two daughters, admitted to being current smokers themselves. Despite caring for a relative with a smoking related illness and seeing how the relative had suffered from respiratory symptoms most likely caused by smoking behaviour, all three smoking participant carers had had no intentions at that time of quitting smoking. Many participants talked as if they were personally exempt from the dangers of smoking (past and present) despite knowing about the generally accepted association between smoking and respiratory disease. As one participant commented:

“K’s brother was a heavy smoker and he had emphysema. In fact that’s what eventually killed him” (C9/75-6). (C3/221)

All three current smokers put forward rationalisations for why they continued to smoke. The comments included:

“I don’t smoke an awful lot – err 20 a day if that, and I only smoke menthol.... You blank it out and think it’ll never happen to you – don’t you? And you think –ah I’ll be all right” (C3/221-2, 238-9).

“I think if I was going to have a bad chest I would have one by now, after 32 years. My two brothers have got bad chests and they’re non-smokers. I think it’s hereditary” (C6/214-6,220).

Not all the participants were convinced by conventional explanations, as they had perceived contradictory evidence in family and friends as illustrated above.

All three-smoker carers were keen to emphasise that they did not smoke in front of their ill relative to avoid causing an exacerbation of breathing problems. Comments included:

“I don’t smoke in his house ...not since he’s given it up” (C6/208-9),

“I always go outside in the garden” (C8/71-2)

“I always go outside- I don’t smoke in front of her” (C3/225-6).

## **8.22. Chapter summary**

In order to enhance further understanding of the issues and concerns inherent in the family caregiver role, this chapter set out to explore the experience of living with COPD from the carer’s perspective. Three conceptual phases of caring were identified from the data, which evolved in tandem with the COPD illness trajectory stages. These were: (1) transition from being a caring relative to becoming a care-giving relative; (2) caring through a time of crisis; and (3) becoming the full-time carer.

During the initial phase of the caring role; the transition from caring relative to caregiver role reflected the ill-defined and vague beginnings of the disease experienced by the individual with COPD. The carer was seen as providing mostly affective care including understanding, empathy, co-operation and morale support, for example, giving the ill-relative time to mobilise or perform an activity unaided but slowly. However, over time, affective caring extended to include behavioural care

giving within the caring role as the ill relative became more disabled and dependent on others to meet increasing care-need demands, which were often compounded by effects of aging or co-existing morbidities. Relatives of individuals with COPD often made lifestyle changes or adaptations to accommodate the growing care-needs of the ill relative. However, for many spouses this was considered a natural progression of events brought on by the impact of the illness. Many couples tackled the problems together as a partnership, not just as a duty of care on the part of the well relative. Hence during this part of the illness trajectory many relatives did not consider themselves to be carers.

Many carers and COPD sufferers found themselves becoming more knowledgeable in managing the illness and its symptoms by devising practical strategies to avoid undue breathlessness, recognising potential risk factors and managing medication doses and treatment regimes. Carer participants described taking on new roles and responsibilities as the relative became more impaired and housebound. Examples include carrying out heavier household or garden tasks and the management of finances.

Most carers recalled a time during the COPD illness when the relative experienced a sudden unexpected acute exacerbation of symptoms, which could not be controlled by the usual medication. Participants described how, during this second distinct phase of the illness they were plunged into caring through a crisis, having the responsibility imposed upon them to act in the relative's best interests. Despite seeking immediate help by phoning for an ambulance or the GP and attending to urgent needs of the relative, carers claimed to feel useless, helpless and inadequate in caring for the relative. But they nevertheless felt the relative needed their presence. Carers revealed feeling terrified or frightened at seeing their relative having serious breathing problems and many confessed to fearing a repeat crisis episode. This crisis event, in some cases a near-death experience, often had a deleterious affect upon the carer's own physical and mental health. However, many carers demonstrated that they had learnt from the first crisis experience to avert or be better prepared for a subsequent occurrence.

Becoming the full-time carer was the third phase of caring for relatives with COPD. This phase usually evolved during the advanced stages of the illness. Relatives talked

about feeling the strain as they experienced physical and emotional exhaustion of their care-giving role. Caring for individuals with severely incapacitating COPD was revealed as a physically demanding role. Carers felt they needed to be available for the relative day and night, to assist with care needs as required in addition to the running of the household. Consequently, these carers revealed not only having no time to themselves but also having lost out on social activities as they felt tied to the house with the ill-relative.

However, a significant part of caring for a relative with COPD was the psychological work involved by the carer in maintaining the relative's morale. Carers were perceived as boosting the relative's confidence, morale and self-esteem by reminding them and others of their former abilities and achievements, legitimising their disability and dependency on others and by playing down the effort of caring for them. Arduous aspects of the caring role were counterbalanced by emphasising the positive aspects of caring. Ensuring the relative's well-being and comfort brought role satisfaction and feelings of freedom from regret or guilt for most carers.

Major concerns of the carer during the advanced stage of the illness focused upon feelings of uncertainty about the future nature and course of the illness, prompting questions, which had not been clearly answered by medical staff. In particular some carers were concerned whether their own health problems might not allow them to continue caring for their spouse. Paradoxically a few carers caring for relatives with severely advanced COPD had continued smoking cigarettes and when questioned, stated that they had no immediate intentions to give up.

Although most individuals with advanced COPD were severely disabled by their breathlessness and fatigue, many continued to struggle to retain some independence, requiring the minimum of assistance for care needs, whilst others became totally dependent on the carer. Hence, due to the non-standard progression of the disease and impact of the symptoms on the individual's lifestyle, many relatives did not consider themselves to be carers until the spouse or relative became house or chair-bound. Even then care tasks undertaken during the later stage of the illness were often considered part of the role of being a spouse or adult daughter; giving a helping hand or being supportive rather than that of being a carer. Also, as many individuals with COPD appear able-bodied while seated or resting, and have unimpaired cognitive

functioning, some families did not recognise the severity of the illness until a crisis episode of breathing difficulties was experienced by the ill relative. Hence, patients with COPD and their families in the past have not been recognised as needing formal care services with the consequence that care of the individual has been left solely to family and friends.

The issues explored in this study related to family caring of individuals with COPD highlight circumstances, which may have contributed in the past to the neglect of this client group of patients and their carers. The study highlights how this COPD carer group need targeting both for education and appropriate health and social support services, in particular for the increased availability of respite care to improve quality of life for both patient and their carers.

## **9.0. Chapter 9: Discussion, implications and final conclusions**

### **9.1. Introduction**

The study set out to describe and explore the experiences and perceptions of individuals and their carers living with COPD, to elicit insights and gain a deeper understanding into the life-worlds of individuals living with their progressive degenerative illness COPD.

Exploration of participants' lives from within a symbolic interactionist perspective provided new data and further understandings of what is already known about living with COPD, from the view point of the patient or the family carer. The study used an interpretive approach to consider the lives of participants in their social context, including the part played by relationships and situational factors along the COPD illness trajectory.

This chapter discusses the overall findings of the study and their implications for health care provision, particularly in terms of nursing practice for patients and their carers living with COPD. It also considers the study's limitations and recommendations for further research.

### **9.2. The COPD illness trajectory and the approach of symbolic interactionism**

The study highlights how the principal characteristic symptoms of COPD, breathlessness or dyspnoea, fatigue, anxiety and fear of breathing difficulties, are central to understanding the experience of living with COPD. Participants' narratives of living with COPD revealed how a degenerative illness was characterised by the symptoms becoming more severe, disabling and frightening. The characteristics of the illness were found to have significant consequences for participants' (patients and carers) self-identity, lifestyle and relationships with others. These 'biographical disruptions' could be mapped out along the chronic illness trajectory framework within phases of the illness over time (Corbin and Strauss 1988; Glaser and Strauss, 1968; Strauss et al, 1985).



The study identified how the course of the COPD illness was characterised by a slow, uncertain onset often lasting many years, followed by a steady downward progression interrupted by increasingly frequent, unpredictable and crisis-provoking episodes of acute exacerbation of symptoms. For patients with COPD, an acute exacerbation of symptoms is potentially life threatening and an estimated 15% of COPD patients die following such events (RCP and BTS, 2004). The study found that the illness course of COPD was rarely linear, but fluctuated between a steady decline and acute episodes of worsening symptoms, some of which resulted in emergency admissions to hospital.

A symbolic interactionist approach was used to explore the participants' experiences of living the illness trajectory of COPD. The participants revealed their life worlds of living with COPD, by telling stories which raised issues and concerns they perceived to be relevant to their lives. Using the symbolic interactionist perspective, this study explored the interrelationships between the participant and others and how these social interactions influence their perceptions, decision-making and self-identity along the illness trajectory.

Exploration of the illness trajectory identified conceptual stages of COPD as: the early days; adapting to changes in self and lifestyle; the daily struggle and living with terminal COPD: fears and facing the future. Although these stages of the illness are identifiable by various characteristics, the boundaries of the latter stages often are indistinguishable and overlap. The study confirmed that COPD is an ill-defined illness, characterised by a vague onset gradually progressing from a condition incorporated into normal daily lifestyle, usually protracted over many years, to an illness with symptoms that eventually become unpredictable and severely disabling.

The early days revealed the slow and insidious onset of the disease portrayed by the presence of mild, unobtrusive symptoms over many years. Lack of a medical diagnosis at this stage was seen to perpetuate a general vagueness about COPD as a defined illness, its aetiology and its future course.

As the characteristic symptom of breathlessness increased, individuals started to learn to adopt strategies by which they could not only minimise or avoid undue

breathlessness but were also able to moderate, and sometimes disguise from others the impact of their breathlessness while carrying out normal daily activities. Hence, individuals learned to adapt to physical and life style changes.

However over time, this coping behaviour became less effective and degenerated into a daily struggle to breathe normally and to avoid breathlessness-related functional difficulties. Severe breathlessness and fatigue on even gentle exertion increasingly imposed loss of independence and a greater reliance upon others for assistance.

Living with severe or terminal COPD raised feelings of extreme vulnerability, uncertainty and multiple fears relating to the unrelenting breathlessness and future coping with its consequences. Not knowing how much worse the symptoms will get, not knowing when the next exacerbation will occur and often not realising the seriousness of their deteriorating illness, contribute to the general uncertainty characteristic of living with COPD in its latter stages. Striving to prevent exaggerated breathlessness and acute exacerbations was found to become a major preoccupation of daily living, as individuals with advanced COPD live in perpetual anxiety/fear of a potential sudden episode of breathlessness. Consequently, individuals with severe COPD typically withdraw from social engagements and act out sedentary lives centred around pre-planned strategies and daily routines to avoid any unexpected event or situation which could lead to a cycle of unmanageable breathlessness, panic and fear (refer to chapter 7). Thus an increasing preoccupation with the failing body contributes to increasing social disengagement.

The COPD illness trajectory becomes unpredictable in its latter stages due to more frequent and severe exacerbations followed by shorter periods of recovery while in overall decline. This illness trajectory contrasts with that of lung cancer (Edmonds et al, 2004) but is not dissimilar to that of heart failure (Teno et al, 2001; Willems, et al, 2004). The literature identifies how death often occurs suddenly and unexpectedly after having lived complacently with the milder symptoms for many years (Stoller, 2002). Hence, understanding the illness trajectory of COPD gives rise to a deeper understanding of the fear and anxieties experienced by individuals as they live in continual uncertainty of future unpredictable and potentially life-threatening episodes of breathlessness / dyspnoea characteristic to the condition COPD.

This study identifies how an understanding of the illness trajectory of COPD based on the insights of living with COPD as explored and discussed through chapters 4-8, can give rise to increased professional knowledge as a first step towards the provision of more appropriate health and social care / support for this patient group.

The contribution of this study is to provide insights into how and why uncertainties and difficulties surrounding COPD exist, and to expose the vulnerability and fears of people living with the illness COPD. Most notably is the fear of not being able to breathe, as symptoms and their impact on daily living become more severe in the latter stages of the illness.

Although perceived by outsiders as being physically ‘intact’, individuals with COPD experience frightening breathlessness and progressive debilitating functional and psychosocial difficulties as a consequence of actual and potential breathlessness. Restricted movement and ambulation renders individuals dependent upon others, causing feelings of vulnerability and a sense of loss of the able-bodied person they used to be. Struggling to come to terms with an altered self, body and circumstances, many individuals with advancing COPD experience multiple feelings of loss and fear. Loss of self-reliance, personal fulfilment or self-confidence, and fears such as fear of losing one’s self-respect, being seen as a fraud, considered a burden or in a minority of cases the stressful dilemma of whether to undergo lung surgery are experienced. These concerns compounded with the unrelenting breathlessness and restricted daily functioning contribute to considerable anxiety, fear or depression, which in turn impact upon the psychosocial well-being of individuals with COPD.

This study contributes to a more detailed understanding of the small but multiple issues, concerns and problems inherent in living with COPD which may have previously been ignored by health services as considered trivial or inconsequential. A key contribution of this study is the illumination of the ‘little things’ encountered in the lives of people with COPD. It is hoped that the study raises an awareness and realisation within clinical practice / healthcare that these small but significant issues are often of paramount importance to a patients’ sense of well-being and should be recognised as such in the provision of appropriate health and social care for

individuals with COPD. For example at the patient – health professional interpersonal level, as well as in the provision of aids / equipment and financial entitlements.

As a group, individuals with COPD share common experiences with others in similar situations, which understood within the context of symbolic interactionism, can give rise to recommendations for practice and policy change. Corbin and Strauss (1992:10) suggest that by taking into account the theoretical chronic illness trajectory framework, the illness course can be anticipated and managed by health professionals to benefit patients. According to these writers, insights and an understanding into the problems of the illness from research and the cumulative findings of the existing literature on chronic illness can help to provide direction for nursing practice, research and policy making.

With this in mind, the following points are extracted from the study to highlight what has been learned and what new questions are raised in relation to improving health and nursing interventions for patients with COPD and their family carers.

### **9.3. The uncertainties of living with COPD**

Despite a recent surge of interest in COPD, this study confirmed the continuing uncertainty surrounding the identification, characteristics, management and life expectancy of this illness. Although previous studies have found that individuals do not initially approach their doctor until the symptoms of COPD have developed in severity (Engstrom et al, 1996; Rodriguez-Roisin, 2000); explanations for late presentation remain unclear. Several themes emerged from the study to explain the late presentation to a doctor by individuals with the early mild symptoms of COPD.

Government health policies and initiatives highlight the harmful effects of smoking for major killer diseases, but COPD often has not been named alongside heart disease and cancer. Consequently the general public are unaware of COPD as a major identifiable disease and are not conversant with the term COPD. There has been a general lack of recognition of the mild symptoms or their significance, being the onset of a serious disease, which will potentially develop into a severely disabling, degenerative, and irreversible illness.

Some individuals felt there was no justification for taking up the doctor's time for what they considered insignificant symptoms. In addition, individuals experienced long symptom-free periods and so for many years did not consider themselves to be ill. Hence the mild symptoms were ignored, tolerated and accommodated into normal living until their intrusion into daily life became problematic leading to seeking out professional intervention.

So an initial issue raised by this study is: how can awareness of the disease and the importance of seeking early professional attention be raised among the general public? Opportunistic primary healthcare screening of patients, as for smoking cessation, is recommended using spirometry to identify mild symptoms indicative of early COPD (Van Schyack et al, 2002). However not all GPs are convinced of the benefits of this time-consuming strategy (McEwen et al, 2001). As COPD is increasingly recognised as a significant disease, characterised at the onset by subtle unobtrusive symptoms, then it is possible that the general public will be less reticent about approaching their GP to investigate minor symptoms and subsequently be medically diagnosed earlier on in the illness.

Having sought out medical attention, participants (irrespective of socio-economic status) demonstrated a (varying) lack of knowledge of the diagnosis and familiarity with the term COPD, even after years of treatment by their respiratory physician and GP. This situation indicates potentially inadequate professional knowledge/ diagnosis and /or poor communication between health professionals and patients.

Identification of COPD had differing impact on participants, but most notably for some it was received with relief that their symptoms were not due to heart disease or cancer. At the time of diagnosis the illness COPD/emphysema/chronic bronchitis was felt to be less threatening than some other diseases and was perceived as being a manageable condition. However this lay perception of COPD indicates the general lack of knowledge of the severity and progression of COPD, and the intensely frightening symptoms, which are experienced in the later stages of the illness. For some participants, initial contact with the GP led to the prescription of inhaled medication, which controlled mild symptoms and temporarily improved life quality,

so delaying the psychological impact of the diagnosis. A medical diagnosis provided a rationale for the symptoms and their restrictive effect on activity levels for some participants, so legitimising their reduced activity and justifying retirement from employment. Confirmation of the illness for others, however, was upsetting as it meant enforced retirement and severing social links and the decline into social isolation.

This study confirms previous evidence identifying the low level of knowledge about COPD held by health professionals and the incomplete implementation of recommended COPD management guidelines (GOLD Executive Committee, 2006). Inaccurate differential diagnosis, mis-diagnosis of COPD as asthma, absence of clear diagnosis due to existing co-morbidity and failure to confirm diagnosis by spirometry were issues raised by the study. Frequently COPD was perceived by patients and medically treated by professionals as being little different from asthma. It seems likely that professional knowledge and competency in COPD management will improve as a result of the recent focus on COPD as a chronic condition (NCCC, 2004; GOLD Executive Committee, 2006, British Medical Association, 2006).

Smoking cessation has become a major component of health promotion initiatives and primary care advice to prevent illness and reduce the risk to health. Most of the study's participants recalled receiving brief and sometimes 'blunt' advice from a health professional to quit. However surprisingly, despite medical advice and media anti-smoking campaigns, some participants remained unclear about the harmful effects of smoking, often recounting having observed health professionals smoking while off-duty.

Five study participants (n=5/53) continued to smoke at the time of interview, despite repeated attempts to give up. Nicotine addiction, habit, uncertain benefits of giving up, or adverse reaction to nicotine replacement therapy or Zyban®, were identified reasons for smoking cessation failure while a supportive family and effective alternative therapies were instrumental in assisting successful smoking cessation, factors identified elsewhere (Pracy and Chevretton, 2000; West et al, 2001).

A substantial number of study participants failed to identify cigarette smoking as the primary cause of their respiratory illness, although most acknowledged that it contributed towards the condition. Employment during war-time and the immediate post-war period, involving occupational exposure to dusts, fumes, chemicals and heavy urban air pollution was identified by many as a likely causative factor for COPD, and this is in line with scientific evidence (GOLD Executive Committee, 2006). Due to advances in modern technology and the implementation of Health and Safety legislation, further exposures are unlikely in the UK but may remain a problem in developing countries.

Although no participants of the study were aware of high genetic risk of COPD, as is the case for a tiny minority (McElvaney and Crystal (1997), a few suggested the role of gender-related inherited predisposition noting that only the female members of a family were affected despite some being life-long non-smokers.

A minority of participants disclosed feelings of guilt, shame and self-blame that they had previously smoked, or even continued to smoke and felt stigmatised for doing so. Feeling guilty that smoking related symptoms are self-inflicted may contribute towards delayed presentation to the doctor but this was not made explicit in the study.

The majority of participants however considered that smoking was the normal thing to do in the past, encouraged by peers and government, but said they had since given up when they realised its risk to health. Ironically just as smoking rates for older people are decreasing, they are increasing in a specific section of the younger female population (Soriano et al, 2000). It would appear that health promotion campaigns are failing, and that this may have implications for the future prevalence of COPD in the UK.

As the disease steadily progressed in severity, participants revealed using strategies such as pacing self, limiting activities, planning ahead, stopping and resting to conserve breath, energy and social respectability, supporting the findings of other qualitative studies of COPD (Barstow, 1974; Fagerhaugh, 1973; Jeng et al, 2002; Barnett, 2005; Fraser et al, 2006). This study noted how the participants incorporated these strategies into a way of life to play down the impact of the illness on daily

living, which is generally not noticed by the casual onlooker. Consequently, individuals cope for years with mild COPD not perceived by others nor perceiving themselves as having a chronic illness and being ill, until they experience a distressing episode of an acute exacerbation of symptoms. Long symptom-free periods lull patients into thinking the illness is abating, creating a sense of uncertainty about the illness progression and whether to contact the doctor to pursue for further investigations, until the next acute episode of uncontrollable breathlessness.

The study found that the unpredictability of COPD symptoms was a perceived concern of participants where the breathlessness, wheeze, cough, phlegm production, not only impacted on their physical well-being but were a cause of social embarrassment and self-consciousness. Difficulty in eating and swallowing, and a predisposition to prolonged bouts of coughing and choking due to breathlessness, dry throat or a smokey atmosphere were deterrents for eating in company or socialising. The study noted how as the disease severity progresses the breathless symptoms restrict and limit mobility. Severely compromised individuals with COPD find their ambulation curtailed often limiting them to the home. Some participants in this situation revealed resorting to a wheelchair in order to maintain a degree of social activity, but were dependent upon the availability and willingness of others. Hence those individuals who live alone or have no supportive family or friends, or whose spouse is likely to be elderly and frail are unlikely to benefit from this approach.

Some of the more severely affected COPD participants received long-term home oxygen therapy which further tied patients to the home, although a few benefited from the use of portable oxygen cylinders which were taken in the car for short exertions. However continuous portable oxygen has a limited duration so limiting time away from the house to an hour or so.

The above findings support those of previous studies, which highlight how patients with COPD and their spouses often become socially isolated and/or lonely (Seamark et al, 2004; Bergs, 2002; Elofson and Ohlen, 2004). The study revealed how reduced social outings by participants led to reduced participation in physical activities and a more sedentary lifestyle.



Reduced activity however runs counter to the recommendations of pulmonary rehabilitation experts regarding which exercise is the cornerstone (BTS Standards of Care Subcommittee on Pulmonary Rehabilitation, 2001). At the time of interviewing the local NHS Trust did not hold a formal pulmonary rehabilitation program for COPD patients. Consequently the study's participants raised pertinent issues of concern regarding management of their illness about which they were uncertain.

In adapting to the changes imposed upon their lifestyles, many respondents raised concerns about taking their medication. The different inhalers and different prescribed tablets confused some participants, especially which and when to take. This despite printed instructions on the labelling. Some participants became non-compliant due to the perceived ineffectiveness of the recommended treatment and altered doses to a level they considered more beneficial. Unintentional non-conformity in treatments occurred with others due to functional disability and a lack of dexterity to use inhalers as medically prescribed. Difficulty in using pMDI's due to a lack of co-ordination or being too breathless, not knowing how to assemble the bulky volumatic spacer or having a personal preference for a particular device were identified as other reasons for not adhering to pharmacological treatments. Non-intentional non-compliance to medical advice has been noted in asthmatic patients elsewhere (Jones et al, 2004). The study found that compliance with professional advice or treatment often dropped off over time due to the patients' perceived lack of benefits, perceived lack of interest by the doctor or due to conflicting advice from health professionals. A fear of dependency upon medication, particularly the long-term oxygen therapy was noted in a few participants, who did not realise the benefit of taking continuous oxygen, which is physically non-addictive.

Based on specific criteria, four participants with COPD (n=4/53) of the study were offered elective lung surgery to potentially improve the quality of their lives. This however raised further uncertainties based upon the risk of the procedure and the outcome benefits of the surgery. Lung volume reduction surgery (LVRS) is likely to become more widespread as an option for selected younger patients with COPD. This study identified a new area of concern for COPD patients who are faced with the prospect of possible lung surgery, as few studies at present investigate patient's attitudes or experiences of undergoing LVRS.

While some participants had made changes in living arrangements to accommodate the illness, others were reluctant to acknowledge their likely inability to cope for much longer without the help of services and/or house adaptations and aids. Again uncertainty and a lack of understanding of the disabling nature of the illness and the unpredictability of its trajectory led many participants to believe that there was no need to make lifestyle changes or provision for the future impact of the illness. Not understanding or realising the severity of the illness, many participants considered that their illness was unlikely to deteriorate to the point that they would not be able to manage as they were currently doing. However this mis-conception was brought home to one married respondent when he and his elderly wife, both severely disabled, found they were about to be placed in separate nursing homes as a consequence of lack of forward planning.

Many participants become familiar with the gradual decline from stable-mild to moderate symptoms and, still feeling in control of their lives, are reluctant to seek outside help. However this changes when they experience an unpredicted significant attack of dyspnoea. This is often the stage when they first realise the seriousness of their situation and their vulnerability, and seek out professional intervention. Nearly all the participants recalled at least one distressing incident whereby they experienced difficulty in breathing, which precipitated feelings of fear and panic. Thereafter participants often curtail their activities and lifestyle, anxious to minimise the risk of further attacks.

The study revealed how participants struggled with their illness limitations to retain a level of independence but became increasingly dependent upon significant others - family members, neighbours, friends - and health professionals as the illness worsened.

The family carer, in particular the patient's spouse, also lived with the uncertainties raised by the illness COPD. Over time the patient and carer adopted a way of life often working collaboratively to accommodate the illness into the routine of daily life, for example by swapping traditional roles in carrying out household tasks and responsibilities. Family carers become sensitive to the needs of the patient and gained a practical understanding of how to manage and avoid trigger factors so as to control unwanted breathlessness. However, the study highlighted how the crisis situation of an acute exacerbation of symptoms experienced by the sufferer led to the carer feeling inadequate and helplessness as they were unable to manage the relatives' dyspnoea and fear. Uncertain of how to handle distressing situations, carers sought professional intervention but at the same time were reluctant to hand over total responsibility to health professionals. Carers felt that they understood the psychological impact on their relative and that their presence was particularly needed at the time of crisis to interpret and convey the needs of the ill relative to healthcare staff.

The study's findings suggest that individuals with COPD would benefit from pulmonary rehabilitation to better cope with exacerbations of symptoms and increase exercise tolerance. In addition the study identified the need for patient and family education to support their management of stable symptoms and to provide COPD-related information to address the issues of patient uncertainty and lack of knowledge about the illness and its consequences. Close support and monitoring within the primary care setting, with emphasis on the community nursing team could help prevent or reduce exacerbations and enhance the confidence and self-esteem of patients with COPD.

#### **9.4. Feeling vulnerable due to living with COPD**

Participants highlighted how they lose self-confidence with their loss of independence and perceive themselves as vulnerable members of society. This sense of vulnerability was compounded by user-unfriendly local health services and a lack of understanding about the condition by public service providers. Not perceived as disabled in the usual sense, participants with COPD were not considered priority cases for house renovations, installation of aids, provision of equipment or for receipt of financial benefits. Consequently participants doubted their entitlement despite experiencing severe disability comparable to other chronically ill patients. Feeling that they lack a legitimate claim to receive social support aids and equipment, this elderly patient group are further demoralised, unsupported and marginalized.

On a personal level, participants highlighted how they tried to stifle emotions to avoid triggering increased breathlessness as they lived in constant fear of acute exacerbated dyspnoea, in line with the well-known aphorism that COPD patients live in 'emotional straitjackets' (Dudley et al, 1980). Depression, or 'feeling down', emerged in the interviews as a factor that reduced capacity to carry out normal daily activities and increased dependency on others to assist in carrying out daily activities. It seemed to go hand in hand with the unrelenting breathlessness and fatigue experienced in advanced COPD. During this phase of the illness trajectory, as individuals become disabled and dependent upon others due to the progressive impact of the illness, sufferers tend to reappraise and re-negotiate their sense of self, reformulating their identities. Consequently the mood states of the participants with COPD fluctuated between despondency and optimism, which were influenced by the availability of personal resources, most notably supportive family members and approachable, understanding health professionals.

Carers of patients with advanced COPD were anxious to play down the exhausting effort of their full time caring role in front of the ill relative, so as to hide the burden of caring. The carer participants were aware of the relative's loss of self-esteem induced by the impact of the illness and were anxious to boost patient morale whenever possible. Carer participants highlighted the psychological work alongside the physical demands involved in family caring. Although spouse carers tended to

accept the caring role unconditionally, the daughter carers revealed wanting more time for themselves as they juggled between conflicting demands on time from the ill parent and their family. Despite the work involved, all carers refused to have the ill relative put into a nursing home and most were reluctant to receive formal care services. One spouse carer stopped social service care visits as she felt that they were not beneficial. She noted that the carers did not understand her husband's fear of breathing difficulties, as they tended to dismiss the breathlessness and rushed while washing and dressing him. A similar situation has been noted elsewhere (Yohannes et al, 1998) and may explain why family carers of COPD relatives take up less statutory support than families of relatives with other chronic conditions.

The study highlighted the lack of empathy by some health professionals including GPs and hospital nursing staff who did not understand the patient's experience of coping with the COPD symptoms and had unrealistic expectations of the patient. Health professionals not understanding the fear and anxiety related to the dyspnoea or severe breathlessness caused by exertion were perceived as being judgemental by participants, especially when they questioned the need for assistance or to allow the patient to remain resting. Needing time to plan an activity ahead of execution, to mobilise in stages interrupted by resting phases, being allowed time to carry out an activity, and taking steps to minimise breathlessness on exertion were strategies noted by participants considered necessary and appreciated by participants to avoid distressing situations. These findings support those of Lomborg et al, (2005) who noted that assisted body care for dependent hospitalised patients with COPD was not always perceived as being beneficial owing to a lack of understanding by nursing staff of the breathless experience. Earlier work by DeVito (1990) noted the perceived unhelpful attitudes of nurses towards breathless patients due to not understanding the seriousness of the breathlessness as COPD patients often appear normal while sitting.

Poor patient experiences while in hospital may influence decision-making at the onset of an exacerbation and explain the low contact rate with health services by COPD patients and their carers. Generally participants with severe COPD revealed feeling physically, psychologically and socially vulnerable not only due to the impact of the illness on self but also due to the perceived lack of understanding by others of the consequences of the illness.

Frequency of exacerbation is linked to increasing disease severity, so the focus of living with advanced COPD becomes inextricably linked to avoiding frightening breathless situations. This study found that as the illness condition deteriorated, participants lived in fear and anxious apprehension of developing further episodes of dyspnoea and breathing difficulties, supporting the findings of previous studies (Hill-Bailey, 2001, 2004). Participants acknowledged facing dying and death during previous occasions, thinking that each breath may be their last. Mentally learning to survive the breathless episodes and/or drawing moral strength from supportive others helped participants to get through the exacerbations.

The study demonstrated how the participants devise self-supporting strategies as they stoically manage their COPD illness adapting medical advice and treatments to manage the consequences of their degenerative condition over many years. They tend to avoid medical intervention until they experience a sudden deterioration or crisis in condition. However if the future management of COPD (and other chronic illnesses) is to be focused upon successful intermediate care and patient self-management then the contradictory concepts of self-reliance and concordance with professional advice will need to be reconciled (Thorne, 1990).

The findings of this study suggest that the general public, patients with COPD and health professionals, all require educating about COPD if treatment and appropriate support for COPD patients and their carers is to be improved. Earlier detection and treatment would reduce disease progression, while pulmonary rehabilitation and sensitive professional support for patient and family could enhance disease management and health-related quality of life. However, in order to support patients and their family carers, the study highlighted the importance of health professionals needing to recognise and understand the psychological consequences of the illness on the patient living with COPD.

### **9.5. Limitations of the study**

The study design had three limitations, which may have influenced the findings. Firstly, most patient participants had not undergone spirometry testing, so their

disease stage was not categorised by FEV1/FVC values according to recognised guidelines, but based upon arbitrary clinical assessment. Secondly, some participants were too breathless to give lengthy and elaborate accounts but conveyed stories with an economy of words. Thirdly, despite the researcher requesting separate interview accounts from the patient and carer, each was conducted in the presence of the other, which was likely to have influenced the content of the interview. The carer in particular revealed sensitive issues about caring for the relative when out of earshot of the patient and not caught on audiotape.

This study used a cross-sectional approach to elicit participant accounts of the experience of living with COPD relying on the participant's memory to recall past events. Although from a perspective of symbolic interactionism, each account is validly constructed, it is likely to differ each time the story is relayed and re-told over time. Further research into the patient's experience using a longitudinal method to interview patients and carers over time perhaps provide a more detailed account of the process of the illness trajectory and the shifting experience of living with COPD. Alternatively patients classified by illness stage according to spirometry values could be interviewed to provide a series of snapshots capturing participant experiences at each stage of the illness.

#### **9.6. New developments since commencement of study**

Several important schemes have been introduced since the commencement of this study, which identify COPD as a focus for healthcare intervention. These include:

- Updated national and international guidelines for the diagnosis and management of COPD (NCCC, 2004; GOLD Executive Committee, 2006)
- Introduction of the new General Medical Services contract (BMA, 2004)
- Abolition of prescription charges in Wales (2007)
- The company Airproducts® took over the provision of the long-term oxygen therapy home service throughout the UK (2006)
- National guidelines were introduced for LTOT (BTS, 2005).
- The Smoke-free Premises etc. (Wales) Regulations 2007 (National Assembly for Wales, 2007).

- Air forecast system introduced to inform the public of pollen count levels (2007)
- Introduction of an intermediate care scheme by the local NHS Trust (winter 2005)
- Community chronic care specialist nurses appointed in the local NHS Trust (winter 2006-7).
- Introduction of World COPD day annually (the third Wednesday in November).

Clearly COPD is gaining a higher priority on the health service agenda. However this study highlights how healthcare professionals, in primary and secondary care, not only need to update professional knowledge on COPD, but also require to take into consideration patient needs as perceived and defined by patients with COPD and their carers.

## **9.7. Conclusion**

This study generally supports the findings of previous quantitative and qualitative work on COPD as a chronic degenerative disabling disease. However, this study employed a sociological symbolic interactionist approach and thematic analysis of narrative interviews to explore the illness trajectory of living with COPD. The participants revealed detailed accounts of how they perceived the impact of the progressive illness on their life-worlds, on their responses to the illness, and on their self-identity. The study gives rise to a deeper understanding of previously identified issues of living with COPD, and suggests reasons why individuals act in the way they do.

The use of an interpretive approach provided further insight into the consequences of the illness on participants' daily lives, especially how feelings and actions changed as participants negotiated meaning for their experiences as they live through the downward illness trajectory. These findings have implications for health professionals, particularly nursing staff whose professional role is to interact with patients and their families during the later stages of this illness trajectory. Through understanding the illness related issues and concerns from the perspective of the



individual, and taking some uncertainty out of the illness trajectory, healthcare professionals could be better placed to provide improved empathetic, holistic and appropriate healthcare to support patients and their carers living with COPD.

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## Appendix 1. Spirometric Classification of Severity

For educational reasons, a simple spirometric classification of disease severity into four stages is recommended (**Figure 1-2**). Spirometry is essential for diagnosis and provides a useful description of the severity of pathological changes in COPD. Specific spirometric cut-points (e.g., post-bronchodilator FEV<sub>1</sub>/FVC ratio < 0.70 or FEV<sub>1</sub> < 80, 50, or 30% predicted) are used for purposes of simplicity: these cut-points have not been clinically validated.

A study in a random population sample found that the post-bronchodilator FEV<sub>1</sub>/FVC exceeded 0.70 in all age groups, supporting the use of this fixed ratio.

Figure 1-2. Spirometric Classification of COPD Severity Based on Post-Bronchodilator FEV <sub>1</sub>		
Stage I:	Mild	FEV <sub>1</sub> /FVC < 0.70 FEV <sub>1</sub> = 80% predicted
Stage II:	Moderate	FEV <sub>1</sub> /FVC < 0.70 50% = FEV <sub>1</sub> < 80% predicted
Stage III:	Severe	FEV <sub>1</sub> /FVC < 0.70 30% = FEV <sub>1</sub> < 50% predicted
Stage IV:	Very Severe	FEV <sub>1</sub> /FVC < 0.70 FEV <sub>1</sub> < 30% predicted or FEV <sub>1</sub> < 50% predicted plus chronic respiratory failure

*FEV<sub>1</sub>: forced expiratory volume in one second; FVC: forced vital capacity; respiratory failure: arterial partial pressure of oxygen (PaO<sub>2</sub>) less than 8.0 kPa (60 mm Hg) with or without arterial partial pressure of CO<sub>2</sub> (PaCO<sub>2</sub>) greater than 6.7 kPa (50 mm Hg) while breathing air at sea level.*

### Stages of COPD

*Stage I: Mild COPD* - Characterized by mild airflow limitation (FEV<sub>1</sub>/FVC < 0.70; FEV<sub>1</sub> = 80% predicted).

Symptoms of chronic cough and sputum production may be present, but not always. At this stage, the individual is usually unaware that his or her lung function is abnormal.

*Stage II: Moderate COPD* - Characterized by worsening airflow limitation (FEV<sub>1</sub>/FVC < 0.70; 50% = FEV<sub>1</sub> < 80% predicted), with shortness of breath typically developing on exertion and cough and sputum production sometimes also present. This is the stage at which patients typically seek medical attention because of chronic respiratory symptoms or an exacerbation of their disease.

*Stage III: Severe COPD* - Characterized by further worsening of airflow limitation ( $FEV_1/FVC < 0.70$ ;  $30\% = FEV_1 < 50\%$  predicted), greater shortness of breath, reduced exercise capacity, fatigue, and repeated exacerbations that almost always have an impact on patients' quality of life.

*Stage IV: Very Severe COPD* - Characterized by severe airflow limitation ( $FEV_1/FVC < 0.70$ ;  $FEV_1 < 30\%$  predicted *or*  $FEV_1 < 50\%$  predicted plus the presence of chronic respiratory failure). Respiratory failure is defined as an arterial partial pressure of  $O_2$  ( $PaO_2$ ) less than 8.0 kPa (60 mm Hg), with or without arterial partial pressure of  $CO_2$  ( $PaCO_2$ ) greater than 6.7 kPa (50 mm Hg) while breathing air at sea level. Respiratory failure may also lead to effects on the heart such as cor pulmonale (right heart failure). Clinical signs of cor pulmonale include elevation of the jugular venous pressure and pitting ankle edema. Patients may have *Stage IV: Very Severe COPD* even if the  $FEV_1$  is  $> 30\%$  predicted, whenever these complications are present. At this stage, quality of life is very appreciably impaired and exacerbations may be life threatening.

*Source: Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. Copyright 2006. MCR Vision Inc.*

**Appendix 2: Patient information sheet and letters of ethical approval and consent to access**

Researcher's address

Tele. No.

Date

Dear

I am a staff nurse employed on a medical ward at Withybush Hospital, who is interested in patients with a respiratory condition known under the umbrella term as Chronic Obstructive Pulmonary Disease or COPD. (COPD includes e.g. chronic asthma, bronchitis, emphysema). I am carrying out a small research study as part of a degree studied for at the University of Wales Swansea, which will investigate the effects of COPD on the daily living of patients and carers.

Pembrokeshire and Derwen NHS Trust have agreed that the study can go ahead subject to the agreement of individual patients and carers. It has also been approved by Dyfed-Powys Research Ethics Committee and has the consent of Consultant Hospital Physicians and G.P.s to approach their patients who may have chest problems.

As a patient who may have Chronic Obstructive Pulmonary Disease, I am inviting you to take part in this study. This would involve a simple test called Spirometry and carrying out interviews, which may be tape-recorded. Spirometry testing requires the patient to blow out into a mouthpiece to measure the air volume expired from the lungs. You may have already carried out this test with your Doctor or Practice Nurse, in which case you will not be required to do so again.

If you agree, I would ask you some simple questions about yourself and how you manage day-to-day activities with your condition of COPD. If you give permission to go ahead, I will approach your main carer (i.e. spouse/ partner/ relative/ home-help) to ask if he/she also agrees to be interviewed. My research will examine what it is like to live with Chronic Obstructive Pulmonary Disease by paying attention to the experiences of both patient and carer.

The interview may be held either in a private room at the hospital or at your own home (depending on which is best for you), at a time suitable to you,

preferably within a couple of weeks. A few weeks after this interview is completed, I may like to meet you again in order to check that I have not misunderstood what you told me. I will do the travelling either to the hospital, clinic or to your home.

The interview would take as long as you wanted, but would probably be most useful if you could spare about an hour. All information given to the researcher would be strictly confidential – no names or information that would identify participants would be revealed at any time. Should a tape-recorder be used to record the interview, the tape will be destroyed or given to you - the participant – at the end of the study. Your confidentiality and anonymity would be guaranteed as no names or means of identification would be used in the writing up of the study. You would be entitled to withdraw from the study at any time with no detriment to any ongoing care. You are under no obligation whatsoever to take part but a reply would be appreciated, indicating whether or not you are willing to participate in the study. Please return the slip below as soon as possible in the stamped self-addressed envelope provided.

Thank you for your time in reading this letter,

Staff nurse – Researcher’s name

.....

Research Study on Living and Coping with COPD.

Please indicate your intentions below by ticking the appropriate box and returning your reply in the self-addressed envelope to myself (T.W.)

Participant’s name: .....

I am interested in taking part in the above study ☐

My telephone number is -----

I am not interested in taking part in the above study ☐



**A RESEARCH STUDY: LIVING AND COPING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE.**

Researcher's name:

Researcher's tele. no.:.....

**AIM: TO INVESTIGATE THE EXPERIENCES OF PATIENTS AND PATIENTS' CARERS LIVING AND COPING WITH COPD.**

**PARTICIPANT'S CONSENT TO TAKE PART IN THE STUDY.**

Please initial or tick each box:

- I confirm that I have read and understand the information sheet dated ..... for the above study and I am willing to carry out the Spirometry test if it is required. ☐
- I understand that the research study will involve one interview and a follow-up meeting several weeks later carried out by T. W., which may take place either in the hospital or at my home. ☐
- I am willing for the interview to be tape-recorded but I understand that the tape will be destroyed or given to me at the end of the study and at no time will my identity be revealed. ☐
- I understand that I may withdraw from the study at any time with no detriment to my medical and nursing care. ☐
- I agree to take part in the above study. ☐

PARTICIPANT'S NAME .....  
ADDRESS .....  
.....  
.....  
.....

TELE. NO. ....

PARTICIPANT'S SIGNATURE .....

DATE .....

**A RESEARCH STUDY: LIVING AND COPING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE.**

Researcher’s name:

Researcher’s tele. no.....

AIM : TO INVESTIGATE THE EXPERIENCES OF PATIENTS AND PATIENTS’ CARERS LIVING AND COPING WITH COPD.

**CARER’S CONSENT TO TAKE PART IN THE STUDY.**

Please initial or tick each box:

- I confirm that I have read and understand the information sheet dated ..... for the above study . ☐

- I understand that the research study will involve one interview and a follow-up meeting several weeks later carried out by T. W., which may take place either in the hospital or at my home. ☐

- I am willing for the interview to be tape-recorded but I understand that the tape will be destroyed or given to me at the end of the study and at no time will my identity be revealed. ☐

- I understand that I may withdraw from the study at any time with no detriment to the patient’s medical and nursing care. ☐

- I agree to take part in the above study. ☐

CARER’S NAME .....  
ADDRESS .....  
.....  
.....  
.....

TELE. NO. ....

CARER’S SIGNATURE .....

DATE .....

# **Dyfed Powys RESEARCH ETHICS COMMITTEE**

Cadeirydd/Chairman: Dr M Snow  
Is Cadeirydd/Vice Chairman: Dr M J Turtle



c/o Department of Public Health, PO Box 13, St David's Hospital, Carmarthen, SA31 3YH

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MS/acg/00/046

22 May, 2000

Ms Toni Williams  
Medical Unit  
Withybush General Hospital  
Fishguard Road  
Haverfordwest  
Pembrokeshire

Dear Ms Williams

**A Study to Explore "Living and Coping" with End-Stage Chronic Obstructive Pulmonary Disease:  
The Experiences of the Patient and the Patient's Carer**

I write with reference to the above, and to your correspondence dated 15 May, 2000.

As we are now in receipt of your assurance that the amendments as requested by this Committee will be incorporated into the study design, I am pleased to be able to grant ethical approval for the study to proceed.

A copy of the amended documentation is requested for our files, together with a progress report in six months time.

Yours sincerely

Dr M Turtle  
Vice-Chairman, Dyfed Powys Research Ethics Committee

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Eich Cyl/Your ref:

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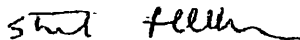
31 January 2000

## TO WHOM IT MAY CONCERN

### CHRONIC OBSTRUCTIVE PULMONARY DISEASE

I am writing to confirm my agreement for Staff Nurse Toni Williams to participate in a research study which will form the basis of a thesis for a PhD degree at the University of Wales, Swansea.

I understand the research will involve gathering information, via interviews, observation and documentary analysis on how patients and carers within the Pembrokeshire & Derwen Trust cope with Chronic Obstructive Pulmonary Disease.



**Stuart Fletcher**  
**Chief Executive**

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29 June 2000

Dear Toni

Thank you very much for coming down to see me today and talk about your proposed research study. You have certainly picked a very important area of health care and I am pleased to give you my full support.

I note that you have approval from the Research Ethics Committee and I was reassured to note that you will be obtaining consent from the patients, not only for their own involvement but also for the involvement of their carers.

I wish you well with this project and hope that all will go well. If you do hit any unexpected snags and feel that I can be of help please do not hesitate to let me know.

Kind regards.

Yours sincerely



**Peter Jackson**  
**DIRECTOR OF MEDICAL SERVICES**

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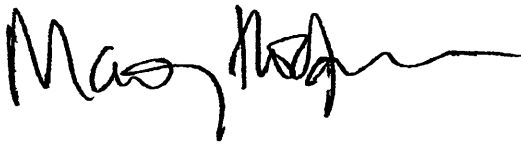
Ffacs/Facsimile:

Thank you for your letter of 19<sup>th</sup> June 2000.

I shall be very pleased to support you in your research study to investigate the experience of patients and their carers coping with Chronic Obstructive Pulmonary Disease. I am delighted that you are progressing towards a Ph.D., and would be very pleased to hear about the whole study proposal, if you have time to see me, at your convenience.

I confirm that it will be in order for you to approach staff and note that you will liaise directly with the Senior Nurse, ~~XXXXXXXXXX~~, in the Medical Directorate, ward and community Sisters/Team Leaders, and Respiratory Nurse Specialist, ~~XXXXXXXXXX~~.

With best wishes



Mary Hodgeon  
Director of Nursing and Community Services

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### Appendix 3: Summary table of participant characteristics

Participant Code No.	Age	Gender	Family Situation	Prescribed Long-term oxygen therapy, (LTOT), or oxygen cylinders	MRC dyspnoea scale grade (NICE, 2004)	Carer Interviewed
P1	76	M	LR	LTOT	5	C1
P2	45	M	LP	No oxygen	5	C2
P3	55	F	LP	No oxygen	4	
P4	69	F	LA	No oxygen	4	
P5	71	M	LA	No oxygen	5	
P6	73	F	LSH	No oxygen	4	
P7	59	F	LA/LR	No oxygen	5	C3
P8	56	M	LP	No oxygen	4-5	
P9	73	M	LA	LTOT	5	
*P10	81	F	LR	No oxygen	4	
P11	64	M	LP	LTOT declined	4-5	
P12	71	M	LA	No oxygen	4	
P13	80	F	LA	No oxygen	4	
P14	73	M	LP	No oxygen	4	
P15	63	F	LP	No oxygen	4-5	
P16	69	F	LP	No oxygen	4	
P17	73	M	LA	LTOT	4-5	
P18	74	M	LP	oxygen cylinders	5	C5
P19	81	F	LA	No oxygen	4	
P20	71	M	LP	LTOT	4	
P21	68	M	LP	LTOT declined	4	
P22	80	F	LA	No oxygen	4-5	
P23	73	M	LP	LTOT	5	C13
P24	49	F	LP	LTOT	5	C14
* P25	69	M	LA	LTOT	4	
P26	77	M	LA	LTOT	5	C6
P27	71	F	LP	LTOT	5	C7
P28	85	M	LP	No oxygen	4-5	C8
P29	79	F	LP	LTOT	4-5	
P30	69	F	LA	LTOT	5	
P31	70	F	LA	No oxygen	5	
P32	90	M	LA	No oxygen	4	
P33	75	F	LSH	No oxygen	5	
P34	70	M	LP	oxygen cylinders	4	C15
P35	71	M	LP	No oxygen	5	C16
P36	73	F	LA	No oxygen	4	
P37	73	M	LA	No oxygen	4	

Participant Code No.	Age	Gender	Family Situation	Prescribed Long-term oxygen therapy, (LTOT), or oxygen cylinders	MRC dyspnoea scale grade (NICE, 2004)	Carer interviewed
P38	78	M	LA	LTOT	5	
P39	72	M	LA	No oxygen	4	
*P40	57	M	LP	No oxygen	3	
P41	73	M	LP	oxygen cylinders	5	
P42	56	M	LP	No oxygen	4	
P43	70	F	LP	No oxygen	4	
P44	74	M	LP	No oxygen	4	
P45	59	M	LP	No oxygen	4	
P46	85	M	LP	No oxygen	4-5	C9
P47	78	M	LP	No oxygen	4	C11
P48	80	F	LA	oxygen cylinders	5	
P49	72	M	LP	LTOT	5	C12
P50	67	M	LP	No oxygen	4	
P51	68	F	LP	LTOT	5	
P52	65	F	LA	No oxygen	4	
P53	55	M	LP	No oxygen	4	
*P54	82	F	LR	No oxygen	5	
*P55	79	M	LP	oxygen cylinders	5	C10
*P56	54	F	LP	oxygen cylinders	5	
P57	80	M	LP	No oxygen	4	
P58	78	M	LP	No oxygen	4	C4
P59	53	F	LP	No oxygen	4	
*P60	79	M	LSH	LTOT	5	

**Key:**

LA - Living Alone

LP - Living with Partner

LR - Living with Relative

LSH - Living in Supported Housing.

**Medical Research Council (MRC), Dyspnoea scale (National Institute for Clinical Excellence, (NICE), 2004).**

Grade: Degree of breathlessness related to activities

- 1 Not troubled by breathlessness except on strenuous exercise
- 2 Short of breath when hurrying or walking up slight hill
- 3 Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace
- 4 Stops for breath after walking about 100m or after a few minutes on level ground
- 5 Too breathless to leave house, or breathless when dressing or undressing



Oxygen therapy administered via a medically prescribed oxygen concentrator or an oxygen cylinder is used as a proxy of disease severity. However medical prescribing for oxygen therapy was inconsistent prior to the implementation of the clinical guidelines for oxygen assessment (DoH, 2004b)

\*P10 – interview abandoned, interview used as complaint against local NHS services

\*P25 – interview not included, participant had asbestosis.

\*P40 – interview not included, participant had asthma

\*P54- interview abandoned, participant became emotional due to recent bereavement

\*P55- interview abandoned, participant had dementia

\*P56- interview not included, participant had bronchiectasis

\*P60 –interview abandoned, participant hard of hearing

### **Summary of sample population approached by researcher:**

#### **Patient participants**

94 individuals approached – identified as potential participants by various health professionals

34 individuals declined to be interviewed – reasons included:

- (4) too ill/weak/not feeling well enough
- (3) sudden hospital admission/ deterioration in condition
- (4) replied that they did not have a respiratory illness
- (1) about to move house
- (22) no reason given

60 individuals recruited

53 interviews valid

7 interviews not used or abandoned

#### **Carer participants**

29 patient participants lived with partner

16 partners agreed to be interviewed

13 partners were not interviewed – reasons included:

- (5) appeared reluctant/ felt they had nothing to offer
- (4 ) difficult to arrange/ no spare time
- (2) too ill themselves
- (2) declined with no reason

#### Appendix 4a: Example of transcription extract

Page	Transcription extract – participant P18	Theme identified
138	Oh the worst part of the day is in the morning- no doubt about it. Sometimes I get out	Impact on normal daily living/ADL
139	of bed and go to have a shower- always used to having a daily shower but now it's	Having to compromise ADL
140	sometimes a quick wash and that. Well I don't really need a shower everyday but	
141	there- I get to the bath room, sit on the bath board, get my breath and carry on for a	Short-term strategy to cope with SOB
142	bit and it takes an hour or so –imagine! I'm exhausted after that, my wife well she's	Feeling exhausted
143	got some health problems so I don't like to ask her for help you know. I do miss it, the	Not wanting to be a burden
144	the ability to go and do things that we take for granted until we can't do them, now , well	Feelings of loss(independence)
145	I have to pluck up courage before starting. I wash myself, face and that and then have	Psychological and physical struggle
146	To lean on the sides of the sink waiting and then start again.	
147	I take the nebuliser three times a day, the first on in bed before I get up in the	Medication routine /regime
148	morning and two puffs of the Pulmicort after. Now they've changed that one to the	
149	Oxis so that one is, it's every twelve hours to take but you know, sometimes I take it	Adapting medication to suit self
150	more than that!	
151	As for affecting lifestyle- well the wife says not to go shopping with her to save	Not wanting to relinquish autonomy / struggling on
152	getting so breathless and the like but I feel if I can't do it then there's not much point	
153	In being here so I carry on- well I'm not just going to sit here doing nothing.	Displaying a fighting stance
154	Wednesday is our day out- we go and have lunch out. My wife if she goes shopping, I	Maintaining normality
155	Can sit in the car and if I get short of breath, I'll sit there and can compose myself into a rhythm	Knowing how to manage daily breathlessness
156	Of breathing and perhaps take a whiff of the turbo-inhaler Ventolin.	
157	I do miss to take charge and do things myself, you know the mundane everyday	Feelings of loss
158	Things. I'm not in charge of myself now- only to a certain extent because there's an ...	Aware of altered self

Page	Transcription extract – participant P18	Theme identified
159	automatic reliance on somebody else. It encroaches on your normal way of life -for	Becoming dependent on others
160	example, half-way down the stairs I have to stop and lean on the rail and get my	Aware of deteriorating condition impacting on lifestyle
161	breath back and like if we've been out in the car shopping- I like a Stella (beer), and	
162	I have to leave that in the car and wait until my son-law comes to take it out- before	Increased reliance on others
163	it would be the first thing to take out and get in the house, you know!	Loss of ability to pursue indiv. choice
164 R	Yes. When were you first diagnosed with this chest problem?	
165	Well when I first had chest problems about fifteen years ago, they said it was	Lived with chest problems for years
166	bronchial asthma, and over the years I've had different medicants and I find that no	Diagnosis bronchial asthma
167	medicants are helping, although they have altered the types, the inhalers and all and I	Perceived poor response to various medications
168	find the doctors , there's always a different one when you go up to the hospital there -	
169	with Dr. J. and you go up there and there's another chap and he goes through the same	
170	old routine and several times I've said to them, well look- that's all in my records. I	Not understanding NHS system-
171	said you're asking me all the same questions as the guy before and the guy before that	feel anonymous impersonal service
172	and I said I still walk out with the same problems and the same medicants. Then , oh	Losing hope in receiving effective treatment
173	"I'll listen to your chest a minute", I thought well, bloody hell, you know and all that, but	
174	it does annoy me a bit. I mean to say that's not on the medical line I see but it does	
175	annoy me that. You're asked the same line of questions so now I've got – it's down	
176	there- a list of what I'm taking and how I take it. Now I goes in, taking it with me and	
178	plonk it down in front of them and tell them it's all there...written down, you're	Getting to know the system
179	driven to it, you know. R -Mmm	
180	So anyhow, well one time I said to the chest nurse, I said I don't seem right- she said ah I'll take	

## **Appendix 4b**

### **Example of theme/ Category code card: Not wanting to be a burden / feeling a burden:**

**P1/140:** “(you) just can’t do anything at all- you know, got to have help, but they just haven’t got the time sometimes- so you feel terrible, terrible...”

**P3/355:** “and that’s the worst part of it altogether is that your independence is gone because you have to rely on everyone else”

**P9/147-51:** “if the chest is bad then I usually, normally ask them for a cup of tea which helps – right- then someone told me I’d have to wait, they’re (nursing staff) too busy. Ah well you’ve got to accept that. Well what I want to do now ‘cos I don’t like asking, is to get a flask...”

**P17/428- 30:** “the future for me is I think, one of apologies to everybody because I’ve probably become a bloody pest I should think, could you help me out here? Could you do this? And I’ve never I’m not the type...”

**P18/141-4:** “I get to the bathroom, sit on the bath board, get my breath and carry on for a bit and it takes an hour or so- imagine! I’m exhausted after that, my wife- well she’s got some health problems so I don’t like to ask her for help you know..”

**P26/93-5:** “ Oh I sit here and I can see things that what need doing and I’m er can’t do them myself, I have to ask my daughter to pass me this or that, and it hurts you know...”

**P27/116-8:** “My daughter – well they did come and visit when I was in hospital ‘cos I was quite ill but they’ve got full-time jobs and the children... so it’s difficult”.

**P28/134-6:** “I know it won’t get better but I hope it won’t get worse. I do miss the gardening however and that is an extra burden on my wife. I do what I can around the house but that is precious little..”

**P31/160-63:** “Yes I’ve four sons and they’re very good but they’ve got their families and jobs you know, so they’re busy and I don’t like to keep on to them. I know they don’t mind but you know..”.

**P34/204-9:** “And of course the boss (wife) has to do all the gardening and that psychologically doesn’t do me any good. It upsets me because it’s something I know I should be doing as man of the house and it’s made worse by.... having dislocated her left arm”.

**P41/125-7:** “Without the emphysema I would be more capable of doing things – like helping my wife around the house and garden than I am now..”

**P51/180-90/266:** “It was the same in hospital, I had to ask the nurse to wheel me in to the toilet ....I know they’re busy like but you know I felt such a nuisance and you’re so embarrassed to keep ringing for them”.