An exploration of the experiences of people living with COPD in rural Australia and the influence of pulmonary rehabilitation

by

Michelle E. Brooke

Bachelor of Applied Science (Physiotherapy), Graduate Certificate in Clinical Rehabilitation

Rehabilitation, Aged and Extended Care

Flinders Clinical Effectiveness

School of Medicine

Faculty of Health Sciences

Flinders University, South Australia

Date of Submission: 28th June 2012

Declaration

This work does not contain any material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

Michelle E. Brooke

Acknowledgements

I would like to acknowledge the immense encouragement and support given by my principal supervisor, Associate Professor Julie Pryor, throughout this research process. I would like to thank Julie for helping me to develop the confidence and skills needed to pursue a research project in this area. Her positive and encouraging words gave me the motivation to continue, particularly when the research process seemed overwhelming and unachievable. She has shown me the value of qualitative research methodologies in physiotherapy practice for which I am extremely grateful. I would also like to acknowledge the assistance and support of Dr Stacey George and Dr Helen Cameron-Tucker. Both provided valuable feedback and encouragement throughout the course of this project for which I am greatly appreciative.

I would like to acknowledge the participants who took part in the interviews in this study. They willingly gave of their time and openly shared their experiences with me and I have learnt more from them than I could have imagined.

I would also like to acknowledge the support of my colleagues at the Shoalhaven COPD Service - Ms Tod Adams who gave me the motivation to embark on this journey and Mrs Margaret Collins who provided the encouragement to continue on. Both have given freely of their time, supporting my academic endeavours and making themselves available to discuss developing themes and ideas. Their interest and assistance in this project has been a great encouragement.

Finally, it is to my family and friends, who have patiently and lovingly supported me throughout the last two years, that I express my deepest thanks.

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Key to Transcripts

When presenting excerpts from participant's interview transcripts in Chapter Three, the following conventions are used:

Shorter excerpts from participants are presented in double inverted commas in the text. Longer excerpts are indented and single spaced.

All participants are identified by a specific code. Participants who have completed pulmonary rehabilitation are identified using the letters PR and a number from one to four. Participants who have not completed pulmonary rehabilitation are identified using the letters NPR and a number from one to four.

Excerpts from interview transcripts are identified using the participant's code and the transcript line number. For example (PR3 235) indicates that the excerpt comes from pulmonary rehabilitation participant number three and 235 refers to the line number at the commencement of the excerpt in the interview transcript.

Square brackets [ ] are used to insert words to clarify meaning, for example, to give an explanation of what the participant was referring to, or where additional words were inserted. Parentheses ( ) are used to insert field notes into transcripts.

To indicate that content from an interview transcript has been edited out, an ellipsis ... has been used.

Abstract

Chronic obstructive pulmonary disease (COPD) is a progressive and incurable respiratory condition. In Australia, COPD affects one in five adults over the age of 40. According to the international literature, those living with COPD experience breathlessness, declining physical function as well as significant psychosocial impacts resulting from their disease. Additionally, individuals with COPD have been identified as having a poor understanding about their illness and its progression. Pulmonary rehabilitation is known to be effective in reducing symptoms of dyspnoea, improving health related quality of life and exercise capacity in people with COPD, however, its impact on everyday life is less well documented. While the international literature provides insight into the experience of living with COPD, only one recent study has explored this experience from an Australian perspective.

Using a descriptive qualitative design, this study has provided a rich description of the experiences of people living with COPD in one rural region of Australia and how participation in pulmonary rehabilitation can influence these experiences. Semi-structured interviews were conducted with four participants who had completed pulmonary rehabilitation and four who had not. Data from these interviews were analysed using inductive thematic analysis.

Data analysis revealed two major themes and one minor theme. The first major theme, the realisation of breathlessness as COPD, describes a journey that starts with the slow, insidious onset of breathlessness and gradually progresses towards knowing and understanding breathlessness as a medical condition called COPD. The second major theme, the everyday reality of life with COPD, describes life with COPD, including the experience of declining physical function and alterations to connectedness with others. These themes were evident in both groups of participants.

The minor theme considers the influence of pulmonary rehabilitation on the experience of living with COPD by identifying the differences apparent between the two groups of participants. While recognising that the experience of living with COPD is influenced by many factors, the findings support the view that pulmonary rehabilitation can positively influence everyday symptoms of breathlessness and physical functioning, provide opportunities for social interaction, and develop effective relationships with health professionals.

The findings of this study provide insight into the Australian experience of living with COPD, having implications for health professionals, service delivery and future research. The need for improved communication between health professionals as well as with those who have COPD is indicated, with further research required to identify factors which contribute to a lack of understanding of COPD, particularly at the time of diagnosis. The ongoing need for effective communication is also recognised. Managing COPD requires effective partnerships between those with COPD and health professionals. In these partnerships good communication is vital with health professionals needing to understand the declining physical function and alterations to connectedness that come when living with COPD. This study has identified that effective partnerships can develop during pulmonary rehabilitation and future research is needed to explore how these positive components of pulmonary rehabilitation might be continued in the long term. Finally, the study recognises that physiotherapy work during pulmonary rehabilitation involves psychological and social processes as well as exercise training. Further research should identify the work done by physiotherapists, which is beyond the physical, in this setting.

CHAPTER ONE: Introduction to the study

Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive and incurable respiratory condition characterised by airflow limitation and obstruction which cannot be reversed (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2008). Individuals with COPD experience worsening lung function and associated breathlessness, coughing, wheezing and sputum production. These symptoms influence an individual's physical abilities (Kanervisto, Kaistila, & Paavilainen, 2007; Ek & Ternestedt, 2008; Sossai, Gray, & Tanner, 2011), psychological wellbeing (Ek, Sahlberg-Blom, Andershed, & Ternestedt, 2010; Ek & Ternestedt, 2008), social interactions (Nicholls, 2003; Barnett, 2005; Berger, Kapella, & Larson, 2010; Sossai, et al., 2011) and relationships with family members (Barnett, 2005; Seamark, Blake, Seamark, & Halpin, 2004), health professionals (Nicholls, 2003; Gysels & Higginson, 2008; Seamark, et al., 2004) and the wider community (Nicholls, 2003; Gysels, Bausewein, & Higginson, 2007; Gysels & Higginson, 2008).

An estimated 64 million people worldwide have COPD, with the World Health Organization (2009) predicting that deaths from COPD will rise by 30% over the next ten years unless urgent action is taken to reduce risk factors such as tobacco use. Cigarette smoking is the most common risk factor for COPD, with 15 to 20% of smokers developing severe lung problems (The Asthma Foundation, 2010). Other risk factors for COPD include genetic factors, such as alpha 1-antitrypsin deficiency, exposure to toxic particles and pollution, and a history of respiratory infections (GOLD, 2008).

This chapter presents information regarding the prevalence and management of COPD in Australia as well as a review of the international literature related to the experience of living with COPD. It provides background to and explains the rationale for the study, situated in rural Australia, which explores the experience of living with COPD and the influence of pulmonary rehabilitation on this experience.

The prevalence and healthcare costs of COPD in Australia

It is predicted that by 2050 4.5 million Australians will be affected by COPD (The Australian Lung Foundation, 2010). In Australia, rates of COPD in males have reduced over the last 15 years due to decreased rates of smoking, however, the rate of COPD in females is likely to rise in the coming decades due to the higher smoking rates in females currently aged 20-29 years (Frith, Cafarella, & Duffy, 2008). Currently in Australia, approximately one in five people over the age of 40 years are affected by COPD (The Asthma Foundation, 2010). COPD is the fifth leading cause of death and third leading cause of disease burden in Australia (The Australian Lung Foundation, 2008).

COPD has been identified as one of the contributing factors to poorer health outcomes for people living outside of major cities (Australian Centre for Asthma Monitoring, 2011) and significantly higher hospital admission rates are recorded for people living with COPD in rural areas of Australia (Australian Centre for Asthma Monitoring, 2011). Reasons suggested for these poorer health outcomes are differences in access to health services, environmental factors and higher rates of risky behaviours (Australian Institute of Health and Welfare, 2012). A Canadian study (Goodridge, Hutchinson, Wilson, & Ross, 2011) has suggested that people living with advanced respiratory illness in rural areas face challenges such as extensive travel to access health care, erratic local physician availability and a lack of respiratory-related education and support.

The Australian Institute of Health and Welfare has ranked COPD second in a list of conditions resulting in avoidable hospitalisations in Australia (Glover, Page, Ambrose, & Hetzel, 2007). When hospitalised due to COPD, individuals over the age of 55 have an average length of stay of between five and six days (Australian Centre for Asthma Monitoring, 2011). COPD costs the Australian health care system between $800-900 million annually (The Australian Lung Foundation, 2008). Not surprisingly, these statistics have generated considerable interest in optimising the medical management of COPD.

Medical interventions for COPD in Australia

Historically, the approach to COPD in the Australian healthcare system has focused primarily on management of acute exacerbations (McKenzie, et al., 2011). Acute exacerbations are events in the natural course of COPD when individuals experience an acute onset of breathlessness, coughing or sputum production which is beyond their normal day-to-day fluctuations (McKenzie, et al., 2011). Effective management of acute exacerbations of COPD is important as exacerbations are known to be associated with a more rapid decline in lung function, poorer quality of life and increased mortality (Soler-Cataluna, et al., 2005). However, it has been suggested that the increasing burden of chronic diseases like COPD requires the development of health service models which are anticipatory and proactive in care as well as including components of acute reactive care (McKenzie, et al., 2011).

With these aims in mind the Thoracic Society of Australia and New Zealand and The Australian Lung Foundation developed the COPDX plan, a guideline for the management of COPD in Australia and New Zealand. The COPDX plan is designed to provide support and assistance to health professionals to manage established COPD as well as exacerbations of COPD (McKenzie, et al., 2011). Disease management using the COPDX plan involves: **C**onfirming the diagnosis and assessing the severity of COPD; **O**ptimising an individual's function using medications, pulmonary rehabilitation and surgical interventions; **P**reventing further decline in respiratory function by encouraging and assisting smoking cessation, yearly vaccinations and the use of long term oxygen therapy; **D**eveloping support networks for individuals and their families, and encouraging self management; and managing acute e**X**acerbations (McKenzie, et al., 2011).

An important component of optimising the function of individuals with COPD is the intervention of pulmonary rehabilitation. Because physiotherapists take a physical approach to disease management, they often have a particular interest and central role in the delivery of pulmonary rehabilitation programs. These programs use the non-pharmacological elements of exercise and education to improve an individual's physical abilities as well as to provide information about COPD and its management.

The majority of pulmonary rehabilitation programs throughout Australia are based on the guidelines provided in the Pulmonary Rehabilitation Toolkit (Alison, et al., 2009), a joint project of The Australian Lung Foundation and the Thoracic Society of Australia and New Zealand. Programs include the key elements of patient assessment, exercise training, education, nutritional intervention and psychosocial support. A brief review of pulmonary rehabilitation both internationally and in Australia follows.

Pulmonary rehabilitation

Prior to commencing pulmonary rehabilitation participants undergo assessment of their exercise capacity, breathlessness, quality of life and nutritional status using a variety of standardised measurement scales. A brief medical history is also taken. Assessment at the commencement of pulmonary rehabilitation aims to objectively assess the person's pre-program status as well as assisting in the formulation of an exercise prescription. Standardised assessment tools allow an objective evaluation of the effectiveness of pulmonary rehabilitation by the comparison of pre and post program measurements (Nici, et al., 2006).

Exercise is the major component of pulmonary rehabilitation (Ries, et al., 2007) and includes endurance, strengthening and flexibility training (Alison, et al., 2009). Exercise during pulmonary rehabilitation aims to improve participants' exercise tolerance as well as reducing their sensitivity to the sensation of breathlessness (Nici, et al., 2006).

Education during pulmonary rehabilitation occurs as an integral part of assessment, exercise training and outcome measurement as well as during formal information sessions. Educational topics may include pathophysiology of lung disease, medication and oxygen usage, benefits of and safety during exercise, prevention and early treatment of respiratory exacerbations, breathing strategies, bronchial hygiene, energy conservation and work simplification techniques, nutritional advice, anxiety and panic management including relaxation techniques, leisure, travel, sexuality and informed end of life decision making (Alison, et al., 2009; Nici, et al., 2006). These sessions aim to address shortfalls in participant and carer knowledge and skills for managing health and disease.

More recently, self-management programs have been suggested as having an important role in pulmonary rehabilitation by educating and empowering people with COPD to better manage their disease (Bourbeau, 2010). Rather than simply providing information about a disease and its management, self-management programs aim to teach skills required to carry out medical regimens specific to the disease, guide behaviour change (Effing, et al., 2007), and build an individual's confidence in managing emotional and social roles (Lorig, et al., 1999). A systematic review of the effectiveness of self management programs for people with COPD, demonstrated that interventions which included symptom management were likely to be associated with a reduction in hospital admissions (Effing, et al., 2007)

Other components of pulmonary rehabilitation include nutritional interventions which focus on the management of either excessive or low body weight, (McKenzie, et al., 2011) and psychosocial support which occurs via the development of patient support networks, access to counselling services and development of panic, anxiety and stress management techniques (Nici, et al., 2006).

Pulmonary rehabilitation programs can vary in duration from four to 12 weeks (GOLD, 2008; Ries, et al., 2007; Alison, et al., 2009), and while shorter programs can produce short term benefits, programs of 12 weeks have demonstrated greater sustained benefits (Ries, et al., 2007). Successful pulmonary rehabilitation involves individuals undertaking complex behavioural changes. Longer programs provide the opportunity for these changes to occur by facilitating the development of competencies in and adherence to new skills, strategies, techniques and habits required by the individual to optimally manage their health problems (Ries, et al., 2007).

Evidence has shown that pulmonary rehabilitation can be effectively provided in an inpatient, outpatient and community based setting as well as at home (GOLD, 2008). While some guidelines have primarily focused on hospital based outpatient programs (Ries, et al., 2007), it is recommended that programs be flexible to suit the cultures and health care systems in which they are situated (Nici, et al., 2006)

The benefits of pulmonary rehabilitation are well known. Two meta-analyses (Lacasse, Goldstein, Lasserson, & Martin, 2006; Puhan, et al., 2011) have demonstrated significant improvement in symptoms of dyspnoea and health related quality of life using the Chronic Respiratory Disease Questionnaire (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987). Following pulmonary rehabilitation, improvements in the domains of dyspnoea, fatigue, emotional function and mastery were seen which were larger than the minimal clinically important difference of 0.5 units. Improvement in physical capacity was also seen in people with COPD, with Lacasse et al. (2006) reporting improvements of 48 metres in the six minute walk test following pulmonary rehabilitation. Pulmonary rehabilitation has also been determined to be a cost effective therapy. Golmohammadi, Jacobs and Sin (2004) showed that over one year, pulmonary rehabilitation was associated with decreased health service utilisation, reduced direct costs (approximately $344 per person per year) and improved health status of patients with COPD, while Cecins, Geelhoed and Jenkins (2008) demonstrated a 42% reduction in the number of patients admitted to hospital with an exacerbation of COPD and a 62% reduction in total bed days following pulmonary rehabilitation.

However, despite the benefits of pulmonary rehabilitation, it is estimated that in Australia only 1% of people with COPD who would benefit from pulmonary rehabilitation have access to these programs (The Australian Lung Foundation, 2009). While access to pulmonary rehabilitation is less than ideal, the uptake and attendance of pulmonary rehabilitation programs is also poor. An Australian study has shown that between 8% and 50% of individuals referred to pulmonary rehabilitation never attend, while between 10% and 32% of those who commence pulmonary rehabilitation do not complete the program (Keating, Lee, & Holland, 2011).

Living with COPD

Understanding COPD, its costs and management enables the burden of COPD to be recognised. However, the true burden of COPD is felt by the individual, who experiences breathlessness as well as the physical and psychosocial impacts of COPD on a daily basis. Furthermore, an individual's struggle to understand the diagnosis, prognosis and causes of a chronic disease like COPD and the implications this has for their life is an additional burden carried by people with COPD. Literature on the experience of living with COPD in Australia is limited, with only two published qualitative study about living with COPD in the Australian context (Gullick & Stainton, 2008; Sossai et al., 2011). However, this experience has been described outside of Australia, in terms of the experience of breathlessness, physical and psychosocial consequences of COPD as well as individual knowledge about COPD. These topics are explored in the following review of the literature.

The experience of breathlessness

Breathlessness is recognised as the most prominent and troublesome symptom experienced by people with COPD (Jonsdottir, 1998). Breathlessness has been defined as a "subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (American Thoracic Society, 1999). The subjective nature of breathlessness is demonstrated in the lack of relationship between breathlessness and any physiological measurements (Heyse-Moore, Beynon, & Ross, 2000). Attempts to measure breathlessness are often compared to the measurement of pain, where the experience depends on the individual's threshold for noticing, reporting and rating the severity of the symptom (Victorson, Anton, Hamilton, & Yount, 2009). While numerous scales exist which attempt to measure breathlessness objectively, this current study looks at the lived experience of COPD, a feature of which is breathlessness. Consequently, the focus of the following discussion is the individual's experience of breathlessness.

Conveying the experience of breathlessness is often challenging for people with COPD. Nicholls (2003) notes how those with COPD convey the experience of breathlessness using physical sensations and functional limitations as well as feelings and emotions, narratives and metaphors. During Gullick and Stainton's (2008) study, 15 participants with emphysema described how breathing could no longer be taken for granted, while Williams, Bruton, Ellis-Hill, and McPherson's (2011) analysis of interviews with 18 people with COPD reports breathlessness as a physical sensation of having a tight chest, restricted airways and an inability to breathe enough air. In addition to these physical sensations, their participants also described how breathlessness evoked feelings of panic, fear and helplessness.

The psychological impact of breathlessness was described in a New Zealand study (Sheridan, et al., 2011) of 29 people with COPD. Participants spoke of having little control over symptoms of breathlessness and this resulted in an overwhelming sense of helplessness. Other studies have demonstrated how breathlessness results in feelings of anxiety (Gysels & Higginson, 2011; Ek & Ternestedt, 2008), fear (Oliver, 2001) and frustration (Barnett, 2005), while people with COPD have also been described as experiencing embarrassment or shame, particularly in social settings, as a result of breathlessness and its attached stigma (Gysels & Higginson, 2008; Berger, et al., 2010; Nicholls, 2003; Gullick & Stainton, 2008). Stigma is socially constructed, defining an individual in terms of a distinguishing characteristic or mark and devaluing them as a consequence (Dinos, Stevens, Serfaty, Weich, & King, 2004). As breathlessness becomes a visible and disabling symptom of COPD it has the potential to be stigmatising (Johnson, Campbell, Bowers, & Nichol, 2007). In addition, seeing breathlessness as a symptom of the 'self-inflicted' disease of COPD has also been described as stigmatising, with individuals blaming themselves for causing breathlessness and fearing negative reactions from others as a result (Gysels & Higginson, 2008).

Characteristics of breathlessness noted in a number of qualitative studies were its unpredictability (Nicholls, 2003; Gysels & Higginson, 2008), variability or deceptiveness (Barnett, 2005; Gysels & Higginson, 2008). Symptoms of breathlessness could vary from day to day and even hour to hour (Barnett, 2005). This deceptive nature of breathlessness was described in Gysels and Higginson's (2008) study of 18 COPD participants, who explained how symptoms of breathlessness, normally severe and disabling, could be absent at rest. The unpredictable nature of breathlessness was described as 'mysterious' by these participants because of their inability to find reasonable explanations for why they would experience either an onset or disappearance of their breathlessness. Despite being unpredictable and deceptive, certain triggers for variations in breathlessness are identified in the literature, including dust, smoke and poor air quality (Chan, 2004; Gullick & Stainton, 2008), weather conditions such as extremes of temperature (Chan, 2004; Gullick & Stainton, 2008) and changing body positions such as bending down or reaching up (Barnett, 2005).

Although breathlessness is recognised as the most prominent and troublesome symptom of COPD, in the early stages of COPD, breathlessness has been described as an “inside experience” (Gullick & Stainton, 2008, p. 609). Barnett’s (2005) study revealed that nine out of ten participants experienced a slow progression of breathlessness over four years and during this time participants accepted, ignored or dismissed their symptoms as not serious. Similarly, Gysels and Higginson’s (2008) participants did not see their early symptoms of breathlessness as signalling the presence of a serious condition. Rather than seek information about and treatment for early symptoms of breathlessness, individuals with COPD tend to wait until a severe acute episode of breathlessness is experienced (Nicholls, 2003) or breathlessness becomes a significant impairment and restriction to everyday life (Gysels & Higginson, 2011).

Physical consequences of COPD

The physical consequences of COPD are described throughout the literature and provide further insight into the experience of living with COPD. Arne, Emtner, Janson and Wilde-Larsson’s (2007) interviews with ten participants newly diagnosed with COPD found that the change in physical ability was expressed as loss of energy, a feeling of fatigue or of becoming physically restricted compared to others. In addition, several qualitative studies found participants developed increased body awareness; notably, its progressive failure (Gullick & Stainton, 2008), lack of predictability (Ek, et al., 2010; Leidy & Haase, 1999) and decreasing strength (Ek & Ternestedt, 2008).

Qualitative studies have shown how individuals with COPD recognise their ineffectiveness at performing simple everyday activities (Leidy & Haase, 1999) as well as their inability to perform a combination of tasks simultaneously (Gullick &

Stainton, 2008). A perception of physical ineffectiveness made participants in Barnett's (2005) study reduce activity levels, resulting in further deconditioning, weakness of skeletal muscle and disability. Barnett (2005) suggests that this perception of physical ineffectiveness causes individuals with COPD to enter a vicious cycle of inactivity, a consequence of which is increasing dependence, disability and worsening quality of life.

Of particular interest in relation to the loss of physical ability is the activity of walking, an essential component of activities such as self care tasks, household chores, leisure and social activities. Williams, Bruton, Ellis-Hill and McPherson's (2007) participants emphasised the importance of walking and maintaining their level of walking even if this required the use of embarrassing bulky portable oxygen systems. While walking was physically difficult, it was also important and enjoyable and had a value which was beyond its functional purpose (Williams, et al., 2007).

To cope with the physical consequences of COPD, individuals use a variety of strategies or adaptations, including stopping frequently for rests (Gullick & Stainton, 2008), decreasing the intensity at which an activity is performed (Arne, et al., 2007) and planning or making preparations for activity (Leidy & Haase, 1999; Kanervisto, et al., 2007). They have also been reported to use assistive devices such as supplemental oxygen (Kanervisto, et al., 2007), mobility aids (Ek & Ternestedt, 2008; Ek, et al., 2010) and the assistance of others (Kanervisto, et al., 2007; Seamark, et al., 2004; Ek & Ternestedt, 2008) to cope with changes in their physical functioning.

Kanervisto, et al. (2007) found that people with COPD were concerned about being helpless and dependent on someone else, particularly family members. However, their five participants found that over time, accepting the help of family members became easier. In contrast, seeking and accepting help from external services was described as being more difficult. Participants in a study by Ek, et al. (2010) also found it difficult to receive help from those other than family members or known carers as it required the expenditure of more energy to explain their wishes and needs.

Psychosocial consequences of COPD

The psychosocial consequences of COPD have been well documented in the literature, but are often under-recognised in practice. Depression and anxiety are common co-morbidities in individuals with COPD, with rates significantly higher in this population compared to the general population (Frith, et al., 2008; Simpson & Rocker, 2008). Despite these high levels, Simpson and Rocker (2008) suggest that less than 30% of health professionals recognise anxiety or depression in people with COPD or follow best practice treatment guidelines.

For individuals with COPD, being breathless and having declining physical abilities makes participation in social activities more difficult (Leidy & Haase, 1999). Individuals with COPD are often restricted to their home (Gullick & Stainton, 2008; Williams, et al., 2007), limiting opportunities for social interaction and potentially causing social isolation (Gysels & Higginson, 2011). Barnett’s (2005) participants found that social participation was limited by the distance they were required to walk, weather conditions and the need for oxygen or nebulised therapies. However, physical limitations were not the only cause of social isolation experienced by people with COPD. Two qualitative studies (Ek & Ternestedt, 2008; Williams, et al., 2007) suggest that people with COPD are often socially isolated because friends and family members choose to avoid or not visit them. Neither Ek and Ternestedt (2008) nor

Williams, et al. (2007) suggest a reason why participants in these studies experienced social isolation in this way.

Living with COPD also affects interpersonal relationships and the roles individuals hold within those relationships. Declining physical abilities and a lack of predictability about how the body will function makes it difficult for individuals with COPD to maintain roles, such as husband or wife, mother, father or grandparent (Gullick & Stainton, 2008). Ek, et al. (2010) and Seamark, et al. (2004) noted their participants to have feelings of loss related to their inability to fulfil the role they perceived a grandparent should play. In these studies, the role of grandparent was viewed as important and valuable, with the grandparent gaining an important sense of belonging. Opportunities for social interaction, particularly with children, were also valued by participants in Ek and Ternestedt's (2008) study. They suggested that relationships with children and grandchildren contained life-confirming elements allowing the person with COPD to feel they had meaning and importance to someone other than themselves.

Understandings of COPD

An individual's knowledge and understanding of the diagnosis, prognosis and management of COPD is an integral part of their experience of living with COPD. A person's knowledge about diagnosis, prognosis and management form the basis of perceptions they hold about their illness (Kaptein, et al., 2008). Perceptions about illness are formed from personal and observed encounters with illness as well as from information gained from health professionals, books, leaflets, the internet, friends, family and fellow sufferers (Kaptein, et al., 2008). Illness perceptions of people with COPD, whether medically accurate or not, have been demonstrated to shape coping behaviours and the experience of illness (Kaptein, et al., 2008) and can determine quality of life and adherence to various treatments (Fischer, et al., 2007; Scharloo, et al., 2007). Resultantly, understanding illness perceptions and addressing any misconceptions would seem an important part of caring for people with COPD.

Studies have demonstrated that people with COPD often have a poor understanding of what COPD actually is (Gore, Brophy, & Greenstone, 2000). They can be unaware of the implications of having COPD and the progressive deterioration associated with the disease (Gardiner, et al., 2009; Gardiner, et al., 2010; Sheridan, et al., 2011). In a recent Australian study (Sossai, et al., 2011) eight participants with COPD described the diagnostic and prognostic information they received as being inconsistent and difficult to interpret; this was found to negatively influence participants' perceptions of their illness. Participants in some studies have attributed the gap in knowledge to a lack of information given by health professionals. Thirty percent of participants with COPD in a study by Gore, et al. (2000) felt information about the diagnosis of COPD received from hospital doctors was lacking, while 78% of participants felt they had received insufficient information on the prognosis and future management of their disease. Similarly, Gysels and Higginson's (2010) 18 participants with COPD reported receiving only limited prognostic information. A review of the literature by Gardiner, et al., (2009) found that the implications of the diagnosis and prognosis of COPD are not routinely discussed by health professionals with people who have COPD. Seamark, et al. (2004) suggested that some of their participants deduced prognostic information from health professionals' comments rather than having an open discussion.

The role of health professionals in giving diagnostic and prognostic information has been recognised as an important variable in an individual's experience of understanding and living with COPD. In a qualitative study of 16 COPD participants, Oliver (2001) proposed that it was how the doctor dealt with the consultation in which the diagnosis of COPD was given, the level of empathy and support provided, that remained in the participant's memory. Oliver's (2001) participants experienced a strong sense of loss and hopelessness after being given a diagnosis of COPD, recalling statements made by doctors such as "nothing could be done" (Oliver, 2001, p. 432). Both Oliver (2001) and Gysels and Higginson (2010) have suggested that time constraints during consultations and a lack of attention paid by health professionals to the problems faced by people with COPD results in barriers to accessing and acquiring information. Gysels and Higginson's (2010) participants held a perception that the key source of diagnostic and prognostic information would be their general practitioner or respiratory physician. Similar to participants in another study (Rodgers, Dyas, Molyneux, Ward, & Revill, 2007), when these expectations were not met, information was accessed from alternate sources including books or pamphlets or other health professionals.

An individual's poor understanding of diagnostic and prognostic information could also be attributed to the array of medical terminology used to label COPD. Participants in numerous studies (Gysels & Higginson, 2011; Gardiner, et al., 2009; Arne, et al., 2007; Walters, Hansen, Hayden-Walters, & Wood-Baker, 2008) used the terms COPD, asthma, emphysema or bronchitis interchangeably to label their respiratory symptoms, while in other studies (Parker, Goldman, & Eaton, 2008; Rodgers, et al., 2007) participants were unable to recall or were unfamiliar with the terminology that had been used to label their respiratory symptoms. Confusion of the terms COPD and asthma could lead to the misunderstanding that COPD was reversible (Sheridan, et al., 2011) and the term "chronic" in the acronym COPD could imply that the disease was relatively manageable in comparison to a disease such as cancer (Gysels & Higginson, 2011). Both misunderstandings cause further confusion surrounding the prognosis of COPD.

Experiences of participating in pulmonary rehabilitation

While there are many studies which report the objective beneficial outcomes of pulmonary rehabilitation, studies reviewing the influence of pulmonary rehabilitation on the experience of living with COPD are less common. Williams, Bruton, Ellis-Hill and Macpherson's (2010) interviews with nine participants found that the exercise component of pulmonary rehabilitation increased physical activity and improved performance of household related activities. Importantly, improving performance of these activities meant participants could resume former roles held within their family. Likewise, Gysels and Higginson (2009) found pulmonary rehabilitation improved the ability to perform everyday activities in their 18 participants, resulting in an improvement in their quality of life. However, another study of 23 participants with COPD who had completed pulmonary rehabilitation (Rodgers, et al., 2007) found a mixed reaction to the exercise component of pulmonary rehabilitation. Some participants found exercise beneficial while others found it made little difference to their everyday physical abilities.

More notable is the value participants in several qualitative studies placed on the social environment and interactions occurring at pulmonary rehabilitation (Gysels & Higginson, 2009; Halding, Wahl, & Heggdal, 2010; Rodgers, et al., 2007). The environment in which pulmonary rehabilitation is held was recognised as being supportive, cheerful and informal, and this facilitated communication by engaging participants and encouraging the establishment of supportive relationships (Halding, et al., 2010). Participants in several qualitative studies (Halding, et al., 2010; Gysels & Higginson, 2009; Kanervisto, et al., 2007; Williams, et al., 2010) identified that one of the most valuable aspects of participating in pulmonary rehabilitation was the opportunity to meet other people with COPD. Meeting with peers gave participants the opportunity to exchange ideas and share experiences of living with COPD with someone who understood (Williams, et al, 2010; Gysels & Higginson, 2009). However, social participation could also be challenging for some pulmonary rehabilitation participants. Halding, et al. (2010) recognised that differences in participants' personal backgrounds, interests and cognitive skills could result in a lack of cohesion within a pulmonary rehabilitation peer group. As a result, these participants did not gain the benefits of social support or a sense of belonging.

Another valuable aspect of pulmonary rehabilitation is the interaction participants had with health professionals. While the content of talks provided by health professionals have been considered helpful (Rodgers, et al., 2007; Gysels & Higginson, 2009; Halding, et al, 2010), it is the relationships built with health professionals during pulmonary rehabilitation that appears to be most valued. Participants in a study by Halding, et al. (2010) found that health professionals at pulmonary rehabilitation provided emotional and practical support in addition to the information they were able to provide about COPD and its treatment. Gysels and Higginson's (2009) participants described how pulmonary rehabilitation provided the opportunity to develop trusting relationships with health professionals. This trust was built on the support that participants had received during their experience of pulmonary rehabilitation.

Summary

The international literature provides insight into the experiences of people living with COPD. Experiences most often recalled by participants are those related to breathlessness, declining physical function as well as the psychosocial impacts of living with COPD. It would appear that individuals with COPD are often poorly informed about the diagnosis, prognosis and management of their disease and this has the potential to influence perceptions an individual holds about their illness. To date there are two published Australian studies (Sossai, et al, 2011; Gullick & Stainton, 2008) which explore individuals' experiences of living with COPD. These studies indicate that the experiences of individuals with COPD in Australia are similar to those overseas. Gaining further insight into the experience of living with COPD, particularly in rural Australia, will assist clinicians in Australia to plan and provide care for those with COPD into the future.

As a treatment intervention for COPD, the effectiveness of pulmonary rehabilitation is well documented and there is good evidence of its ability to improve objective measures of quality of life, breathlessness and exercise capacity. Outside of Australia, qualitative studies (Williams, et al., 2010; Toms & Harrison, 2002; Gysels & Higginson, 2009) have shown some impact of pulmonary rehabilitation on the lived experience of COPD. However, the international literature has shown little interest in comparing the experiences of those who have and have not participated in pulmonary rehabilitation. By comparing these two groups this study aims to gain further insight into how pulmonary rehabilitation might influence the everyday experiences of individuals living with COPD in Australia. This could assist clinicians in refining the delivery and components of pulmonary rehabilitation to meet the needs of Australians with COPD.

Purpose of the study

The purpose of this study was to find out about the experience of living with COPD in a rural Australian setting and whether participation in a pulmonary rehabilitation in the last twelve months could alter the experience of living with

COPD. The researcher was interested in exploring individuals' knowledge and experiences of diagnosis, prognosis and disease management and whether these varied between individuals who had or had not participated in pulmonary rehabilitation.

Research question

This study was guided by the following question:

What are the experiences of people living with COPD in rural Australia and is there any variation between the experiences of those who have completed a pulmonary rehabilitation program and those who have not?

Study aims

This study aims:

- To explore the experience of living with COPD in rural Australia
- To explore what individuals diagnosed with COPD understand about their diagnosis, prognosis and disease management;
- To compare the experiences and understandings of people with COPD who have participated in pulmonary rehabilitation with the experiences and understandings of people with COPD who have not participated in pulmonary rehabilitation

Significance of the study

Exploring the experience of living with COPD allows individuals, carers and health professionals to gain insight into the issues faced by people living with COPD. Understanding the issues faced by this population provides the opportunity to improve the quality of care they receive. Using qualitative research to understand the lived experience of both individuals who have and have not participated in pulmonary rehabilitation will not only provide a rich description of the lived experience of COPD, it may indicate how pulmonary rehabilitation influences these experiences.

Overview of thesis

This thesis is presented in four chapters. This chapter provided a review of the literature and outlined the purpose and aims of the study. Chapter Two outlines the study methodology and research process. Chapter Three presents the findings of the study, while Chapter Four discusses these findings.

CHAPTER TWO: Methodology

Introduction

In this chapter the methodology underpinning this qualitative study is presented. The research focus of exploring the experiences of people living with COPD in rural Australia is explained as well as the descriptive qualitative methodology used. The setting and participants as well as the processes used during the course of the study, including ethical considerations, recruitment, sampling, consent, data collection and analysis are outlined. Finally, strategies used to enhance the rigour of this study are presented.

The research focus

This study aims to explore the experience of living with COPD in a rural Australian setting. In addition, the study seeks to identify any similarities or differences in the experiences of living with COPD between persons who have participated in pulmonary rehabilitation in the last 12 months (PR participants) and persons who have not participated in pulmonary rehabilitation (NPR participants).

The study was conducted within a constructivist paradigm, within which there is a relativist ontology (Denzin & Lincoln, 2003), that is, an assumption of multiple realities. This assumption was congruent with the researcher's clinical observations of people living with COPD in her work as a physiotherapist. A constructivist approach also assumes a subjectivist epistemology, whereby understanding is co-created (Denzin & Lincoln, 2003). In this study, understandings regarding the lived experience of COPD were developed through collaborations between each study participant and the researcher. It was recognised that individuals with COPD develop subjective meanings of their experiences through social interactions, historical and cultural influences (Creswell, 2003). In addition, the researcher’s own background of cultural and historical experiences, beliefs and ideology is acknowledged as influencing her interpretation of the lived experiences of people with COPD (Denzin & Lincoln, 2003).

To capture study participants’ subjective meanings of their experiences, a broad research question about the experience of living with COPD was adopted. This enabled participants to shape the focus of the study at the same time as the researcher explored her interest in influences participation in pulmonary rehabilitation may have on the experiences of living with COPD.

Research design

This study uses a descriptive qualitative design to provide a rich, straight description (Neergaard, Olesen, Andersen, & Sondergaard, 2009) of the experiences of people living with COPD in a rural Australian setting. In line with Sandelowski’s (2000) explanation of descriptive qualitative studies, this study aims to describe the everyday experiences of individuals living with COPD, staying close to the data, to the surface of words and events that are recounted by participants. Furthermore, the study aims to present perceptions and reports of the experience of living with COPD in rural Australia using language which is similar to the informant’s own language (Neergaard, et al., 2009), yet in a coherent and useful manner (Sandelowski, 2000).

The transcripts of semi-structured interviews were analysed using inductive thematic analysis as described by Braun and Clarke (2006). Thematic analysis involves minimally organising and describing data by identifying, analysing and reporting patterns or themes within the data (Braun & Clarke, 2006). In inductive thematic analysis, the data is coded without trying to fit it into a pre-existing coding frame. This results in the themes identified being strongly linked to the data themselves (Braun & Clarke, 2006). Resultantly, it is an appropriate analytical method to use in a descriptive qualitative study.

The research process

The following section outlines how the study was conducted, providing an overview of the setting, ethical considerations and participants. Procedures related to data collection and analysis are also described.

Setting

The study was conducted in two locations within the Illawarra and Shoalhaven Local Health Network (ISLHN). The ISLHN covers an area of 5,620 square kilometres on the south coast of New South Wales, Australia. The study recruited participants from the Shoalhaven COPD Service as well as patients who presented or were admitted to the emergency departments or medical wards of Shoalhaven District Memorial Hospital or Milton/Ulladulla Hospital. These services are located in rural areas of the ISLHN.

Ethical considerations

Approval for the study was obtained from the joint Human Research and Ethics Committee of the University of Wollongong and South East Sydney and Illawarra Area Health Service (now known as the ISLHN) as well as the Southern Adelaide Flinders Clinical Human Research Ethics Committee. A site specific application was also submitted to the Research Governance Officer, Research Directorate of the ISLHN and approval gained for the project to be conducted at the Shoalhaven and Milton/Ulladulla Hospital sites. The three approval letters are included in Appendix A.

The main ethical issues considered in this project related to recruitment, consent, beneficence and confidentiality. There was potential for pre-existing clinical relationships to exist between the researcher and study participants through the researcher's role as a physiotherapist on SCOPDS. Consequently, a person external to the research project (the Shoalhaven COPD Service [SCOPDS] clinical nurse consultant) recruited study participants. This aimed to decrease the risk of participants feeling pressured or coerced to participate in the project. Issues related to consent are discussed later in this chapter.

The study also considered issues of beneficence; every effort was taken to design the research to minimise the risk of harm or discomfort to participants. Consideration was given to the fact that people with COPD could find prolonged interviews physically uncomfortable due to periods of breathlessness or bouts of coughing. Furthermore, the emotional distress study participants may experience when talking about their experiences of living with COPD could add to their breathing difficulties. The study design aimed to minimise these risks by ensuring participation was voluntary, providing close supervision during interviews and providing access to follow-up services if requested. Follow-up services were provided to two NPR participants at their request following completion of interviews. This involved linking these two participants with the clinical nurse consultant from the Shoalhaven COPD Service who provided information and support as required. Respect for individual's beliefs, perceptions, customs and cultural heritage were considered during interviews and collection of demographic data. Participants were given the opportunity to specify the location and time for data collection and the opportunity to withdraw their participation in the study at any time.

Respect of participants' privacy and confidentiality was considered by ensuring any identifying information was removed from interview transcripts as well as storing interview and demographic data in password protected files to which only the researcher and her academic supervisors had access.

Participants

To be considered for inclusion in the study, participants had to meet the criteria of having a primary diagnosis of COPD, documented by a respiratory physican or hospital medical officer, and be eligible to participate in a pulmonary rehabilitation program consisting of educational and exercise components. Contraindicating factors to participation in pulmonary rehabilitation are severe cognitive or psychotic impairment, presence of a relevant infectious disease, unstable cardiac function and musculoskeletal or neurological conditions which prevent the performance of exercise (Alison, et al., 2009). Patients with unstable cardiac function and musculoskeletal or neurological conditions preventing performance of exercise may be included in the education component of pulmonary rehabilitation (Alison, et al., 2009), however, for the purposes of this study, these people were excluded as they did not complete both the exercise and education components of pulmonary rehabilitation.

Two groups of participants were recruited for the study. PR participants consisted of participants recruited from the SCOPDS who had completed pulmonary rehabilitation in the last 12 months. NPR participants consisted of participants recruited from the emergency departments or hospital wards of Shoalhaven and Milton-Ulladulla Hospital. These participants had a primary diagnosis of COPD, but had not participated in pulmonary rehabilitation.

Recruitment

A list was collated of individuals who had completed pulmonary rehabilitation with the SCOPDS in the last 12 months. Starting with those who had attended pulmonary rehabilitation 12 months ago, an initial mail out, which included a letter of invitation, information sheet and consent form was sent to the first five people on this list. After two weeks, a subsequent set of five invitations were sent. From these 10 invitations, four PR participants contacted the researcher and were recruited.

To recruit participants who had not participated in pulmonary rehabilitation, the SCOPDS clinical nurse consultant collected potential participant details during routine emergency department and ward visits over a two month period. These contacts were collated on a list. A letter of invitation, participant information sheet and consent form was sent to the first 12 contacts on this list. If no contact had been made within two weeks, a follow-up phone call was made to gauge potential participants' interest in the project. From the 12 invitations sent out, five participants were recruited. However, at the time of interviewing, one participant was identified as not meeting the criteria of having a primary diagnosis of COPD, instead having a primary diagnosis of heart failure. Data from this participant was excluded from analysis, so only four NPR participants were included in the study.

In total, there were eight participants in this study; four participants in each group. There were two women and two men in each group. The age of individual participants ranged from 51 to 85 years, with a mean age of 69.6 years. Additional demographic data which were collected are presented in the following chapter.

Sampling

In line with Popay, Rogers and Williams (1998), the sampling techniques used in this study sought to reflect the diversity of the population under study rather than to achieve a statistical representativeness. Resultantly, the study used purposive sampling to select the two groups of participants as this allowed cases to be selected that would provide rich information relevant to the topic under study (Patton, 1999).

Decisions regarding the size of the sample were made during the course of data collection and analysis. Sampling ceased when the developing themes were considered as being robust. This is in line with Morse's (1995) suggestion that the signals of data saturation are that adequacy and comprehensiveness of the results can be demonstrated. In this study, data saturation was identified and sampling ceased when the developing themes had a significant amount of data to support them as well as the subthemes they contained.

Consent

Potential participants were mailed a consent form with their letter of invitation and participant information sheet to allow them time to consider the request to participate in the project as well as the opportunity to seek further information about the study. Participants returned written consent forms by reply paid post to the researcher to indicate their interest in participating in the study. On receipt of signed consent forms, the researcher contacted each potential participant by phone to ensure they understood their role in the study and to arrange an interview. Consent was confirmed on the day of each interview, prior to commencing the interview. Participants consented to a 30 to 90 minute digitally recorded interview and use of the information obtained during interviews in a Master's thesis, journal publications and conference presentations. Participants were informed that they would not be identified in reports or publications resulting from the project. A copy of the letter of invitation, participant information sheet and consent form are included in Appendix B.

Data collection

The study collected demographic data as well as data from semi-structured interviews. Additionally, field notes were made during and after interviews which were also considered during data analysis. All data was stored in electronic password protected files according to the protocols specified in the ethics application. Hard copies of interview transcripts were stored in locked filing cabinets in the researchers' office.. The master file of matched participant codes with participants' names was stored separately to the coded transcripts.

Demographic data

Demographic data were collected to provide background information regarding participants' physical, medical and social characteristics. Information collected included age, sex, highest educational achievement, smoking status, co-morbidities, use of home oxygen, presence of a COPD action plan, number of emergency department visits or admissions in the last 12 months, distance and time from the nearest pulmonary rehabilitation program and mode of transport. A measure of the disability impact of COPD was also taken using the modified Medical Research Council's (mMRC) dyspnoea scale. The mMRC dyspnoea scale quantifies disability associated with breathlessness, is widely used to describe patient cohorts (Stenton, 2008) and can be related to a patient's stage of disease severity (Mahler, Ward, Waterman, McCusker, ZuWallack, & Baird, 2009). It is not subject to copyright and permission is not required to use it. The mMRC dyspnoea scale is a self administered five point paper scale graded zero to four. Zero indicates no impact of breathlessness, while four indicates severe impact of breathlessness. A copy of the demographic data collection sheet and mMRC dyspnoea scale are included in Appendix C.

Semi-structured interviews

Each participant was involved in one face to face semi-structured interview and all interviews were successfully digitally recorded. The interviews varied in duration between 36 and 71 minutes. Collecting data via semi-structured interviews involved the use of open ended questions and probes in order to gain in-depth responses about the experiences, perceptions, opinions, feelings and knowledge a person has about living with COPD (Patton, 2001).

Prior to the interviews, an interview guide was developed which provided a list of topics which could be explored during the course of each interview. The interview guide gave prompts and potential areas to explore during interviews rather than fixed wording or order of the questions. The initial interview guide used in this study was based on a review of the literature as well as clinical experiences and personal interactions with people living with COPD and is included in Appendix C.

As suggested by Minichiello, Aroni, Timewell, and Alexander (1992), the interview guide was refined in a number of ways during the data collection period. Firstly, the initial interview was opened by asking the participant specific questions about the diagnosis of his COPD. However, during the course of this interview, it became clear that the participant’s greater concerns were related to the experience of living with COPD. Consequently, subsequent interviews were opened by asking participants to tell their story of breathing problems. Opening the interview in a more general way facilitated participants to share those experiences which were most meaningful for them. Areas of interest related to the research question were then explored as they arose during the interview.

Secondly, the interview guide initially included a greater focus on the knowledge and understanding participants had of their diagnosis and treatment of COPD. After completing two interviews it became apparent that participants were more often concerned about the everyday experiences of living with COPD. Resultantly, the interview guide was revised to reflect the concerns of participants.

Each interview was conducted at a time and place chosen by the participant. Only one participant chose not to be interviewed in her home. In this case, the interview was conducted in a clinic room at Shoalhaven Hospital. Great effort was made to make this environment as informal as possible by removing medical equipment and offering tea or coffee during the interview. Despite these efforts, field notes indicate this interview appeared to be more ‘clinical’ in nature and that probing questions used successfully during other interviews failed to result in the participant elaborating on the experiences she recalled. All other interviews were conducted in participants’ homes. Two PR and three NPR participants had family members join them for some or the entire interview without being invited. As has been the case in other qualitative studies of people with COPD (for example, Seamark, et al., (2004)), having a family member present gave an extra dimension or perspective to individual accounts of living with COPD, however, for one NPR participant it appeared to limit his willingness to convey some aspects of his experience of living with COPD.

Breathlessness and periods of coughing are common symptoms of COPD and talking for prolonged periods during interviews caused some participants to experience episodes of coughing and breathlessness. At these times participants were offered the option of terminating or taking a break from the interview. No participant accepted the offer to do so. Only once did an extended period of coughing appear to disrupt a participant’s train of thought, however, the interviewer was able to recall the topic being discussed and the interview continued.

Field notes

During and following each interview, notes were made to provide a richer description of the interview, including non-verbal cues or information conveyed to the interviewer before or after the recorded interview. Verbal consent was obtained from participants to use this information in the same way as the recorded interview data. The field notes provided additional information about the course of the interview, for example, whether the interview had been disrupted by visitors, phone calls, family members, coughing or breathlessness. An impression regarding the attitude conveyed by the participant during the interview visit was also recorded; for example, one field note records how a participant was seated at the front door waiting for the researcher to arrive and began conveying feelings of anger and frustration about having COPD before the interview could even commence.

Data analysis

The interview transcripts were analysed using thematic analysis as described by Braun and Clarke (2006). Thematic analysis is often not considered a specific qualitative methodology (Holloway & Todres, 2003), however, Braun and Clarke (2006) describe it is as a specific qualitative method and “a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data” (Braun & Clarke, 2006, p. 78). They refer to thematic analysis as a foundational method of qualitative analysis, which involves identifying, analysing, interpreting and reporting themes within data (Braun & Clarke, 2006).

Similar to other qualitative research processes, thematic analysis is not a linear process, rather it moves back and forth between various phases of data collection and analysis (Newton Suter, 2011). The non-linear nature of thematic analysis allows collected data to be reflected on and influence the ongoing process of data collection and analysis.

Braun and Clarke (2006) identify six phases of thematic analysis. Phase one involves becoming familiar with the data through the process of transcription and re-reading. In this study, phase one began with the transcription of each interview by the researcher, as soon as possible, following the interview. During transcription, all identifying information was removed in order to ensure participant anonymity. Non-verbal cues identified in field notes were inserted into the transcripts to provide a richer description of the interaction which had taken place during the interview. Following transcription, the transcripts were checked for accuracy by listening to the interviews while reading the transcripts. These transcripts were then read and re-read by the researcher to familiarise herself further with the data.

In phase two initial coding begins through the identification and labelling of short and interesting segments of data systematically across the entire data set. This type of coding has been described as “identifying a meaning unit” (Ely, Vinz, Downing, & Anzul, 1997) or “assigning tags or labels to the data” (Coffey & Atkinson, 1996) and involves reading and re-reading a portion of data and providing a label for each portion of data. In this study, codes from the transcripts of PR and NPR participants were compiled into two separate data sets in order to explore the experience of living with COPD in the two groups. Phases one and two of thematic analysis were closely linked; as transcription, reading and re-reading of transcripts occurred, each transcript was coded. Additionally, this process of transcription, reading and coding influenced further data collection by highlighting areas for exploration in subsequent interviews.

Braun and Clarke (2006) describe phase three as the beginning of the search for themes and this occurs by collating the codes into groups or clusters. In this study, this process occurred separately within the two data sets. Codes with similarities were clustered together and these clusters developed into the early themes identified within each data set. Data within each cluster were reviewed to check its fit within the developing early theme and this involved returning to the transcripts to ensure data were being analysed and interpreted in the context of the entire interview. Reviewing early themes often prompted recall of other relevant interview data and this was added to the collected data as further evidence of the developing theme.

Braun and Clarke (2006, p. 82) define a theme as capturing "something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set". A theme has also been defined as "a statement of meaning that (1) runs through all or most of the pertinent data or (2) one in the minority that carries heavy emotional or factual impact" (Ely, et al., 1991, p. 150). Resultantly, identification of a theme does not rely on the number of occurrences of the theme in the data set, but whether the theme captures something important in relation to the overall research question. Braun and Clarke (2006) recognise the important role a researcher plays in actively identifying patterns or themes in data in contrast to the idea that themes simply 'emerge' from the data. Ely et al. (1997) suggest it is the way in which the researcher thinks about the data and makes links as the data is understood that results in the development of themes.

In phases four and five themes are reviewed to ensure they work in relation to the codes identified and the entire data set (Braun & Clarke, 2006). Themes are refined through further analysis in order to generate definitions and names for each theme. "Writing", as noted by Braun and Clarke (2006, p. 86), was an integral part of data analysis throughout this study. Review and refinement of themes was aided by written summaries of developing themes. During this process some data extracts were excluded because they did not fit within the developing theme, while new extracts were added as transcripts were reviewed.

Initially, nine early themes were identified in PR participant transcripts and eight in NPR participant transcripts. These were compared to identify similarities and differences between the two groups and resultantly, eight common early themes were identified. Early themes described the experience of living with COPD as well as participant understanding of the diagnosis and treatment of COPD; these related directly to the research question. Written summaries and discussions with an academic supervisor collapsed the eight common early themes into three interim themes. Further refining reduced these three to two final themes, which were labelled *the realisation of breathlessness as COPD* and *the everyday reality of life with COPD*. Finally, the minor theme of *the influence of pulmonary rehabilitation on the experience of living with COPD* was developed as the differences between the two groups in relation to the major themes became apparent. Areas identified during the process of developing and refining major themes are presented in Appendix D.

Phase six of thematic analysis involves reporting the findings using examples from the data to illustrate the identified themes and relating the themes back to the original research question and literature (Braun & Clarke, 2006). These processes are reported in Chapters Three and Four of this thesis.

Throughout data collection, analysis and presentation of findings, an academic supervisor provided assistance, advice and feedback. In the early stages of analysis, Word tables were used to organise the data into clusters of similar topics. These clusters were then reviewed in relation to each other to find any relationships which might exist between the clusters. These larger groupings became the basis for the development of early themes. During this process, the academic supervisor reviewed interview transcripts, guided the coding process and reviewed each theme as it developed. Two additional academic supervisors reviewed findings once themes began to take shape.

Throughout the study, the researcher kept a reflexive journal (Lincoln & Guba, 1985) to document her thoughts over time about the research question, data collection and data analysis. The journal documented her experiences and responses to data collection as well as patterns she felt were developing during data analysis. Memos were used to track the development of thoughts and formation of ideas about the data and developing themes. The reflexive journal also provided the opportunity to understand the researcher's reactions to data collection and analysis and to acknowledge the influence these reactions had on interpretation of the data. For example, the researcher's biomedical background was often prominent in her attempts to understand and interpret the experiences of people with COPD. Memos allowed these thoughts to be recognised and acknowledged and other perspectives to be considered. An example of the reflexive journal is provided in Appendix E.

Enhancing rigour in this study

Qualitative research is not judged by the same criteria as quantitative approaches, however, criteria do exist which provide a way of evaluating the quality or rigour of qualitative research. Braun and Clarke (2006) suggest that in a good thematic analysis, the way in which the analysis has been performed must be clearly and explicitly described. They provide a 15 point checklist which covers: 1) the process of transcription; 2) issues relating to coding of data; 3) the importance of ensuring that analysis and data match and that analytical claims are supported by data excerpts; 4) the overall process of analysis, considering whether all phases of analysis have been conducted adequately; and 5) ensuring the underlying theoretical assumptions of a constructivist paradigm and an inductive approach to analysis are made clear during report writing. Their 15 point checklist has been used to ensure the quality of data analysis and reporting of findings in this study and is included in Appendix F.

Trustworthiness was also considered in relation to the rigour of this inquiry (Guba & Lincoln, 1994). Trustworthiness has four components: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). The concept of credibility involves ensuring the data collected from the participants has been adequately conveyed and represented (Schwandt, 2001). Returning frequently to the transcripts to review the context of extracted data as well as to search for other examples of developing themes ensured that the findings were grounded in the data. Furthermore, examples of participants' words (data excerpts) are used in the next chapter to demonstrate the themes identified in the study. Credibility was further enhanced using peer debriefing (Lincoln & Guba, 1985). Peer debriefing involved discussing the developing themes and subthemes with academic supervisors and clinical colleagues. This ensured other perspectives on the data were gained and explored as the themes developed rather than simply relying on a single point of view.

Transferability considers the researcher's ability to convey the context and situation within which the research has taken place (Tobin & Begley, 2004). In this study, transferability was considered by providing the reader with an understanding of the intervention of pulmonary rehabilitation, a description of the setting in which the study was undertaken and information regarding the participants' demographic characteristics. This information allows an informed decision to be made about the transferability of the findings to other populations.

Issues related to dependability require a logical, traceable and clearly documented research process to be demonstrated (Schwandt, 2001). The research process used in this study has been described in this chapter. To enhance dependability, guidelines published in the literature have been used to direct the processes of data collection and analysis (Braun & Clarke, 2006). Memos written throughout the study provide evidence of processes used and evidence of the way themes and subthemes developed through understanding of the data.

Confirmability involves ensuring that findings related to the data are clearly derived from the data (Tobin & Begley, 2004). The use of peer debriefing in this study provided a mechanism for reviewing interpretations of the data against the data collected. In addition, the use of an audit trail, in the form of a reflexive journal, provided evidence of the process by which conclusions were reached (Morse, 1994), including the role and influences of the researcher in the analytical process.

Chapter summary

This chapter identified the research focus of exploring the experience of living with COPD in two groups of individuals using a qualitative research methodology. The theoretical perspective underpinning the research has been described as well as the research process. Issues of quality in relation to qualitative inquiry were discussed and strategies used to enhance rigour were described. The following chapter will present the findings of this process.

CHAPTER THREE: Findings

Introduction

This chapter presents the findings of this study. It starts by describing the participants and then presents the two major themes, *the realisation of breathlessness as COPD* and *the everyday reality of life with COPD*. Finally, it summarises the differences identified between the two groups of study participants.

The participants

In total, there were eight participants in this study; the four participants who had completed pulmonary rehabilitation are referred to as PR participants and the four who had not completed pulmonary rehabilitation are known as NPR participants. There were two women and two men in each group. The age of participants ranged from 51 to 85 years. Scores on the modified Medical Research Council (mMRC) dyspnoea scale quantifying disability resulting from breathlessness (Stenton, 2008) ranged from one (minimal disability) to four (almost complete incapacity). Only two NPR participants did not recall being given a COPD action plan and two PR participants had been prescribed home oxygen. Most had visited a hospital emergency department or been admitted to hospital in the 12 months before being interviewed for this study (see Table 1).

Table 1: Study participants

Participant code	Sex	Age	Education	mMRC[1] score	Smoker	Co-morbidities	Home O2	Action plan	ED visits/ admission last 12 months
PR1	M	73	secondary	2	former	0	yes	yes	3
PR2	M	85	post-grad	3	former	2	no	yes	1
PR3	F	72	certificate	1	former	2	yes	yes	0
PR4	F	58	certificate	2	former	1	no	yes	0
NPR1	M	71	secondary	3	former	2	no	no	1
NPR2	F	51	secondary	2	current	0	no	yes	1
NPR3	M	77	secondary	2	former	3	no	no	2
NPR4	F	70	secondary	4	former	2	no	yes	2

[1] mMRC indicates modified Medical Research Council dyspnoea scale

Participants lived between 2.5 and 64.2 kilometres away from their local pulmonary rehabilitation program; travelling there took between four and 53 minutes. Most participants reported their mode of transport as being self driven, although two used community transport (see Table 2).

Table 2: Distance, time and mode of transport from home to pulmonary rehabilitation

Participant Code	Distance from PR (kms)	Time from PR (mins)	Mode of Transport
PR1	64.2	53	Self car
PR2	27.8	24	Self car
PR3	26.2	26	Community transport
PR4	32.4	31	Self car
NPR1	59.9	48	Self car
NPR2	4.4	8	Self car
NPR3	2.5	4	Self car
NPR4	45	36	Community transport

Key findings

Two major themes were identified in this study. The first theme, *the realisation of breathlessness as COPD,* describes the journey from the onset of breathlessness to knowing and understanding breathlessness as a medical condition called COPD. The second theme, *the everyday reality of life with COPD,* describes the realities of life with COPD including the experience of declining physical function and the alterations to connectedness with others (see Table 3). In general, the two themes were common to both PR and NPR participants. One minor theme, *the influence of pulmonary rehabilitation on the experience of living with COPD,* was also identified. This describes the small but notable differences that were evident between PR and NPR participants in relation to some aspects of the two major themes.

Table 3: Major themes

1.The realisation of breathlessness as COPD	***2.The everyday reality of life with COPD***
1.Developing an awareness of breathlessness	1.Sentiments about life with COPD
2. Acquiring knowledge about COPD • participants knowledge about the diagnosis and prognosis of COPD • participants understandings of the causes of COPD	2. Declining physical function • psychological consequences of declining physical function • coping strategies for declining physical function
3. Experience and knowledge of medical treatments for COPD • acute treatment • long term treatment • pulmonary rehabilitation	3. Alterations to connectedness with others • The impact of declining physical function on interactions with others • Being aware of the changing perceptions of others • Pulmonary rehabilitation: an opportunity for social interaction and meaningful relationships

Major theme 1: The realisation of breathlessness as COPD

The realisation of breathlessness as COPD refers to the long and often complex journey a person had to understand that their experiences of breathlessness were the result of having a medical condition known as COPD. All participants recalled a slow and insidious onset of breathlessness. After many years, breathlessness eventually compelled them to seek advice and an explanation for the symptoms they were experiencing. This explanation often came in the form of a medical diagnosis and treatment. Being breathless over many years gave participants significant insights into the experience of breathlessness. For the majority of participants in this study an acute severe episode of breathlessness was a significant event, marking the beginning of numerous attempts to acquire diagnostic and prognostic information. When information was acquired, it enabled participants to understand that their breathlessness was a symptom of the illness called COPD. Additionally, knowledge and experience of medical treatments for COPD further supported the explanation that symptoms of breathlessness were the result of having COPD.

Developing an awareness of breathlessness

Evident in the findings was an awareness of breathlessness over time. Participants described a slow and insidious onset of breathlessness “over a number of years” (PR4 6), but ignored or downplayed these symptoms. Initial experiences of breathlessness were not acknowledged as a warning of lung disease. Consequently, seeking medical advice was not felt to be appropriate. Instead, participants recalled using explanations, such as ageing, to normalise the experience of breathlessness:

> *I just found out that I was getting a bit puffed out and I just sort of didn't take that much of a notice, fair enough, I'm getting old and it just goes along with age* (PR1 39).

Breathlessness was a daily experience for all study participants and while the experience of breathlessness was unique to each individual, the findings highlighted some common descriptions and characteristics of breathlessness between participants. Similarities were noted in the terminology used by all participants to convey experiences of breathlessness. The terms “puffing” (NPR1 49) or “puffed” (PR1 30) described a constant or usual level of breathlessness, while the word “gasping” (PR2 246; NPR5 132) indicated that breathlessness had increased beyond normal or tolerable levels. This change in language reflected a worsening state of breathlessness that was only tolerable for a short period. Gasping for breath was often related to thoughts about dying for both NPR and PR participants.

Negative descriptors such as “hard” (PR3 215), “terrible” (NPR1 49), “suffering” (PR1 29) and “fighting” (PR1 125) were also used by participants to indirectly describe breathlessness. These words provide greater insight into the experience of breathlessness by indicating that breathlessness was not merely a physical discomfort associated with breathing, but also an unpleasant and undesirable life experience.

A notable difference between NPR and PR participants was that NPR participants often conveyed their experience of breathlessness through its impact on everyday activities. NPR participants spoke at length about the effect of breathlessness when “under the shower” (NPR1 335) and “getting dressed” (NPR3 103, when trying to “walk” (NPR2 276) and when doing household chores such as “washing” (NPR2 479). In contrast, PR participants simply used descriptive terms such as being “out of breath” (PR4 148) or “can’t get a good breath” (PR1 125) to describe their experiences of breathlessness. They were less likely to refer to specific examples of breathlessness during everyday activity.

In addition to participants’ descriptions of breathlessness, one NPR and two PR participants described how being breathless caused them to have an overwhelming sensation to urinate, for example:

> *Just walking across the room here I’m puffing and panting something terrible and when that happens you’ve got an uncontrollable urge to pee your trousers, just can’t stop it* (NPR1 49).

These participants expressed concern and bewilderment about the unexpected association of breathlessness with urinary urgency; none recognised this association as being linked to anxiety induced by breathlessness and activation of the ‘fight or flight’ response. All three wondered if this was a common problem for people who experienced breathlessness or whether this was something they suffered alone.

A characteristic of breathlessness described by all participants in this study was that breathlessness could be fluctuating and at times unpredictable. Four participants noted how breathlessness could become insignificant or absent when sitting or lying down but would reappear when they attempted to move. An absence of breathlessness at rest was deceptive and gave participants the perception they could carry out their usual daily activities as illustrated in the following two examples:

> *You're laying in bed and due to get up in the morning and you feel as good as gold and you think to yourself well today I'm going to go out and do this this this this and this. And you get up and you have breakfast and you go out to start to do something and 2 minutes out there and you can't do anything because you're puffed out* (PR1 284).

> *If I'm sitting down having a cup of tea with someone or chatting, there's nothing wrong with me. I'm a very healthy person! ... it's only when you get up* (NPR4 141).

Fluctuating symptoms of breathlessness were sometimes attributed to environmental factors. Extremes of temperature and specific weather events could make breathlessness significantly worse. Three participants described how breathlessness could fluctuate depending on the weather during the day:

> *When there's rain building up is actually worse I think than when the rain's falling. It's that pre-rain, high humidity, that's hard, it's like breathing fairy floss, you can't get it in or out* (NPR4 434).

Breathlessness was also described as controlling, with this experience more common for NPR participants. It exerted control over the most basic of tasks, including being able to "move" (NPR4 416) and "talk" (NPR3 352) and dictated how the most simple of everyday tasks were performed as demonstrated by NPR3:

> *I can only take so much to fill the bin, then, I can carry a chair with me and as soon as I get breathless I can sit down 10 minutes* (NPR3 126).

NPR participants tried various ways to prevent breathlessness from taking control. This included using "pursed lip breathing" (NPR4 123), taking a "deep breath" (NPR2 486) or having to "slow down" (NPR3 364). Using these strategies forced participants to acknowledge the control breathlessness exerted them. Nevertheless, these strategies also aimed to reduce the control participants' perceived breathlessness held over them:

> [Breathlessness]*'s not gonna control me, but it must control me to a degree, that I have to slow down, that's the only control* (NPR3 364).

Acute and severe episodes of breathlessness also illustrated the controlling nature of breathlessness. Eventually, for six of the eight study participants breathlessness became so intense or restrictive they were forced to seek medical assistance. Acute episodes of breathlessness were a crisis or turning point in a participant's journey towards realising breathlessness as COPD. Episodes of severe breathlessness requiring medical intervention exposed participants to health services, health professionals and medical jargon related to the diagnosis and treatment of their condition.

Acquiring knowledge about COPD

Realising breathlessness to be a symptom of a medical condition called COPD occurred as participants acquired diagnostic and prognostic information about COPD and understood the causes of this disease. All participants used similar sources to access information, although PR participants had the additional resource of a pulmonary rehabilitation programme. NPR participants were more likely to describe negative experiences related to the process of acquiring information about COPD. There were some differences between the diagnostic and prognostic knowledge of PR and NPR participants, however, no differences between the two groups in their understanding of the causes of COPD were identified.

Respiratory physicians and general practitioners were recognised as a major source of information for all study participants. Each participant expected their respiratory physician to provide explanations for their breathlessness and effective medical treatment for COPD. In particular, NPR participants held high expectations regarding the ability of their respiratory physician to explain the diagnosis and prognosis of COPD. Unfortunately, these expectations were not often met:

> *I'm talking about* [name of respiratory physician]. *Anyone will tell you, he might be the worlds best, but he doesn't tell you anything* (NPR1 119).

One PR and three NPR participants recalled negative experiences they had with respiratory physicians and each attributed these to the physician's interpersonal skills, for example:

> *The first specialist in Sydney I found to be quite abrupt. I guess it was like, well I've spoken to* [name of husband] *about this too ... I know that health professionals can't afford to be all that personal with every patient that they have. They can't really, you know, I feel, have that personal approach with everyone, but I think that they can be a bit more, um, understanding, of people's concerns with a disease that they have been diagnosed ... I felt it was a bit paternal at times, to tell you the truth* (PR4 193).

In comparison, all participants held lower expectations of general practitioners to provide diagnostic and prognostic information about COPD. While participants were often satisfied with the interpersonal skills of their general practitioner they described them as having limited knowledge about COPD:

> *I think* [name of general practitioner]*'s really at the stage where he can't tell me anymore, because he doesn't know anymore* (NPR2 184).

For NPR participants diagnosed with COPD in the last three to six months, interactions with health professionals were described as disappointing and frustrating with information needs often unmet. One participant felt that his general practitioner "didn't know" (NPR3 23) what was wrong with his lungs, while the limited interactions which occurred during hospital rounds were perceived as health professionals not having the time or the desire to provide information:

> *They'd walk around, you know, when they did the rounds of a morning and say 'how you going, there's your pills, there's your tablets', and away they'd go* (NPR1 286).

As a result, these NPR participants relied on other methods to acquire information, for example, overheard conversations of nursing staff in a hospital setting or asking technicians for information during the course of medical investigations. Acquiring information this way gave participants small, unrelated pieces of information and inadequate explanations of what was happening to their bodies. Furthermore, they developed the impression that it was not their right to have access to information about their bodies; this information was owned by health professionals and was subject to certain rules and regulations regarding how and when it was conveyed. One participant described how he “tried everything” (NPR3 285) to gain the results of investigations performed by a doctor at a medical imaging practice. While he was able to get “a few answers” (NPR3 285), he left the practice with a sense of being excluded from knowing about his own medical condition.

Experiences of acquiring information about COPD for newly diagnosed NPR participants were overwhelmingly negative and frustrating. While they had contact with many different health professionals during the diagnostic phase of their illness, clearly, their information needs remained unmet:

> *Nobody’s got answers ... I’m mean why can’t the hospital give you answers, that's what you go up there for, 6 hours I was there* (NPR3 329).

To illustrate the disappointment he felt about his communications with health professionals about COPD, one NPR participant contrasted experiences of acquiring information about COPD with previous experiences of acquiring information about cancer. Health professionals had openly discussed cancer and its treatment with both him and his wife, and this communication had resulted in a sense of confidence and reassurance. He had found none of this confidence or reassurance in his experiences of communication with health professionals about breathlessness or COPD.

For all PR participants, attending pulmonary rehabilitation had been a valuable additional way of acquiring information and developing a better understanding of COPD. Accessing information at pulmonary rehabilitation occurred over an extended period of time and participants were able to absorb and process information, returning later with questions or concerns. This differed from experiences of acquiring information in the respiratory physician's office or hospital bedside, where information was expected to be absorbed and processed during the one consultation. These situations provided little opportunity for asking questions or expressing concerns. In contrast, one participant described how:

> *At pulmonary rehab I got a lot more information, especially with the education side of it um, getting all the printed material on, you know, the things like how the lungs work and all of that um I found really beneficial because, you're not expected to take it all in, you know, in one sitting um, just talking about it like, with the doctors. You've got written information that you can take home and look at* (PR4 213).

Another resource for acquiring information identified during this study was the internet and this was used by the two youngest participants, one NPR and one PR participant. These two participants regularly used the internet to gather information about COPD as well as to find out the meaning of medical terminology used by health professionals.

Overall, the processes involved in acquiring information significantly contributed to participants' knowledge about the diagnosis and prognosis of COPD.

Participant knowledge of the diagnosis and prognosis of COPD

Knowing about the diagnosis of COPD aided a participant's transition from simply being breathless to seeing themselves as having the medical condition COPD. Furthermore, knowing and understanding the prognosis of COPD gave participants insight into the potential impact COPD might have on their lives in the future.

There were notable differences in the knowledge of PR and NPR participants regarding the diagnosis of COPD. PR participants recalled being diagnosed with COPD and had received results of medical investigations which provided a description and evidence of the damage to their lungs. In contrast, NPR participants were uncertain about what was wrong with their bodies. They could recall and explain at length how acute conditions such as a pneumothorax, pulmonary embolism or lung infection had affected their lungs. However, there was much uncertainty about why they were experiencing ongoing breathlessness. This uncertainty and need for further explanation was clearly articulated by NPR1:

> *I don't know anything about it really. I want it explained to me* (NPR1 55).

Understanding the diagnosis of COPD involved participants learning the language used by health professionals to describe breathlessness. All PR participants used medical jargon to give a diagnostic label to their lung disease, using the terms 'COPD', 'CAL' and 'emphysema' interchangeably to name their breathing problem. However, most were unaware of what COPD or CAL meant. Only two NPR participants used medical terminology and similarly, they also interchangeably used the terms 'COPD', 'CAL' and 'emphysema'. The two participants unable to label breathlessness using medical terminology were those who had been most recently diagnosed with COPD. Medical terminology used by health professionals appeared to be meaningless "words" (NPR2 240) for one NPR participant, providing no useful information regarding the diagnosis or prognosis of COPD.

Knowledge about the prognosis of COPD varied between participants. The two most recently diagnosed NPR participants were unable to describe the prognosis of COPD. Both appeared confused about the chronic nature of COPD and wondered why there was not a medical intervention to "cure" (NPR3 231) breathlessness.

The other six participants, with a minimum of two years since diagnosis, had acquired more information regarding the prognosis of COPD. Their respiratory physician or general practitioner had informed them that their lungs were not repairable and these participants were aware that breathlessness was something they would live with into the future. Less well understood was the progressive nature of COPD. It was evident in the findings that understanding the progressive nature of COPD was more likely to develop as the result of a person's lived experience than from knowledge acquired from health professionals. Two participants were yet to develop this understanding as demonstrated in the expectation they had that they would be able to maintain their current level of functioning in the long term. However, the other four understood the progressive nature of COPD as they had experienced it over an extended period of time.

Participant understanding of the causes of COPD

Participants spoke about a range of causes for COPD including smoking, hereditary factors, having a history of respiratory infections and occupational exposure to noxious gases. While some participants discussed willingly and at length what they felt was the cause of their breathlessness, others approached the topic reluctantly and briefly. There was no identifiable pattern distinguishing NPR from PR participants in this area.

Smoking was the most commonly identified cause of COPD. All participants had been told by health professionals that smoking was the cause of COPD, although the contribution of other factors was noted in some cases. All participants in this study were either current (one NPR participant) or former smokers. Half of the participants had no doubt that smoking caused their breathlessness and had resulted in COPD. Three others reluctantly concluded that smoking was at least partly responsible for causing COPD. Only the one participant who continued to smoke believed that smoking was not the cause of COPD.

Two participants noted that the consequences of smoking could vary between individuals and it was for this reason they believed smoking was only partly responsible for causing COPD. They were unable to understand how their smoking habit could result in COPD, while for other smokers, there were no respiratory consequences:

> *I know other people that smoked 2 or 3 packs a day and they're running around like a bloody rabbit (laughs). It hadn't worried them* (PR1 564).

Health professionals, family and friends were often quick to identify previous smoking habits as the cause of COPD. Two participants recalled being blamed by others for causing their COPD, because of their previous smoking habit. The following extract provides an account of how one participant experienced being blamed for having caused his disease:

> PR1: [Name of doctor] *come in and he stood up there at the end of the bed and he said 'you're a bloody good ad for smoking aren't ya'*
> I: *How did that make you feel, when he said that to you?*
> PR1: *A bit, to be honest, a bit pissed off (laughs), I was, I yeah*
> I: *Did you say anything?*
> PR1: *No I didn't, I just let it go*
> I: *Do you get that very often? Do many people say that to you?*
> PR1: *No, no, no, that was the only second time I've had it, the wife said something about smoking and I said 'that's bloody alright for you, you don't, you're not suffering the way I'm suffering', and that was the finish of it and she never said it again. And then* [name of doctor] *said it the other day and I thought ... off you ...* (PR1 587).

Hereditary factors were recognised by participants as a significant contributor to COPD. One participant felt her COPD was primarily caused by hereditary factors, while two other participants felt that a combination of smoking and hereditary factors provided the best explanation for the cause of their COPD. Having the opportunity to attribute COPD at least in part to hereditary factors appeared to reduce the responsibility and guilt felt regarding the perceived self-inflicted nature of COPD:

> [Name of respiratory physician] *told me that the smoking didn't help, but that, I don't know whether he's trying to make me feel better, but the fact that mum had emphysema fairly badly and never had a smoke, he said, you already probably would have had it anyway* (NPR4 274).

Experience and knowledge of medical treatment for COPD

Experience and knowledge of medical interventions for COPD supported the explanation that a participant's breathlessness was part of a medical condition known as COPD. Medical interventions were used by study participants to manage acute exacerbations of their COPD as well as to maintain a stable state of health in the long term.

Acute treatment

During interviews, all four NPR participants recounted experiences of treatment for an acute episode of breathlessness in a hospital setting in the last 12 months. While two of the four PR participants had also been hospitalised in the last 12 months, only one spoke about these experiences.

For NPR participants, treatment for an acute episode of breathlessness began in the emergency department and involved being monitored, undergoing medical procedures, receiving medication and using supplemental oxygen. In this setting, NPR participants described themselves in a passive role and appeared to have a limited understanding about the treatment they were receiving:

> *They put me on a bed, put the things on me chest and put me to a machine, I suppose that were heart, right? Put a needle in, and ah they had put needles in stuff you know medicine, whatever ah, pills, ah they gave me pills I had them there. I had the mask on; they put some stuff into the mask ... and just sat, and that was it. And I had a couple of biscuits and a cup of tea, and I just sat there until things settled down* (NPR3 95).

As they moved from the emergency department to general wards, treatment for breathlessness included intravenous antibiotics and continuing use of supplemental oxygen. Advice to stop smoking was also recalled by one participant as part of the treatment she received in hospital. However, despite being encouraged to stop smoking by one health professional and contrary to hospital policy, she was supported by another to continue smoking by being given assistance to access outdoor areas. Two NPR participants also experienced physiotherapy interventions during hospitalisation. For one, physiotherapy was ineffective in managing bronchial secretions, while for the other breathing techniques (such as pursed lip breathing or breathing control strategies) were effective strategies which could be used during acute episodes as well as in the long term management of breathlessness.

Long term treatment

Both groups of participants spoke about ceasing smoking, medications, long term oxygen therapy, exercise and pulmonary rehabilitation as medical treatment used in the long term management of COPD. There were notable differences between treatments NPR and PR participants found useful.

Ceasing smoking was a treatment participants initiated themselves or with the help of health professionals. There was no discernible difference in PR and NPR participants' experiences of smoking cessation. All participants expected that smoking cessation would be recommended by health professionals as part of the treatment they received for COPD.

Two participants found ceasing smoking to be a brief process, requiring no pharmaceutical or other intervention. However, for the majority, ceasing smoking was a process occurring over an extended period, with frequent relapses. All had been offered and most had used interventions such as nicotine replacement therapy or oral medications to assist them to stop smoking. Antidepressant medications had also been offered to one participant to assist her attempts to stop smoking:

> *That was* [name of general practitioner]*'s idea of antidepressants, you know, he said, 'you lead a pretty stressful life', he said 'the antidepressants will slow you down so you sort of don't care too much and find it easier to give up smoking'* (NPR2 523).

Participants held varying opinions regarding the effectiveness of smoking cessation as a treatment for COPD. The majority perceived quitting smoking to be an ineffectual treatment for COPD. One participant recalled television advertisements which had spoken about how the body healed itself when you stop smoking; this was not the experience of study participants. Disappointingly, most found that ceasing smoking did not fix breathlessness or COPD:

> *Well, I felt better when I was smoking (laughs), and people ask me how do I feel, do you feel any better? Now, what do you say to that, you know, that's the answer, I don't feel any better. In fact at this particular moment I feel really worse, yeah, its queer isn't it* (NPR3 79).

Only one of the eight participants described ceasing smoking as a way of being able to improve breathlessness, however, she simply described herself as being "better" (NPR4 285) since ceasing smoking, but did not elaborate on what this meant. Another participant found that as a consequence of quitting smoking she felt eligible to seek help for her breathlessness:

> *I think in a way, before hand, I was probably embarrassed about going to the doctor, because I was still smoking. I think I found after I quit smoking, I had made that first step by quitting smoking you know, then I could go seek help* (PR4 57).

Reports of medication use to treat COPD were common amongst all participants. Medication was the primary long term treatment participants received from general practitioners and respiratory physicians. All participants had been given access to antibiotics and prednisolone for use during an exacerbation of their COPD and while most had a plan for when these medications should be used, none spoke about an experience of initiating their use. Only one participant felt that oral medications had made a significant difference to the symptoms of COPD. Seven of the eight participants were underwhelmed in regards to the effectiveness of the oral medications they took. Despite this perception, they continued to be compliant with their medication use:

> [Name of doctor] *put me on different medications which I've continued to use in this time. Sometimes I show improvements, other times it's, the position has been rather static* (PR2 18).

Inhaled medications were specifically mentioned by all NPR participants but no PR participants. One NPR participant described her inhaled medication as "a crutch" (NPR4 157) when it came to performing everyday activities, however, the others appeared to find them ineffective:

> *I feel better sometimes sitting down doing 10 minutes of really deep breathing than I do if I take a puffer* (NPR2 189).

Only two PR participants reported being prescribed long term oxygen therapy (LTOT) as treatment for COPD. One participant welcomed the use of LTOT, finding that it had reduced his feelings of panic associated with breathlessness. The other described reluctantly accepting LTOT as being a necessary part of the treatment of her COPD, which she had "no choice" (PR3 122) but to comply with.

Exercise was identified as a medical intervention for COPD by one NPR and all PR participants. Specifically, two participants (one NPR and one PR) spoke about daily exercise as being able to maintain fitness and reduce breathlessness, as well as assisting in the management of co-morbid conditions, such as diabetes. Exercise was viewed as a useful way of managing other body functions such as "metabolism" (PR4 261) and contributing to improved mental health.

Pulmonary rehabilitation

Pulmonary rehabilitation was discussed at length by all PR participants, however, only two NPR participants identified pulmonary rehabilitation as a possible treatment for COPD. While these NPR participants identified pulmonary rehabilitation as a medical treatment for COPD, they had little or no understanding of what it involved:

> *Nobody has actually explained what it is, you know, like nobody has actually explained what the program is… it's just like a, a rehabilitation program for people with COPD, that's what I've been told. That's it. That's the extent of my knowledge. I don't know what it is, is it exercise, is it breathing, is it pins and needles in the arms or like, I've got no idea, nobody has ever explained what it actually is. It's just a rehabilitation program for people with lung problems* (NPR2 201).

All PR participants recalled how their respiratory physician had referred them to pulmonary rehabilitation as part of the treatment for COPD during or immediately following their initial consultation. These participants highlighted exercise and breathing techniques learnt during pulmonary rehabilitation as effective long term treatments for COPD, with participants and their family members noticing changes in physical abilities following pulmonary rehabilitation. Other beneficial outcomes of pulmonary rehabilitation identified by participants are outlined in the sub-theme *acquiring information about COPD* while the social experience of pulmonary rehabilitation is described in later findings.

Major theme 2: The everyday reality of life with COPD

The second major theme identified is *the everyday reality of life with COPD,* which refers to the impact COPD had on study participants' lives. Participants expressed a diversity of sentiments about life with COPD, yet despite this diversity, the everyday realities of life seemed quite similar for all participants. Participants identified a decline in their physical functioning and saw themselves as less active than they had previously been. The decline in physical function was most obvious in participants' abilities to walk, perform household tasks and participate in leisure activities. A range of strategies were used to cope with this decline.

In addition to physical manifestations, having COPD also altered participants' connectedness with others. Changes to relationships and social interactions resulted from an individual's declining physical function. In addition, connectedness was also altered by the awareness participants had about the observations or judgements made by those around them regarding the everyday reality of life with COPD. A notable difference between PR and NPR participants was the influence pulmonary rehabilitation had on a participant's sense of connectedness. Pulmonary rehabilitation provided participants with unique opportunities for social interaction. It was an opportunity to develop meaningful relationships with others who had COPD as well as with health professionals.

Sentiments about life with COPD

The sentiments expressed by study participants about life with COPD ranged from despair and hopelessness through acceptance and resignation to life being positive and fulfilling. These sentiments were expressed as participants talked about various elements of their lives.

Despair and hopelessness stemmed from beliefs that COPD had taken away opportunities to live a fulfilling and worthwhile life. These sentiments were more common in NPR participants, with three of the four describing these feelings in relation to living with COPD. Half of the NPR participants found life had become less fulfilling as their bodies felt the consequences of COPD. They felt trapped and frustrated inside the "poor old shell" (NPR4 409) of a body which no longer reflected who they perceived themselves to be and stopped them from expressing their true identity. Sentiments of despair and hopelessness were also identified by individuals in both groups, as they described how COPD "destroys" (PR1 491) and "upsets your life completely" (PR1 492); one felt he "may as well be bloody dead" (NPR1 105) than to live with COPD. Current perceptions about life were reflected in these participants' concerns about "how... life will, will go on" (NPR1 256) into the future.

Most commonly identified in participants was the attitude of resignation to the experience of living with COPD. Seven of the eight participants in this study concluded that there was a need to accept COPD and its consequences as a part of their life. According to one PR participant, accepting COPD and getting on with life was something that "you learn everyday" (PR1 507). It involved not complaining about breathlessness or the decline in physical functioning and accepting that some things, which were previously a part of life, were just no longer possible:

> *You've just got to work around these things. You've got the problem, and you've got to go with it, and you know, no use um, brooding over it or, getting yourself down or depressed about it* (PR3 317).

> *Just get on with life; you know what you can do and what you can't do. You try, if you can't do it, you don't do it, you know, but, it's simple* (NPR2 466).

In contrast to the above experiences, one PR participant found his life remained fulfilling and worthwhile. Although he described his "poor old body" (PR2 53) as being in "a hell of a mess" (PR2 53), he continued to participate in a variety of community activities and participation in these groups gave him "personal satisfaction" (PR2 129). He described feeling satisfied with life:

> *Ah ... I'm not missing any specific part of life that normally people would regard as a source of happiness. I'm happy here in the environment I'm living in* (PR2 100).

Declining physical function

All participants described a decline in physical function as part of the everyday experience of having COPD with becoming less active over time being one way the decline in physical functioning was recognised. They used the terms “active” (PR1 491), “healthy” (PR4 10) and “normal” (NPR1 193) to describe their former selves, and noticed how they had become less active when tasks they had previously performed became difficult or impossible to do. This change in physical functioning was negative and unwanted:

> *I've always been very fit, oh I won't say fit, maybe very active is the word and now you just can’t do it and ah I can't even walk to my shed which is just the other side of the house there, without suffering* (PR1 28).

Three participants described “ageing” (PR4 82; PR2 227) or “getting old” (PR1 40) as being partly responsible for them becoming less active. Growing old provided some participants with an alternate explanation for the changes they were experiencing, allowing them to downplay the impact COPD had on everyday life:

> *I guess it has restricted me a bit in what I’m able to do, um, and I guess part of that’s ageing as well (laughs)! It’s not all the emphysema. We all have to get used to not working at the same pace that we used to* (PR4 82).

A decline in physical functioning was noticed by all participants during the activity of walking and as a component of many activities, a reduction in the ability to walk restricted participants in significant ways. However, this restriction was most notable in the limitations participants experienced in basic walking tasks, such as moving around the home:

> *Some mornings I get up and I’m battling to walk from the bedroom out to here* [the lounge room] (NPR2 276).

Declining physical function made household tasks more difficult or impossible to do. In this study, gender differences were apparent in participants’ household activities with women more likely to describe indoor household tasks such as vacuuming, mopping and washing, while men spoke more of outdoor activities, such as lawn mowing, gardening, painting and fixing the roof. Nevertheless, the experiences of men and women were the same in relation to performing these tasks. Some activities were impossible to perform, while others were adapted to cope with declining physical function:

> *Vacuum the floors, sweep the floors and things like that, I can't do. I can't just zap through and do the whole house, you know, I got to do a room at a time, or depending on how I am on that particular day it might only be half a room at a time, stop and have a rest* (NPR2 344).
>
> *I tried to mow the lawn. Took me (laughs), I had a chair out on the front lawn and I'd mow a bit and sit down and mow a bit. It took all day and I did the front. Took me a few days to do the back cause its bigger* (NPR1 186).

Going shopping for everyday household items was limited by a participant's walking ability as well as their ability to lift and carry heavy shopping bags. While shopping was more likely a task undertaken by women in this study, two male participants identified they had an important role assisting their wives with the shopping. A decline in physical function had resulted in them no longer being effective in fulfilling this role:

> [Name of wife] *she's been shopping today… we used to go together and go in there, and I did the usual man, push the trolley around, but, I couldn't do that now, I couldn't last an hour, in that, I'd finish up running over everyone and goin' berserk in there (laughs). Bloody pushing a trolley round trying to get a breath, so, yeah, that's what's happened* (NPR1 194).

Participants also found they were no longer able to enjoy hobbies such as bushwalking, fishing and golf. While the amount of walking involved in these activities could be modified, participation required high levels of physical strength or fitness. The following description of playing golf demonstrates how a once pleasurable activity had become an onerous task:

> *When we play golf, a mate he'll drive right up to the ball, alright, I'll hit the ball, get in the cart, which is good and I'll puff and pant just from hitting the ball. By the time you get to the next one, you've got breath back again (laughs) but then you do the same thing. It goes over and over and over and ... on Monday, once, I finished up in a bunker. Well, that stuffed me, well you gotta get in there and hit, get out, I could get out alright, then you got to rake it all*

> *and then climb back out of it again, and I was buggered when I got back in the cart then* (NPR1 223).

In this study grandchildren were an important part of the lives of five participants. While two described their grandchildren as older, three had young grandchildren. These three participants found that caring for young children could be physically demanding and they were often unable to perform tasks such as carrying children. One participant felt that she could not take on the responsibility of caring for her grandchildren, because her decline in physical functioning meant she could not keep up or ensure the safety of the children in her care:

> *Some of my grandchildren I can't take them out because if they run, that's it I couldn't, I couldn't catch them* (NPR2 348).

Psychological consequences of declining physical function

Participants described feelings of frustration, agitation and loss resulting from a decline in physical functioning. Frustration resulted from the realisation participants had that they were incapable of doing things they had previously done. As their physical function declined, participants faced the reality of being unable to participate in activities that other people enjoyed and became spectators rather than participators in life:

> *Frustrated because, um, you've got to be the spectator, you can still go out and do the things, but you can't participate, you have to sit back and just watch everybody else* (NPR2 459).

In addition to frustration, two participants described feelings of agitation. Being unable to participate in physically demanding activities forced participants to consider more sedentary activities. For some, these more sedentary activities were intolerable to do or even consider:

> [Reading] *was one of the things I took up when I first got sick with COPD ... I used to sit down and read a little bit but I couldn't sort of sit in one place for long, like a bloody tiger in a cage* (PR1 330).

Declining physical function could also provoke feelings of loss as a consequence of being unable to enjoy and participate in life. As such, a decline in physical function had the potential to influence the quality of life participants experienced:

> *The ability to get out there and run around and play footy with the kids and cricket with the kids and um go out dancing, when we go to the clubs and things like that. I can't do that. Um karaoke, you know, I can't do that, because I can't sing. I go (makes choking noise) can't get the notes out because I can't breathe; there's no air there left to come out. Yeah, you do lose a lot of, the little finer pleasures in life, you know* (NPR2 455).

The decline in physical function and resultant psychological consequences significantly impacted on participants' everyday life. A variety of coping strategies were employed by participants which aimed to reduce the impact of declining physical function on everyday life.

Strategies for coping with declining physical function

Participants outlined a number of strategies they used to cope with the decline in physical functioning. They spoke of slowing down, planning or making preparations prior to attempting tasks, adapting to change, using assistive devices and having the assistance of another person. In comparison to PR participants, NPR participants spoke at length about the coping strategies they used, however, there were no notable differences in the strategies used by the two groups.

The most common coping strategy described by participants was to perform activities at a slower pace. This sometimes involved slowing down the speed at which the task was performed but more often implied that frequent rests were taken during the task. The strategy of slowing down could be applied to many activities including walking, household and personal care tasks. It was viewed by participants as an effective and tolerable way of coping as it required little change or modification to the way a task was previously performed as noted by NPR3, who said:

> *Basically my life hasn't really changed except for slowing down* (NPR3 377).

Planning or preparing for a task was another coping strategy commonly used by participants. New or unfamiliar tasks required thought and planning prior to being attempted. Familiar tasks like showering and dressing were given a preparation stage, during which participants assembled items and strategically placed them to ensure they were easily accessible during the task. Having to plan or make preparations was a new and unfamiliar way of doing things:

> *It wasn't so long ago I could rush in, jump in the shower and come out and say ok, here we go. No, not anymore, it's a whole preparation* (NPR4 86).

Another coping strategy was adaptation. Participants described how they "adapted" (PR4 224) tasks, indicating they had organised the task to be performed in a new or different way than it had been previously performed. An example of adaptation made by one participant was to attempt to achieve only one activity each day. This was a significant change to how she had previously gone about doing things:

> *I do one thing. If I have to go to the doctors, then that's the thing for today. If I have to go and get pills, that's the thing. Park right at the chemist. Wait for a park there. Park there, then walk in. You can only do one thing. You can't go to the chemist then across to the bakery and down to the food shop. Like I used to do. Can't do any of that now. It's one thing* (NPR4 127).

Assistive devices helped participants to cope with declining physical function by reducing breathlessness during activities as well as the effort required to perform certain tasks. Assistive devices included walkers, reaching and bending aids and supplemental oxygen. Most assistive devices were viewed positively because of their ability to enable participants to accomplish tasks that had previously been difficult or impossible. However, assistive devices were also viewed as burdensome; they could brand a participant as incapable or “old” (NPR4 481), and consequently make them reluctant to participate in the social aspects of life.

Using supplemental oxygen as an assistive device was a topic of much interest to participants and past experiences of oxygen use, either by themselves or by others, caused participants to form strong opinions about this particular assistive device. All participants had used supplemental oxygen as a treatment for COPD and in general, most participants viewed the use of supplemental oxygen as an effective coping strategy for breathlessness experienced during physically demanding tasks. Supplementary oxygen enabled participants and made difficult or even impossible activities feasible:

> *Because going to the rehab, I found out that, being down at the basket ball field at* [name of location], *I couldn't walk the full length of the court without oxygen, but when I had the oxygen I had no worries in doing it* (PR1 156).

Despite its positive aspects, some participants viewed the use of supplemental oxygen negatively. While participants viewed the use of supplemental oxygen as an effective strategy for coping with breathlessness during strenuous activities, seeing themselves as dependent on oxygen during everyday activities was highly undesirable. It signalled they had reached a critical point in their illness; that living was now limited to how far the nasal cannula could stretch from their oxygen source:

> *I’m sure if I started to get short of breath and you had the oxygen bottle sittin’ there, you’d be sucking on it, I think. So not having it, means, well, stiff, you either pass out or you bloody keep going* (NPR1 239).

Having the assistance of others was another way participants coped with the decline they experienced in physical function, although this strategy was often perceived as undesirable. Four of the five participants who received assistance from a partner or family member were troubled by the onerous load they felt they placed on this person. For example, PR1 recognised that COPD had changed his wife’s life “a terrible lot" (PR1 422). His wife's assistance was required while on holidays as well as during everyday tasks such as shopping and he felt that his wife's involvement in helping him had become "fairly heavy" (PR1 420).

Receiving assistance from service providers was another coping strategy, though it was often a last option. For seven of the eight participants, using services was an indication they had reached a new level of incapacity and their attitude was to save up this type of assistance "for a rainy day" (NPR4 345). One participant, who had declined having assistance from services, perceived that receiving such assistance for self care tasks would be demeaning:

> *Imagine sitting here waiting and someone has to come in and say 'oh time for your shower' ... I suppose, it's a bit silly, you feel a little bit it's a bit demeaning that someone's got to come and help you in the shower and help you get dressed* (NPR4 361).

Two of three participants who used services felt that those performing the tasks were "very slack" (PR3 160) and did not do the task the way that they wanted it done. This resulted in feelings of anger and frustration. Being able to control how and what assistance was provided appeared to reduce these feelings for one participant. He had worked out how to exert control over the services he received and expressed satisfaction with his current arrangements:

> *I told them a few, more than white lies that I was having difficulty in cooking and things like that. Now that is not true. Ah, while I still have a lady come in here to help me with cleaning once every 2 weeks, I wouldn't allow anyone else in my kitchen. And I pride myself on being able to cook. Had I said I'd not needed that assistance, I would not have got the allowance. Now that's it quite bluntly* (PR2 38).

Interactions between participants and those providing care could at times be challenging. However, challenges were not limited to interactions with caregivers; changes were also seen in participants' interactions with family and friends and were part of the everyday reality of living with COPD.

Alterations to connectedness with others

Having COPD caused changes in family relationships and social interactions and this influenced participants' sense of connectedness with those around them. Changes to a participant's sense of connectedness resulted from their declining physical function. In addition, connectedness was influenced by the perceived judgements of others. Participants had an awareness that they were observed by those around them, perceiving these observations to be either supportive or lacking in understanding of the everyday reality of life with COPD. In general, experiences of relationships and social interaction were similar between PR and NPR participants, however, participation in pulmonary rehabilitation gave PR participants opportunities for social interaction and to develop meaningful relationships that NPR participants did not have. These opportunities impacted positively on a participant's sense of feeling 'connected' with those around them and were a notable difference between the two groups.

The impact of declining physical function on interactions with others

The decline participants experienced in physical functioning had implications particularly on family relationships. In this study, only one participant lived alone. The remaining seven lived with a family member (their wife, husband or daughter) and five of these participants relied on family members to provide them with some degree of assistance to cope with their declining physical function. As such, family members had taken on responsibilities that were previously held by study participants.

Becoming increasingly dependent on a family member was experienced in a diversity of ways. Increased dependency, while being a noticeable change from normal, was not particularly troublesome for one participant and her husband; it was explained as a normal part of the fluctuations they had experienced supporting one another during their relationship. In contrast, two male participants' increasing dependency on their wives appeared to have changed the status they held from being the provider to being dependent. Wives took on responsibilities previously belonging to participants and this change was concerning:

> *It's ah changed my wife's life around a lot cause she has got so many things to do now that I can't do that she tries to do for me and ah and she's got a lot more on her side of the fence* (PR1 345).

The relationship between one participant and her daughter seemed to have undergone a reversal of roles. The participant's declining physical function and breathlessness had led to increasing dependence on her daughter and the daughter taking on the role of comforter and protector of her mother:

> [Name of daughter] *does understand, she lives it with me. And she knows if I've had a bad night or a bad afternoon or something she'll sleep in my bed with me, you know, my gatekeeper* (NPR2 558).

Instead of speaking about family members, the participant who lived alone described the strong and valuable connections he had developed, as a result of his declining physical function, with people in his neighbourhood as well as with caregivers from a number of services. The following extract demonstrates how the positive and valued relationships described by this participant provided him with a sense of security and contentment. Concerns related to dependency, like those described by other participants, were not apparent:

> *You've got no idea what a lovely place I'm living in. I look across the road, I look over there, I look behind me, someone will call in, if they don't they'll give me a ring. 'Are you ok* [name of participant]*?' I've had a couple of falls by the way. The one fall when I had to use this (shows personal alarm pendant), I had people here in 5 minutes. One from across the road and one from over towards* [name of place]. *They were all within 10 minutes. The ambulance was here within 10 no 20 minutes. That's how quick everything was done and co-ordinated. Um, yesterday was Thursday. Now Thursday ... a gentleman takes me shopping we go to* [name of shopping centre]. *He even gets me a trolley. I get out of the car, with trolley and away we go* (PR2 124).

As well as affecting family relationships, declining physical function also reduced participants' opportunities for social interaction. Decisions about attending social events were impacted or "limited" (PR4 226) by whether participants thought they were physically able to walk to the location. In addition, opportunities for social interaction with friends were lost when participants became unable to participate in activities such as golf, dancing or bushwalking. One participant found she was unable to continue bushwalking with friends as they expected her "to keep up to their pace" (NPR2 336). While she had found understanding with family members, her declining physical function excluded her from bushwalking with friends and this took away opportunities for social interaction beyond her family members. Being unable to participate in leisure activities decreased participants' opportunities for social interaction and increased feelings of being alone or isolated.

A clear indication of the impact of declining physical function on social interaction was the experience of one participant, whose loss of the ability to fix his friends' golf buggies greatly contributed to his social isolation. His physical inability to fix golf buggies had resulted in people no longer visiting him and it appeared that his inability to be physically useful to others had resulted in him losing the opportunity for social interaction:

> *I used to have a lot of friends that used to come, well you'd probably call em friends but ah, they used to come to the shed there and I used to do their buggies. We used to talk and mag and that. I miss out on that a lot because I can't do that* (PR1 352).

Being aware of the changing perceptions of others

Participants had an awareness they were observed by those around them, perceiving these observations or judgements to influence the way people interacted with them. While observations could be positive and result in supportive relationships, they could also be negative and result in feelings of misunderstanding.

Two participants recalled relationships where understanding had been shown in relation to the discomfort of breathlessness. Having breathlessness recognised by others was reassuring and appeared to authenticate the suffering and impact COPD had on everyday life. The value of having the everyday reality of life with COPD understood by others was demonstrated by NPR1:

> *A mate lives across the road well we've sort of grown up from kids together, he knows (long pause), he'll come over and ... he'll give me a hand to do something and I'll say 'I gotta sit down'. And he'll say, 'yeah I know, it'll be right, it'll be right ...' and he said to me 'I know if you gonna, if something's gotta be done, you'll do it, or die trying', you know* (NPR1 235).

Another described the helpful and supportive responses he received from those around him while using his portable oxygen during a cruising holiday. As a result, participation in a physically demanding activity became positive and also gave new and unexpected opportunities for social interaction:

> [People] *couldn't do enough for you, mmm, everyone would help, 'can I take this, can I do that, can I do this, can I do that'. It was amazing (laughs) there are a lot of people out there with a lot of kindness in them* (PR1 174).

Alternatively, participants experienced a lack of understanding related to their COPD. This lack of understanding was isolating, often causing participants to conclude that those observing them had failed to understand the experience of living with COPD. Participants explained how:

> *Yeah, there's a lot of lack of understanding. A lot of people don't understand what's going on with you* (NPR2 551).
>
> *I said to* [name of wife] *I think it was yesterday, that neither her nor anyone could understand how bad you feel. Now I often think they think I say, 'oh Jesus I gotta sit down', that they think, 'you bludger'* (NPR1 234).

An important part of the everyday experience of COPD observed by others was the experience of being breathless. Only one participant recognised that the everyday reality of living with someone who was breathless could be anxiety provoking. One partner regularly sat up at night watching to make sure the study participant was breathing correctly. This participant felt that his breathlessness had "affected" (NPR3 166) his wife more than himself.

Watching someone in a state of breathlessness can be frightening and stressful for the observer, however, this was not recognised by the majority of participants. While participants identified the physical burden placed on others as a result of breathlessness only two conveyed experiences of when others had found their breathlessness frightening to observe:

> *(Talks very quietly, leaning into interviewer) between you me and the gate house, I think the wife panicked that morning when we took me to the hospital, I was breathless, definitely oh yeah, but I think if I had sat down for 10, 15, 20 minutes, I might have been alright* (NPR3 99).

> *The other day, someone wanted to ring me an ambulance because I'd just come out of the shower and there were people waiting and I (pants for breath) was gasping for air as I got to the chair and you know, just give me 5 minutes I said, I'll be OK* (NPR4 120).

Most participants seemed unaware that the frightening, stressful and unpredictable nature of breathlessness as experienced by those around them could influence social interaction. As such, it was not identified by participants as playing a major role in the alterations to connectedness they experienced.

Pulmonary rehabilitation: an opportunity for social interaction and meaningful relationships

Only PR participants were able to speak about their experiences of social interaction during pulmonary rehabilitation. These interactions occurred among program participants as well as between program participants and health professionals. All PR participants described the social experience of pulmonary rehabilitation as valuable.

Outpatient pulmonary rehabilitation was an opportunity for participants to engage in social interaction, with both the exercise component and information sessions occurring in groups. Outside these sessions, PR participants had not come into contact with others who had COPD; outpatient pulmonary rehabilitation had been the first opportunity to share experiences of breathlessness and declining physical function with others who also had a diagnosis of COPD. All PR participants found interaction with others at pulmonary rehabilitation to be satisfying as there was a commonality of experiences and shared understandings:

> *I don't know what it was, whether it was talking to all the other people who were going through the same, the same, ah, syndromes as me um, I'm not sure, but it did help me* (PR3 19).
>
> *PR4: Doing the exercises with other people who are in the same boat as you, so to speak. Other people that you can talk to, relate to, um, yeah, and exchange ideas.*
> *I: Why is that helpful?*
> *PR4: Um (long pause) I think because you feel that other people who have the same disease understand, um, what you're talking about* (PR4 143).

PR participants also found opportunities to develop relationships with health professionals during pulmonary rehabilitation sessions. One participant found the relationships she built with pulmonary rehabilitation staff provided a source of advocacy when she interacted with other sectors of the healthcare system, in particular her general practitioner and respiratory physician:

> *I expressed concern again to* [name of nurse] *at* [pulmonary rehabilitation] *that I was still getting high readings at home and she asked me if I'd seen my GP. I said yes, and told her what he had said, and I told her I didn't feel confident going back to him about it again, and she rang up and got an appointment with* [name of respiratory physician] *for me* (PR4 171).

In addition to providing advocacy, the relationships built between health professionals and participants at pulmonary rehabilitation provided support, security and encouragement for PR participants:

> *When you've got someone there, I think it becomes like a prop, ah, or a crutch if you like, to have that, to know that that's there for you and they're guiding you and, they're not only sympathetic, sometimes they can be bullying. But just the same, the effect is good* (PR2 207).

These relationships were greatly valued and appeared to help PR participants cope with the demands of living with COPD.

Minor theme: The influence of pulmonary rehabilitation on the experience of living with COPD

A comparison of the differences between the two groups of participants in this study has already been undertaken during the presentation of the preceding two major themes. The small but notable differences which have been identified between the two groups of participants are summarised in Table 4.

The findings suggest that participation in a pulmonary rehabilitation program may have been influential in the differences apparent between the two groups of participants. Participation in pulmonary rehabilitation appeared to positively influence the realisation of breathlessness as COPD and the everyday reality of life with COPD. However, the effect of other life experiences were not explored in great depth and should not be disregarded when considering the influence of pulmonary rehabilitation.

Table 4: Summary of differences between PR and NPR participants

Theme/Subtheme	
1. The realisation of breathlessness as COPD	
• Developing an awareness of breathlessness	In comparison to PR participants, NPR participants were more likely to convey the experience of breathlessness through its impact on everyday activities suggesting NPR participants may have a greater awareness of breathlessness during everyday activities. Additionally, a greater awareness of breathlessness during everyday activities may also have contributed to perceptions held by NPR participants that breathlessness was controlling as PR participants were less likely to describe breathlessness as a controlling force.
• Acquiring knowledge about COPD	NPR participants were more likely to recall negative experiences related to acquiring diagnostic and prognostic information and had a poor understanding of the diagnosis and prognosis of COPD. Conversely, PR participants were able to name and give an explanation of COPD and recalled positive experiences of acquiring this information. These positive experiences occurred during participation in pulmonary rehabilitation.
• Experience and knowledge of medical treatments for COPD	All NPR participants had experienced acute treatment for COPD in a hospital setting in the past 12 months, whereas this was only the case in two PR participants. PR participants were more likely to describe experiences related to the long term treatment of COPD, including the use of medications, oxygen and pulmonary rehabilitation. NPR had little or no knowledge of pulmonary rehabilitation.
2. The everyday reality of life with COPD	
• Sentiments about life with COPD	Despite the reality of life with COPD being similar for both PR and NPR participants, NPR participants were more likely to express sentiments of hopelessness and despair about living with COPD. PR participants had more positive perceptions about living with COPD and were often resigned and accepting of the consequences of COPD.
• Declining physical function	PR and NPR participants experienced declining physical function as part of the everyday reality of living with COPD. In comparison to PR participants, NPR participants spoke at length about the coping strategies they used for their declining physical function, however, the strategies described by both were similar.
• Alterations to connectedness with others	PR and NPR participants experienced alterations to their connectedness with others as a result of changes to family relationships and social interaction. Participating in pulmonary rehabilitation gave PR participants the opportunity for social interaction and to develop meaningful relationships with others who had COPD as well as health professionals.

Chapter summary

The findings of this study describe the long and complicated journey of realising breathlessness to be a medical condition known as COPD. While participants developed an awareness of breathlessness over a long period of time, it also took time for participants to realise that their breathlessness was actually a medical condition known as COPD. This realisation came about as a result of a number of processes including: experiencing acute and severe exacerbations of breathlessness; interacting with respiratory physicians, general practitioners and other health professionals; and receiving medical treatment for COPD.

While participants experienced the journey of realising breathlessness to be COPD, they also lived with the everyday realities of having COPD, namely declining physical function and alterations to connectedness with others. They expressed a diversity of sentiments about life with COPD and described a variety of strategies for coping with the limitations they faced. Declining physical function as well as the observations and perceived judgements of others resulted in changes to relationships and social interaction and often these changes were challenging. Pulmonary rehabilitation appeared to provide new opportunities to interact socially and build relationships with others who were living with COPD as well as with health professionals. These relationships were valued by PR participants.

The differences identified in this study between those who had and had not participated in pulmonary rehabilitation provide evidence of positive influences pulmonary rehabilitation can have on an individual's everyday experience of living with COPD. These findings are discussed in the following chapter.

CHAPTER FOUR: Discussion

Introduction

The concluding chapter of this thesis discusses the findings of this study in relation to the existing literature. This qualitative study is the first to compare the experience of living with COPD in those who have and have not participated in pulmonary rehabilitation and has revealed three key findings: firstly, the realisation of breathlessness as COPD; secondly, the everyday reality of life with COPD; and thirdly, the influence of pulmonary rehabilitation on the experience of living with COPD. These findings have implications for health professionals and service delivery and this chapter will consider these issues along with implications for future research and the limitations of this study.

Key finding 1: The realisation of breathlessness as COPD

Over time, study participants developed an understanding that symptoms of breathlessness were in fact a medical condition known as COPD. While the literature has documented the slow and insidious onset of breathlessness in COPD, this study has given new insight into the process through which individuals' experiences of breathlessness are transformed into a medical condition known as COPD.

Realising symptoms of breathlessness to be COPD was a long and complicated journey with an uncertain beginning. Uncertainty resulted from the fact that symptoms of breathlessness developed over a long period of time and this is similar to the findings of Pinnock et al., (2011), whose participants were unable to identify a beginning to their 'COPD story'. Inevitably, breathlessness eventually became unmanageable and this was a significant milestone which started the difficult process to search for and acquire information about the diagnosis and prognosis of COPD. It also began an individual's experience of medical treatment for COPD.

The experience of breathlessness

The primary experience of COPD for all study participants was breathlessness and this supports other findings (Barnett, 2005; Seamark, et al., 2004; Sheridan, et al., 2011; Ek & Ternestedt, 2008), which report the experience of living with COPD. Breathlessness had a slow and insidious onset, but with time permeated into many aspects of everyday life. In the early stages, breathlessness was often invisible to others; initial symptoms were endured without complaint and resultant physical and social limitations were accommodated into everyday life. Similar to the findings of Gullick and Stainton (2008), breathlessness appeared to be unobtrusive and was suffered in isolation. Walters, et al., (2008) have described a five year discrepancy between the onset of symptoms of breathlessness and individuals being recognised or 'diagnosed' as having COPD, with diagnosis being most commonly made in a hospital setting. Likewise, symptoms of breathlessness in the current study were downplayed and not identified as COPD until a severe acute exacerbation resulted in hospitalisation, or significant limitations were experienced in everyday activities. Overlooking or discounting symptoms of breathlessness by individuals as well as general practitioners in Australia has been identified as contributing to the under-diagnosis of COPD in the community and is partly responsible for the delay in receiving treatment for COPD (Walters, 2010).

Breathlessness was characterised by study participants as unpredictable and fluctuating. Fluctuations in breathlessness were attributed to weather conditions and body position and these factors have been identified elsewhere in the literature (Barnett, 2005; Gysels & Higginson, 2008) as contributing to the fluctuating nature of breathlessness. Breathlessness was also controlling, particularly in relation to everyday activity and at times, this characteristic of breathlessness could result in feelings of powerlessness. Feelings of powerlessness or helplessness associated with breathlessness have also been recognised in a New Zealand study (Sheridan, et al., 2011) of the experiences of people living with COPD. However, although feelings of powerlessness and helplessness were the experience of participants in the current study, similar to the findings of Nicholls (2003), the use of coping strategies allowed individuals to develop a perception of having some degree of control over the breathlessness they were experiencing.

An interesting finding in the current study was the bewilderment felt by participants regarding the association between breathlessness and urinary urgency, with some having a real fear of urinary incontinence. A Swedish study (Hrisanfow & Hagglund, 2011) found urinary incontinence to be present in 49.6% of women and 30.3% of men with COPD. Despite this higher than normal prevalence compared to the general population, awareness and discussion of continence issues amongst those with COPD as well as those caring for people with COPD appears to be limited. A fear of urinary incontinence made some participants in the current study reconsider participation in physical activities and had the potential to further increase the cycle of inactivity. This finding supports Hrisanfow and Hagglund (2011), who suggest that assessing and managing continence issues should be included as an important part of the care offered to people living with COPD.

Acquiring knowledge about COPD

Early attempts to acquire information about COPD were often difficult for participants in this study. In most cases, diagnostic and prognostic information given by hospital doctors, respiratory physicians and general practitioners was insufficient and confusing. An Australian study (Sossai, et al., 2011) has highlighted the limited information and education people with COPD receive at the time of their diagnosis, with diagnostic and prognostic information described as confusing and difficult to obtain.

The overseas literature (Gardiner, et al., 2010; Gore, et al., 2000) supports the assumption that a great deal of misunderstanding exists among those with COPD regarding the diagnosis, prognosis, causes and treatment of COPD. Reasons suggested for this misunderstanding are the significant variation and complexity in the information needs of those with COPD (Gore, et al., 2000), with some people wishing to receive more diagnostic and prognostic information while others do not want to know. Likewise, health professionals may also feel the need to maintain an optimistic outlook and shield patients from distressing information. For example, an Australian study (Walters, et al., 2008) has identified that general practitioners rationalise the delay in giving the diagnosis of COPD on the misperception that patients do not wish to receive a diagnosis. Walters et al. (2008) also found that this delay can be attributed to the pessimistic attitudes doctors have regarding the prognosis of COPD.

While these factors may have contributed to problems with obtaining information, in the current study, difficulties were described as resulting from deficiencies in health professionals' interpersonal skills and knowledge base. Furthermore, when individuals perceived access to their personal health information was obstructed or taken away by health professionals, communication was further impaired and feelings of anxiety and frustration developed. These factors were important findings in this study as they were a significant impairment to the process of realising and understanding symptoms of breathlessness to be a medical condition called COPD.

While patient and health professional factors are important in developing an understanding of COPD, differences in knowledge about disease chronicity can be related to the time since diagnosis (Fischer, et al., 2010). This was apparent in the current study, where more recently diagnosed participants showed a significantly poorer grasp of medical terminology and disease chronicity. Prognostic information given to people with COPD is known to be poor (Gardiner, et al., 2010; Habraken, Pols, Bindels, & Willems, 2008) and the progressive nature of COPD was understood only by study participants who had lived through this experience; it was not information acquired from health professionals. This supports the assumption of other authors (Gysels & Higginson, 2011), who suggest people with COPD often draw their own conclusions about their prognosis based on the experiences they have over a long period of time.

Previous smoking habits were accepted by most participants as the probable cause of their COPD, however, multi-causal explanations for COPD were preferred. Having a multi-causal explanation appeared to lessen the responsibility associated with the perceived self-inflicted nature of COPD and this supports the findings of another Australian study (Hansen, Walters, & Wood Baker, 2007) regarding perceptions about the role of smoking in COPD. People with COPD have been found to experience significant feelings of guilt or shame related to their previous smoking habit (Halding, et al., 2010; Lindqvist & Hallberg, 2010) and having alternate explanations to smoking for the cause of COPD has been suggested by Berger et al. (2010) as a way feelings of self- blame and blame from others might be reduced.

Medical treatment for COPD

Experiencing medical treatment for COPD gave further support to the explanation that symptoms of breathlessness were the result of having a medical condition called COPD. However, in the current study, perceptions about the effectiveness of medical treatment were not overwhelmingly positive. Decreased compliance with medical interventions was recognised (Bourbeau & Bartlett, 2008) as a consequence of individuals perceiving interventions to be ineffective. Unfortunately, a lack of compliance with interventions, such as smoking cessation, medications and oxygen use, in people with COPD increases the burden of this disease both personally as well as economically (Bourbeau & Bartlett, 2008). Bourbeau and Bartlett (2008) suggest that adherence with smoking cessation interventions, medication and oxygen use can be improved when health professionals effectively communicate the chronic nature of COPD and the rationale for medical treatments.

This study has highlighted the strong opinions held by those with COPD regarding the use of long term oxygen therapy (LTOT). Supplemental oxygen was seen as an effective coping strategy for symptoms of breathlessness associated with strenuous activity, however, requiring LTOT as a daily treatment for COPD was viewed as highly undesirable because of the concern of becoming dependent on it. Another Australian study (Sossai, et al., 2011) has also indicated that people with COPD are concerned by an increasing dependence on supplemental oxygen. Sossai, et al. (2011) suggest that the use of supplemental oxygen is seen as imposing significant lifestyle restrictions on those requiring its use.

Key finding 2: The everyday reality of life with COPD

A variety of sentiments about life with COPD were conveyed during this study. At times, participants were resigned and accepting of the consequences of having COPD. Pinock et al., (2011) have suggested that this attitude is an appropriate adaptation or coping strategy for the limitations and restrictions COPD places on an individual’s life. However, in the current study, feelings of acceptance and resignation about having COPD were often linked to feelings of responsibility or expressions of self-blame for causing COPD. A similar association has been identified in a Swedish study (Lindqvist & Hallberg, 2010), with the perceived self-inflicted nature of COPD and the resultant feelings of guilt causing individuals to feel they have no right to complain and must accept the consequences of the disease.

Identifying daily struggles and areas of life affected by COPD resulted in feelings of hopelessness and despair with one participant even expressing he would be better off dead. Barnett’s (2005) qualitative study describes how people with COPD have thoughts about wanting to end their life and fluctuations in their mood, and these were attributed to worsening symptoms of COPD. Symptoms of anxiety and depression are known to be greater in the COPD population (Frith, et al., 2008; Simpson & Rocker, 2008) and an Australian study (Sossai, et al., 2011) has reported symptoms of depression to be significant among people with COPD. Although feelings of hopelessness and despair might be identified as depression, surprisingly, participants in the current study did not see themselves as depressed – one even told of his surprise at being offered antidepressant medication after expressing feelings of hopelessness and despair to his general practitioner. Like those in Barnett’s (2005) study, rather than identifying feelings of depression, participants were more likely to speak about feelings of frustration. Declining physical effectiveness

Declining physical function resulted in individuals becoming physically ineffective. Often declining physical function was related to symptoms of breathlessness, as breathlessness, with its unpredictable fluctuations, made the body unreliable. Seeing themselves as unreliable often changed an individual’s self-image; study participants saw themselves as being unproductive and less physically useful to others compared to what they had previously been. The impact of chronic diseases such as COPD on self-image has been explored in a number of studies. Participants with COPD in a Swedish study (Lindqvist & Hallberg, 2010), described how they had changed or saw themselves differently as a result of having COPD. Charmaz’s (2006) study of people with various chronic diseases describes how self- measures of previous abilities relating to recreation and fitness are used by individuals to represent a past well self while present inabilities are used to represent the present sick self. Physical predictability of the body has been described as one aspect of effectiveness or being able (Leidy & Haase, 1999; Gullick & Stainton, 2008) and is considered to be an important part of personal integrity or seeing oneself as whole (Leidy & Haase, 1999). Barnett (2005) suggests a perception of ineffectiveness can cause those with COPD to reduce their activity levels further and enter a vicious cycle of inactivity resulting in increasing dependence on others. In this study, declining physical function restricted participants fulfilling previously held roles and responsibilities and impacted on activities such as walking, performing household tasks, participating in hobbies and being a grandparent. Losing the perception of effectiveness resulted in feelings of frustration, agitation and loss. Various authors (Leidy & Haase, 1999; Lindqvist & Hallberg, 2010; Ek & Ternestedt, 2008) have suggested these feelings result as individuals with COPD recognise the lack of personal control they have over their disease.

In an attempt to combat feelings of ineffectiveness, study participants used coping strategies, similar to those described in the international literature. The most common strategy was to slow down or take frequent breaks and while this strategy was preferred and most effective when alone, in a social setting it could be potentially stigmatising. Gullick and Stainton (2008) described how stopping to rest during walking activities increased the visibility of breathlessness and made those with COPD stand out from others in their social environment. Similarly, the use of assistive devices such as walkers or oxygen therapy was considered an effective coping strategy when alone but potentially stigmatising in a social setting. While assistive devices enabled study participants to do activities they would have otherwise been unable to, they also recognised that a consequence of using these devices was that others labelled them as being sick or old. Assistive devices have been identified in the literature (Berger, et al., 2010) as a potential trigger for experiencing stigma in COPD.

Having assistance from others was another undesirable yet unavoidable coping strategy. Like those in other qualitative studies (Lindqvist & Hallberg, 2010; Barnett, 2005; Kanervisto, et al., 2007), participants felt burdened by the fact that their family members had to assist them with everyday activities, while some who had assistance from external service providers were unsatisfied with the help they received and this resulted in feelings of frustration. A Swedish study (Ek, et al., 2010) has shown that stress related to the unhappiness with care given by service providers during self-care tasks resulted in worsening breathlessness for people with COPD. While experiences in the current study related to household chores, those receiving assistance from external providers appeared to have the perception that assistance from this source was undesirable as they were unable to exert control over how the assistance would be given. These experiences might be influential in the decision to accept help for personal care in the future.

Alterations to connectedness with others

Having COPD altered relationships with family and friends and limited opportunities for social interaction. Watching a loved one experience breathlessness and other symptoms of COPD could be frightening and anxiety provoking for family members and similar to carers in Gullick and Stainton's (2008) study, family members expressed feelings of anxiety and helplessness when they were unable to alleviate symptoms. Ethical approvals gained for this study did not allow the opportunity to fully explore the experiences of participants' family members, however, their importance was evidenced by the fact that five of the six participants who had family members available at the time requested input from them during interviews. A person's family members were an inseparable part of their experience of living with COPD.

Experiences of breathlessness and declining physical function resulted in changes to longstanding family relationships, often adding issues of dependency. Barnett (2005) suggests that living with COPD can alter roles within families and this may result in disharmony within family relationships. Although in the current study there were significant changes to roles held within the family and most felt burdened by the increasing load they placed on family members, no disharmony in relationships was identified. Similar to the findings of another Australian study (Sossai, et al., 2011), the valuable contribution of family members in providing assistance during everyday activities was recognised.

While disharmony in family relationships was not seen, the study clearly demonstrated how the negative impact of COPD could extend to the role of grandparenting, in particular, when physical care needed to be provided for young children. Fulfilling the role of grandparent has been shown to give those with COPD a sense of belonging and purpose as well as increasing an individual's sense of connectedness (Ek, et al., 2010; Seamark, et al., 2004). In this study, being unable to fulfil this role was an indication of physical ineffectiveness and reduced opportunities for interaction with grandchildren. This added to feelings of frustration and loss and a reduction in quality of life.

Social interaction was significantly impacted by declining physical function. Like in other qualitative studies of people with COPD (Barnett, 2005; Ek & Ternestedt, 2008; Gullick & Stainton, 2008), opportunities for social interaction were lost when the focus of the social gathering was participation in physically challenging activities. Furthermore, there was uncertainty whether other non-physical social events could be attended because of the day to day fluctuation in symptoms of COPD. Considering the outdoor and sporting culture of Australian society, it could be suggested that the inability to participate in physically demanding activities could have greater implications for people with COPD living in rural Australia. Certainly for participants in this study, the limitations or inability to play golf, go bushwalking and engage in other outdoor activities were significant factors limiting social participation and interaction and had the potential to result in social isolation.

While declining physical function impacted on the ability to connect with others, the perceived observations and judgments of those around them also influenced an individual's sense of connectedness. These observations or judgements were often perceived to be related to experiences of breathlessness with one participant describing how he felt others thought he feigned illness, because of the lack of breathlessness he had at rest and the onset of breathlessness with movement. Barnett

(2005) described how the fluctuating nature of breathlessness had led to "misunderstandings" (p. 811) for her participants when they were identified by others as healthy when sitting, but displayed symptoms of breathlessness on movement. Such experiences could result in decreased social interaction for people with COPD because of the fear of these fluctuations in breathlessness being misinterpreted as malingering.

Despite these negative experiences, when participants perceived others to understand the impact of COPD on their life, meaningful and valuable relationships developed. Gaining understanding from others appeared to make the everyday reality of life with COPD more tolerable.

The role of pulmonary rehabilitation in facilitating social connectedness

In keeping with the findings of other qualitative studies (Halding, et al., 2010; Gysels & Higginson, 2009; Rodgers, et al., 2007), attending pulmonary rehabilitation was an opportunity to engage in social interaction. A valuable aspect of this social interaction was forming relationships with others who had COPD. For participants in the current study it was the first opportunity they had to meet others suffering COPD and like those in a Norwegian study (Halding, et al., 2010), the opportunity to share experiences, offer and receive support and develop new friendships was greatly valued. When considering the losses individuals with COPD experience in social interaction, it is not surprising that the opportunity to develop new social networks is a valued aspect of participating in pulmonary rehabilitation. In addition, Charmaz (2006) suggests that a favourable social situation provides the opportunity for individuals' responsibility for their health to "flourish" (Charmaz, 2006, p.31). The setting at pulmonary rehabilitation described by participants in this study appears to provide a favourable social environment and therefore has the potential to facilitate individuals taking responsibility to participate in the management of their chronic disease.

Developing supportive and trusting relationships between those with COPD and health professionals was another valuable aspect of participating in pulmonary rehabilitation recognised in this and other qualitative studies (Gysels & Higginson, 2009; Halding, et al., 2010). In this study, the health professionals who provided pulmonary rehabilitation were experts in COPD. They supported individuals as they coped with the demands of living with COPD and often became their advocates, assisting them to navigate through the various layers of the health system and gain timely access to respiratory physicians, general practitioners and other health professionals and agencies.

Key finding 3: The influence of pulmonary rehabilitation on the experience of living with COPD

This study is unique in that it has provided a comparison of the lived experience of two groups of people with COPD – those who have and have not participated in pulmonary rehabilitation. In doing so, a number of small but notable differences have been identified between the two groups. These differences suggest that the experience of living with COPD can be positively influenced by participation in an outpatient pulmonary rehabilitation program, however, the effect of other life experiences are also acknowledged and have not been disregarded when considering the influence of pulmonary rehabilitation.

NPR participants were more likely to convey the experience of breathlessness through its impact on everyday activities and also held the perception that breathlessness was controlling. These findings suggest NPR participants may have had a greater awareness of breathlessness during everyday activities. Many factors are known to affect the experience of breathlessness including a person's experiences, emotions and social relations, as well as participation in pulmonary rehabilitation which can reduce symptoms of breathlessness (Nicholls, 2003) . Participation in pulmonary rehabilitation may provide some explanation for PR participants being less aware of breathlessness during everyday activities in comparison to NPR participants as a reduction in symptoms of breathlessness is a well documented outcome of pulmonary rehabilitation (Lacasse, et al., 2006).

NPR participants were also more likely to recall negative experiences related to acquiring information about their disease, while PR participants recalled positive experiences of acquiring information during participation in pulmonary rehabilitation. Other qualitative studies (Gysels & Higginson, 2009; Rodgers, et al., 2007) support the finding that pulmonary rehabilitation is an opportunity for acquiring and understanding information about COPD, its progression, medical terminology, information on a variety of pharmacological and non-pharmacological disease management strategies and other information that has been previously lacking.

Despite the reality of life with COPD being similar for both NPR and PR participants, NPR participants were more likely to express sentiments of hopelessness and despair about living with COPD. In contrast, PR participants had more positive perceptions about living with COPD and were often resigned and accepting of the consequences of COPD. Fischer et al. (2010) demonstrated that one outcome of pulmonary rehabilitation is the development of more positive illness perceptions (Fischer, et al., 2010) Proposed reasons for these positive perceptions are improved knowledge and understanding about diagnosis, prognosis and management of COPD (Gysels & Higginson, 2009; Fischer, et al., 2010), improved physical functioning (Matheson, et al., 2010; Williams, et al., 2010), positive and supportive interactions with health professionals (Gysels & Higginson, 2009) and opportunities for interaction with others who have COPD (Matheson, et al., 2010; Gysels & Higginson, 2009; Williams, et al., 2010). The experiences shared by PR participants in the current study regarding their participation in pulmonary rehabilitation indicate that participation was a positive influence on the illness perceptions they held.

The differences identified between PR and NPR participants in this study support the widely held assumption that pulmonary rehabilitation can positively influence the everyday experience of living with COPD.

Implications of the study findings

A number of implications arise from this study. These implications relate to the role of health professionals and delivery of health services to people with COPD as well as future research in this area.

Implications for health professionals and service delivery

The findings indicate that symptoms of breathlessness continue to be downplayed and under recognised by those with COPD as well as their general practitioners. Efforts to improve awareness of COPD among those in the general and medical communities have been made by The Australian Lung Foundation as well as the Thoracic Society of Australia and New Zealand, however, the findings of this study suggest an ongoing need in this area. Strategies used by both The Australian Lung Foundation and the Thoracic Society of Australia and New Zealand require continual review to ensure they meet their target population and are effective in increasing awareness of COPD.

The process of realising symptoms of breathlessness to be COPD was highlighted in this study and poor communication between health professionals and people with

COPD was a significant impairment to this process. In the current study, health professionals' interpersonal skills and knowledge base were identified as factors which impeded communication. While time constraints and a lack of attention paid by health professionals during consultations have been identified in other studies as factors resulting in poor communication (Oliver, 2001; Gysels & Higginson, 2010), the information needs of people with COPD are also known to be variable and complex (Gore, et al., 2000). Health professionals need to undertake a careful appraisal of the information requirements of people with COPD, rather than providing the same information to all. In addition, Gardiner et al. (2010) suggest that health professionals working with people with COPD may benefit from participation in continuing education courses which aim to enhance communication and interpersonal skills between health professionals and patients. Enhanced communication may also give the added benefit of improving compliance with treatment interventions as poor compliance is known to occur when individuals have a poor understanding of their disease and the interventions being offered (Bourbeau & Bartlett, 2008).

Consultations with a variety of health professionals at the time of diagnosis were confusing for participants in this study, particularly when conflicting information was given. An Australian study (Yen, et al., 2010) has recognised fragmentation of service delivery as a problem for people with chronic disease, with patients feeling frustrated by the contradictory messages and poor communication which occurs between health professionals and with health professionals. Individuals with a chronic disease like COPD require cohesive service delivery, not only to meet early information needs, but to provide stable and reliable support in the long term. While this study has demonstrated that supportive and effective relationships occur with health professionals during pulmonary rehabilitation, access to this type of support is required in the long term. A need for ongoing support following pulmonary rehabilitation has been recognised in another qualitative study (Rodgers, et al., 2007), however, the challenge remains to provide this without further service fragmentation.

The findings of this study have described the reality of life with COPD to be breathlessness, declining physical function and alterations to connectedness with others. The demographic data has also indicated that people with COPD live with a significant number of co-morbidities. Relationships with health professionals at pulmonary rehabilitation helped individuals cope with the assortment of problems they faced when living with COPD. Health professionals at pulmonary rehabilitation were seen as experts. They understood COPD, its diagnosis, management and impact on other health problems. To a degree, they also understood the reality of life with COPD and were able to answers questions or give explanations in a time frame which was relevant to a participant’s needs. Health professionals working in pulmonary rehabilitation need to recognise the important role they have in developing a partnership with people who have COPD. Gysels and Higginson (2010) see this partnership as providing expert advice and professional support, while recognising and respecting the individual’s treatment decisions which are based on their illness experiences, life circumstances and relationships with others.

Finally, the valuable element of social interaction during pulmonary rehabilitation programs was recognised in this study. Social interaction during a pulmonary rehabilitation program was unique as it gave access to others who also suffered from COPD. However, the setting was also unique in that it provided a purpose for sufferers to meet together – to exercise and attend information sessions. Having a purpose and motivation for meeting others suffering COPD appeared to facilitate social interaction between participants in comparison to simply meeting with others where there was no purposeful work to be done. Further research might investigate why social interaction is facilitated during pulmonary rehabilitation.

There is growing interest in the management of chronic diseases like COPD, especially considering the burden they will place on the health system into the future. This study supports the ongoing use of outpatient pulmonary rehabilitation programs which have expert health professionals available to develop partnerships with those who have COPD. These programs facilitate opportunities for social interaction, develop an individual's understanding of COPD and improve physical functioning.

This study was set in a rural community. Australian and overseas literature has provided valuable insight into the experiences of people living with chronic diseases in a rural setting, including difficulties faced finding the right doctor and travel or distance as a barrier to healthcare (Fitzgerald, Pearson, & McCutcheon, 2001; Goodridge, et al., 2010). While the rural setting of this study gave the potential for issues related to rurality to be explored, these were not specifically raised by participants during interviews. This may be due to the small sample size of the study.

Implications for future research

This study has provided an example of how qualitative research can be used by physiotherapists to explore the experiences of their patients and gain a greater understanding of how the interventions they offer impact on everyday life. While qualitative research has been undertaken in areas of musculoskeletal and neurological physiotherapy, qualitative research by physiotherapists exploring the impact of cardiopulmonary interventions like pulmonary rehabilitation is less common. In a qualitative study of physiotherapists providing rehabilitation to spinal cord injured patients, Papadimitriou (2008) describes physiotherapists as being most comfortable treating an individual's medical diagnosis rather than their illness experience. When working in rehabilitation settings physiotherapists often see their work with patients as consisting primarily of hands-on activity or exercise (Papadimitriou, 2008). However, research has shown that a person's sense of coherence and predictability is challenged when faced with the diagnosis of a long-term medical condition (Ellis-Hill, Payne, & Ward, 2008) and this requires the work of rehabilitation to involve more than just the physical elements of adjustment to disease, but also psychological and social processes. It is in the psychological and social processes of pulmonary rehabilitation that further research is required to recognise and understand the work done by physiotherapists. This will enable physiotherapists to see their work as more than just physical exercise training.

Individuals living with COPD in rural Australia delay seeking help and information about early signs of breathlessness. When advice is sought, information needs are often unmet and this results in feelings of anxiety and frustration. While this study identified some factors which contribute to the delay in diagnosis and unmet information needs, further research is required to identify other issues which contribute to the lack of understanding about the diagnosis and prognosis of COPD. Understanding these issues may assist in the development of earlier and improved access to, and understanding of, information about COPD, reducing frustration and anxiety felt during the diagnostic phase of this disease.

This study has provided insight into the reality of life with COPD. The findings highlight the impact of COPD on physical function and social connectedness, as well as the struggle individuals have to understand the diagnosis and prognosis of COPD. Experiences of participants in this study have indicated that pulmonary rehabilitation provides timely access to information as well as support from expert health professionals, and facilitates interaction between those suffering from COPD. Further research into how these positive components of pulmonary rehabilitation might be incorporated into the long term care of people with COPD would be valuable.

Finally, it is acknowledged that this study only looks at the experience of living with COPD in non-indigenous Australians. COPD is a significant health problem in Australia's indigenous population, with COPD affecting approximately 20% of indigenous adults nationally (The Australian Lung Foundation, 2012). Further research which specifically explores the experience of living with COPD and pulmonary rehabilitation in the indigenous population is required.

Limitations

The limitations of this study are acknowledged. The sample size for the two groups in this study was small with only four participants in each, however, qualitative research aims for depth and richness in data rather than a larger number of participants. The knowledge, perceptions and the experiences documented during this study are only those of individuals living in the Shoalhaven area, and while it is reasonable to suggest that the findings of this study may provide greater insights into the experience of living with COPD, the findings were not generated for generalisation.

One criterion for participation in the study was that participants had a primary diagnosis of COPD. The researcher's initial plan was to ensure the accurate diagnosis of COPD with spirometric assessment prior to interviews, however, ethics approval was not given for spirometry to be performed and an alternate method of diagnosis had to be found. This resulted in the use of a diagnosis given by either a respiratory physician or hospital medical officer. Shirtcliffe, Weatherall, Marsh, Travers, Hansell, McNaughton, et al. (2007) suggest that the prevalence of COPD varies markedly depending on the definition used and this was demonstrated during the course of the research project. One potential participant was excluded from the study following an interview during which the researcher determined the diagnosis of COPD given by a hospital medical officer was instead more likely a diagnosis of chronic heart failure.

Participants who had completed pulmonary rehabilitation were all known to the researcher in contrast to those who had not completed pulmonary rehabilitation. This may have influenced the data collection in regards to the depth and topics disclosed during the interview process. Recruitment of NPR participants was limited to those presenting to an emergency department or having a hospital admission. This has resulted in those not requiring this level of care being unrepresented in this study. While the two different recruitment methods used could limit comparisons between the two groups, future research wishing to compare PR and NPR participants should consider using the same recruitment strategy for both groups. This would assist in minimising differences between the two populations being studied.

It is acknowledged that the findings of this study may have been strengthened by repeated interviews with participants. Future studies may benefit from using multiple interviews which would facilitate an understanding over time of influence of pulmonary rehabilitation on the experience of living with COPD.

Despite these limitations, the study provides valuable insight into the experience of living with COPD in a rural Australian setting. The strength of this study lies in the personal accounts and experiences gained during interviews. These give a deeper and richer description of living with COPD than measurements taken on quality of life scales.

Conclusion

This study gives insight into the experience of living with COPD in rural Australia and provides these insights from the perspective of those who suffer daily with COPD. It is the first Australian study to compare those who have and have not participated in pulmonary rehabilitation and in doing so demonstrates the positive influence participation can have on the experience of living with COPD. The findings describe the long and complex journey individuals take to realise symptoms of breathlessness to be an illness known as COPD. Furthermore, the study reveals that the reality of life for those with COPD is of declining physical function and alterations to one's sense of connectedness.

While this study has explored and identified the experience of living with COPD in rural Australia, the findings are also congruent with the international literature and add to the growing body of knowledge in this area. The findings suggest that the experience of living with COPD is difficult and challenging. Individuals experience breathlessness silently over a long period of time. Great difficulty is encountered when acquiring and understanding information about the diagnosis and prognosis of COPD and often the progressive nature of the disease is only understood as it is experienced over time.

Furthermore, declining physical function leaves those with COPD feeling ineffective. It limits participation in both physical and social activities and changes relationships. The impact of COPD is felt not only by those with the disease but by family members who observe and assist those with COPD on a daily basis.

Importantly, however, differences identified between the two groups of participants in this study demonstrate that the experience of living with COPD can be positively influenced by participation in pulmonary rehabilitation. Participation in a pulmonary rehabilitation program provides access to peer support networks, results in the development of supportive relationships with health professionals, develops a better understanding of COPD and improves physical functioning.

The study gives valuable insight into the communication deficiencies between health professionals and those with COPD and the resultant impact on an individual’s illness experience. Participation in pulmonary rehabilitation was an opportunity to develop meaningful relationships with health professionals where effective and timely communication of information occurred.

For physiotherapists, this study has demonstrated the value of qualitative research in understanding their role in pulmonary rehabilitation. It recognises the importance of physiotherapy work beyond that which is physical, in particular, the time they spend talking and assisting individuals to explore and understand their illness experience.

Looking to the future, this study challenges health professionals to consider how they might support people with COPD in the long term as they face the difficulties of understanding COPD, declining physical function and alterations to connectedness with others, particularly considering the long and slow progression of this disease.

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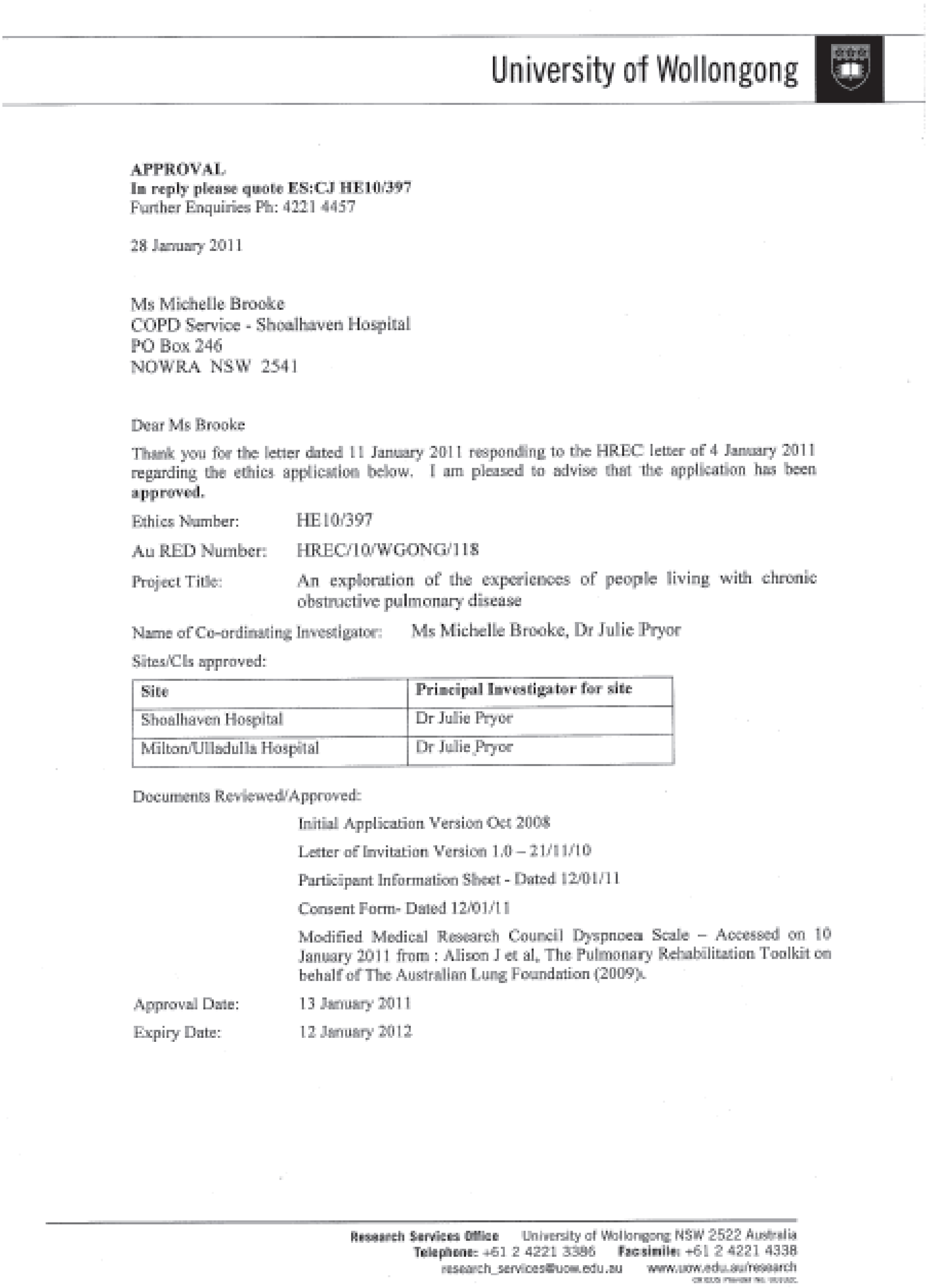
Appendix A: Ethics Forms



University of Wollongong

APPROVAL
In reply please quote ES:CJ HE10/397
Further Enquiries Ph: 4221 4457

28 January 2011

Ms Michelle Brooke
COPD Service - Shoalhaven Hospital
PO Box 246
NOWRA NSW 2541

Dear Ms Brooke

Thank you for the letter dated 11 January 2011 responding to the HREC letter of 4 January 2011 regarding the ethics application below. I am pleased to advise that the application has been **approved.**

Ethics Number: HE10/397

Au RED Number: HREC/10/WGONG/118

Project Title: An exploration of the experiences of people living with chronic obstructive pulmonary disease

Name of Co-ordinating Investigator: Ms Michelle Brooke, Dr Julie Pryor

Sites/CIs approved:

Site	**Principal Investigator for site**
Shoalhaven Hospital	Dr Julie Pryor
Milton/Ulladulla Hospital	Dr Julie Pryor

Documents Reviewed/Approved:

Initial Application Version Oct 2008

Letter of Invitation Version 1.0 – 21/11/10

Participant Information Sheet - Dated 12/01/11

Consent Form- Dated 12/01/11

Modified Medical Research Council Dyspnoea Scale – Accessed on 10 January 2011 from : Alison J et al, The Pulmonary Rehabilitation Toolkit on behalf of The Australian Lung Foundation (2009).

Approval Date: 13 January 2011

Expiry Date: 12 January 2012

Research Services Office University of Wollongong NSW 2522 Australia
Telephone: +61 2 4221 3386 **Facsimile:** +61 2 4221 4338
research_services@uow.edu.au www.uow.edu.au/research

Dear Michelle Brooke

This is a formal correspondence from the ***Southern Adelaide Clinical Human Research Ethics Committee****. Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements with the registration number EC00188. This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." This department only uses email correspondence for all documents unless prior arrangements have been made with the manager. No hard copy correspondence will be issued.*

Application Number: 073.11

Title: An exploration of the experiences of people living with chronic obstructive pulmonary disease

Chief investigator: Michelle Brooke

The Issue: The Southern Adelaide Health Service / Flinders University Human Research Ethics Committee (SAFUHREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following document:

- Cover Letter
- General Research Application
- Letter of invitation version 1, dated 21 November 2010.
- Participant information sheet, dated 20 March 2011
- Consent form, dated 20 March 2011
- Letter of Approval University of Wollongong/SESIAHS HREC
- Letter of Endorsement, Department Head, Shoalhaven COPD Service

Approval Period: 23 March 2011 to 23 March 2014

Please retain a copy of this approval for your records.

TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

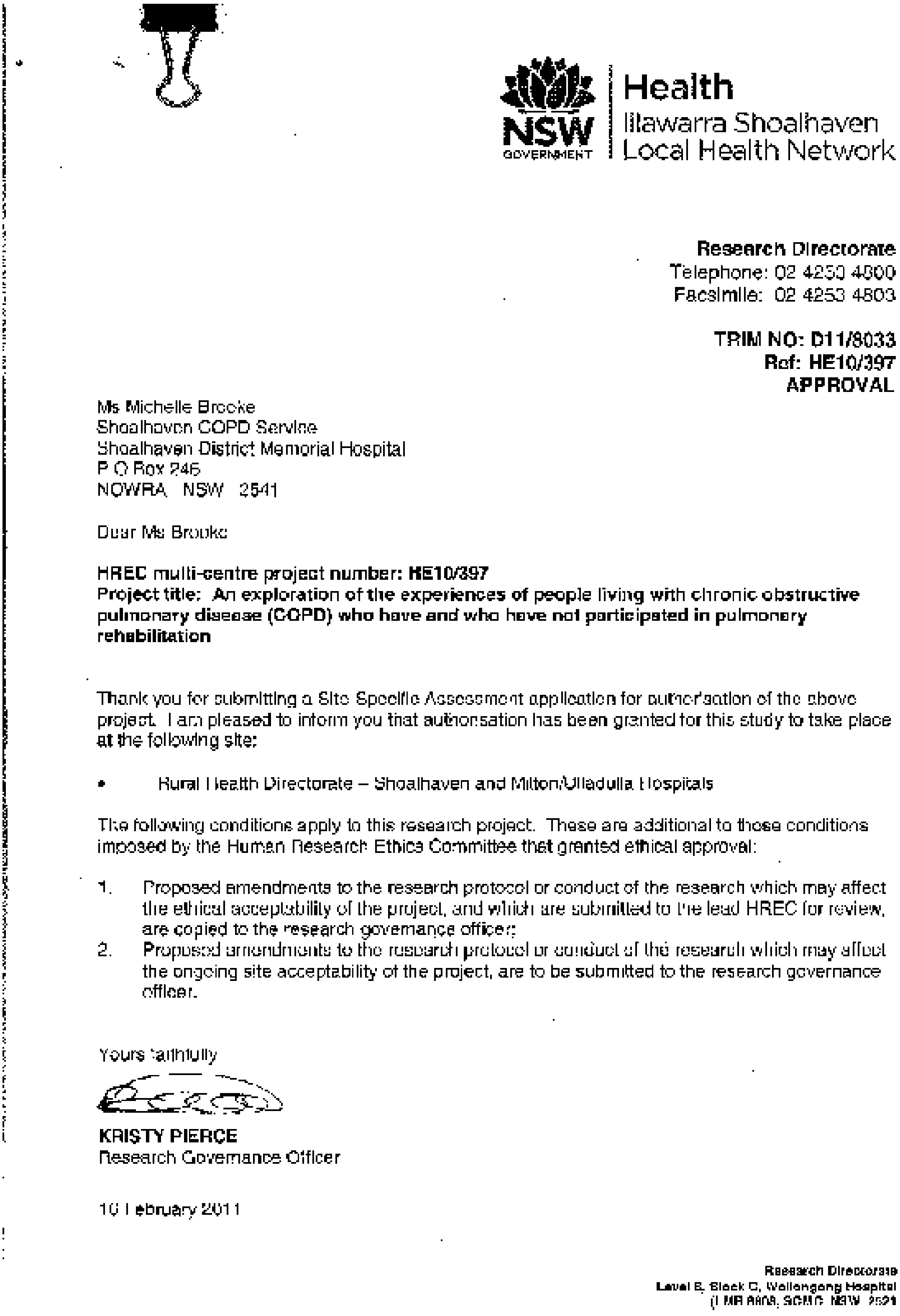
1. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007)
2. To immediately report to FCREC anything that may change the ethical or scientific integrity of the project.
3. To regularly review the FCREC website and comply with all submission requirements as they change from time to time.
4. Submit an annual report on each anniversary of the date of final approval and in the correct template from the FCREC website
5. Confidentiality of research participants MUST be maintained at all times.

6. A copy of the signed consent form must be given to the participant unless the project is an audit
7. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
8. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
9. The researchers agree to use electronic format for all correspondence with this department.
10. All requests for access to medical records at any SAHS site must be accompanied by this approval email.

Kind regards,
Monika

Monika Malik
A/Administrative Services Officer
Southern Adelaide Clinical Human Research Ethics Committee
SA Health
Room 2A221 - Inside Human Resources
Flinders Medical Centre, Bedford Park SA 5042
Tel: 08 8204 6453
Fax: 08 8204 4586
Email: research.ethics@health.sa.gov.au
Website: http://www.flinders.sa.gov.au/research/pages/ethics/6590/

This email may contain confidential information, which maybe legally privileged. Only the intended recipient(s) may access, use, distribute or copy this e-mail. If this email is received in error, please inform the sender by return e-mail and delete the original. If there are doubts about the validity of this message, please contact the sender by telephone. It is the recipient's responsibility to check the e-mail and any attached files for viruses.



NSW GOVERNMENT
Health
Illawarra Shoalhaven
Local Health Network

Research Directorate
Telephone: 02 4253 4800
Facsimile: 02 4253 4803

TRIM NO: D11/8033
Ref: HE10/397
APPROVAL

Ms Michelle Brooke
Shoalhaven COPD Service
Shoalhaven District Memorial Hospital
P O Box 246
NOWRA NSW 2541

Dear Ms Brooke

HREC multi-centre project number: HE10/397
Project title: An exploration of the experiences of people living with chronic obstructive pulmonary disease (COPD) who have and who have not participated in pulmonary rehabilitation

Thank you for submitting a Site Specific Assessment application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Rural Health Directorate – Shoalhaven and Milton/Ulladulla Hospitals

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

KRISTY PIERCE
Research Governance Officer

10 February 2011

Research Directorate
Level 8, Block C, Wollongong Hospital
LMB 8808, SCMC NSW 2521

Appendix B: Participant documents

SOUTH EASTERN SYDNEY
ILLAWARRA
NSW HEALTH

(Insert date)

Dear

I would like to inform you of a research project that may interest you. The research looks at the experiences of people with breathing problems who have or have not participated in pulmonary rehabilitation.

The researchers are looking for approximately 10 to 15 people who have completed pulmonary rehabilitation and 10 to 15 people who have not completed pulmonary rehabilitation to talk about what they know about their breathing problems, how they manage their breathing problems as well as their experiences related to their breathing problems. The attached participant information sheet outlines the project as well as risks and benefits associated with the project. Also included is a consent form which will allow you to indicate your willingness to participate in the project.

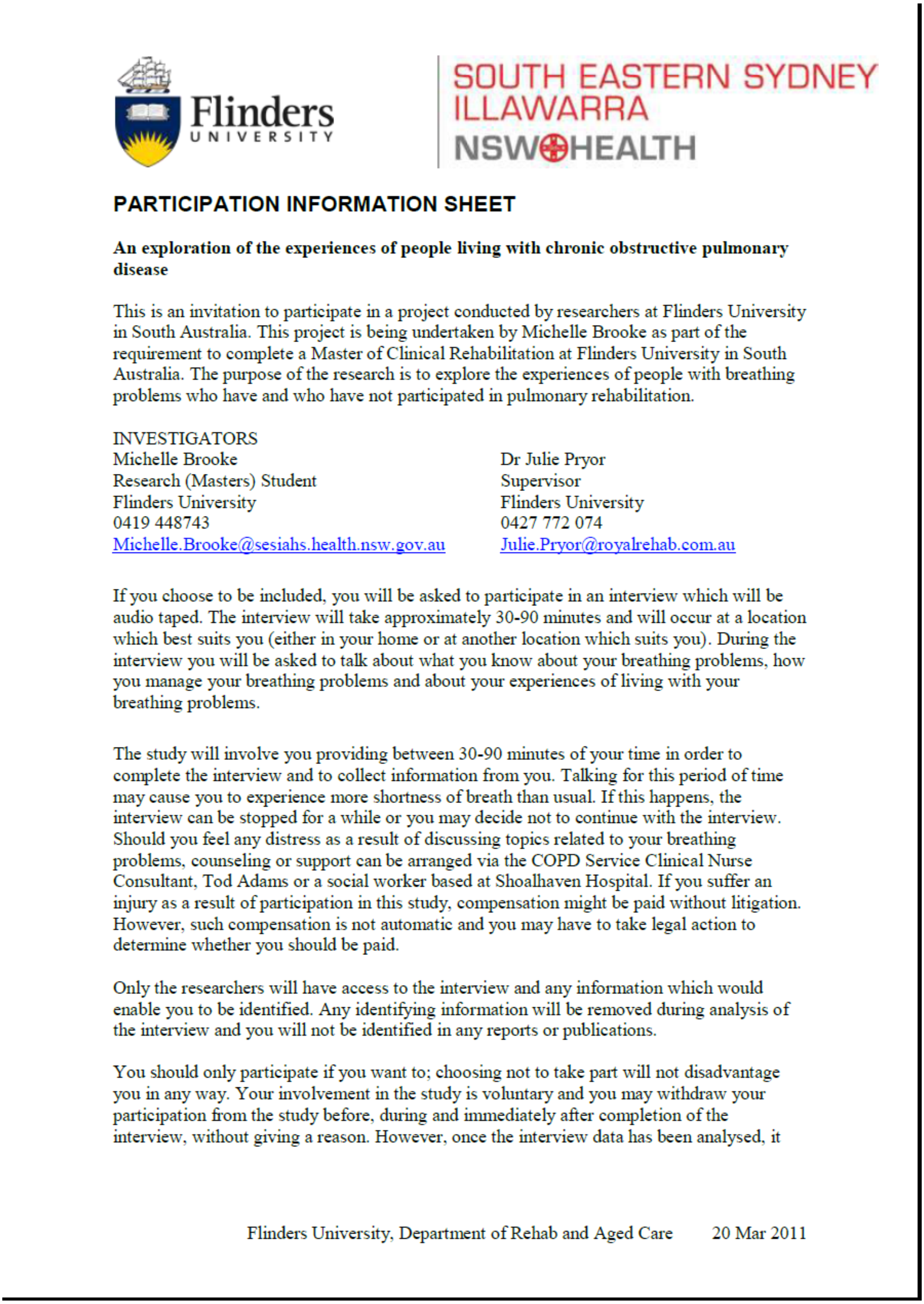
Should you be interested in participating in the project, please sign and return the consent form in the addressed and reply paid envelope as soon as possible. The researchers will then contact you to arrange a time and place most convenient for you to participate in the interview.

For further information, please refer to the participant information sheet which outlines the project. You can also contact me or use the contact details provided on the information sheet if you wish to ask further questions regarding your involvement in the project.

Yours sincerely,

Tod Adams
Clinical Nurse Consultant COPD Service
Tod.Adams@sesiahs.health.nsw.gov.au
Ph: (02) 44239705

Ver 1 Flinders University, Department of Rehab and Aged Care 21 Nov 2010



Flinders UNIVERSITY

SOUTH EASTERN SYDNEY ILLAWARRA
NSW HEALTH

PARTICIPATION INFORMATION SHEET

An exploration of the experiences of people living with chronic obstructive pulmonary disease

This is an invitation to participate in a project conducted by researchers at Flinders University in South Australia. This project is being undertaken by Michelle Brooke as part of the requirement to complete a Master of Clinical Rehabilitation at Flinders University in South Australia. The purpose of the research is to explore the experiences of people with breathing problems who have and who have not participated in pulmonary rehabilitation.

INVESTIGATORS

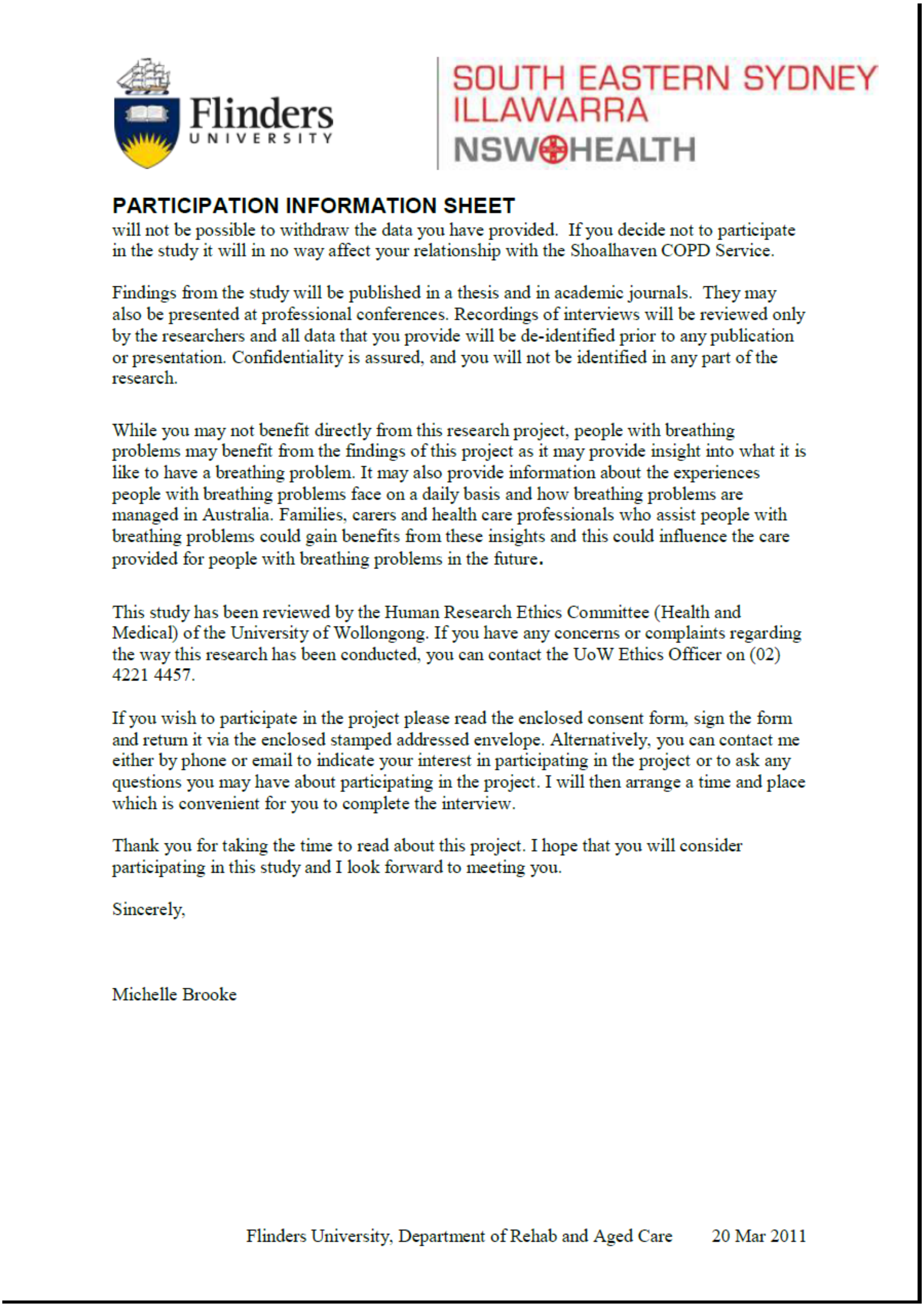
Michelle Brooke	Dr Julie Pryor
Research (Masters) Student	Supervisor
Flinders University	Flinders University
0419 448743	0427 772 074
Michelle.Brooke@sesiahs.health.nsw.gov.au	Julie.Pryor@royalrehab.com.au

If you choose to be included, you will be asked to participate in an interview which will be audio taped. The interview will take approximately 30-90 minutes and will occur at a location which best suits you (either in your home or at another location which suits you). During the interview you will be asked to talk about what you know about your breathing problems, how you manage your breathing problems and about your experiences of living with your breathing problems.

The study will involve you providing between 30-90 minutes of your time in order to complete the interview and to collect information from you. Talking for this period of time may cause you to experience more shortness of breath than usual. If this happens, the interview can be stopped for a while or you may decide not to continue with the interview. Should you feel any distress as a result of discussing topics related to your breathing problems, counseling or support can be arranged via the COPD Service Clinical Nurse Consultant, Tod Adams or a social worker based at Shoalhaven Hospital. If you suffer an injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

Only the researchers will have access to the interview and any information which would enable you to be identified. Any identifying information will be removed during analysis of the interview and you will not be identified in any reports or publications.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Your involvement in the study is voluntary and you may withdraw your participation from the study before, during and immediately after completion of the interview, without giving a reason. However, once the interview data has been analysed, it



Flinders
UNIVERSITY

SOUTH EASTERN SYDNEY
ILLAWARRA
NSW HEALTH

PARTICIPATION INFORMATION SHEET

will not be possible to withdraw the data you have provided. If you decide not to participate in the study it will in no way affect your relationship with the Shoalhaven COPD Service.

Findings from the study will be published in a thesis and in academic journals. They may also be presented at professional conferences. Recordings of interviews will be reviewed only by the researchers and all data that you provide will be de-identified prior to any publication or presentation. Confidentiality is assured, and you will not be identified in any part of the research.

While you may not benefit directly from this research project, people with breathing problems may benefit from the findings of this project as it may provide insight into what it is like to have a breathing problem. It may also provide information about the experiences people with breathing problems face on a daily basis and how breathing problems are managed in Australia. Families, carers and health care professionals who assist people with breathing problems could gain benefits from these insights and this could influence the care provided for people with breathing problems in the future.

This study has been reviewed by the Human Research Ethics Committee (Health and Medical) of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UoW Ethics Officer on (02) 4221 4457.

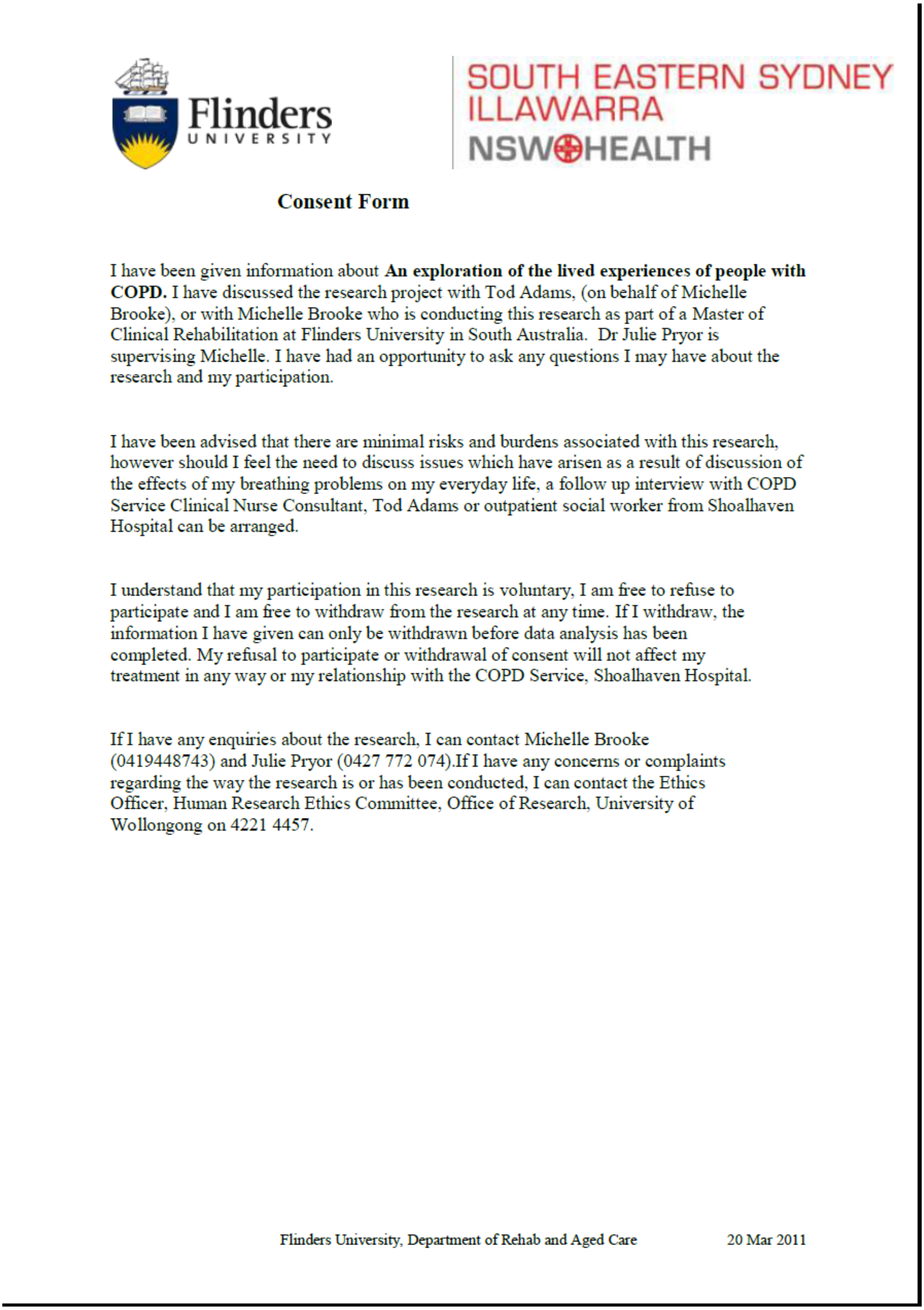
If you wish to participate in the project please read the enclosed consent form, sign the form and return it via the enclosed stamped addressed envelope. Alternatively, you can contact me either by phone or email to indicate your interest in participating in the project or to ask any questions you may have about participating in the project. I will then arrange a time and place which is convenient for you to complete the interview.

Thank you for taking the time to read about this project. I hope that you will consider participating in this study and I look forward to meeting you.

Sincerely,

Michelle Brooke

Flinders University, Department of Rehab and Aged Care 20 Mar 2011



Consent Form

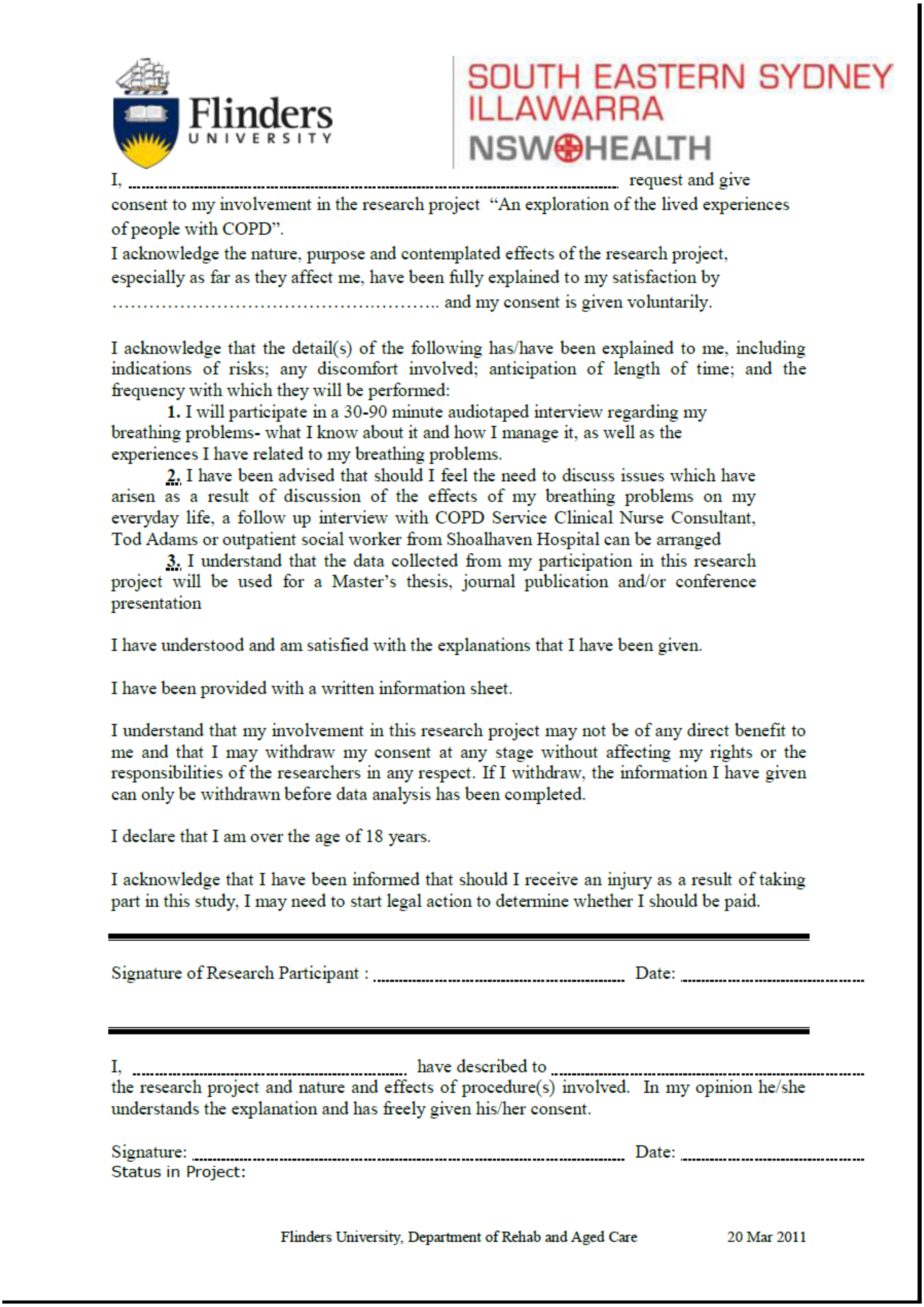
I have been given information about **An exploration of the lived experiences of people with COPD.** I have discussed the research project with Tod Adams, (on behalf of Michelle Brooke), or with Michelle Brooke who is conducting this research as part of a Master of Clinical Rehabilitation at Flinders University in South Australia. Dr Julie Pryor is supervising Michelle. I have had an opportunity to ask any questions I may have about the research and my participation.

I have been advised that there are minimal risks and burdens associated with this research, however should I feel the need to discuss issues which have arisen as a result of discussion of the effects of my breathing problems on my everyday life, a follow up interview with COPD Service Clinical Nurse Consultant, Tod Adams or outpatient social worker from Shoalhaven Hospital can be arranged.

I understand that my participation in this research is voluntary, I am free to refuse to participate and I am free to withdraw from the research at any time. If I withdraw, the information I have given can only be withdrawn before data analysis has been completed. My refusal to participate or withdrawal of consent will not affect my treatment in any way or my relationship with the COPD Service, Shoalhaven Hospital.

If I have any enquiries about the research, I can contact Michelle Brooke (0419448743) and Julie Pryor (0427 772 074).If I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

Flinders University, Department of Rehab and Aged Care 20 Mar 2011



Flinders
UNIVERSITY

SOUTH EASTERN SYDNEY
ILLAWARRA
NSW HEALTH

I, ... request and give consent to my involvement in the research project "An exploration of the lived experiences of people with COPD".

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by ……………………………………………. and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. I will participate in a 30-90 minute audiotaped interview regarding my breathing problems- what I know about it and how I manage it, as well as the experiences I have related to my breathing problems.

2. I have been advised that should I feel the need to discuss issues which have arisen as a result of discussion of the effects of my breathing problems on my everyday life, a follow up interview with COPD Service Clinical Nurse Consultant, Tod Adams or outpatient social worker from Shoalhaven Hospital can be arranged

3. I understand that the data collected from my participation in this research project will be used for a Master's thesis, journal publication and/or conference presentation

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect. If I withdraw, the information I have given can only be withdrawn before data analysis has been completed.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

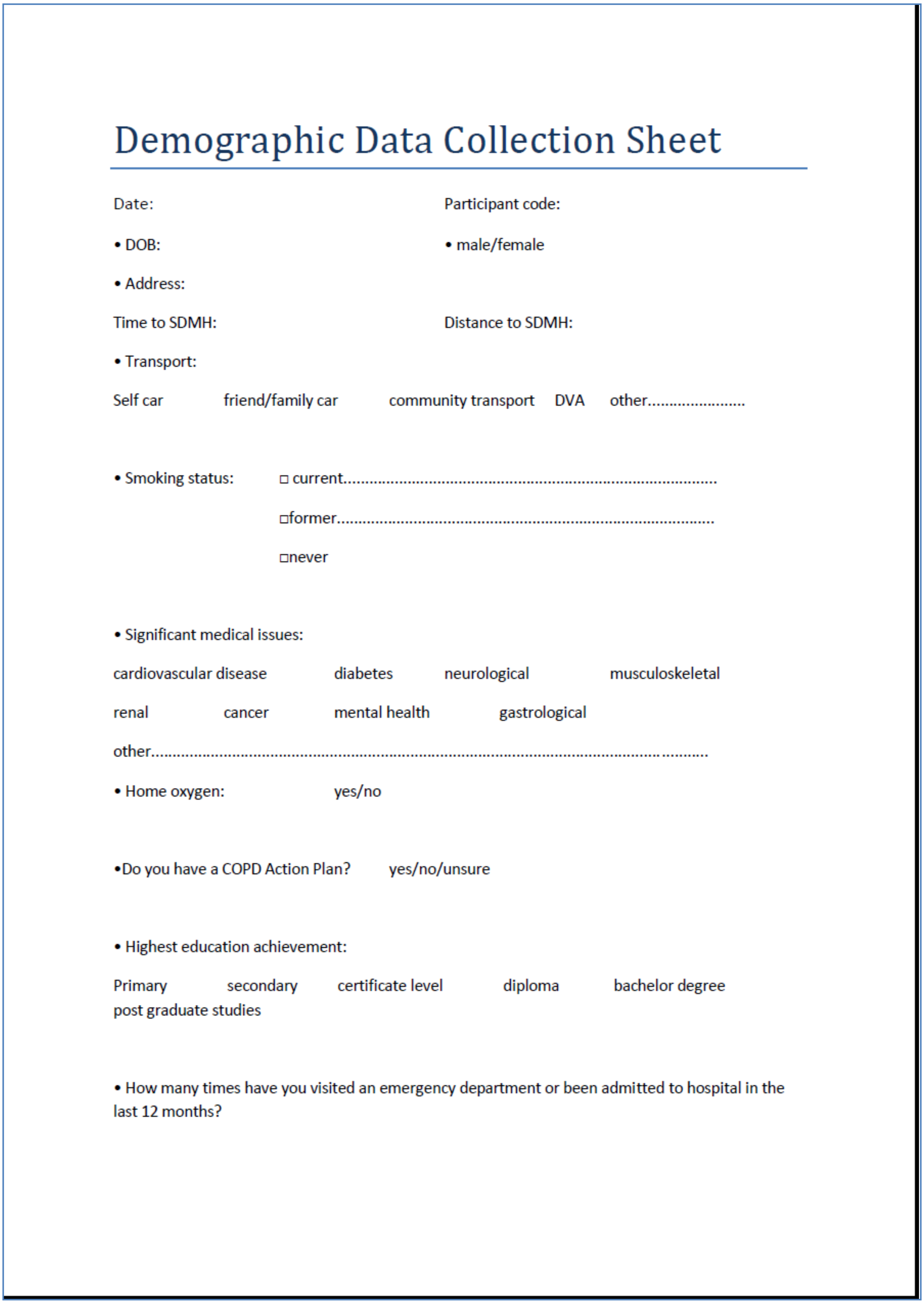
Signature of Research Participant : .... Date: ....

I, ... have described to .... the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: .... Date: ....
Status in Project:

Flinders University, Department of Rehab and Aged Care 20 Mar 2011

Appendix C: Data collection tools



Demographic Data Collection Sheet

Date: Participant code:

• DOB: • male/female

• Address:

Time to SDMH: Distance to SDMH:

• Transport:

Self car friend/family car community transport DVA other......................

• Smoking status: ☐ current...

☐former...

☐never

• Significant medical issues:

cardiovascular disease diabetes neurological musculoskeletal

renal cancer mental health gastrological

other...

• Home oxygen: yes/no

•Do you have a COPD Action Plan? yes/no/unsure

• Highest education achievement:

Primary secondary certificate level diploma bachelor degree
post graduate studies

• How many times have you visited an emergency department or been admitted to hospital in the last 12 months?

Modified Medical Research Council Dyspnoea Scale

Grade

0 "I only get breathless with strenuous exercise"

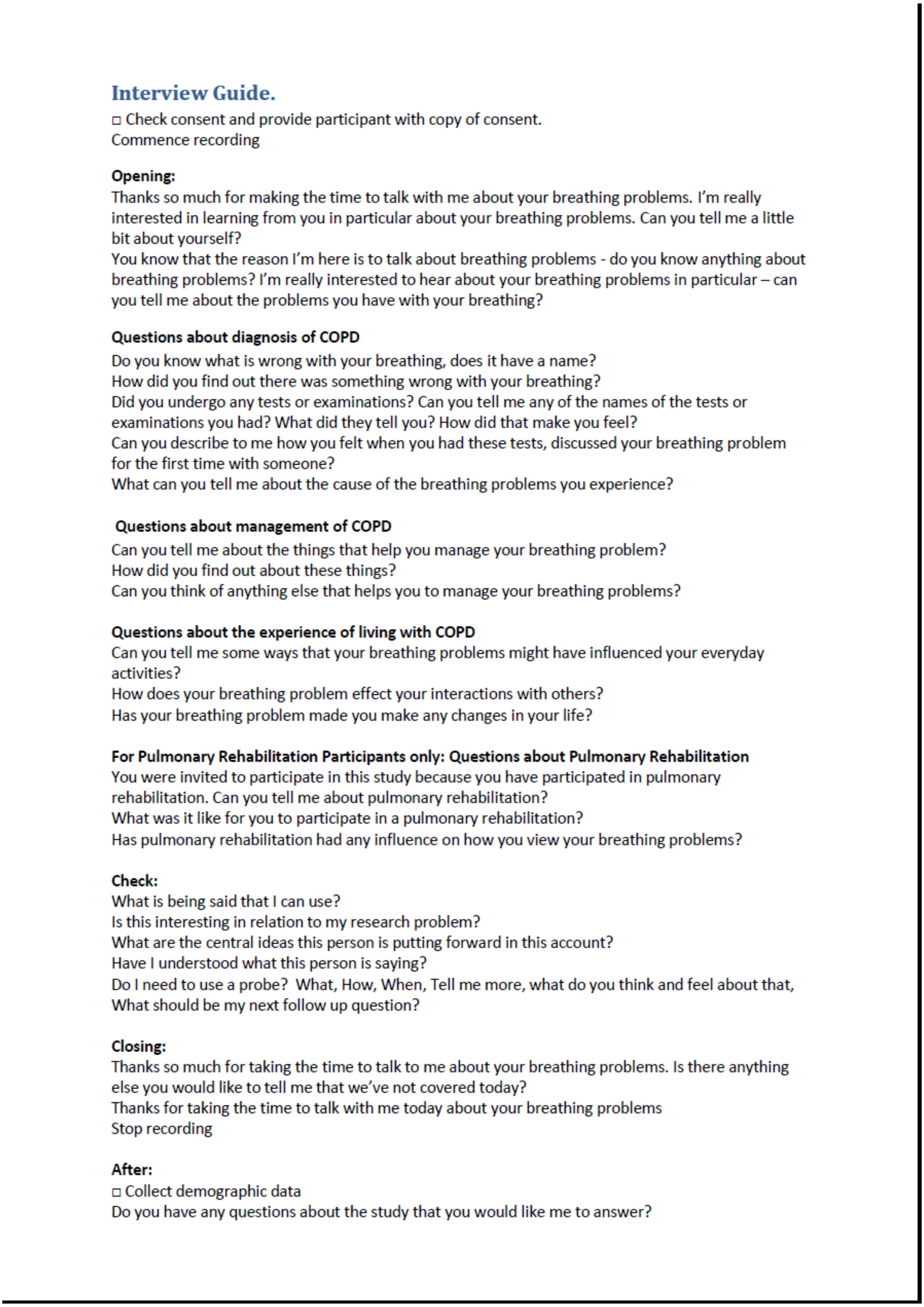
1 "I get short of breath when hurrying on the level or walking up a slight hill"

2 "I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level"

3 "I stop for breath after walking about 100 yards or after a few minutes on the level"

4 "I am too breathless to leave the house" or "I am breathless when dressing"

From Alison J et al, The Pulmonary Rehabilitation Toolkit on behalf of The Australian Lung Foundation (2009).



Interview Guide.

☐ Check consent and provide participant with copy of consent.
Commence recording

Opening:
Thanks so much for making the time to talk with me about your breathing problems. I'm really interested in learning from you in particular about your breathing problems. Can you tell me a little bit about yourself?
You know that the reason I'm here is to talk about breathing problems - do you know anything about breathing problems? I'm really interested to hear about your breathing problems in particular – can you tell me about the problems you have with your breathing?

Questions about diagnosis of COPD
Do you know what is wrong with your breathing, does it have a name?
How did you find out there was something wrong with your breathing?
Did you undergo any tests or examinations? Can you tell me any of the names of the tests or examinations you had? What did they tell you? How did that make you feel?
Can you describe to me how you felt when you had these tests, discussed your breathing problem for the first time with someone?
What can you tell me about the cause of the breathing problems you experience?

Questions about management of COPD
Can you tell me about the things that help you manage your breathing problem?
How did you find out about these things?
Can you think of anything else that helps you to manage your breathing problems?

Questions about the experience of living with COPD
Can you tell me some ways that your breathing problems might have influenced your everyday activities?
How does your breathing problem effect your interactions with others?
Has your breathing problem made you make any changes in your life?

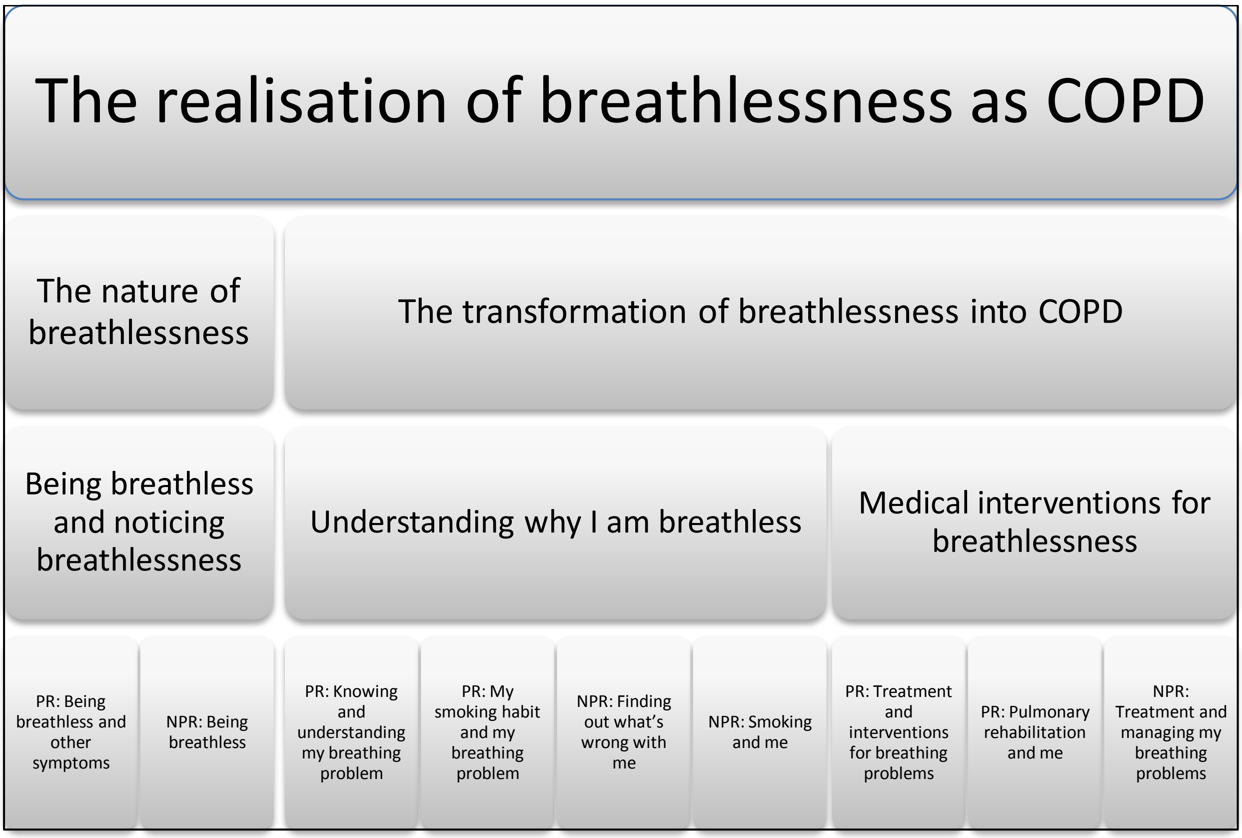
For Pulmonary Rehabilitation Participants only: Questions about Pulmonary Rehabilitation
You were invited to participate in this study because you have participated in pulmonary rehabilitation. Can you tell me about pulmonary rehabilitation?
What was it like for you to participate in a pulmonary rehabilitation?
Has pulmonary rehabilitation had any influence on how you view your breathing problems?

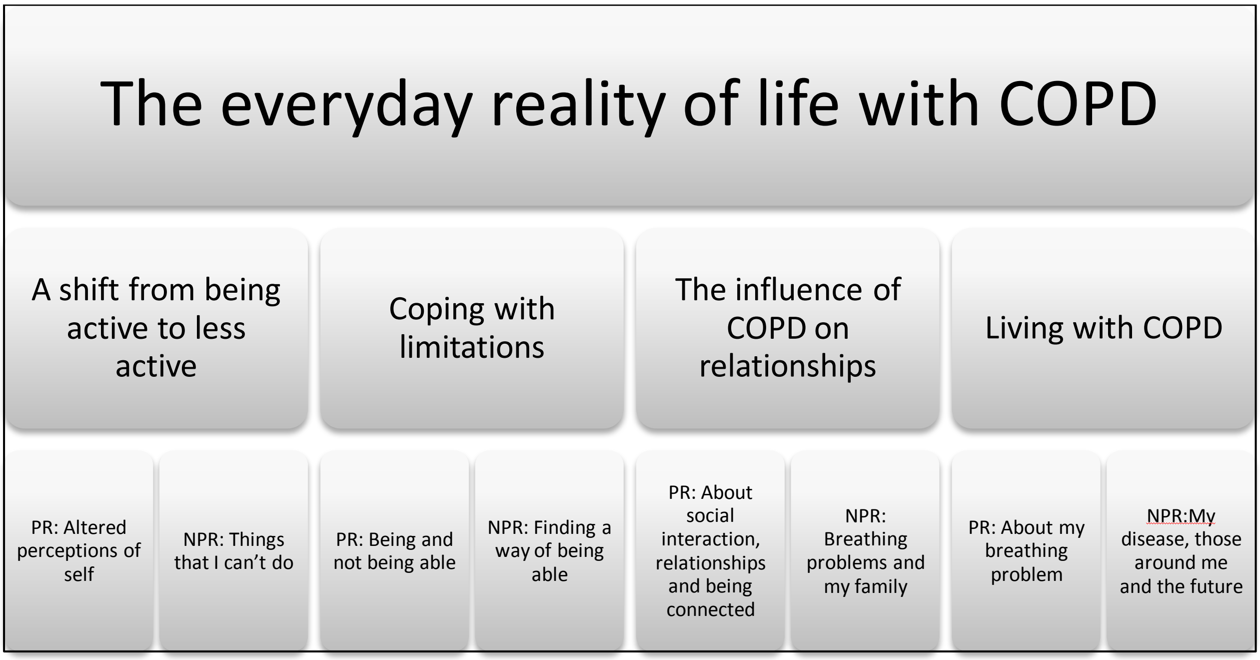
Check:
What is being said that I can use?
Is this interesting in relation to my research problem?
What are the central ideas this person is putting forward in this account?
Have I understood what this person is saying?
Do I need to use a probe? What, How, When, Tell me more, what do you think and feel about that,
What should be my next follow up question?

Closing:
Thanks so much for taking the time to talk to me about your breathing problems. Is there anything else you would like to tell me that we've not covered today?
Thanks for taking the time to talk with me today about your breathing problems
Stop recording

After:
☐ Collect demographic data
Do you have any questions about the study that you would like me to answer?

Appendix D: Theme development





Appendix E: Example of Reflexive Journal

Memo: 30/6/2011- Changing Perspectives

This research project has changed my perspective on clinical practice. I used to think (and I think I was taught this) that as the clinician I knew best and it was my responsibility to impart that knowledge and insist (gently) on change in a person's life in order that they manage their disease/impairment in the most efficient and effective way. This fits with a medical model as well as being time efficient in getting through a certain number of consultations per day. That perspective has now been influence by my research project. I now see value in listening to what people have to say about their disease. I don't become concerned during my research interviews that they are too long or that I am missing certain questions like I would normally during a clinical interview because these research interviews have shown me that if an issue is important to a person they will (more than likely) raise that issue during the course of discussion. Can these research skills influence my practice? I'm not sure. Does public health value the time spent understanding an individual's perspective on their disease or is this considered inefficient use of time and public health resources? Can I as a physiotherapist be allowed to value the time I spend with individuals and not see it as something that is outside my clinical practice (in the domain of the nurse instead?). Physiotherapists should value spending time understanding their clients – and we do have great opportunities to do this but often seem to off load it to other health professionals. We need to learn the value of it and recognise ourselves as capable coaches rather than therapists who simply objectively assess, apply an intervention and measure an objective outcome. People, life and disease are more complicated than that.

Appendix F: Specifications for quality of data analysis and reporting in thematic analysis based on 15 criteria of Braun and Clarke (2006).

No	Criteria	Evidence for meeting criteria
1	Transcription is adequate and accurate.	Verbatim transcription of interview transcripts occurred and these were checked by listening and reading the transcripts simultaneously.
2	During coding all data is given equal attention.	Coding was undertaken in a systematic way by the researcher and was checked by academic supervisor.
3	Themes are generated via a thorough, inclusive and comprehensive coding method rather than from a few vivid examples.	Evidence is provided of the way in which themes developed from a list of 17 key areas to the final two major themes presented in the findings.
4	All relevant data for themes is collated.	Codes from the two participant groups were compiled into separate lists and clustered. These clusters were used to develop early themes.
5	Themes are compared to each other and are checked against the original data set.	During theme development, clusters were compared to look for areas of commonality. During this time, there was constant reviewing of transcripts to ensure data were used in context.
6	Themes are internally coherent, consistent, and distinctive.	Identifying areas of commonality between early themes ensured that developing themes were distinct. Using written summaries, themes developed internal consistency and were checked for coherence.
7	Analysis: Data are analysed and interpreted, rather than simply described or paraphrased.	The researcher has attempted to make sense of the data, recognising the indirect way that the perceptions and experience of living with COPD are conveyed
8	Data extracts provide an illustration of the analytic claims.	Data extracts were checked for context and interpretation by both the researcher and supervisors and included in the presentation of findings.
9	Analysis tells a convincing and well-organized story about the data and topic.	Using written summaries to develop and refine themes assisted in the presentation of an organised account of the dynamic nature of living with COPD.
10	There is a balance between analytic narrative and illustrative extracts	In reporting the findings the researcher has provided data extracts to illustrate the findings of the analysis
11	Overall, there has been adequate time taken to complete all phases of the analysis	All six phases of thematic analysis were applied thoroughly and rigorously to the data. Analysis of data occurred over a six month period.
12	Written report: The approach to and assumptions about thematic analysis are clearly described	The researcher's paradigm as well as the approach to thematic analysis have been described.
13	The description of thematic analysis and the actual analysis performed are consistent	The six phases of thematic analysis provided a clear description and guidelines which were followed.
14	The epistemological position of the analysis are consistent with the language used in the report	The constructivist paradigm in which the research is based is consistent with the reporting of the study findings about the experience of living with COPD
15	The researcher is positioned as active in the research process; themes do not just 'emerge'	The audit trail documented in the researcher's reflexive journal provide evidence of the researcher as being active in the development of themes from the data.