A pilot investigation of illness representations and coping in people with chronic obstructive pulmonary disease, and their relationship with quality of life

Thesis

OXFORD REGIONAL TRAINING COURSE

IN CLINICAL PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

A pilot investigation of illness representations

and coping in people with chronic obstructive

pulmonary disease, and their relationship with

quality of life.

Lindsay Jones

July 1998

1995 intake

Dissertation submitted in part fulfilment of the

Open University Validation Service/British

Psychological Society Doctorate in Clinical Psychology

Word count 25,000

OXFORD REGIONAL TRAINING COURSE

IN CLINICAL PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

A pilot investigation of illness representations

and coping in people with chronic obstructive

pulmonary disease, and their relationship with

quality of life.

Lindsay Jones

July 1998

1995 intake

Dissertation submitted in part fulfilment of the

Open University Validation Service/British

Psychological Society Doctorate in Clinical Psychology

Word count 25,000

DATE OF AWARD: 15 SEPTEMBER 1998.

ABSTRACT

This study investigates the relationship between illness representations, coping strategies and the quality of life domains of anxiety, depression, activity levels and psychosocial functioning in people with chronic obstructive pulmonary disease (COPD). Leventhal's Self Regulation Model is used as a theoretical framework. Twenty – six people with COPD completed a series of questionnaires and a semi – structured interview. The sample was found to have high levels of anxiety, lowered activity levels and reduced psychosocial functioning. The illness representations of the sample could be characterised as a high illness identity, a chronic time line, a perception of serious consequences, a perception of multiple causes and a lack of control over the illness. These representations would all be expected to cause distress. In common with other chronic illnesses, emotion focused coping strategies were most commonly used. Regression models were produced for the outcome variables of anxiety, depression, activity levels and psychosocial functioning. Independent variables were demographic and disease variables, illness representations and coping strategies. It was hypothesised that illness representations and coping would explain more of the variance in the outcome measures than demographic and disease variables. Only one of the four hypotheses relating to the regression analyses was upheld. Nevertheless, it would seem that illness representations and coping strategies may be important in the understanding of what influences outcome in COPD, and are worthy of further study. The clinical implications of the findings are discussed, and suggestions made for future research.

Acknowledgements

Contents

Figures

Tables

Appendices

1. IPQ

2. Brief Cope

3. Hospital Anxiety and Depression Scale (HADS)

4. St. George's Respiratory Questionnaire

5. Semi-structured interview

6. Copy of ethics committee approval letter

7. Information sheet

8. Consent form

9. Letter to General Practitioners

1. INTRODUCTION

This study investigates the relationship between illness representations, coping strategies, and quality of life, including mood and functioning, in people with Chronic Obstructive Pulmonary Disease (COPD). In the introduction, the nature of COPD, including its aetiology, prevalence and treatment will first be described. Research suggesting that COPD has considerable physical and psychosocial impacts, and is associated with reduced quality of life, including increased anxiety and depression and reduced functioning, will then be discussed. As there is little association between the severity of the clinical condition and quality of life of people with COPD, psychological variables that may underlie adaptive responses to illness are discussed with particular reference to research in the field of illness representations and coping. Leventhal's Self Regulation Model (Leventhal, Meyer and Nerenz, 1980) is used as a theoretical context in which to examine the most predictive variables in the psychological and functional adjustment of people with COPD. Methodological limitations of previous studies in this area and gaps in the literature are considered. Finally the rationale, along with the specific aims and hypotheses, of the present study is presented.

1.1 The nature of COPD

The term Chronic Obstructive Pulmonary Disease (COPD) refers to respiratory disorders that are characterised by persistent slowing of airflow during forced expiration. It is a disorder that progresses slowly and does not change markedly over several months. A diagnosis of COPD in clinical practice requires a history of chronic progressive symptoms such as cough, wheeze and breathlessness, and objective evidence of airway obstruction by spirometric testing that does not return to normal with treatment (British Thoracic

1

Society, 1997). There are differences of opinion as to the precise definition of COPD, but it is generally taken to encompass emphysema, chronic bronchitis and some cases of chronic asthma. These disorders are subsumed under the same term (COPD) as they often coexist, and share the main symptom of airway obstruction, making differential diagnosis difficult in practice. Reversible intermittent asthma and non - obstructive chronic bronchitis which features a chronic cough and expectoration, but without air flow obstruction, should not be included within the term COPD (Snider, Klenerman, Thurlbeck and Bengali, 1985). It is also not generally taken to include other specific conditions that can cause airways obstruction such as cystic fibrosis, bronchiectasis, or bronchiolitis obliterans (British Thoracic Society, 1997).

1.1.1 *Chronic bronchitis*
The term "bronchitis" means inflammation, infection or irritation of the bronchi. In chronic bronchitis, the bronchial walls are thickened by inflammatory cells, many of the ciliated cells are destroyed, and there is an increase in mucus - producing goblet cells. The airways in some of the smaller bronchi can be completely blocked by a combination of the thickened walls and the excess of fluid inside the airway. In addition, there may be a narrowing of the larger bronchi. The result is that less air can reach the alveoli for oxygen exchange with the circulation (British Thoracic Society, 1997).

1.1.2 *Emphysema*
The alveoli are the site at which oxygen enters the bloodstream, and where carbon dioxide is collected before it is exhaled from the lungs. In emphysema, the alveolar walls break down, and the lung gradually loses its natural elasticity. This leads to the lungs becoming

permanently inflated and enlarged. As a result, there is less surface area for oxygen exchange between the air and the circulation, and fewer normal capillaries to take up this oxygen (British Thoracic Society, 1997).

1.1.3   Chronic asthma

Asthma is characterised as obstruction that is variable spontaneously and in response to treatment. However, over a period of years, the obstruction may become less reversible, and may then be subsumed under the heading of COPD (Williams, 1993).

1.1.4   Aetiology and pathogenesis

COPD is a progressive disorder. Because the onset is insidious the age at which the disease first develops is difficult to determine. By far the most important cause of COPD is smoking (Doll, Peto, Wheatley, Gray and Sutherland, 1994). The age, method and intensity of smoking, as well as years of exposure, all correlate with the risk of developing COPD (Burrows, Knudson, Cline and Lebowitz, 1979). However, many people who smoke do not develop COPD, probably because of tissue defence mechanisms that have not yet been discovered (Mitchell, 1991).

Other factors have also been associated with the development of COPD. There is an increase in mortality from COPD during periods of heavy pollution, although the

importance of pollution in the pathogenesis of COPD is small (Mitchell, 1991). A heredity deficiency of alpha - 1 antitrypsin accounts for about two per cent of emphysema cases, but the risks are greatly magnified by smoking (Burrows et al, 1979). The effect of urbanization, social class and occupation may also play a part in aetiology, but these

effects are difficult to separate out from those of smoking (Williams, 1993). Childhood asthma and respiratory infections are also a risk factor for developing COPD in later life, possibly because they are an indication of pre - existing bronchial hyper - responsiveness (O'Connor, Sparrow and Weiss, 1989).

1.1.5 Epidemiology

In 1992, COPD was responsible for 26,033 deaths in England and Wales, representing 6.4% of male and 3.9% of female deaths (HMSO, 1993). It is a major cause of morbidity with heavy use of medical services. For example, a survey in the Mersey Health Region found that twenty – five per cent of all medical admissions were due to respiratory disease, of which over half were COPD (Pearson, Littler and Davies, 1994). COPD and consequent use of health services increases with age (Pearson et al, 1994). Furthermore, COPD in the UK disproportionately affects those from working - class backgrounds, who may be least able to cope with its consequences (Townsend, Davidson and Whitehead, 1988).

1.1.6 Management

The most important approach to management is smoking cessation (Mitchell, 1991). There is no cure for COPD and medical management includes the use of antibiotics, bronchodilators, corticosteroids, and a variety of other medications to prevent influenza

and related medical complications, and to clear the bronchi of excess secretions (Petty, 1988). However, long term use of these medications may cause side effects. Most patients can be treated with bronchodilators delivered by metered dose inhalers and spacers or by dry powder devices. A few with severe disease may benefit from high dose bronchodilator

treatment which is usually delivered via a nebuliser (British Thoracic Society, 1997). Oxygen therapy can increase survival and improve cognitive performance in some advanced cases, where it may be administered for up to 16 hours a day, or even continuously, but is not advised for all patients (British Thoracic Society, 1997).

Other aspects of management include exercise, nutrition for weight reduction, techniques to clear the bronchi of excess secretions such as physiotherapy and postural drainage, breathing exercises, and vaccination against influenza (Williams, 1993). Management of acute exacerbations requires hospital treatment and antibiotics. As COPD is not curable, the British Thoracic Society (1997) goals for treatment encompass control of symptoms, prevention of deterioration, prevention of complications and improved quality of life.

1.2   Quality of Life in COPD

1.2.1   Definitions

As COPD is not curable, one of the goals of treatment is "improved quality of life" (British Thoracic Society, 1997). A fundamental problem for the concept of Quality of Life (QoL) is that although it is widely used in clinical research, it does not have a well conceptualized theoretical basis. Curtis, Deyo and Hudson (1994) point out that QoL is influenced by factors such as financial status, housing and employment, none of which are directly

affected by health care provision. They propose that a more appropriate term is "Health Related Quality of Life" (HRQoL), which refers to the subjective experience of the impact of the illness on the ability to carry out and enjoy activities of daily life. Whilst in agreement with this point, the broader term QoL will be retained here to maintain

consistency with the British Thoracic Society (1997) Guidelines, and other recent research in the area.

A working definition is provided by Hyland (1994), who defines QoL as representing "the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient" (p. 147). To assess QoL it is therefore necessary to quantify the patients own, as opposed to the professional's perception of their state. In a review of the literature, Fallowfield (1990) describes four core domains of QoL. These are psychological (e.g. mood, emotional distress, adjustment to illness); social (e.g. relationship, social and leisure activities); occupational and physical (e.g. mobility, pain, sleep and appetite). Similarly, McSweeny, Grant, Heaton, Adams and Timms (1982) used a definition of QoL which encompassed the dimensions of emotional functioning including mood changes and other psychiatric symptoms; social role functioning, including employment, home management, and social and family relationships; daily living activities, including self care skills and mobility and lastly, the ability to engage in enjoyable hobbies and other recreational pastimes.

In summary, COPD is a severe illness that results in great physical and psychosocial losses over time, leading to significant life - style and social restrictions. Studies have shown that people with COPD suffer a reduction in their QoL in a number of different domains when compared with the general population (e.g. McSweeny et al, 1982). Changes that may occur in QoL will be briefly reviewed in terms of the physical, psychological and functional impact of COPD.

1.2.2   *Physical impact of COPD*

As we have seen, COPD is characterised by a slowly progressive, insidious deterioration in lung function that can slowly develop for years before the disease becomes apparent. Mild disease may be put down to "smokers cough" or the ageing process rather than disease.

As the disease develops, a wide range of respiratory symptoms become apparent, including combinations of coughing and sputum production, which may be infected, and breathlessness and wheezing on moderate exertion. Individuals experience a significant increase in their respiratory symptoms with chest infections, to which they become increasingly prone. Severe COPD results in increasingly disabling breathlessness which may occur on minimal exertion or even when resting. Complications may occur, such as development of oedema, right - sided heart failure (cor pulmonae) and respiratory failure (British Thoracic Society, 1997). In some advanced cases, oxygen deficiencies (hypoxaemia) and blood gas abnormalities are found, sometimes leading to neuropsychological dysfunction (Prigatano and Grant, 1988). Eventually, death results.

1.2.3   *Psychological impact of COPD*

There is a great deal of evidence that COPD is associated with negative psychological states. A number of authors have suggested that people with COPD experience higher than average levels of anxiety and depression (e.g. Yellowlees, Alpers, Bowden, Bryant and Ruffin, 1987). Consequently, in sufferers minds these symptoms may come to form as much a part of the experience of COPD as the physical symptoms described above (Williams, 1993).

In a sample of 50 consecutive patients attending a respiratory clinic in Australia, Yellowlees et al (1987) found a high rate of psychiatric morbidity (58%) using a structured interview, with panic and other anxiety disorders (34%) being particularly prevalent. McSweeny et al (1982) compared patients with COPD with normal controls. They found major emotional disturbances including depression, generalized dissatisfaction with life, and somatic preoccupation. The most common pattern was of reactive depression, with 42% of the patients fitting into this category as compared with only nine per cent of the controls. Patients with COPD also described themselves as more tense, depressed, confused, fatigued, and lacking in vigour than controls. Various physiological and psychological explanations for the high rates of anxiety and depression in people with COPD have been proposed. As breathlessness is made worse by anxiety, a vicious cycle may develop where anxious situations lead to increased breathlessness, which further increases the anxiety and so on (Dudley, Glaser, Jorgenson and Logan, 1980). Differing opinions exist about the causal factors in depression in COPD. Most writers have hypothesised that it is the psychosocial consequences of COPD such as loss of pleasurable activities, economic hardship, and difficulties in coping that account for the increased rate of depression (e.g. Gift, 1993). Others have suggested that physiological factors, including the hypoxygenation of the limbic system and related brain mechanisms, might also be relevant (McSweeny et al, 1982).

Anxiety and depression in respiratory outpatients are likely to cause problems in terms of increased functional disability above that necessitated by the physical limitations due to the illness. They may also result in increased use of resources, including more frequent visits to physicians and over use of medications (Osman, Godden, Friend, Legge and Douglas,

1997). It is therefore important to increase understanding of what influences anxiety and depression in these patients.

1.2.4   Impact on Functioning

Dealing with the ongoing demands of a chronic illness often requires the learning of new skills and adjustments in daily life style. Common themes are found across all chronic illnesses, including problems with work, income, social and family life (Livneh and Antonak, 1997). However, there are also other problems which are specific to COPD and which seem to stem from its unique symptomatology (Williams, 1993). For example, Fagerhaugh (1975) points out that the disabling breathlessness and reduced oxygen supply means that sufferers may need to develop a strategy of selectively allocating their diminished supplies of what she calls "basic mobility resources" such as time, energy and money.

McSweeny et al (1982) attempted systematically to assess life quality, utilising the Sickness Impact Profile, a quality of life questionnaire designed for the general population. They found COPD patients to be impaired with respect to age matched controls. Particular areas of impairment included household management, physical mobility, sleep and rest, social interactions and recreation and pastimes. Another study by Hanson (1982) utilised a questionnaire survey of eleven areas of social role functioning and activities of daily living including employment, self - care, home / personal business, marriage, care of grandchildren and dependency on others. This study also found that COPD had a generally negative impact across all the categories explored.

1. 2.5   Relationship between disease severity and QoL in COPD

It might be expected that the more severe the illness, the greater the impact would be on

QoL in terms of the domains described above. However, in a review of the literature,

Curtis et al (1994) found that although this hypothesis has been generally upheld, most

studies have found only weak correlations between severity and various measures of QoL,

including physical disability and activities of daily living, psychological and social

functioning, and some studies have found no correlation at all. This suggests that there is

not a straightforward relationship between the severity of the clinical condition and QoL

outcomes. Thus COPD is similar to many other chronic medical conditions where the

degree of psychological distress and functioning is not a simple function of the severity of

the condition (e.g. Livneh and Antonak, 1997). Williams (1990) found that spirometric

measures of lung function were only weakly related to dyspnoea, physical disability and

psychosocial aspects of QoL. Guyatt, Townsend, Berman and Pugsley (1987) report

similar findings in their study, in which the severity of airflow obstruction was not

significantly related to scores on the St. George's Respiratory Questionnaire, a disease

specific QoL measure. Early studies showed that patients with respiratory diseases who

suffered from breathlessness disproportionate to the degree of physiological impairment

had more psychological symptoms, including anxiety and depression, than patients whose

breathlessness was consonant with the results of pulmonary tests (Burns and Howell,

1969).

Demographic variables have also been suggested to be more strongly related to QoL than

disease variables. McSweeny et al (1982) examined the relationship between QoL and a

range of disease related and socio-demographic variables. They found a strong relationship between their QoL measures and patients age, socioeconomic status, neuropsychological status and exercise capability. A much weaker relationship was found to exist between QoL and various measures of physical functioning, including spirometry and oxygen transportation. As McSweeny and Labuhn (1990) commented, "these findings demonstrate some of the complex interrelationships that exist between various aspects of QoL, as well as between QoL and other spheres of functioning in COPD".

1.3 Cognitive factors which mediate QoL in COPD

Health psychologists have viewed the outcomes, which are typically measured in QoL assessments (psychological and social functioning; ability to perform activities of daily living, etc.) as being dependent on a range of psychological processes and influences. Models of how cognitive factors produce various social behaviours, including outcomes subsumed under the heading of QoL, are known as Social Cognition Models. Cognitive factors have been found to mediate the effects of many other factors and can lead to the development of interventions designed to change the prevalence of harmful behaviours (Connor and Norman, 1996).

Research on cognitive factors, including illness representations and coping strategies has helped to explain why individuals adapt differently to the same disease episode, with some people adjusting more successfully than others. The role of coping in adjustment to chronic illness will now be discussed in more detail, followed by a discussion of the Self Regulation Model, which provides a framework guiding the selection of variables to be investigated in the present study.

1.4   Coping and adjustment to chronic illness

In the area of health psychology and the study of adaptation to illness, coping is a key theoretical concept (e.g. Lazarus, 1993). There is an extensive literature on coping, and on coping with chronic illness in particular (e.g. Cohen and Lazarus, 1983). This provides considerable support for the importance of coping in mediating both physical and psychological outcomes of chronic illness.

Lazarus and Folkman's (1984) transactional model has been the most influential model of coping with chronic illness. This model views the patients coping response as determined by both their appraisal of the degree of threat posed by an illness, and the patients perception of the resources available to help them cope with their illness. Lazarus and Folkman (1984) define coping as:

> "Constantly changing cognitive and behavioural efforts to manage specific external and / or internal demands that are appraised as taxing or exceeding the resources of the person" (p 144).

Coping responses in this model can be divided into emotion - focused and problem focused strategies. The function of problem focused coping is to actively alter the stressful situation in some way, while emotion focused coping is directed at regulating the patient's emotional response to a stressor. A wide variety of potential strategies have been identified by different writers and several strategies are usually used together to cope with health problems. Examples of problem focused coping include active coping, planning, suppression of competing activities, restraint coping and seeking of instrumental social support, and examples of emotion focused coping include seeking of emotional social

support, positive reinterpretation, acceptance, denial and turning to religion (Carver, Scheier and Weintraub, 1989).

Each chronic illness is made up of a large number of stressors, and patients may apply different coping responses to each of their illness related problems. Each response can be potentially adaptive or maladaptive depending on the situation (Cohen, Reese, Kaplan and Roggio, 1986). Nevertheless, certain generalizations have appeared in the literature. Problem focused strategies, which in theory should be more adaptive, often appear to be unrelated to outcome in chronic illness (e.g. Livneh and Antonak, 1997). However, two problem focused strategies of seeking information about the illness and planning do seem to be consistently related to positive outcomes (e.g. Felton, Revenson and Hinrichsen, 1984). The lack of a strong relationship between problem - focused strategies and positive outcomes in chronic illness may be due to the nature of the illness, which may not be amenable to change or control, and thus in some circumstances emotion focused strategies may be more useful. Some emotion focused strategies, such as reframing the illness in a positive light, acceptance of the disease, and utilizing social support appear to be adaptive coping strategies in many chronic illnesses whilst other emotion focused strategies such as self blame, emotional ventilation and cognitive and behavioural avoidance have generally been found to be associated with poorer adjustment (Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat and Clark, 1993). It has been suggested that interventions need to be developed for patients with chronic illnesses which encourage the use of coping strategies which are matched to the particular characteristics of the illness (Petrie and Moss - Morris, 1997).

A relatively recent development is research into the role that peoples cognitive representations of their illness play in informing the use of coping strategies, and their subsequent influences on outcome (Petrie and Moss - Morris, 1997). It is to this that we now turn.

1.5   Illness representations and self - regulation theory

Leventhal, Nerenz and Steele (1984) suggest that, in order to make sense of and respond to illness, patients create their own models or representations of the illness. These schema, or cognitive representations, give personal meaning to the symptoms and act as a framework for directing and appraising persons coping efforts. Some of the ideas which patients have about aspects of the illness may be similar to a conventional medical view, whereas others may be very different. It seems that illness representations may have a critical role, perhaps through their influence on coping strategies, in influencing adjustment to a range of common diseases such as heart disease, cancer and diabetes (Weinman, Petrie, Moss-Morris and Horne, 1996). The most influential theoretical framework adopted in this work is Leventhal's Self Regulation Model (SRM).

1.5.1   Illness representations

Using interviews with individuals who were chronically ill, had recently been diagnosed as having cancer, and healthy adults, Leventhal and his colleagues (1980) suggested that individual illness representations can be described in terms of four distinct components. The Identity component indicates ideas relating to the nature of the problem and associated signs and symptoms. Time Line refers to the patient's beliefs about the probable duration of their health difficulties. The Causal component is concerned with ideas about

the causes of the health problem, including ideas relating to personal responsibility. The Consequences dimension indicates perceptions about the severity of the health threat and the effect this will have on the persons life. Each patient will have their own ideas about the Identity, Time Line, Cause and Consequences of their illness. Lau, Bernard and Hartman (1989) have indicated that patients models also incorporate beliefs about the Cure and controllability of the condition.

1.5.2   Evidence for illness representations

The extent to which beliefs about illness consist of these different dimensions has been studied using both interview research and experimental studies. Leventhal et al (1984) argued that interviews are the best way to access illness representations, as this methodology avoids the possibility of priming the subjects. However, other studies have used more artificial and controlled methodologies, and both methods have provided support for the validity and consistency of the five dimensions of illness cognitions outlined above. For example, Lau et al (1989) used a card - sorting technique to evaluate how subjects conceptualised illness. They reported that the subjects piles of categories reflected Leventhal's dimensions plus the Cure / Control dimension which they identified. Further evidence was provided by Schiaffino and Cea (1995), who examined illness representations of students and patients concerning three illnesses: rheumatoid arthritis, multiple sclerosis and human immunodeficiency virus (HIV). Representations differed across illnesses and between patients and students suggesting that illness representations may be different depending on the experience of, and the relevance to, the individual.

In research with various illnesses, illness representations have been shown to have implications for the decision to seek health care (Cameron, Leventhal and Leventhal, 1993), adherence to treatment programmes (Leventhal, Diefenbach and Leventhal, 1992), and emotional responses to signs and symptoms of a health threat (Easterling and Leventhal, 1989). A study by Moss - Morris, Petrie and Weinman (1996), in the field of chronic fatigue syndrome, found that illness representations accounted for more variance in disability and psychological functioning than coping, demographic and disease variables. The authors concluded that illness representations and coping are an important area of research in understanding the variance in day to day functioning and psychological well being in chronic fatigue syndrome. The importance of illness representations and coping in adjustment to chronic disease has also been suggested in other chronic illnesses including rheumatic disease (Pimm, 1997) and breast cancer (Buick, 1997). In summary, it has been suggested that illness representations are relatively independent of objective disease severity and are thought to play an important role in adjustment to chronic illness (Lacroix, Martin, Avendano and Goldstein, 1991).

1.5.3   The Self - Regulation Model (SRM)

The illness representations described above are components of Leventhal's Self Regulation Model (SRM), which was developed in order to describe and predict how people cope with stressful health threats (Leventhal et al, 1980; Leventhal et al, 1984; Leventhal et al 1992). The model consists of three recursive stages: illness representation, coping and appraisal. The process is self regulating in that the components interrelate dynamically in order to regulate the system so that it keeps in balance. According to this model, individuals have an information processing system which integrates internal and external

16

information in order to give the illness experience meaning (the *representation* stage). It is the illness representation which directs the persons illness behaviours, including self-management, emotional response, coping efforts and compliance with treatment (the *action planning* or *coping* stage). These coping efforts are then evaluated against the criteria that has previously been set (the *appraisal* stage). The illness representation model is shown in diagrammatic form in Figure 1.
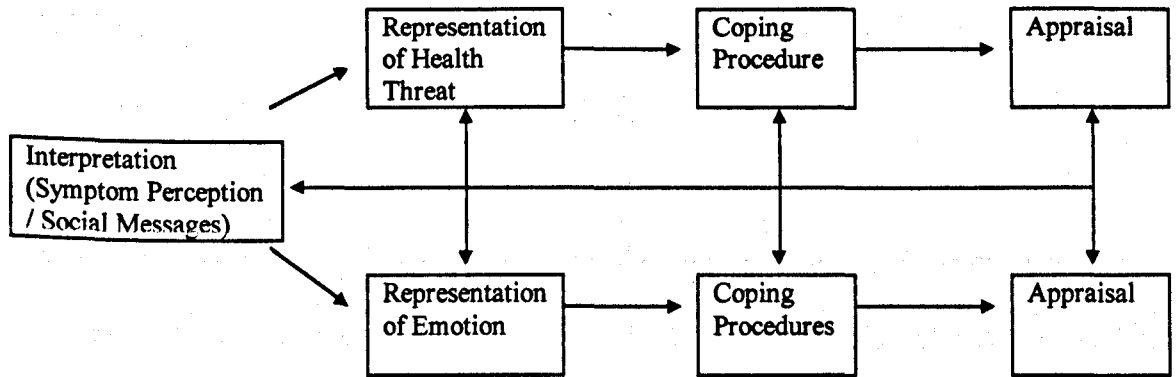
Figure 1: Leventhal's Self Regulation Model

An important feature of the model is that emotional responses are processed in parallel to the cognitive responses. Thus there are two types of feedback loops active in the self regulation of illnesses: one for the regulation of danger, the other for the regulation of fear. Leventhal et al (1980) describe the danger control system as consisting of representations of the health threat and of plans for changing the impact of the threat. The emotion control system consists of the representation of feelings and of the plans for changing the emotional state of the individual. Therefore, any coping strategies have to relate to both the illness cognitions and the emotional state of the individual.

1.6   Summary and implications for the present study.

As COPD is not curable, one of the goals of treatment, as defined by the British Thoracic Society (1997) in their most recent "Guidelines for the Treatment and Management of COPD" is improved QoL. The research reviewed here indicates that the QoL of people with COPD is likely to be reduced in terms of physical, psychological and psychosocial impacts (e.g. Alonso, Anto, Gonzalez, Fiz, Izquierdo and Morere, 1992). Some of these deficits are common to many chronic illnesses and others result from the unique symptomatology of COPD (Fagerhaugh, 1975).

However, a wide range of measures have been used to measure QoL spanning a wide range of physical, functional, occupational, attitudinal and behavioural variables, and using various methodologies including questionnaires and interviews, making studies difficult to compare and generalisability uncertain (Weinman, 1994). In addition, most studies have used general QoL measures such as the Sickness Impact Profile (Bergner and Bobbit, 1981), which appear to be relatively insensitive to mild to moderate airways disease (Jones, Baveystock and Littlejohns, 1989). Jones, Quirk, and Baveystock (1991) suggest that disease – specific measures might be more sensitive because a higher proportion of their content is directly relevant to the disease under investigation.

Research looking at the psychological impact of COPD, including anxiety and depression, also show a great deal of variation in findings. For example, Karajgi, Rifkin, Doddi and Kolli (1990) found a prevalence rate for anxiety of 16 per cent whereas Yellowlees et al (1987) found a prevalence rate of 34 per cent. Such differences may be due to different methods of assessment and diagnosis, and differences in samples (Carr, Lehrer and

Hochron, 1995). Once again, it has been recommended that psychometrically sound measures be used, in order to aid comparison and increase generalisability of findings.

In common with other chronic illnesses, the physical severity of the condition in COPD does not show a strong relationship with QoL outcomes (e.g. Curtis et al, 1994), and it has been suggested that psychological factors such as illness representations and coping strategies may mediate the effect of the disease on outcome (e.g. Williams, 1993). The Self Regulation Model provides a theoretical framework for understanding how psychological factors may mediate outcomes and adjustment in chronic illness (Leventhal et al, 1980). It has been suggested that the cognitive variables of illness representations and coping strategies influence outcome in other illnesses, such as chronic fatigue syndrome (Moss – Morris et al, 1996); rheumatic disease (Pimm, 1997) and breast cancer (Buick, 1997). However, the relationship between cognitive variables and outcome has not been studied to date in COPD.

This may reflect the fact that there has been very little psychological interest in COPD generally. Creer (1983) noted that in comparison with the large amounts of psychological studies in the field of asthma, very little work has been done with patients with COPD. He suggests two reasons for this. The first is that neither chronic bronchitis or emphysema are thought to be significantly influenced by psychological factors, in contrast to asthma which is highly reactive to anxiety and panic disorder (Porzelius, 1992). Secondly, Creer felt that the behavioural aspects of COPD have been over shadowed by the life – threatening medical complications. Williams (1993) also comments that COPD is a disease that has "little appeal to public sentiments" (p. 134), and also discusses issues relating to the stigma

and legitimacy of COPD, which is further reinforced by its links with deprived occupational and social circumstances.

The literature on adjustment to illness and QoL in the past has focused on differences between groups of people with different disorders, and differences between people with illnesses and those without. Livneh and Antonak (1997) recommend that more within group studies be carried out. This type of analyses allows the examination of relationships among illness related variables, cognitive processes, including illness representations and coping, and psychosocial outcomes. For these reasons, this is the design that will be used in the present study.

1.7   Rationale for present study

The aim of the present study is to investigate the psychological factors that may mediate people's adjustment to COPD, using Leventhal's Self-Regulation Model as a framework. A focus on psychological variables, including illness representations and coping strategies adopted would address a gap in the literature and has important clinical and theoretical implications. This study aims to explore how illness representations and coping attempts influence QoL in patients with COPD. Whilst chronic illness occurs within the wider context of family, social and cultural systems, this is beyond the scope of the present study which focuses on individual cognitive factors that may influence QoL.

A common criticism of the concept of QoL is that it is subjective and difficult to measure. However, it is imperative that QoL is subjective, as it is the individual's perspective that is important when measuring QoL (Curtis et al, 1994). To improve on previous QoL

20

measures, the domains of QoL investigated are anxiety, depression, activity levels and psychosocial functioning. These domains were chosen as previous research has shown reductions in these domains as a result of COPD, and they are measurable using well established, psychometrically sound questionnaires.

In order to test the utility of Leventhal's Self – Regulation Model in relation to COPD the hypothesis will be tested that illness representations and coping strategies will be more strongly predictive of QoL domains of anxiety, depression, activity levels and psychosocial functioning than demographic and disease variables. We will also look at the interaction of the above factors. For example, according to Leventhal's model, it would be expected that illness representations will inform the use of coping strategies, and we would therefore expect that illness representations held by the individual and the coping strategies used would be logically consistent.

1.8   Research questions and hypotheses

Research questions:

1. What is the impact of COPD on QoL in terms of anxiety, depression, activity levels and psychosocial functioning?

2. What are the illness perceptions of people with COPD?

3. Which coping strategies do people with COPD use?

4. Do illness representations relate to the coping strategies used, i.e. are they logically consistent?

5. To what extent are the illness representations and coping strategies used predictive of the QoL domains of anxiety, depression, activity levels and psychosocial functioning in patients with COPD?

21

Hypotheses:

Hypothesis 1: COPD will be associated with a reduction in the QoL domains of anxiety, depression, activity levels and psychosocial functioning.

Hypothesis 2: People with COPD will use more emotion focused coping strategies than problem focused coping strategies.

Hypothesis 3: Coping will be directed by the illness representation, and will be logically consistent. For example, illness representations that would be expected to cause the most distress , such as a strong illness identity, chronic time line and perception of serious consequences, will be associated with emotion focused coping, and representations that would be expected to cause least distress, such as a perception of control over the illness, will be associated with problem focused coping.

Hypothesis 4: Illness perceptions and coping strategies will account for more of the variance in anxiety than demographic and disease variables.

Hypothesis 5: Illness perceptions and coping strategies will account for more of the variance in depression than demographic and disease variables.

Hypothesis 6: Illness perceptions and coping strategies will account for more of the variance in activity levels than demographic and disease variables.

Hypothesis 7: Illness perceptions and coping strategies will account for more of the variance in psychosocial functioning than demographic and disease variables.

2   METHOD

In this section, the design of the study will be introduced, followed by a description of the participants. Next, the measures that were used are described. The ethical considerations which were taken into account are then outlined, followed by a description of the procedure.

2.1   Design

The study involved collecting questionnaire and interview data from a single group of participants. The study employed a within subjects cross - sectional design. It examines the relationships between illness perceptions and coping strategies, and their effects on the QoL domains of anxiety, depression, activity levels and psychosocial functioning, in people with COPD.

2.2   Participants

The participants were patients who were attending an out - patient chest clinic who had a clinical diagnosis of COPD. A diagnosis of COPD was defined as a Forced Expiratory Volume in one second (FEV_1) of less than 80% predicted, and a FEV_1 / Forced Vital Capacity (FVC) ratio of less than 70% predicted, and which does not change markedly over several weeks. This is the definition of COPD outlined in the British Thoracic Society's Guidelines for the Management of Chronic Obstructive Pulmonary Disease (British Thoracic Society, 1997), and is comparable to the criteria used in other studies of COPD (e.g. Williams and Bury, 1989). The following conditions led to exclusion: the inability to give informed consent, the presence of severe mental illness and airways

obstruction as a result of terminal lung cancer. Other illnesses which affect breathing such as asthma, which has a degree of reversibility, are not included.

2.3   Measures

2.3.1   Demographic information

Demographic details were collected at the beginning of the interview. These included age, date of birth, gender, whether or not the person lived alone, and a self reported estimate of the duration of their illness.

2.3.2   Physical Measures

The measure chosen to represent the severity of the clinical condition was spirometric testing of the Forced Expiratory Volume in one second (FEV_1), expressed as a percentage of the level that would be predicted for the patient's age, height and sex (Quanger, 1993). In effect, this measures the degree of fixed obstruction (Guyatt et al, 1987). It was measured by the physician when the patient attended the clinic and scores were subsequently extracted from the medical notes.

The FEV_1 is thought to be the best indicator of abnormality in COPD because it is a reproducible and objective measurement with well defined normal ranges that allows for the effects of age, height and sex. In addition, the variance of repeated measurements in the same person is well documented and is low (British Thoracic Society, 1997).

The British Thoracic Society (1997) has classified COPD as mild, moderate or severe based on spirometric testing of FEV_1 as follows: Mild: FEV_1 = 60 - 79% of predicted;

Moderate: $FEV_1 = 40 - 59\%$ of predicted; and Severe: $FEV_1 = < 40\%$ predicted. These classifications are used in the present study to give an indication of the spread of severity in the sample.

2.3.3   The Illness Perception Questionnaire (IPQ)   (Weinman, Petrie, Moss - Morris and Horne, 1996).

The IPQ is a theoretically derived measure based on Leventhal's Illness Representation Model. It has five sub - scales, relating to the illness representation components of Time Line, Consequences, Control / Cure, and Causes. It has good levels of both internal consistency and test - retest reliability. Data collected from a variety of chronic illness populations showed that internal sub - scale consistency ranged from .73 to .82 and test - retest sub - scale reliability coefficients ranged from .49 to .84, $p < .01$ (Weinman et al, 1996).

The Identity scale, which forms the first part of the questionnaire, consists of twelve core symptom items that participants are asked to rate according to how often the symptom is experienced as part of the illness. Ratings are on a four point scale ranging from "All of the time", "Frequently", "Occasionally", to "Never". As suggested by Weinman et al (1996), the core list of symptoms was tailored to suit the specific illness under investigation, in this case, COPD. Twelve symptoms were chosen, in conjunction with a chest physician, because they are commonly reported by COPD patients and are central to the British Thoracic Society (1997) definition of the illness. These included breathlessness, tiredness, coughing and oedema. The Identity scale is scored by summing the number of items rated

at "Occasionally" or greater, so that the total score ranges from 0 - 12, giving a simple measure of the number of symptoms perceived. A high number of symptoms indicates a stronger illness identity.

The second part of the questionnaire consists of items which are based on the other four illness representation components, presented in a mixed order. The items are rated by the participant on a five point scale ranging from "Strongly agree", "Agree", "Neither agree nor disagree", "Disagree" to "Strongly disagree". There are three Time line items, including "My illness will last for a long time", five Consequences items, including "My illness has not had much effect on my life", and six Control / cure items including "There is very little I can do to control my illness". Scores for Time line, Consequences and Control / cure scales are obtained by summing all the scales items (after reverse scoring appropriate items) and dividing by the number of items. Higher scores on the Time line scale (range 1 - 5) indicates a perceived longer duration of the illness episode. A high score on the Consequences sub - scale (range 1 - 5) indicates a perception of more serious consequences. High scores on the Control / cure sub - scale (range 1 to 5) indicates a greater perception of control over symptoms. As each item on the Cause scale represents a specific causal belief, the number checked as "agree" or "strongly agree" were totaled. As cigarette smoking is the main cause of COPD, an item relating to this was added to the other 10 items on the Cause scale, which includes items such as "A germ or virus caused my illness". High scores on this sub - scale (range 0 - 11) therefore indicate a perception of multiple causative factors.

A copy of the IPQ is included as Appendix 1.

2.3.4 Brief COPE (Carver, 1994)

The original COPE is a 60 - item multidimensional coping inventory developed by Carver et al (1989). The Brief COPE was developed by Carver and colleagues originally for use in research with breast cancer patients and represents an abbreviated version of several COPE scales (Carver et al, 1993). The brief COPE was used in this study because it was felt that the original COPE was too long, especially in the context of the length of the other questionnaires to be administered.

The brief COPE consists of twenty - four questions covering twelve coping strategies. Carver et al. (1993) reported a Cronbach's alpha coefficient of over 0.6 for each scale. The scales are

1. Distraction (turning to other activities to distract oneself from thoughts of the illness);

2. Active coping (concentrating efforts on taking action to improve the situation);

3. Denial (attempting to reject the reality of the illness);

4. Alcohol/drug use;

5. Use of emotional social support;

6. Behavioural disengagement (giving up the attempt to cope with the illness);

7. Venting (expression of emotional distress);

8. Positive reframing (viewing the illness in a more favourable light);

9. Planning (planning ways of dealing with the illness);

10. Use of humour;

11. Acceptance (accepting the fact that one has the illness); and

12. Finding comfort in religious beliefs.

Items are rated on a four point scale from "I haven't been doing this at all" (1) to "I've been doing this a lot" (4), with scores for each scale indicating the extent to which each type of coping strategy is used. Participants in the present study were asked to respond to the items in terms of the coping strategies they used to deal with COPD, and to answer by thinking back over the last month.

A copy of the Brief COPE is included as Appendix 2.

2.3.5 *Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).*

The HADS is a 14 item scale designed for use in medical out - patient clinics to detect and assess the severity of anxiety (7 items) and depression (7 items). It does not include somatic symptoms of anxiety and depression that may be confounded with reports of physical symptomatology. Total scores for each sub - scale (range 0 to 21) are obtained by summing responses to individual items, with higher scores indicating greater anxiety or depression. Scores can be split into four ranges, classified as "Normal" (0 - 7), "Mild" (8 - 10), "Moderate" (11 - 14) and "Severe" (15 - 21) (Zigmond and Snaith, unpublished study; quoted in Johnston, Wright and Weinman, 1995).

The HADS has good psychometric properties for medical patients aged 16 - 65 years (Zigmond and Snaith, 1983) and also in samples aged 65 years and above (Johnson, Burvill, Anderson and Jamrozik, 1995). The HADS sub - scales correlated significantly with psychiatric rating scales of anxiety and depression in a study of 100 medical outpatients (anxiety, $r = 0.54$; depression, $r = 0.79$) (Zigmond and Snaith, 1983). The construct validity of the scale as a measure of two factors was confirmed in a factor

analysis of the responses of 568 cancer patients (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson and Bliss, 1991). These authors also found that the internal consistency of the anxiety and depression sub - scales, as assessed using Cronbach's alpha coefficient was 0.93 for anxiety and 0.90 for depression. In addition, the HADS has good face validity and is easy and quick to complete.

A copy of the HADS is included as Appendix 3.

2.3.6 St. George's Respiratory Questionnaire (SGRQ): (Jones, Quirk and Baveystock, 1991).

The SGRQ is a standardized 76 item disease specific questionnaire developed to provide a measure of perceived "health related quality of life" in COPD. The questionnaire has been demonstrated to be a valid measure of impaired health in diseases of chronic airflow limitation, that is repeatable and sensitive. The intraclass correlation for the total score obtained on two occasions separated by two weeks was 0.92 for COPD patients (Jones et al, 1992).

The SGRQ has three component scores: Symptoms, which quantify the distress due to the respiratory symptoms themselves; Activity, a measure of the disturbance to physical activity limited by breathlessness; and Impacts, a measure of the overall disturbance of daily life and well being, covering a range of aspects concerned with social functioning and psychological disturbances resulting from airways disease. A total score can also be calculated. In the present study, only the Activity and Impacts scales are used, as these measure the domains of QoL that we are interested in for the purposes of the present

study. The Symptoms sub - scale has been shown to be strongly related to measures of objective severity of the clinical condition (Jones et al, 1992). Therefore the Symptoms scale and the total score were not used as an outcome measures in the present study because the use of symptoms as an outcome measure is not in line with the theoretical model guiding this study. For each scale, responses are weighted and summed, before being converted into a percentage figure.

A copy of the SGRQ is included as Appendix 4.

2.3.7 Semi - structured interview

Interviews were used to obtain more information about the specific difficulties facing people with COPD that would not necessarily be picked up via standardised questionnaires. These enabled a more qualitative exploration of areas of physical, social and emotional dysfunction.

An outline of the semi - structured interview is included as Appendix 5.

2.4   Ethical Considerations

Ethical approval was obtained from the responsible ethics committee. A copy of the approval letter is included as Appendix 6.

2.4.1   Consent

The study was explained by both written information via an information sheet (included as Appendix 7) and verbally in person. There were many opportunities to ask questions about

the study. Consent forms (included as Appendix 8) were completed at the start of individual interviews once all questions had been answered. Due to the procedure of the research, participants had up to two weeks to decide whether or not to participate prior to interview. In addition, consent was viewed as an ongoing process, and so it was made clear to participants that they were free to drop out of the research at any stage, and that this would not affect their medical or psychological care in any way.

2.4.2 Confidentiality

To protect confidentiality, a research code was allocated to each participant. This code, rather than participant's names, was used to identify subjects on the scoring sheets for questionnaires, and for recording of data for analysis. Lists of names and codes were kept separately. Only the researcher had access to personal data from questionnaires, which were stored in a locked file. All findings were reported anonymously.

2.4.3 Distress

Clinical judgement was used throughout interviews to monitor potential distress. Nobody became distressed during the interviews but, in three cases, and with agreement, information was passed on to medical staff involved in the participant's care, along with the suggestion of a referral to mental health services.

It was appreciated that some participants, due to their illness, would find the interview schedule tiring and, for this reason, short forms of questionnaires were used in order to keep time to a minimum. One person was visited twice in order to reduce the time spent at each visit. The short form Social Support Questionnaire (Sarason, Levine, Basham and

Sarason, 1983) had initially been included, but was dropped from the study because participants found it difficult and time consuming to complete.

2.5   Procedure

Medical and nursing staff at the chest clinic gave out the information sheets to patients who met the inclusion criteria for the study, and did not meet the exclusion criteria. The information sheets described the aims of the study and what participation would involve. A stamped addressed envelope was included and participants were requested to return a slip to the researcher if they wished to participate. It was not possible to know the response rate because of the method of recruitment. As it was a self - selected sample, we do not know whether the people who took part were different from non – volunteers in terms of demographic or disease variables.

All people who returned consent forms agreeing to take part were contacted by telephone and, after any further information required was given, appointments were made to meet them. Most people (23) chose to be interviewed in their own homes, but three people chose the option of being interviewed at the hospital. At interview, the rationale was again explained, and participants were asked to sign a consent form. The interviews, including administration of the questionnaire measures, lasted from between one and a half to two hours. Participants' General Practitioners were informed that their patient had participated in the study (Appendix 9).

2.6   Data analysis

The stages of analyses were:

1. Descriptive analyses of demographic and disease variables.

2. Descriptive analyses of QoL domains (anxiety, depression, activity levels and psychosocial functioning) in people with COPD.

3. Descriptive analyses of the illness representations and coping strategies used by people with COPD.

4. Correlations between illness representations and coping strategies.

5. Multiple regression analyses to determine the relative contributions of demographic and disease variables, illness perceptions, and coping, to the QoL domains of anxiety, depression, activity, and psychosocial functioning.

All analyses were conducted using the Statistical Package for Social Sciences for Windows, Version 7.5 (SPSS Inc. 1997).

3.   RESULTS

Demographic and illness variables are presented first, followed by descriptive data on the illness representations and coping strategies used by the sample. Initial exploratory analyses of the data are described before the results relating to the specific hypotheses are presented. Finally, a summary of the interview data is given.

3.1   Demographic characteristics of the sample

Table 1: Age, gender and living situation of the sample

	Number	Mean Age (SD)[a]	Number living alone	Number living with others
Females	11	66.72 (8.22)	3	8
Males	15	65.86 (8.13)	6	9
Total	26	66.46 (8.00)	9	17

[a] Standard Deviation

The sample consisted of 15 (57.7%) men and 11 (42.3%) women. The mean age of participants was 66.46 years (SD = 8.00; median = 67.5; range 49 - 82 years). The mean age of women was 66.72 years (SD = 8.22; median = 67 years; range = 49 - 78 years), and for men was 65.86 years (SD = 8.13; median = 66 years; range = 55 - 82 years). Of all the participants, nine lived alone and 17 lived with spouses or other relatives. All of the sample except one were retired from employment.

3.2   Disease variables

3.2.1   Illness duration and number of hospital visits in the last year

Table 2: Illness duration and number of hospital visits in the last year

	Mean duration of illness in years (SD)[a]	Mean No. of hospital visits (SD)[a]
Females	22.45 (21.68)	4.80 (2.15)
Males	15.4 (15.55)	6.13 (3.70)
Whole sample	18.38 (18.32)	5.60 (3.19)

[a] Standard Deviation

The mean duration of illness for the whole sample was 18.38 years (SD 18.32, range = 3 - 67 years). For women this was 22.45 years (SD = 21.68; range = 5 - 67 years), and for men 15.4 years (SD = 15.55; range = 2 - 60 years). The mean number of hospital visits in the last year was 5.60 (SD = 3.19, range = 2 - 14). For women, this was 4.80 (SD = 2.15, range = 2 - 8), and for men 6.13 (SD = 3.70, range = 2 - 14).

3.2.2   Severity of COPD

Table 3: Severity of COPD according to British Thoracic Society (BTS) (1997) Guidelines.

	Mild FEV$_1$ 60 - 79% predicted.	Moderate FEV$_1$ 40 - 59% predicted	Severe FEV$_1$ below 40% predicted
Females	2	6	2
Males	4	4	7
Total	6 (24%)	10 (40%)	9 (36%)

Note: the total number of people do not add up to 26 (n = 25) because data was unobtainable for 1 person.

Table 3 shows that six people (24%) were classified in the "mild" category according to the BTS (1997) guidelines. Ten (40%) were in the "moderate" category and nine (36%) in the "severe" category. The mean FEV_1 was 46.41% predicted, (SD = 18.37, range = 20 - 80). For women, the mean FEV_1 was 48.11% predicted (SD = 12.09, range = 31 - 64), and for men 45.40% predicted (SD = 21.64, range = 20 - 80).

3.3   The impact of COPD on the QoL domains of anxiety, depression, activity levels and psychosocial functioning

Hypothesis 1: *COPD will be associated with a reduction in the QoL domains of anxiety, depression, activity levels and psychosocial functioning*

Table 4: Levels of anxiety and depression in people with COPD, as measured on the Hospital Anxiety and Depression Scale (HADS).

HADS[a] range	Anxiety	% anxiety	depression	% depression
normal	11	42.31%	21	80.77%
mild	9	34.62%	4	15.38%
moderate	4	15.38%	1	3.85%
severe	2	7.69%	0	0%

[a]Hospital Anxiety and depression Scale

a   Anxiety

Participants' scores on the anxiety scale of the HADS were classified according to Zigmond and Snaith's (1983) categories of normal, mild, moderate and severe anxiety.

Eleven people (42.31%) were in the normal range, nine people (34.62%) were in the mild range, four people (15.38%) were in the moderate range, and two people (7.69%) were in the severe range. Overall 15 people (57.69%) were above the cut off score for mild anxiety.

b.   *Depression*

Participants' scores on the depression scale of the HADS were also classified according to Zigmond and Snaith's (1983) categories of normal, mild, moderate and severe depression. Twenty - one people (80.77%) fell in the normal range. Four people (15. 38%) were in the mild range, one person was in the moderate range, and no one was in the severe range. Overall five people (19.23%) scored above the cut – off level for depression.

Table 5: Summary of measures of activity levels and psychosocial functioning, as measured on the St. George's Respiratory Questionnaire (SGRQ)

	Activity[a] mean score	Impacts[b] mean score
Females	87.47	64.66
Males	75.78	47.11
Total	80.73	54.54

[a] The Activity scale on the SGRQ measures the disturbance to physical activity imposed by breathlessness
[b] The Impacts scale on the SGRQ is a measure of psychosocial functioning

Table 5 shows that the activity mean score was 80.73 (SD =17.12, range = 41.45 - 100). The Impacts mean score was 54.54 (SD = 18.90, range = 13.29 - 86.17). The mean score for women on the Activity scale was 87.47 (SD = 14.19, range = 59.46 - 100), for men it was 75.78 (SD = 17.81, range = 41.54 - 100). The mean score for women on the Impacts

scale was 64.66 (SD = 18.50, range = 27.69 - 86.17), and for men it was 47.11 (SD = 15.93, range = 13.29 - 76.80).

3.4 Illness representations of people with COPD

The following section describes the illness representations of people with COPD, as measured on the Illness Perception Questionnaire (IPQ) (Weinman et al, 1996).

3.4.1 Illness identity

Table 6: Symptoms reported by people with COPD

Symptom	Number reported				
	all the time	frequently	occasionally	never	total (all the time/frequently/ occasionally)
Shortness of breath	15 (57.69%)	8 (30.77%)	3 (11.54%)	0 (0%)	26 (100%)
Tiredness	7 (26.92%)	11 (42.31%)	8 (30.77%)	0 (0%)	26 (100%)
Infections	1 (3.85%)	8 (30.77%)	17 (65.39%)	0 (0%)	26 (100%)
Phlegm	8 (30.77%)	6 (23.08%)	11 (42.31%)	1 (3.85%)	25 (96.15%)
Wheezing	5 (19.23%)	6 (23.08%)	14 (53.85%)	1 (3.85%)	25 (96.15%)
Tight chest	3 (11.54%)	8 (30.77%)	14 (53.85%)	1 (3.85%)	25 (96.15%)
Reduced Mobility	10 (38.46%)	7 (26.92%)	7 (26.92%)	2 (7.69%)	24 (92.31%)
Coughing	9 (34.62%)	6 (23.08%)	9 (34.62%)	2 (7.69%)	24 (92.31%)
Sleeping	4 (15.38%)	5 (19.23%)	10 (38.46%)	7 (26.92%)	19 (73.08%)
Pain	2 (7.69%)	4 (15.38%)	10 (38.46%)	10 (38.46%)	16 (61.54%)
Oedema	1 (3.85%)	4 (15.38%)	10 (38.46%)	11 (42.31%)	15 (57.69%)
Cognitive[a]	0 (0%)	0 (0%)	7 (26.92%)	19 (73.08)	7 (26.92%)

[a] Cognitive = forgetfulness and difficulty concentrating.

All the symptoms were commonly experienced by the participants. All of the participants reported experiencing shortness of breath, tiredness and chest infections. The next most common symptoms reported were wheezing, tight chest, reduced mobility and coughing. Cognitive symptoms (Forgetfulness / difficulty concentrating) were the least commonly reported, with seven people reporting that they experienced this occasionally, and 19 claiming that they never experienced these symptoms. The mean number of symptoms reported by each individual (illness identity) was 10.00 (SD = 1.23; range = 6 - 12).

3.4.2 Causes

Table 7: Specific causes and contributing causes of COPD

Cause	no. of people agree/strongly agree	% of people agree /strongly agree	no. of people disagree/ strongly disagree	% of people disagree/ strongly disagree
Pollution	16	61.54%	6	23.08%
Virus	13	50.00%	6	23.08%
Cigarettes	12	46.15%	8	30.77%
Stress	11	42.31%	11	42.31%
Genetic	10	38.46%	15	57.70%
State of mind	9	34.62%	16	61.54%
Own behaviour	7	26.92%	16	61.54%
Other people	7	26.92%	19	73.08%
Chance	7	26.92%	16	61.54%
Diet	5	19.23%	18	69.23%
Poor medical care	1	3.85%	21	80.77%

Note: (N does not equal 26 and % rows do not total 100% as some participants responded to the "neither agree nor disagree" response category).

The table shows that people with COPD attributed a variety of causes to the onset of their disorder. The most commonly perceived cause was pollution. Half of the sample reported that a virus had caused, or had contributed to the onset of, their illness. Poor medical care was the least frequently endorsed item. The mean number of perceived causes was 3.73 (SD = 1.69, range = 1 - 7).

3.4.3   Control/ Cure

Table 8: Perceptions of control

IPQ Items	Strongly agree/agree	Neither agree nor disagree	Disagree/strongly disagree
There is a lot I can do to control my symptoms	13 (50.00%)	2 (7.69%)	11 (42.31%)
There is very little I can do to improve my illness	16 (61.54%)	0 (0%)	10 (38.46%)
My treatment will be effective in curing my illness	1 (3.85%)	2 (7.69%)	23 (88.46%)
Recovery is largely due to chance or fate	4 (15.38%)	3 (11.54%)	19 (73.08%)
What I can do will determine whether my illness gets better or worse	10 (38.46%)	4 (15.38%)	12 (46.15%)
My illness will improve in time	0 (0%)	3 (11.54%)	23 (88.46%)

Thirteen people (50%) felt that there was a lot they could do to control their symptoms, while 11 people (42.31%) disagreed. Sixteen people (61.54%) felt that there was very little they could do to improve their illness while ten people (38.46%) disagreed. Only one person (3.85%) thought that there treatment would be effective in curing their illness, whereas 23 people (88.46%) disagreed. Four people (15.38%) felt that recovery from their illness was largely due to chance or fate, and 19 (73.08%) disagreed with this statement. Ten people (38.46%) perceived that their own actions will determine whether their illness

gets better or worse and 12 people (46.15%) disagreed. Four people responded in the "neither agree nor disagree" response category. Nobody thought that their illness would improve in time. The mean score on the Control / Cure scale was 2.64 (SD = .55 range = 1.33 - 3.83). This information is summarised in Table 8.

3.4.4 Consequences

Table 9: Perceived consequences

IPQ items	Strongly agree/agree	Neither agree nor disagree	disagree/strongly disagree
Serious condition	23 (88.46%)	1 (3.85%)	2 (7.69%)
Major effects on life	25 (96.15%)	1 (3.85%)	0 (0%)
Easier to live with over time	15 (57.69%)	4 (15.38%)	7 (26.92%)
Not had much effect on life	1 (3.85%)	1 (3.85%)	24 (92.31%)
Strongly affected the way others see me	20 (76.92%)	3 (11.54%)	3 (11.54%)
Strongly affected the way I see myself	14 (53.85%)	1 (3.85%)	11 (42.31%)
Financial consequences	8 (30.77%)	3 (11.54%)	15 (57.69%)

The statement that COPD is a serious condition was endorsed by 23 people (88.46%), two people (7.69%) did not share this belief. Twenty-five people (96.15%) thought that the illness has major effects on their life, no one disagreed but one person (3.85%) responded in the "neither agree nor disagree" response category. Fifteen people (57.69%) felt that their illness had become easier to live with over time, seven people (26.92%) did not agree with this. Twenty people (76.92%) felt that their illness had strongly affected the way that other people viewed them, although three people (11.54%) disagreed with this statement. Fourteen people (53.85%) stated that the illness had affected the way that they saw

themselves as a person. Eleven people (42.31%) disagreed. Eight people (30.77%) reported that their illness had serious financial consequences, three (11.54%) neither agreed nor disagreed, and 15 people (57.69%) disagreed with this statement. This information is summarised in Table 9. The mean score on the Consequences dimension was 3.73 (SD = .59, range = 2.42 – 4.86).

3.4.5 Time line

Table 10: Perception of Time Line

IPQ items	Strongly agree/agree	neither agree nor disagree	Disagree/strongly disagree
Short duration	0 (0%)	0 (0%)	26 (100%)
Permanent	25 (96.15%)	1 (3.85%)	0 (0%)
Long time	26 (100%)	0 (0%)	0 (0%)

Table 10 shows that all of the participants agreed that their illness was likely to last a long time and disagreed that it would last a short time. Twenty- five people (96.15%) felt that the illness was likely to be permanent, whilst one person (3.85%) neither agreed nor disagreed with this statement. The mean score for the Time line dimension was 4.71 (SD = .43, range = 4.00 – 5.00).

3.5   Coping strategies

Hypothesis 2: *People with COPD will use more emotion focused coping strategies than problem focused coping strategies*

Table 11: Reported coping strategies

Coping strategy[a]	No. of people who reported using this strategy (sometimes/a lot/all the time)	% of people who reported using this strategy	No. of people who did not report using this strategy	% of people who did not report using this strategy
Acceptance	26	100%	0	0%
Emotional support	23	88.46%	3	11.54%
Distraction	20	76.92%	6	23.08%
Humour	16	61.54%	10	38.46%
Active coping	15	57.69%	11	42.31%
Planning	13	50%	13	50%
Religion	13	50%	13	50%
Positive reframing	10	38.46%	16	61.54%
Venting	9	34.62%	17	65.38%
Disengagement	9	34.62%	17	65.38%
Alcohol / drugs	5	19.23%	21	80.77%
Denial	3	11.54%	23	88.46%

[a] Coping strategies were measured using the Brief COPE (Carver, 1994)

Table 11 shows that the most commonly used coping strategies were acceptance and the use of emotional support. Mental distraction, use of humour, and active coping were also widely used, and were applied by over half of the sample. Planning and finding comfort in religion were used by half the sample. Use of alcohol / drugs and denial were rarely used. As predicted, the most commonly used strategies were emotion focused strategies.

3.6   Illness Perceptions and Coping.

Hypothesis 3: *Illness perceptions and coping strategies will be logically consistent*

Table 12: Correlations between illness representations and coping strategies

	Cause	Consequences	Control/ Cure	Identity	Time Line
Acceptance	.224	.340*	.071	.000	.450*
Active	.188	-.004	.238	.071	-.186
Alcohol / drugs	-.096	-.424*	.056	.105	-.160
Denial	.106	-.133	-.060	.280	.103
Disengagement	.159	.040	.112	.072	.045
Distraction	.186	.033	.031	.079	-.073
Emotional support	.094	.017	-.070	.107	.094
Humour	-.325	.310	-.276	.181	.184
Planning	.267	.190	.062	.015	-.221
Positive reframing	.253	-.150	.107	.023	-.191
Religion	.373*	.159	.142	.110	.030
Venting	.576**	.190	.192	.080	.122

Significant at * $p < .05$; ** $p < .01$.

Pearson's product moment correlations (r) were computed to investigate how patient's views of their illness related to the coping strategies they adopted. These correlations are shown in Table 12. A perception of multiple causes was significantly related to religion (r = .373, $p < 0.05$) and venting (r = .576, $p < 0.01$). A belief in serious consequences was significantly associated with acceptance (r = .340, $p < 0.05$), and negatively related to Alcohol / drug use (r = .-424, $p < 0.05$). A chronic time line was significantly positively correlated with acceptance (r = .450, $p < 0.05$). The control / cure component and the identity component were not significantly related to any of the coping strategies. Overall,

not many significant correlations were found. However, the significant correlations that were found were logically consistent. As predicted, the illness representations that would be expected to produce the most distress were associated with emotion focused coping strategies.

3.7 Multiple regression analyses

3.7.1 Initial exploratory analyses

Initial exploratory analysis was carried out on the IPQ data to explore relationships between the illness representation components, in order to aid the interpretation of the multiple regression analyses. A strong illness identity was positively correlated with a long time line ($r = .533$, $p < 0.01$) and negatively correlated with Control / Cure ($r = -.350$, $p < 0.05$). Time line was also positively correlated with consequences ($r = .542$, $p < 0.01$), and negatively correlated with a belief in controllability and curability ($r = -.467$, $p < 0.01$). A belief in controllability and curability was positively correlated with an attribution of multiple causes ($r = .400$, $p < 0.05$).

3.7.2 The relative contribution of disease and demographic variables, illness representations and coping, to the QoL domains of anxiety, depression, activity levels and psychosocial functioning in people with COPD

A series of stepwise multiple regression analyses were carried out to determine the relative contributions of demographic and disease variables, illness representations and coping to the dependent variables of anxiety, depression, activity levels and psychosocial functioning in people with COPD. Following each regression analysis, a Kolmorogov - Smirnov test

was carried out on the unstandardised residuals. The distribution was normal in each case, and so no evidence was found to suggest that the assumptions underlying the regression models were not valid.

Hypothesis 4: *Illness representations and coping will account for more of the variance in anxiety than demographic or disease variables.*

Three multiple regression analyses were carried out, with anxiety as the dependent variable in each case. In the first regression analysis, demographic and disease factors were entered as the independent variables; in the second, coping strategies were entered as the independent variables; and in the third, illness representations were entered as the independent variables. Independent variables entered into the regression were age, gender, living situation, duration of illness, severity of illness (FEV_1), and number of hospital visits in the last year in the first multiple regression; the twelve components of the brief - COPE in the second; and the five illness representation components of cause, time line, identity, consequences and control / cure, as measured on the IPQ in the third. The results of these multiple regression analyses are presented in Table 13.

Table 13: Multiple regression analyses showing the independent variables that explain significant amounts of variance in anxiety

Dependent variable	Eq. [a]	Independent variables	B	T	R^2	R^2 change	F
Anxiety	1	Gender	3.822	2.344*	.200		5.493*
		(constant)	2.911	1.224			
	2	Cause	1.248	2.665*	.228		7.100*
		(constant)	3.307	1.730			
	3	Religion	.938	3.074**	.541		19.362***
		Venting	1.367	2.304*	.627	.086	
		(constant)	.820	.587			

[a] The numbers in this column denote the separate regression equations

Significant at * $p < .05$, ** $p < .01$, *** $p < .001$

1. In the first analyses (equation 1), gender was found to be most strongly related to anxiety with a T value of 2.344 ($p < 0.05$), accounting for 20% of the variance in anxiety ($R^2 = .200$, $p < 0.05$). Being female was associated with higher anxiety scores.

2. The independent variables in the second analysis were the five illness representations as measured on the IPQ. The perception of multiple causes was most strongly related to HADS anxiety (T = 2.665, $p < .05$), accounting for 22.8% of the variance ($R^2 = .228$, $p < .05$). The positive B value indicates that perception of multiple causes was associated with higher levels of HADS anxiety. As the illness representation of control is correlated with a perception of multiple causes, it may also be predictive of anxiety, but was not included in the multiple regression equation because it does not add any further explanation of the variance.

3.   In the third analysis where the independent variables consisted of the brief COPE

sub scales, religion was shown to be most strongly related to HADS anxiety, with a

T value of 3.074 (p< 0.01), accounting for 54.1% of the variance. Venting was

also shown to relate significantly to anxiety (T = 2.304, p<0.05), adding a further

8.6% of the variance. Together, these two variables explained 62.7% of the

variance of HADS anxiety (R^2 = .627, p< .001). The positive B values indicate that

there is a positive relationship between anxiety and both religion and venting.

Higher use of turning to religion and higher levels of venting were associated with

higher levels of anxiety. Denial and planning are correlated with use of religion,

and distraction is correlated with venting. These variables may therefore also be

predictive of anxiety, although not accounting for any further variance, and so not

appearing in the regression equation.

The results of these regressions support the hypothesis that illness representations and

coping are more predictive of anxiety than disease and demographic variables. However,

gender also explained a significant amount of the variance in the HADS scores.

Hypothesis 5: Illness perceptions and coping will account for more of the variance in

depression than disease and demographic variables.

As with the last section, the three sets of independent variables (disease / demographic

variables, illness representations and coping strategies) were entered in three separate

stepwise regression equations, with depression as the dependent variable in each case. The

results of these regressions are presented in Table 14.

Table 14: Summary of the multiple regressions showing independent variables that explain a significant amount of the variance in HADS depression scores

Dependent variable	Eq.	Independent variables	B	T	R^2	F
Depression	1	Duration (constant)	9.417E-02 2.884	2.746* 3.151**	.255	7.541*
	2	Consequences (constant)	2.326 -4.169	2.097* -.997	.155	4.397*
	3	Venting (constant)	1.229 1.097	2.317* .686	.183	5.369*

ᵃThe numbers in this column denote the separate regression equations.

Significant at * $p < .05$, ** $p < .01$, *** $p < .001$

1.   In the first analysis, duration of illness was the only independent variable that was associated with depression (T = 2.746, p< .05). Duration accounted for 25.5% of the variance (R^2 = .255, p< .05). A longer duration of illness was associated with increased depression.

2.   In the second analysis, a perception of serious consequences was the only independent variable associated with depression (T = 2.097, p < .05), accounting for 15.5% of the variance in HADS depression scores (R^2 = .155, p < .05). A perception of more serious consequences was associated with higher scores on HADS depression. The representation of a long time line may also be predictive of depression, as it is correlated with the perception of serious consequences. However, it is not included in the regression equation as it does not explain any more of the variance.

3.   In the third analysis, venting was the only independent variable that was associated with depression (T = 2.317, p< .05), accounting for 18.3% of the variance (R^2 = .183, p< .05). The positive B value indicates a positive relationship between venting and depression, with higher levels of venting being associated with higher levels of depression. As venting is correlated with use of religion and distraction, these variables may also be predictive of depression, whilst not adding anything further to the explanation of variance.

The results of this set of regressions did not support the hypotheses that illness representations and coping are more predictive of depression, as duration of illness accounted for more of the variance in depression than the most predictive illness representation and coping strategy. However, both illness representations and coping were found to be predictive of depression.

Hypothesis 6: *Illness representations and coping will account for more of the variance in activity levels than disease and demographic variables*

Once again, the three sets of variables: disease and demographic variables, illness representations and coping strategies were entered in separate stepwise regression equations, this time with activity levels as the dependent variable. The results of these regressions are presented in Table 15.

Table 15: Summary of the multiple regressions showing independent variables that explain a significant amount of the variance in activity levels

Dependent variable	Eq.[a]	Independent variables	B	T	R^2	F
Activity	1	Gender (constant)	15.726 60.058	2.368* 6.205***	.203	5.609*
	2	Consequences (constant)	14.139 28.040	2.725* 1.433	.236	7.425*
	3	(no predictors)				

[a] The numbers in this column denote the separate regression equations.

Significant at * p < .05, ** p < .01, *** p < .001

1.   In the first analysis, gender was the only independent variable associated with activity levels (T = 2.368, p < .05), accounting for 20.3% of the variance (R^2 = .203, p < .05). Being female was associated with more impairment in activity.

2.   In the second analysis, a perception of serious consequences was the independent variable most strongly related to activity levels (T = 2.725, p < .05), accounting for 23.6% of the variance (R^2 = .234, p < .05). The positive B value indicates that a perception of greater consequences was associated with lowered activity levels. Time line may also be predictive of lowered activity levels, as it is correlated with consequences. However, it is not included in the regression equation as it does not explain any more of the variance.

3.   In the third analysis, none of the coping strategies entered as independent variables accounted for any variance in activity levels.

The results of these regression analyses showed that the illness representation of perception of serious consequences predicted lowered activity levels better than demographic and disease variables. However, the hypothesis was only partly supported because coping did not predict any of the variance in activity levels.

Hypothesis 7: *Illness representations and coping will predict more of the variance in* _**psychosocial functioning**_ *than disease and demographic variables*

For the last time, the three sets of independent variables: disease and demographic variables, illness perceptions and coping strategies, were entered in three separate stepwise regression equations, this time with psychosocial functioning (as measured on the SGRQ Impacts scale) as the dependent variable. The results of these regression analyses are presented in Table 16.

Table 16: Summary of multiple regressions showing independent variables that explain a significant amount of the variance of the Impacts scale on the SGRQ

Dependent variable	Eq.[a]	Independent variables	B	T	R^2	F
Psychosocial functioning	1	Gender (constant)	22.382 24.731	3.403** 2.579*	.345	11.580**
	2	Consequences (constant)	12.850 6.649	2.139* .293	.160	4.575*
	3	(no predictors)				

[a] The numbers in this column denote the separate regression equations.

Significant at * p < .05, ** p < .01, *** p < .001

1. Gender was the only independent variable that accounted for variance in the Impacts score on the SGRQ ($T = 3.403$, $p < .01$). Gender accounted for 34.5% of the variance in psychosocial functioning ($R^2 = .345$, $p < .01$). Being female was associated with lower levels of psychosocial functioning.

2. In the second analysis, a perception of serious consequences was the only independent variable that accounted for variance in psychosocial functioning ($T = 2.139$, $p < .05$). A perception of serious consequences accounted for 16% of the variance ($R^2 = .160$, $p < .05$). The positive B value indicates that a perception of more serious consequences is associated with a higher score on the Impacts scale, which indicates reduced psychosocial functioning. Time Line may also be predictive of lowered psychosocial functioning, as it is correlated with a perception of serious consequences. However, it is not included in the regression equation as it does not explain any more of the variance.

3. In the third analysis, none of the coping strategies entered as independent variables accounted for any variance in psychosocial functioning.

The results of these analyses did not support the hypothesis that illness representations and coping will account for more of the variance in psychosocial functioning than demographic and disease variables. Gender accounted for more of the variance than illness representations, and coping did not make any contribution to the variance.

3.8 Interview data

The results reported in this section are taken from the interviews with participants. They are included to give more information about the restrictions that COPD imposes on QoL, as well as the ways in which people manage the consequences of their illness. The number of people who mentioned each theme are included in parentheses. Some direct quotations from the interviews are included to illustrate the main themes. Some of the main findings of interest are highlighted in the following section, and a summary of the results is presented in Table 17.

3.8.1 Main themes

a. Symptoms

As with the results from the IPQ data, many symptoms were reported with breathlessness being most often mentioned (26) as the symptom leading to most restrictions. A 60 year old woman illustrated the problem when she commented:

"I can't do things normal people take for granted. It makes you feel inadequate. When I'm doing nothing my breathing is OK, but doing even the slightest thing makes me breathless".

Symptoms commonly reported which were not included in the IPQ were weight gain due to inactivity (8), a reduction in appetite (6), weight loss (2) and digestive problems (6). A 67 year old woman explained the link between her breathing problems and weight loss:

"I've lost a lot of weight. I can't eat too much. If you've got a full stomach it presses on your lungs. Also, because I'm coughing all the time, that uses up calories. I'm very breathless if I do anything. When I'm making a meal, I'm

breathless and coughing everywhere. Then I think I can't be bothered. It doesn't do my digestion any good".

b. Psychological sequelae

Depression was commonly reported (11), and this was often described as a response to loss of the ability to carry out activities. This was illustrated by a 76 year old man who reported:

"It's terribly depressing, because you are surrounded by things that you used to do that you can't do anymore. You feel shut in and cut off from life".

An equal number of participants felt that loss of functioning led to anger and frustration and annoyance (11). A 68 year old woman commented:

"I get angry with myself, because I can't do things, like cutting flowers. . . A lot of frustration is caused by getting worse, doing less and less. I'm getting worse, but there is nothing showing on the X – ray".

Panic and hyperventilation were also widely reported (11). A 65 year old woman who had recognised the links between anxiety and worsened breathing said:

"When I get very anxious my breathing gets even worse. Its like a panic attack – I think I'm dying . . . What I'm most scared of is of suffocating. I know that when I get upset it makes it worse – like a kind of vicious circle".

Many people (11) described fears for the future, such as fears of deterioration, dependence and an unpleasant death, and some people reported feeling anxious and experiencing

worrying thoughts all the time (4). This was illustrated by a 70 year old lady who described her fears as follows:

> "I have a worry in the back of my mind, how am I going to feel in the future, how I am going to get. I can't stand the thought of being in a wheelchair or having to live in an old peoples home. . .It frightens me".

Embarrassment, particularly in public places due to coughing, bringing up sputum or using medication was also commonly mentioned (9). A 69 year old man , who had previously been a regular churchgoer but now went less frequently reported:

> " People look at you. They think you're infectious. Its all right with people who know you. I worry about going to church. I take a cushion, sweets and a mug of water. People go to church to worship, not to hear me cough. The more I stay away, though, the more difficult it is to go".

Some people reported lowered self esteem and feeling inadequate or useless (6). A 67 year old woman described herself as "a pathetic old wreck whose looks have gone". Regrets (3) and resentment (3) were also reported . The same lady commented that:

> "It could be a marvelous life, after all the hard times I've had. Now if I didn't have the lung trouble I would be having a good time like my contemporaries. I'd planned to travel and enjoy myself. Now all that is ruined".

c.   Interpersonal issues

Participants reported becoming isolated because of their illness, both due to the fact that

they were unable to go out, and also because they had to avoid smoky atmospheres (4). A

70 year old woman noted that:

> " I don't see many people. Friends have moved away or are working or have
>
> families. I have to avoid breathing in cigarette smoke, so I can't go to pubs or out
>
> for meals. Its a good job they've stopped it in public places. Visitors come round,
>
> but when they've gone I'm exhausted".

Some participants reported that they felt a nuisance or a burden on their families (9), or

needed practical help (4). On the whole participants felt that others were supportive (8),

but five people claimed that people tended to fuss, which they disliked, and which tended

to make the problem worse. A 69 year man described this problem as follows:

> "People are very supportive, sometimes to an embarrassing degree. People fuss . . .
>
> Sometimes I want to be on my own, I can heal myself more effectively on my own.
>
> Agitation just feeds into it".

d.   Activities

Some people felt that they had given up everything that was important to them (5), Six

people reported that they had given up hobbies. Going out for the day (4) and social visits

(3) were no longer possible for some participants. A 62 year old man described the

problems of going out as follows:

> "If you want to go anywhere, there is so many things you need to check out first.
>
> For one, you need to check out whether there is going to be a lift, because if you

need to go up stairs to get where you're going you might as well forget it. You also need to check that you can park right next to the building . . . You need to sort out all your tablets and you need to be able to use your nebuliser. Most of the time you think its not worth the aggravation".

Five people reported that they hardly ever went out at all because of the illness. Other activities given up included:- exercise (5), going out to pubs, theatres etc. (2), playing with grandchildren (2), and holidays (5). The type of activities that people continued to do tended to be more inactive. Adaptations that people had to make included allowing more time to do things and taking frequent rests (23), changing the balance between active and inactive pursuits (17), and planning things in advance (9). Some people modified previously enjoyed activities, for example they still enjoyed potting plants, although they could no longer do the gardening (8). A 68 year old man who had been a farmer reported that:

"I used to be very active, fencing and making hay. I enjoyed the physical nature of it. I didn't feel I'd had a good day unless I came home knackered. Now cutting grass on the tractor is a major achievement. I can't do the gardening anymore, but I still enjoy sitting in the greenhouse and potting my plants".

e.   Medication and treatment

Participants reported that this placed considerable restrictions on their lives. Their medication and treatment routines were described as very time consuming (7) and unpleasant (5), and side effects were reported by three people. Some people reported that a rigid routine was necessary, and that this interfered with their day to day lives (7). Some

people reported that they did not go away from home because it was too much trouble to organise their medication / treatment (2). Six people felt that their medication was no longer effective, and four people said that they would like more information about their treatment regime. A 75 year old lady described her medication regime as follows:

> "For the last 20 years I've been on antibiotics constantly. I do postural drainage every morning – some days it works. Its horrible, tastes like poison, puts you off your food. I have my oxygen on all night".

Another lady described the restrictions imposed by the routine:

> "Its a lot to do, you need to stick to a routine . . . it takes a lot of energy and organization. Its a bore. The nebuliser and tipping up (postural drainage) takes over my life. I do it at regular times – first thing in the morning, lunch time, tea time and last thing at night. When I go out I have to take my nebuliser, walker, puffers – its a bit of a bind".

Side effects of taking steroids was described by a 69 year old man:

> " Steroids were killing me – 25mg each day. Dreadful. I put weight on, my whole system went wrong. I was worried about the effects these steroids were having on me. The doctor said, well come off them then. Then I wandered why I needed to take them in the first place. I'm feeling better off them, but I'm getting tearing muscular pains. It must be because of withdrawal"".

f.   Symptom variability

Participants reported a wide range of factors that may trigger an exacerbation of their illness or make their breathing better or worse. Most people reported multiple triggers. These included stress (17), the weather (16), smoky atmospheres (11), over exertion and fatigue (10), air quality/ pollution (9), a change from hot to cold air (9), chest infections (7), over eating (4), certain foods such as dairy products (3), being over weight (2), and allergies (2), and disruption to routine (1). In many cases these factors led to avoidance of situations and a further restriction on lifestyle. For example people reported avoiding contact with people with colds, smoky atmospheres, and situations which might raise their levels of stress, such as arguments or upset. A 65 year old woman described a number of factors that she felt made her breathing better or worse:

> "The weather makes it worse. Rainy weather is better, because it washes away pollution. If its a warm breeze, all well and good. Mist is bad, smoke from fires is bad. Dry weather makes you cough. Dampness I cant handle. I watch the weather report to find out about ozone levels. If they are high I don't go out. After a while you can sense it yourself. Since I've had this problem I've been more sensitive to smells. Stress brings on attacks. When my cat died I was very upset. I had to go into hospital then. I can't take stress, because I've got no immune system. A good argument helps, and singing helps".

g.   Management strategies

Some participants reported relying on help from others (4). Other important ways of coping were pacing activities to avoid getting tired or breathless (16), taking frequent rests (9), being organised (5), using equipment such as stair lifts (6), controlling stress levels

(8), guarding against infections e.g. by taking vitamin C and wrapping up (12), eating little and often to reduce bloating (1). Twelve people highlighted the importance of knowing your limitations, and accepting the illness. A 72 year old man commented that:

> "The most important thing is to know your limitations. You cant rush around like you used to do. Everything takes longer and you have to have lots of rests. If you over exert yourself you pay for it the next day. I have a little slogan that I say to myself : 'pace not race' ".

Many people had developed helpful ways of doing certain activities (9) such as wearing a towelling robe after a bath rather than drying oneself. Eight people reported that they had learned to control their breathing and calm themselves down to avert panic attacks. A 79 year old man reported that:

> "The best way to control it when you're breathing gets worse is to sit in the corner quietly. Almost will yourself. Within an hour or so you get back to normal. I imagine that everything inside is calm".

h.   Prognosis

All participants thought that their illness would not improve. Some thought it would deteriorate (10). Of these, three people claimed that their illness deteriorated in a stepwise fashion following each infection. A 67 year old man reported that:

> "Initially you think I can break this, I can crack this, I have in the past. But I'm not going to make any real improvements at 67. Its bad because you know you wont get any better, and don't know how long you're going to live".

i   <u>Smoking</u>

Of the participants who talked about smoking. ten had given up, and one had significantly

cut down. Five people continued to smoke, despite medical advice. Of these all had tried

unsuccessfully to stop. Some participants did not believe that smoking was the main cause

of COPD (2), and others expressed the opinion that it couldn't do any more damage than

there was already (4). As one man commented:

> "Once you've established that your lungs are so knackered, they're never
>
> going to get any better. No matter what you do, they aren't going to mend.
>
> . . I tried to give up smoking, but it didn't make it any better. If your lungs
>
> are buggered, they're buggered. With the withdrawal symptoms, it makes
>
> you feel worse. I'm past the point of no return".

Table 17: Summary of interview data

What symptoms do you experience as part of your illness?	Breathlessness (26); coughing (21); prone to chest infections (19); weight loss / loss of appetite (6); digestive problems (6); weakened immune system (1); tight chest (8); oedema (6); weight gain (8); dry throat (16); poor concentration (2); poor sleep (12); tired (18).
How does your illness affect the way you feel and your mood?	You feel shut in and cut off from life (1); scared on own (3); frustration / anger with self because can't do things (11): resentment at things you can't do any more (3); anxiety / tension (4); panic and hyperventilation (11); embarrassment in public (9); decrease in self esteem / feeling inadequate (6); depressed at loss of functioning (11); irritable / short fuse (8); loss of enjoyment of everyday life (1); worry (4); helpless (1); nightmares (1); fears for the future (11); regrets (3).
How does your illness affect your relationships?	I feel I'm a nuisance (9); family get upset (1); I need help with practical things (4); people get fed up because I can't do things (2); people don't understand (4); I don't like it when people fuss (5); have to turn down invitations / can't socialise (4); people stare in the street (2); it's a worry for my family (4); people are very supportive (8).
What have you had to give up because of the illness?	Social visits (3); going out for the day (4); gardening (7); my hobby – singing (2); photography (1); DIY (2); amateur dramatics (1); everything (5); don't go out because of illness (5); exercise, dancing, sport (5); sex (1) going out to pubs, theatre, etc. (2); playing with grandchildren (2); holidays (5).
What activities do you enjoy now?	Reading (5); knitting / embroidery (3); jigsaws (1); adapt previous activities (8); TV (3); crib / dominoes (1); music (3); cooking (2); writing (1).
What adaptations have you had to make to your lifestyle?	Adapt activities (14); do more alternative inactive things (17); take longer to do things (19); do things more slowly (23); can't walk far (25); frequent rests (23); takes a long time to get going in morning (18); can't use stairs (13) need to plan things (9); sleep propped up (10).
How does having your treatment affect you?	Doesn't seem to work (6); time consuming (7); need to be organised (6); get into a routine (7); hope for a cure (1); doctors not interested in older people (2); great faith in doctors (1); would like more information (4); unpleasant to do / take (5); side effects (3).

Table 17 – Summary of Interview data - continued

Is there anything that makes your symptoms better or worse?	Air quality (9); chest infections (7); weather (16); stress (17); smoky atmospheres (11); avoid people with colds (7); over exertion / fatigue (10); over eating (4); being over weight (2); certain foods (3); change in temperature (9); disruption to routine (1); allergies (2).
What ways do you use to help to deal with the effects your illness?	Help from others (4); pacing (16); rests (9); organisation / think ahead (5); calm self down when over breathing (8); prayer / spirituality (3); reduce stress / keep calm (8); drinks / sweets to reduce dryness (3); think positively (2); use of equipment (6); acceptance / learn to live with it / know limitations (12); information seeking (2); eat little and often (1); guard against infections (12); adapt ways of doing things (9); exercise (1); diet (1).
Do you think your illness will improve?	Won't improve (3); will deteriorate (10); stepwise deterioration following infections (3).
What was the main cause of your illness?	Industrial accident (1); vulnerability from childhood (6); hereditary (2); Legionnaire's disease (1); pollution (2); started after a heart attack (1); stress (1)
Do you / have you ever smoked?	Given up (10); passive smoking (1); cut down (1); still smoke - stress relief (1); still smoke - can't give up (4); don't believe smoking is the main cause (2); smoking main cause of my illness (1); cant do any more harm (4)

3.9 Summary of findings

Hypothesis 1: This hypothesis was supported, as the descriptive data indicated that COPD has a considerable impact in terms of anxiety, depression, activity levels and psychosocial functioning.

Hypothesis 2: This hypothesis was supported, as the most commonly reported strategies were the emotion focused strategies of acceptance and use of emotional social support.

Hypothesis 3: This was partly supported, as the illness representations which would be expected to cause most distress were significantly associated with emotion focused coping strategies. However, overall not many significant correlations were found, limiting the strength of support for this hypothesis.

Hypothesis 4: This hypothesis was supported, as illness representations and coping were more predictive of anxiety than demographic and disease variables.

Hypothesis 5: The results of this regression did not support the hypothesis that illness representations and coping would be more predictive of depression than demographic or disease variables. Duration of illness accounted for more of the variance in depression.

Hypothesis 6: The illness representation of a perception of serious consequences predicted lowered activity levels better than disease and demographic variables. However,

the hypothesis was only partly supported because coping did not predict any of the variance.

Hypothesis 7: This hypothesis was not supported as gender accounted for more of the variance than illness representations or coping strategies used.

4. DISCUSSION

The main aims of the present study were to investigate the impact of COPD on the QoL domains of anxiety, depression, activity levels and psychosocial functioning, and to explore the relationships between the different components of the Self Regulation Model and these QoL outcomes. In this discussion, the characteristics of the sample will be summarised briefly, in terms of demographic and disease variables. Results relating to the hypothesis that COPD will be associated with high levels of anxiety, depression, and lowered activity levels and psychosocial functioning are then discussed, before a consideration of the illness representations and coping strategies used by the present sample of people with COPD. A review of the relative contributions to variance in the QoL domains of anxiety, depression, activity levels and psychosocial functioning explained by disease and demographic variables, and illness perceptions and coping, is then undertaken. A discussion of the methodological limitations of the study is made. Finally, the clinical and theoretical implications of the present study and potential areas for future research are discussed.

4.1   Demographic and disease characteristics

In terms of age, the present sample was similar to other samples reported in the literature, with a mean age of 66.72 years. This is reflective of the later age of onset of COPD (British Thoracic Society, 1997). The reported illness duration of 18.38 years was slightly longer than that reported in other studies, although other studies have also reported relatively long duration. For example, the mean duration of illness in the sample reported by Buchi, Villiger, Sensky, Schwartz, Wolf and Buddeberg (1997) was 12 years. Although there were more males than females in the present study (57% males, 42% females), the difference has been more pronounced in other studies, with males making up to three

quarters of other reported samples (e.g. Yellowlees et al, 1987). The number of people

living alone was broadly consistent with the literatures as was the mean FEV1 % predicted

of 46.41. Only one person was in employment in the present sample, whereas 13% of

Buchi et al's (1997) and 21% of Guyatts et al's (1987) sample were in employment. This

may be because people who were working were less willing to volunteer for the present

study, because of the time and energy involved.

4.2   Summary and interpretation of results

4.2.1 The impact of COPD on the QoL domains of anxiety, depression, activity levels and psychosocial functioning.

Fifteen people (57.69%) were in the mild, moderate and severe range for anxiety. This rate

was higher than other published studies. For example, Karajgi et al (1990) found a

prevalence rate of 16 per cent anxiety in a sample of 50 outpatients, and Yellowlees et al

(1987) found a prevalence rate of 34 per cent. Surveys of the general population suggest a

prevalence rate for anxiety of between 10 – 15 per cent (e.g. Weissman and Merikangas,

1986). The rate of anxiety found in the present study is also higher when compared with

other studies with medical populations which have used the HADS as a measure of

anxiety. For example, Chandarana, Eals, Steingart and Bellamy (1987) reported that 21%

of their sample of patients with rheumatoid arthritis scored above the HADS cut off for

mild anxiety, and Ford, Lewis and Fallowfield (1995) reported that 26% of their sample of

patients with cancer scored above the cut - off level for anxiety on the HADS.

Five people (19.23%) were in the mild, moderate or severe range for depression, which is consistent with epidemiological surveys of the general population (Robins, Helzer, Weissman et al, 1984). Although subjects with COPD are chronically ill and are faced with major physical and social problems, lower rates of depression have been demonstrated with this population (e.g. Goldberg, 1985). Higher rates of depression have been found in some studies, and the levels of depression found may rest, in part, on the type of assessment used (Mitchell, 1991). Yellowlees et al (1987) have noted that people with COPD tend to somatise and deny psychiatric symptoms, meaning that depression may be masked. They also comment that some anxiety symptoms may be atypical signs of depression, leading to an under reporting of depression. This may account in part for the low prevalence found when measured on the HADS. Indeed, the interview data suggested that feelings of depression were very common. It may be that some of the depression items on the HADS were not sensitive to depression in people with COPD because they interpreted them as being a usual and unavoidable part of their illness.

In addition to anxiety and depression, other psychological sequelae were also reported in the interview data. Anger, frustration and annoyance at not being able to do things was as commonly reported as anxiety and depression. The experience of anxiety was described in terms of panic induced by shortness of breath , general anxiety, and specific illness related worries about the future relating to the deteriorating course of COPD. In addition, many people reported that they tried to reduce stress and avoid situations where they might become emotional as they knew that this would worsen their breathing.

The Activity mean score on the SGRQ was 80.73. This score represents the extent to which physical activities either cause or are limited by breathlessness, and is located on a scale from 0 – 100%, with a zero score indicating no impairment. The mean score in this study is higher than in other studies that have used the SGRQ such as Ketalaars, Schlosser, Mostert, Abu – Saad, Halfens and Wouters (1996) who found a mean Activity score of 68 in their sample. The mean score for the Impacts scale on the SGRQ in this study was 54.54. This was also higher than Ketelaars et al (1996) study, where a mean of 46 was found. It was interesting to note that although the present sample was more impaired in terms of the QoL domains under investigation, their mean FEV1 (% predicted) was not more reduced.

The interview data revealed that a wide range of activities had been affected by the illness, and these were in accordance with reports in the literature, which have tended to focus on limitations due to reduced mobility limited by breathlessness. The interview data also draws attention to the fact that many people curtail their activities due to avoidance of situations that may trigger an exacerbation of symptoms, and that people may also avoid social activities because of fear or embarrassment. For example, one lady reported that she no longer went to church because she was concerned that her coughing would disturb other worshippers.

4.2.2 Illness Representations

All of the participants reported experiencing shortness of breath, tiredness and chest infections. The next most commonly reported symptoms were wheezing, tight chest,

70

reduced mobility and coughing. This is consistent with the symptoms of COPD described in the literature (e.g. British Thoracic Society, 1997). The Time line dimension was also consistent with the medical view, with most people agreeing that their illness was likely to last a long time and was likely to be permanent rather than temporary.

People with COPD attributed a variety of causes to the onset of their disorder. The most commonly perceived cause was pollution, with over sixty per cent of the sample believing that this contributed to the onset of their disorder. Half of the sample believed that a virus had contributed to the onset of their disorder. Just under half thought that cigarette smoking had contributed to the onset of their disorder, although interview data revealed that all but one of the sample had smoked at one time of their lives and five of them continued to do so.

The mean score on the control / curability scale was 2.64, with approximately half of the sample agreeing that there was a lot they could do to control their symptoms. It was noted that some people included the taking of medications as actions that they could take to control their illness, whereas others perceived this to be outside their control and in the hands of doctors.

COPD was perceived as a serious condition with major effects on lifestyle. However, only eight people endorsed the item that their illness had serious financial consequences. This may partly reflect the fact that all but one of the sample were past retirement age, but is also likely to reflect the relatively affluent area in which the study was conducted, as

previous studies have indicated that COPD has severe financial consequences across the life span (e.g. Williams, 1993).

In summary, the illness representations of the sample in the present study can be characterised as a high illness identity, a long time line, a perception of serious consequences, and perception of multiple causes. Taken together with the interview data, a perception of lack of control over the illness was also considered to be characteristic of COPD. The perception of a high illness identity and a long time line is consistent with the medical view of the illness. The perception of multiple causes diverges considerably from a medical viewpoint, as smoking is thought to be the main cause of COPD (e.g. Mitchell, 1991). Although the items endorsed by the sample may contribute to exacerbation of symptoms, they are unlikely to be the main cause, and may be attributed as such because they are most salient in participants minds. All of these illness representations would be expected to lead to a high level of distress.

Correlations carried out on the IPQ data showed that the illness representations showed logical interrelationships. For example, a strong illness identity was associated with a long time line and negatively correlated with a perception of control. A long time line was also associated with a perception of serious consequences and negatively correlated with a perception of control. Previous research has also noted that illness representations show logical interrelationships (Weinman and Petrie, 1997).

4.2.3 Coping

The most commonly used coping strategies were acceptance and emotional support. Distraction, active coping and humour were also widely used, and were applied by over half the sample. As predicted, strategies used most often were emotion focused strategies. Problem focused strategies have been traditionally thought to be more adaptive, but have not shown a strong relationship with outcome in chronic illnesses, which may be less amenable to change (Felton et al, 1984). The most commonly used strategies in the present sample, i.e. acceptance and emotional support, have been shown to be adaptive in chronic illness. However, the strategy of distraction, which was also commonly used by the present sample, has been associated with increased distress and disability (Carver et al, 1993). The strategies least used are generally regarded as maladaptive (behavioural disengagement, alcohol / drug use and denial).

The Self Regulation Model would predict that an individuals illness representations would determine the coping strategies used. In this study a perception of multiple causes was related to religion and venting. A belief in serious consequences was associated with acceptance and negatively related to alcohol / drug use. A chronic time line was positively correlated with acceptance. Although the number of correlations between illness representations and coping strategies found in this study were small, they were logically consistent in that the illness representations that would be expected to generate greater distress, e.g. perceptions of multiple causes, serious consequences, and chronic time line, were associated with emotion focused coping strategies.

4.2.4   The relationship between illness perceptions and coping and the QoL domains

of anxiety, depression, activity levels and psychosocial functioning in people

with COPD

Regression models were produced for the outcome variables of anxiety, depression, activity levels and psychosocial functioning. Three sets of regression analyses were carried out in each case, with the independent variables of demographic and disease variables (first analysis), illness perceptions (second analysis) and coping strategies (third analysis). The hypotheses that illness perceptions and coping would account for more of the variance in each of the outcome variables than demographic and disease variables, received mixed support.

In the first set of analyses, illness representations and coping were more predictive of anxiety than demographic and disease variables. The coping strategies of religion and venting together accounted for 62.7% of the variance, with the illness representation of a perception of serious consequences accounting for 22.8% of the variance. Gender accounted for 20% of the variance. This supports the hypothesis that illness representations and coping will explain more of the variance in anxiety than demographic and disease variables.

In the second set of regression analyses, duration of illness accounted for 25.5% of the variance in the first equation, consequences accounted for 15.5% of the variance in the second equation, and venting accounted for 18.3% of the variance in the third equation.

The results of these regressions did not support the hypotheses that illness representations and coping are more predictive of depression, as duration of illness accounted for more of the variance in depression than the most predictive illness representation and coping strategy.

The illness representation of a perception of serious consequences predicted lowered activity levels better than disease and demographic variables. However, coping did not predict any of the variance. Gender accounted for 20.3% of the variance in the first regression, consequences accounted for 23.6% of the variance, and none of the coping strategies entered in the third regression analysis accounted for any variance in activity levels.

Gender accounted for more of the variance in psychosocial functioning than illness representations or coping strategies used. Gender accounted for 34.5% of the variance in psychosocial functioning, with females showing reduced psychosocial functioning as compared with males. In the second analysis, consequences accounted for 16% of the variance with a perception of serious consequences being associated with poorer psychosocial consequences. None of the coping strategies entered in the third analysis accounted for any variance in psychosocial functioning. The results of these analyses do not support the hypotheses that illness representations and coping will account for more of the variance in functioning than demographic and disease variables.

Overall, the results summarised in this section provide some evidence of the importance of illness representations and coping strategies in predicting outcome in COPD, although only one of the hypotheses relating to this section were upheld. Illness representations and coping were more predictive than demographic and illness variables in predicting anxiety. Illness representations, but not coping, were more predictive of activity levels. However demographic variables were more important in predicting outcome in depression and psychosocial functioning.

Although the hypothesis that illness representations and coping would predict more of the variance in anxiety than disease and demographic factors was upheld, coping strategies predicted a greater degree of variance than illness representations. It has been argued that the Self Regulation Model would predict that illness representations would be more predictive than coping, as they precede it in the model, and are thought to inform the use of coping strategies (Moss – Morris et al, 1996). However, the issues are less clear when considering the recursive nature of the model. Using this logic it would also be possible to argue that demographic and illness variables would be more predictive since they may be important in the development of the illness representations.

In summary, only one of the hypotheses relating to the relative contribution of illness representations and coping to QoL outcomes, as compared with demographic and disease variables, was upheld. However, illness representations contributed a significant amount to the variance of all four outcome measures (anxiety, depression, activity levels and psychosocial functioning), suggesting that they may be important in the understanding of

what influences outcome in people with COPD, and are worthy of further study. It was also noted that the severity of the clinical condition was not associated with any of the outcome measures. Some of the variability and ambiguity in findings may be the result of methodological problems, which are considered in the next section.

4.3   Methodological considerations

4.3.1   Sample

The sample size was small partly due to the inherent difficulties in recruiting participants from a population of people with COPD, most of whom were older adults. As mentioned previously, the symptoms of COPD are likely to make people feel tired and they may have been reluctant to volunteer if they thought that the interview would be tiring, or that the talking involved would lead to increased breathlessness. Nevertheless, the work was a useful pilot study, indicating the importance of the area for future study and generating further hypotheses for future research.

Because of the method of recruitment, it was not possible to assess response rate. The self selected nature of the sample may also question its representativeness, although it was similar in terms of age and disease severity to other samples reported in the literature. Socioeconomic status and cognitive functioning were not examined or controlled, and participants were all Caucasian. In addition, questionnaire and interview data revealed that the present sample was relatively affluent, in contrast to epidemiological data which has shown that COPD is socially patterned and more common in people who are socially disadvantaged (Townsend et al, 1988). This may limit the generalisability of the findings

as illness is also affected by social and cultural factors as well as physical, emotional and cognitive factors.

Recruiting from a hospital chest clinic may have also lead to a bias in the sample. On the one hand, people who are stable and coping well with the disease may be less likely to attend the clinic. A large group of people with COPD, especially those with mild forms, do not have contact with these specialist services. On the other hand, there are many severely ill people who have been discharged from the clinic because there is nothing further medically that can be done for them. These two extremes would therefore be screened out of the sample. It could also be suggested that people who attend clinic are more likely to have more severe symptoms and may experience more anxiety and cope less adequately with their illness than is really typical of this patient group. This would be in line with the research of Osman et al (1997), who found that higher levels of psychiatric morbidity were related to greater use of services. This bias may help account for the high level of anxiety reported in this study, which is greater than levels reported by some other authors. It may also be possible that the present sample did not include some of those who coped well with their disease and did not experience significant anxiety. People who were highly anxious may have been more likely to take part in the hope that the research may help shed some light on their difficulties. Indeed, a number of people remarked to the researcher that this was their main motivation for participating. It is also possible that people who experienced significant anxiety may have declined to take part, if they felt that focusing on their respiratory problems might have increased their anxiety.

4.3.2 *Measures*

In general, the measures used were well established and completed without difficulty. A measure of social support would have been useful in the present study because of its well documented association with QoL outcomes. Initially, the short form Social Support Questionnaire (Sarason et al, 1983) was used. However participants found it difficult and time consuming to complete, relying on a lot of input from the researcher. This made it unfeasible to use in the context of the time taken to complete all the measures. In addition, some early participants became distressed at the difficulty they were having in completing it. It was therefore taken out of the study.

Although coping has been shown to be a key factor to outcomes in chronic illness, the number of significant associations of the Brief COPE subscales with the outcome measures was small. The brief COPE allows only a small range of values because it is made up of only two items per scale. However, the full 60 item COPE, and the other coping questionnaires considered would have been too time consuming in the context of the other questionnaires.

The HADS was chosen as a measure of anxiety in this study (HADS) because it was designed specifically for medical out – patients to exclude items that may be confounded with physical symptomatolgy (Zigmond and Snaith, 1983). However, it is difficult to compare anxiety and depression prevalence figures from this study to those in other studies with people with COPD, as a range of different measures have been used to assess anxiety and depression levels in the various studies. For example, Yellowlees et al (1987)

reported a higher rate of anxiety using a psychiatric interview, and Light, Merrill, Despars, Gordon and Mutalipassi (1985) reported a lower rate of anxiety using the State - Trait Anxiety Inventory. In order for valid comparisons to be made between studies, there needs to be more use of equivalent questionnaires.

As with anxiety and depression data, it is also difficult to compare data on the other QoL measures used here with other studies. The problem is particularly acute because of the lack of a consistent conceptual framework for QoL and the large range of variables and methods of measurement that have been used (Livneh and Antonak, 1997). Measures of QoL have sometimes been reported as "soft" data because of their necessary subjectivity (Curtis et al, 1994). However, some of these difficulties have been overcome by using the SGRQ, which is psychometrically sound and disease specific.

Another strength of the present study is the use of interview data to supplement the questionnaire data. This provided a rich supply of information, and allowed links to be made between certain aspects of the illness, such as anxiety and avoidance, that could not have been made with the questionnaire data alone. However, as the questionnaires were completed first, this may have primed the participants to respond in a certain way, limiting the spontaneity of the reports. In addition, it may have been beneficial to use more rigorous qualitative techniques, such as grounded theory, in order to analyse the interview data. This was not done because in the planning stages of the study, the interviews were thought to be secondary to the main statistical analyses planned.

4.3.3 Design and statistical analysis

It is not possible to make conclusions regarding the direction of causality because of the cross - sectional nature of the present study. The understanding of psychosocial adaptation over time requires the use of longitudinal research methodology. The reciprocal and recursive nature of the Self Regulation Model also provides problems in the interpretation of causality. For example, theoretically it is not possible to say whether certain illness representations lead to reduced functioning or vice versa. This presented a problem when deciding on outcome measures. The outcome measures in the present study were chosen because they have been considered important outcomes in health and psychological research, and are a legitimate focus for intervention. Previous research in the field of illness representations and coping have also used variables relating to mood and functioning as outcome variables, including the study by Moss Morris et al (1996) which has already been described.

The multiple regression analyses would have benefited from a larger sample size. However, the regression models produced included a maximum of two variables, making the ratio of predictive variables to sample size adequate. Because of the difficulties in recruitment outlined above, it was not possible to increase the sample size.

4..4   Implications of the present study

4.4.1   Clinical implications

As COPD has identifiable risk factors, prevention and early identification and treatment would seem to be important (Mitchell, 1991). As smoking is the main cause of COPD the

setting up of smoking cessation programmes are an obvious way to reduce the number of people who develop COPD and to reduce the progress of the disease once it has began. This may be beneficial, as the participants in the present study who continued to smoke all reported that they had tried unsuccessfully to stop.

Reduced QoL in terms of anxiety, depression, activity levels and psychosocial functioning were found in this study, and would seem to be a valid focus for intervention. Given the high rates of anxiety and depression found in the present study, and the impact on activity levels and psychosocial functioning, it may be worth screening for difficulties when patients attend the chest clinic, and provision made for referral to mental health services if required.

The experience of anxiety and panic has been found to worsen episodes of breathing difficulty, and may interfere with effective treatment, for example by increasing inappropriate inhaler use (Creer and Wigal, 1989). This was illustrated by one of the participants in the present study purchased her own nebuliser and used it daily, even though her doctor had told her that the severity of her condition was not bad enough to warrant using it. Kinsman, Dirks, Jones and Dahlem (1980) identified two types of anxiety associated with asthma; first, anxiety focused directly on the breathing difficulties, and secondly, anxiety characteristic of the person in many situations, regardless of the illness. Both forms of anxiety were associated with inappropriate medication use, and greater lengths of hospitalisation. These different types of anxiety were also noted in the present study, along with disease specific fears for the future, for example of deterioration,

dependence, and dying gasping for breath. Therefore, more specific evaluations of anxiety may be needed for people with COPD and it may be important to tailor interventions to take account of these disease specific forms of anxiety, rather than providing general anxiety management interventions.

A mismatch between the illness representations of professionals and patients may lead to misunderstandings and poor communication (Park, 1994). One of the findings of the present research was that contrary to a medical view, many patients did not accept that smoking was the main cause of their illness. Some patients reported that they felt persecuted by their doctors and felt that they were being blamed, with the resulting feeling of resentment towards medical staff. Knowledge of illness representations may lead to provision of more appropriate and relevant health education information, and improve understanding and communication between patients and professionals.

An awareness of the illness representations of patients could also lead to the challenging of inaccurate or unhelpful representations. As with other schemas which are targeted in cognitive – behavioural interventions, the Self Regulatory Model proposes that illness representations are amenable to change. Therefore cognitive behavioural interventions are likely to be effective in the modification of unhelpful illness representations.

It has already been noted that although problem focused coping strategies have traditionally been associated with better outcomes, emotion focused coping strategies may be more helpful in people with certain chronic illnesses, including COPD because of the

reduced possibility of being able to improve the situation through active means (Felton et al, 1984). The coping strategies most often used in this study were the emotion focused coping strategies of acceptance and seeking emotional social support. Coping Effectiveness Training (Chesney and Folkman, 1994) acknowledges this and attempts to match the coping strategies used to the given situation. For example, emotion focused strategies are encouraged in situations that are perceived as less amenable to control, and problem focused strategies are promoted for aspects of the illness which may be amenable to control.

4.5   Recommendations for future research

Despite a lack of significant findings, the present study nevertheless suggests that illness representations and coping may be important in the understanding of adjustment to COPD. As these cognitive factors have been shown to be important in other chronic illnesses, it is important that this line of investigation is extended to COPD. COPD is an area which has been under researched, and there is need for further research to increase understanding of the psychological factors that may influence outcomes in this group of patients. Some suggestions for future research are outlined below.

1. As outlined earlier in the discussion, in order to aid comparison between studies and increase the generalisability of findings, an improvement of relevant measures is required. The development of disease specific questionnaires for COPD that assess anxiety, depression and other psychological sequelae, and that address some of the difficulties outlined earlier in the discussion, would be useful.

2. The impact of social support on outcomes in COPD was not investigated in the present study. It would be useful to include this variable in future research, as studies with other illness groups have shown that it is important in the adjustment to chronic illness (Sarason et al, 1983).

3. It has been suggested that people with COPD who experience reductions in QoL in terms of mood and functioning may benefit from therapeutic approaches. However there have been few evaluations of therapeutic approaches in the literature. Research is needed to evaluate the potential of various psychological treatments, including Cognitive Behavioural Therapy (CBT) and Coping Effectiveness Training (CET).

4. The present study employed a cross sectional design which does not allow for any interpretation of causality. Future research employing longitudinal designs would allow the study of the process of adjustment over time, and aid the investigation of causality.

5. As in other chronic illnesses, there are many other outcomes which are influenced by illness perceptions and coping, which could be the focus of future research. Such variables would include self management of the illness, including use of medication and hospital resources.

6. Different methods of sampling in future studies might reduce bias, and increase the access to a greater number of potential participants. For example, the recruitment of

people with COPD through General Practitioners rather than hospitals might reach a wider range of people with COPD.

4.6   Conclusions

The aims of the present study were to examine the impact of COPD on QoL in terms of anxiety, depression, activity levels and psychosocial functioning; to describe the illness representations and coping strategies used in the sample; and to explore the extent to which illness representations and coping strategies are predictive of the QoL domains of anxiety, depression, activity levels and psychosocial functioning. The study therefore provides a pilot investigation of the utility of the components of Leventhal's Self Regulation Model for understanding QoL outcomes in people with COPD.

This study confirmed previous research that people with COPD have a reduction in QoL associated with their illness. Reductions in the QoL domains of anxiety, depression, activity levels and psychosocial functioning were found. When compared with other existing research, the present sample showed higher levels of anxiety, reduced activity levels and reduced levels of psychosocial functioning. This may be partly explainable in terms of sampling bias. Nevertheless, these findings have important clinical implications as they appear to be a legitimate focus for psychological intervention. It was noted that interventions may need to be tailored for this client group, as their presentation of anxiety, depression and other psychological difficulties may be atypical as they may be related to disease specific factors.

In the present study, the illness representations of people with COPD were characterised by a high illness identity, a chronic time line, a perception of serious consequences, a lack of control over the disease process and a perception of multiple causes. These are all illness representations that might be expected to cause most distress. Most of these representations were consistent with a medical view of COPD, with the exception of a perception of multiple causes. Whilst smoking is considered to be the most important cause, most of the participants did not share this view, attributing the main cause of their disease to pollution and viruses, and reporting multiple causes. It was noted that a mismatch of perceptions between patients and professionals might lead to misunderstanding, poor communication and friction between patients and medical staff.

As predicted, the coping strategies most commonly used were the emotion focused strategies of acceptance and emotional support. These emotion focused strategies have been shown to be adaptive in chronic illnesses, where situations may be less amenable to change. However, the strategy of mental distraction, which was also commonly used in this sample, has been shown to be maladaptive (Carver et al, 1993). This could be a potential area for further research and intervention, as research in other chronic illnesses has shown that coping is an important factor in adjustment.

Regression models explored the extent to which illness representations and coping accounted for variance in the QoL domains of anxiety, depression, activity levels and psychosocial functioning. Independent variables were demographic and disease variables, illness representations and coping strategies. Only one of the four hypotheses relating to

the multiple regression analyses was upheld. Some of this may be due to the low numbers in the study. However, illness representations contributed a significant amount to the explanation of variance for all of the outcome measures, suggesting that they might be important in the understanding of what influences outcome in people with COPD, and are worthy of further study, particularly as illness representations and coping have been found to be important in other illnesses and have important clinical and theoretical implications.

REFERENCES

Alonso, J., Anto, J. M., Gonzalez, M., Fiz, J. A., Izquierdo, J. and Morera, J. (1992). Measurement of general health status of non oxygen dependent chronic obstructive pulmonary disease patients. Medical Care, 30 , MS125 - MS135.

Bergner, M. and Bobbitt, A. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. Medical Care, 19 , 8 , 787 - 806.

British Thoracic Society (1997). Guidelines for the management of chronic obstructive pulmonary disease. Thorax, 52 , 5 , S4 - S28.

Buchi, B., Villiger, B., Sensky, T., Schwartz, F., Wolf and Buddeberg, C. (1997). Psychological predictors of long term success of in patient pulmonary rehabilitation of patients with COPD. European Respiratory Journal, 10 , 1272 - 1277.

Buick, D. L. (1997). Illness representations and breast cancer: Coping with radiation and chemotherapy. In K. J. Petrie and J. A. Weinman (Des). Perceptions of Health and Illness. Amsterdam: Harwood Academic Publishers.

Burns, B. and Howell, J. (1969). Disproportionately severe breathlessness in chronic bronchitis. Quarterly of Family Medicine, 38 , 277 - 294.

Burrows, B., Knudson, R. J., Cline, M. G. and Lebowitz, M. D. (1979). Quantitative relationships between cigarette smoking and ventilatory function. American Review of Respiratory Disorders, 115 , 195 - 205.

Cameron, L., Leventhal, E. A. and Leventhal, H. (1993). Symptom representations and affect as determinants of care seeking in a community dwelling adult sample population. Health Psychology, 12 , 171 - 179.

Carr, R., Lehrer, P. and Hochron, S. (1995). Predictors of panic – fear in asthma. Health Psychology, 14 , 5 , 421 - 426.

Carver, C. S. (1994). The Brief COPE. Department of Psychology, University of Miami, Florida.

Carver, C. S., Pozo, C., Harris, S.D., Noriega, V., Scheier, M.F., Rodinson, D.S., Ketcham, A.S., Moffat, F. and Clark, K.C. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. Journal of Personality and Social Psychology, 65 , 375 - 390.

Carver, C. S., Scheier, M. F. and Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology, 56 , 267 - 283.

Chandarana, P., Eals, M., Steingart, A. And Bellamy, N. (1987). The detection of psychiatric morbidity and associated factors in patients with rheumatoid arthritis. Canadian Journal of Psychiatry, 32 , 5 , 356 – 361.

Chesney, M. A. and Folkman, S. (1994). Psychological impact of HIV disease and implications for intervention. Psychiatric Clinics of North America, 17 , 163 - 182.

Cohen, F. and Lazarus, R. S. (1983). Coping and adaptation in health and illness. In D. Mechanic (Ed). Handbook of health, health care, and the health professions. New York: Free Press.

Cohen, F., Reese, L.B., Kaplan, G.A. and Roggio, R.E. (1986). Coping with the stresses of arthritis. In R.W. Moskowitz and M.R. Haugh (Eds.). Arthritis in the Elderly. New York: Springer.

Connor, M. and Norman, P. (1996). The role of social cognition in health behaviours. In M. Connor and P. Norman (Eds.) Predicting Health Behaviour. Buckingham: Open University Press.

Creer, T. L. (1983). Respiratory Disorders. In T. G. Burish and L. A. Bradley (Eds.) Coping with Chronic Disease. Academic Press.

Creer, T. L. and Wigal, J. K. (1989). Respiratory Disorders. In S. Pearce and J. Wardle (Eds.) The practice of Behavioural Medicine. Buckingham: OUP / BPS.

Curtis, J., Deyo, R. A. and Hudson, L. D. (1994). Health related quality of life among patients with chronic obstructive pulmonary disease. Thorax , 49 , 162 - 170.

Doll, R., Peto, R., Wheatley, K., Gray, R. and Sutherland, I. (1994). Mortality in relation to smoking: 40 years observations on male British doctors. British Medical Journal, 309 , 901 – 910.

Dudley, D. L., Glaser, E. M., Jorgenson, B. N. And Logan, D. L. (1980). Psychosocial concomitants to rehabilitation in chronic obstructive pulmonary disease. Part 1: psychosocial and psychological considerations. Chest, 77 , 3 , 413 – 420.

Easterling, D. and Leventhal, H. (1989). The contribution of concrete cognition to emotion. Neutral symptoms as elicitors of worry about cancer. Journal of Applied Psychology, 74 , 787 – 796.

Fagerhaugh, S. (1975). Getting around with emphysema. In A. L. Strauss (Ed). Chronic Illness and the Quality of Life. St. Louis: Mosby.

Felton, B. J. and Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychosocial adjustment. Journal of Consulting and Clinical Psychology, 52 , 343 - 353.

Felton, B. J., Revenson, T. A. and Hinrichsen, G. A. (1984). Stress and coping in the explanation of psychological adjustment among chronically ill adults. Social Science and Medicine, 18 , 10 , 889 - 898.

Ford, S., Lewis, S. and Fallowfield, L. (1995). Psychological morbidity in newly referred patients with cancer. Journal of Psychosomatic Research, 39 , 2 , 193 – 202.

Gift, A. G. (1993). Depression in patients with COPD. Heart and Lung, 22 , 4 , 289 - 297.

Goldberg, D. (1985). Identifying psychiatric illness among general medical patients. British Medical Journal, 291 , 161 - 162.

Guyatt, G. H., Berman, L.B., Townsend, M., Pugsley, S.O. and Chambers, L.W. (1987). A measure of quality of life for clinical trials in chronic lung disease. Thorax, 42 , 773 - 778.

Guyatt, G. H., Townsend, M., Berman, L. B. And Pugsley, S. O. (1987). Quality of life in patients with chronic airflow limitation. British Journal of Diseases of the Chest, 81 , 45 – 54.

Hanson, E. I. (1982). The effects of chronic lung disease on life in general and on sexuality: perceptions of adult patients. Heart and Lung, 11 , 5 , 435 – 451.

HMSO, (1993). Mortality statistics, cause: England and Wales 1992. Series DH2 no. 19, London: HMSO

Hyland, M. E. (1994). Measuring quality of life in adult asthmatics: a patient centred approach. In M. Christie and D. French (Eds.) Assessment of Quality of Life in Childhood Asthma. London: Harwood.

Johnson, G., Burvill, P. Anderson, C. and Jamrozik, K. (1995). Screening instruments for depression and anxiety following stroke. Experience in the Perth community stroke study. Acta Psychiatrica Scandinavia, 91 , 4 , 252 – 257.

Johnston, M., Wright, S. and Weinman, J. A. (Eds.) (1995). Health Psychology: A Users Portfolio. Windsor: NFER Nelson.

Jones, P., Baveystock, C. And Littlejohns, P. (1989). Relationships between general health measured with the Sickness Impact Profile and respiratory symptoms, physiological measures and mood in patients with chronic airflow limitation. American Review of Respiratory Disease, 140 , 1538 – 1543.

Jones, P., Quirk, F. and Baveystock, C. (1991). The St. George's Respiratory Questionnaire. Respiratory Medicine, 85 (Supplement B), 25 - 37.

Jones, P., Quirk, F. , Baveystock, C. and Littlejohns, P. (1992). A self-complete measure of health status for chronic airflow limitation. The St. George's Respiratory Questionnaire. American Review of Respiratory Disease, 145, 6 , 1321 - 1327.

Karajgi, B., Rifkin, A., Doddi, S. and Kolli, R. (1990). The prevalence of anxiety disorders in patients with COPD. American Journal of Psychiatry, 147 , 200 - 201.

Ketelaars, C. A. J., Schlosser, M. A. G., Mostert, R., Huyer Abu – Saad, H., Halfens, R. J. G. and Wouters, E. F. M. (1996). Determinants of health related quality of life in patients with chronic obstructive pulmonary disease. Thorax, 51 , 39 – 43.

Kinsman, R., Dirks, J., Jones, N. And Dahlem, N. (1980). Anxiety reduction in asthma: four catches to general application. Psychosomatic Medicine, 42 , 4 , 397 – 405.

Lacroix, J. M., Martin, B., Avendano, M. and Goldstein, R. (1991). Symptom schemata in chronic respiratory patients. Health Psychology, 10 , 268 - 273.

Lau, R. Bernard, J. and Hartman, K. (1989). Further explorations of common sense representations of common illness. Health Psychology, 8 , 195 - 219.

Lazarus, R. S. (1993). Coping theory and research: past, present and future. Psychosomatic Medicine, 55 , 234 - 247.

Lazarus, R. S. and Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer.

Leventhal, H., Diefenbach, M. and Leventhal, E. (1992). Illness cognition. Using common sense to understand treatment adherence and affect cognitive interactions. Cognitive Therapy and Research, 16 , 2 , 143 - 163.

Leventhal, H., Nerenz, D. R. and Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S.E. Taylor and J.E. Singer (Eds.). Handbook of Psychology and Health, Volume IV: Social Psychological Aspects of Health. New Jersey: Erlbaum.

Leventhal, H., Meyer, D. and Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), Contributions to Medical Psychology, Volume 2. pp. 7 - 30. Oxford: Pergamon Press.

Light, R., Merrill, E., Despars, J., Gordon, G. and Mutalipassi (1985). Prevalence of depression and anxiety in patients with COPD. Chest, 87 , 35 – 38.

Livneh, H. and Antonak, R. F. (1997). Psychosocial Adaptation to Chronic Illness and Disability. Maryland: Aspen.

McSweeny, A. J., Grant, I., Heaton, R. K., Adams, K. M. and Timms, R. M. (1982). Life quality of patients with chronic obstructive pulmonary disease. Archives of Internal Medicine, 142 , 473 - 478.

McSweeny, A. J. and Labuhn, (1990). In B. Spilker (Ed.) Quality of Life Assessment in Clinical Trials. NY: Raven Press.

Mitchell, A. (1991). In A. J. McSweeny and I. Grant (Eds.) Chronic Obstructive Pulmonary Disease: A Behavioural Perspective. New York: Marcel Dekker.

Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B. and Bliss, J. (1991). The factor structure and factor stability of the Hospital Anxiety and Depression Scale in patients with cancer. British Journal of Psychiatry, 158 , 255 - 259.

Moss-Morris, R., Petrie, K. and Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions and coping play a regulatory role? British Journal of Health Psychology, 1 , 15 - 25.

O'Connor, G. T., Sparrow, D. and Weiss, S. T. (1989). The role of allergy and non specific airway hyper responsiveness in the pathogenesis of chronic obstructive pulmonary disease. American Review of Respiratory Disease, 140 , 225 – 252.

Osman, L. M., Godden, D. J., Friend, J. A. R., Legge, J. S. and Douglas, J. G. (1997). Quality of life and hospital readmission in patients with chronic obstructive pulmonary disease. Thorax, 52 , 67 - 71.

Park, D. C. (1994). Self regulation and control of rheumatic disorders. In S. Maes, H. Leventhal and M. Johnston (Eds.) International Review of Health Psychology, volume 3.

Pearson, M. G., Littler, J. and Davies, P. D. O. (1994). An analysis of medical workload by specialty and diagnosis in Mersey: evidence of a specialist to patient mismatch. Journal of the Royal College of Physicians, 28 , 230 – 234.

Petrie, K. and Moss-Morris, R. (1997). Coping with chronic illness. In A. Baum, S. Newman, J. Weinman, R. West and C. McManus (Eds.) Cambridge Handbook of Psychology Health and Medicine. Cambridge: Cambridge University Press.

Petty, T. (1988). Pulmonary rehabilitation in chronic respiratory insufficiency. Thorax, 48 , 855 – 862.

Pimm, T. J. (1997). Self regulation and psycho – educational interventions for rheumatic disease. In K. J. Petrie and J. A. Weinman (Eds.) Perceptions of Health and Illness. Amsterdam: Harwood Academic Publishers.

Porzelius, J., Vest, M., and Nochomovitz, M. (1992). Respiratory function, cognitions, and panic in chronic obstructive pulmonary patients. Behaviour Research and Therapy, 30 , 1 , 75 – 77.

Prigatano, G. P. and Grant, I. (1988). Neuropsychological correlates of COPD. In A. J. McSweeny and I. Grant (Eds.) Chronic Obstructive Pulmonary Disease: A Behavioural Perspective. New York: Marcel Dekker.

Quanger, P. H. (1993). Standardised lung function testing. Official statement of the European Respiratory Society. European Respiratory Journal, 6 , 5 – 40.

Sarason, I., Levine, H., Basham, R. and Sarason B. (1983). Assessing social support: the Social Support Questionnaire. Journal of Personality and Social Psychology, 44 , 127 – 139.

Schiaffino, K.M. and Cea, C.D. (1995). Assessing chronic illness representations: The implicit models of illness questionnaire. Journal of Behavioural Medicine, 18 , 6, 531 – 548.

Snider, G. 1., Klenerman, J., Thurlbeck, W. M. And Bengali, Z. H. (1985). The definition of emphysema: Report of a National Heart and Blood Institute, Division of Lung Disease, Workshop. American Review of Respiratory Disease, 132 , 182 – 185.

Townsend, P., Davidson, N. and Whitehead , M. (1988). Inequalities in Health: The Black Report and the Health Divide. Harmondsworth: Penguin.

Weinman, J. (1994). Quality of life: an overview from the health psychology perspective. In Christie, M. And French, D. (Eds.) Assessment of Quality of Life in Childhood Asthma. Chur, Switzerland: Harwood Academic Publishers.

Weinman, J. And Petrie, K. J. (1997). Illness perceptions: A new paradigm for psychosomatics? Journal of Psychosomatic Research, 42 , 2 , 113 – 116.

Weinman, J., Petrie, K. J., Moss-Morris, R. and Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. Psychology and Health, 11 , 431 - 445.

Weissman, M. And Merikangas, K. (1986). The epidemiology of anxiety and panic disorders. British Journal of Clinical Psychology, 46 , 11 – 17.

Williams, S. J. (1993). Chronic Respiratory Illness. London: Routledge.

Williams, S. J. and Bury, (1989). Impairment, disability and handicap in chronic respiratory illness. Social Science and Medicine, 29 , 5 , 609 – 616

Wright, S. (1988). Quoted in Livneh, H. and Antonak, R. F. (1997). Psychosocial Adaptation to Chronic Illness and Disability. Maryland: Aspen.

Yellowlees, P., Alpers, J., Bowden, J., Bryant, G. and Ruffin, R. (1987). Psychiatric morbidity in patients with chronic airflow obstruction. The Medical Journal of Australia, 146 , 305 - 307.

Zigmond, A. and Snaith, R. (1983). The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavia, 67 , 361 - 370.

APPENDICES

IPQ

Please indicate how frequently you now experience the following symptoms as part of your illness

	all of the time	frequently	occasionally	Never
Shortness of breath.				
Tiredness.				
Coughing.				
Chest infections.				
Waking up feeling breathless.				
Bringing up phlegm (sputum).				
Swelling of legs and ankles.				
Wheezing.				
Forgetfulness / difficulty concentrating.				
Chest pain.				
Chest tightness.				
Reduction in the distance you can walk.				

We are interested in your own personal views of your illness. Please indicate how much you agree, or disagree, with the following statements about your illness.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
My illness is a serious condition.					
My illness has had major effects on my life.					
My illness has become easier to live with over time.					

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
My illness has strongly affected the way I see myself as a person.					
My illness will improve with time.					
Smoking caused my illness.					
My illness has serious economic and financial consequences.					
There is a lot I can do to control my symptoms.					
There is very little I can do to improve my illness.					
My treatment will be effective in curing my illness.					
Recovery from my illness is largely dependent on chance or fate.					
What I do can determine whether my illness gets better or worse.					
My illness will last a short time.					
My illness is likely to be a permanent rather than temporary.					
My illness will last for a long time.					
It was just by chance that I became ill.					
Other people played a large role in causing my illness.					
My illness is hereditary - it runs in my family.					
Stress was a major factor in causing my illness.					
Diet played a major role in causing my illness.					
Pollution of the environment caused my illness.					
My illness is largely due to my own behaviour.					
My illness was caused by poor medical care in the past.					
A germ or virus caused my illness.					
My state of mind played a major part in causing my illness.					

APPENDIX 2

Brief Cope

These items look at the ways you have been coping with the stress in your life due to living with this illness. Different people deal with things in different ways. We want to know to what extent you have been doing what each item says over the past month. Don't answer on the basis of whether it seems to be working or not - just whether or not you are doing it.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it had happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been using alcohol or other drugs to help me get through it.
11. I've been trying to see it in a different light, to make it seem more positive.
12. I've been trying to come up with a strategy about what to do.
13. I've been getting comfort and understanding from someone.
14. I've been giving up the attempt to cope.
15. I've been looking for something good in what is happening.
16. I've been making jokes about it.
17. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
18. I've been accepting the reality of the fact that it has happened.
19. I've been expressing my negative feelings.
20. I've been trying to find comfort in my religion or spiritual beliefs.
21. I've been learning to live with it.
22. I've been thinking hard about what steps to take.
23. I've been praying or meditating.
24. I've been making fun of the situation.

APPENDIX 3

Hospital Anxiety and Depression Scale (HADS)

Please read each item below and underline the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or "wound up"
Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind
A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful
Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like "butterflies" in the stomach
Not at all
Occasionally
Very often
Quite often

I have lost interest in my appearance
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or television programme
Often
Sometimes
Not often
Very seldom

APPENDIX 4

St. George's Respiratory Questionnaire
(Activity and Impacts scales)

SECTION 1

HOW WOULD YOU DESCRIBE YOUR CHEST CONDITION? (PLEASE TICK IN ONE BOX ONLY)

the most important problem I have . . . . __

causes me quite a lot of problems . . . . __

causes me a few problems . . . . __

causes no problems . . . . __

IF YOU HAVE EVER HAD PAID EMPLOYMENT, PLEASE TICK ONE OF THESE:

my chest trouble made me stop work . . . . __

my chest trouble interferes with my work or made me change
my work . . . . __

my chest trouble does not affect my work . . . . __

SECTION 2

QUESTIONS ABOUT WHAT ACTIVITIES USUALLY MAKE YOU FEEL BREATHLESS THESE DAYS.
FOR EACH ITEM, PLEASE TICK EITHER TRUE OR FALSE AS IT APPLIES TO YOU.

	TRUE	FALSE
sitting or lying still	__	__
getting washed or dressed	__	__
walking around the home	__	__
walking outside on the level	__	__
walking up a flight of stairs	__	__
walking hills	__	__
playing sports or games	__	__

SECTION 3

SOME MORE QUESTIONS ABOUT YOUR COUGH AND BREATHLESSNESS THESE DAYS.
FOR EACH ITEM< PLEASE TICK EITHER TRUE OR FALSE AS IT APPLIES TO YOU.

	TRUE	FALSE
my cough hurts	__	__
my cough makes me tired	__	__
I am breathless when I talk	__	__
I am breathless when I bend over	__	__
my cough or breathing disturbs my sleep	__	__
I get exhausted easily	__	__

SECTION 4:
QUESTIONS ABOUT OTHER EFFECTS THAT YOUR CHEST TROUBLE MAY HAVE ON YOU THESE DAYS. FOR EACH ITEM< PLEASE TICK EITHER TRUE OR FALSE AS IT APPLIES TO YOU.

	TRUE	FALSE
my cough or breathing is embarrassing in public	__	__
my chest trouble is a nuisance to my family, friends or neighbours	__	__
I get afraid or panic when I cannot get my breath	__	__
I feel that I am not in control of my chest problem	__	__
I do not expect my chest to get any better	__	__
I have become frail or an invalid because of my chest	__	__
Exercise is not safe for me	__	__
Everything seems too much of an effort	__	__

SECTION 5
QUESTIONS ABOUT YOUR MEDICATION. IF YOU ARE RECEIVING NO MEDICATION GO STRAIGHT TO SECTION 6. TO COMPLETE THIS SECTION PLEASE TICK EITHER TRUE OR FALSE AS IT APPLIES TO YOU.

	TRUE	FALSE
my medication does not help me very much	__	__
I get embarrassed using my medication in public	__	__
I have unpleasant side effects from my medication	__	__
my medication interferes with my life a lot	__	__

SECTION 6
THESE ARE QUESTIONS ABOUT HOW YOUR ACTIVITIES MIGHT BE AFFECTED BY YOUR BREATHING.

	TRUE	FALSE
I take a long time to get washed or dressed	__	__
I cannot take a bath or shower, or I take a long time	__	__
I walk slower than other people, or I stop for rests	__	__
jobs such as housework take a long time, or I have to stop for rests	__	__
if I walk up one flight of stairs, I have to go slowly or stop	__	__
if I hurry or walk fast, I have to stop or slow down	__	__
my breathing makes it difficult to do things such as walk up hills, carrying things up stairs, light gardening such as weeding, dance, play bowls or golf	__	__
my breathing makes it difficult to do things such as carry heavy loads, dig the garden or shovel snow, jog or walk at 5 miles per hour, play tennis or swim	__	__
my breathing makes it difficult to do things such as very heavy manual work, run, cycle, swim fast or play competitive sports	__	__

SECTION 7

WE WOULD LIKE TO KNOW HOW YOUR CHEST TROUBLE USUALLY AFFECTS YOUR DAILY LIFE.

	TRUE	FALSE
I cannot play sports or games	__	__
I cannot go out for entertainment or recreation	__	__
I cannot go out of the house to do shopping	__	__
I cannot do housework	__	__
I cannot move far from my bed or chair	__	__

HERE IS A LIST OF OTHER ACTIVITIES THAT YOUR CHEST TROUBLE MAY PREVENT YOU DOING.
(YOU DO NOT HAVE TO TICK THESE, THEY ARE JUST TO REMIND YOU OF WAYS IN WHICH YOUR
BREATHLESSNESS MAY AFFECT YOU):

        GOING FOR WALKS OR WALKING THE DOG
        DOING THINGS AT HOME OR IN THE GARDEN
        SEXUAL INTERCOURSE
        GOING TO CHURCH OR PLACE OF ENTERTAINMENT
        GOING OUT IN BAD WEATHER OR INTO SMOKY ROOMS
        VISITING FAMILY OR FRIENDS OR PLAYING WITH CHILDREN

PLEASE WRITE IN ANY OTHER IMPORTANT ACTIVITIES THAT YOUR CHEST TROUBLE MAY STOP
YOU DOING:

. . . .

. . . .

. . . .

. . . .

NOW, WOULD YOU TICK IN THE BOX WHICH YOU THINK BEST DESCRIBES HOW YOUR CHEST
AFFECTS YOU:

        it does not stop me doing anything I would like to do . . . .   __
        it stops me doing one or two things I would like to do . . . . . .   __
        it stops me doing most of the things I would like to do . . . . . .   __
        it stops me doing everything I would like to do . . . .   __

THANK YOU FOR FILLING IN THIS QUESTIONNAIRE.

Semi - structured interview

1. What symptoms do you experience as part of your illness?

2. How does your illness affect the way you feel and your mood?

3. How does your illness affect your relationships with other people?

4. What have you had to give up because of the illness?

5. What activities do you do now?

6. What adaptations have you made to your lifestyle?

7. How does your treatment / medication affect you?

8. Is there anything that makes your symptoms better or worse?

9. What ways do you use to help cope with your illness?

10. What was the main cause of your illness?

11. Do you / have you ever smoked?

APPENDIX 6

Copy of ethics committee approval letter

Dear

Re. Project NC786 - An investigation of the impact of illness representations on quality of life in people with chronic obstructive pulmonary disease.

I refer to your application to the Local Research Ethics Committee for consideration of the above project. I am pleased to inform you that the Committee approves the project on ethical grounds on the understanding that:

I   Any ethical problem, arising in the course of the project, will be

reported to the committee.

II   Any change in the protocol will be reported to the committee.

III A brief report will be submitted after completion.

Ethical approval by the Committee is not an authority to proceed. You are advised to discuss your proposal with all heads of departments and others who might be affected, particularly if there are financial and / or staffing implications.

Please note that your research may be subject to review annually by the committee.

Yours sincerely,

Secretary to the Local Research Ethics Committee.

Information sheet

I am a Trainee Clinical Psychologist working with Dr. Paul Kennedy, Consultant Clinical Psychologist, Dr. Steve Williams, Dr. Fiona Robertson – Mackay and the team at the Chest Clinic (Clinic 3a). We are interested in finding out what people think about their experience of breathing difficulties. In particular, we would like to explore the ways in which your illness affects your quality of life, including how it affects your mood and interferes in day to day life. I am hoping to speak to a number of people who have breathing difficulties. You have been given this information sheet to ask if you would consider participating in our research.

<u>What does participating involve?</u>

Your participation would involve meeting with myself, Lindsay Jones. We could either meet at your home or at the hospital if you prefer. It would include an informal discussion where we would talk about your experience of breathing difficulties. You would also be asked to go through five medium length questionnaires. The whole process will probably take in the region of one and a half hours to two hours. I would also need access to your medical notes to obtain information on breathing tests. Any information obtained would be kept entirely confidential.

If you are interested in participating, or would like further information before deciding, please could you complete the slip below and return it to me in the stamped addressed envelope provided. I will then contact you and we can discuss any questions that you may have and, if you decide to participate, we can make a time to meet, either at your home or at the hospital.

I would like to emphasise that <u>participation is entirely voluntary</u>, and that your access to medical and psychological care <u>will not be affected in any way</u> whether or not you decide

to take part. You are free to leave the study at any time, without giving a reason, even after you have already agreed to participate. If you would like to know more information about the study you can contact me on (01865) 226431.

If you do decide to participate we would be grateful for your help in increasing our understanding of some of the factors that contribute to quality of life in people with breathing difficulties. The information we obtain in this study may help us find ways of helping people with breathing difficulties in the future.

Thank you,

Lindsay Jones (Psychologist in Clinical Training).

- To:
Lindsay Jones, Trainee Clinical Psychologist, Oxford (Regional) In – Service Training Course in Clinical Psychology, Isis Education Centre, Warneford Hospital, Roosevelt Drive, Headington, Oxford, OX3 7JX.

I may be interested in participating in the research.

Name: . . . .

Address: : . . . .
. . . : . . . . :
. . . .

Contact Telephone Number: : . . . .

APPENDIX 8

Consent Form

Title of study: "An Investigation of the Impact of Illness Representations on Quality of Life in People with Chronic Obstructive Pulmonary Disease".

Section 1 - to be signed by participant

I . . . . (full name)

of . . . .

. . . .(full address)

hereby consent to participate in the above research study.

The purposes and nature of this study have been explained to me by

. . . .

I have been given an information sheet about the study which I have read
and which I understand.   YES / NO

I have had the opportunity to ask questions and discuss the study.   YES / NO

I understand that my participation in the study is entirely voluntary and
that I may withdraw my consent at any time without giving any reason,
and without any jeopardy to my further medical care.   YES / NO

If I have any further questions about the study at any time then I can contact Lindsay Jones, Oxford Regional Training Course in Clinical Psychology (01865 226431).

Signed . . . . Dated . . . .

Section 2 - declaration by investigator

I confirm that I have explained the study to the participant and that his / her consent is being given freely and voluntarily.

Signed . . . . Dated . . . .

APPENDIX 9

Letter to General Practitioners

Dr.

18th May 1988.

Dear Dr.   ,

Re.

I am writing to inform you that your patient, Mr.   , has participated in a study which is being carried out with patients attending the chest clinic at Stoke Mandeville Hospital. The title of the study is "An investigation of the relationship between illness perceptions and coping on quality of life in people with chronic obstructive pulmonary disease".

The procedure consisted of an interview of about one and a half hours duration during which time we discussed the effects of the illness on mood and everyday functioning. Five questionnaires were also completed. Please do not hesitate to contact me if you have any questions about the study or would like a summary of the research findings once they have been completed.

Yours sincerely,

Lindsay Jones
(Psychologist in Clinical Training).