ANGLIA RUSKIN UNIVERSITY

THE EXPERIENCE OF WOMEN AGED UNDER 65
YEARS WORKING AND LIVING WITH CHRONIC
OBSTRUCTIVE PULMONARY DISEASE (COPD)

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ANGLIA RUSKIN UNIVERSITY ABSTRACT

FACULTY OF HEALTH, SOCIAL CARE AND EUCATION

DOCTOR OF PHILOSOPHY

THE EXPERIENCES OF WOMEN AGED UNDER 65 YEARS WORKING AND LIVING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

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Aim: This study aimed to explore how working women with COPD managed their daily lives, which included work.

Background: The prevalence of COPD in women of working age (65 years old and under) is increasing worldwide. The onset of chronic disease can lead to work cessation, which is a significant burden for the worker, the employer and society as a whole. There is little knowledge of how these women manage to remain active and productive in their work and home lives, despite having COPD.

Method: This was a sequential mixed methods study. The primary phase involved semi-structured qualitative interviews and collection of interim data from a sample of six working aged women in the South East of England over a three month period. The secondary phase was a quantitative content analysis on data collected from an online health forum specific for COPD.

Findings: The main findings were that women in this study experienced issues that were age- and gender- specific. Such issues included the need for support in balancing domestic and employment tasks while managing their disease, and difficulties faced in starting relationships, having children and performing activities involved in the mothering role. Using the ICF model, environmental, social and personal factors were found to influence the degree of disease-related limitations the participants perceived, which in turn effected their participation in activities.

Conclusion: This study highlighted the challenges working age women with COPD can experience on a daily basis, such as difficulties balancing domestic and employment tasks while managing their disease, and the physical demands of pregnancy and child rearing. Those who successfully managed their COPD were able to stay at work and had a good quality of life.

Key words: COPD, working women, work and COPD, chronic disease, long-term conditions

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Abbreviations

COPD: Chronic Obstructive Pulmonary Disease

FEV1: Forced Expiratory Volume in one second

FVC: Forced Vital Capacity

Chapter 1. General Introduction

1.1 Introduction

Chronic obstructive pulmonary disease (COPD) is the third leading cause of death worldwide (WHO, 2014). Until now, COPD has been branded 'a disease of old people' (COPD Digest, 2011), however more than half of the 210 million people estimated to have COPD globally, are aged between 40 and 65 years old (Fletcher et al., 2011; COPD Digest, 2011; Hernandez et al., 2009). The prevalence of COPD continues to increase, as a result of aging populations and incessant exposure to risk factors (Lopez, 2006a). More women now have COPD than men, and the prevalence of COPD in women worldwide continues to rise considerably (American Lung Association, 2013). COPD develops at a younger age in women, who experience a greater severity of disease and symptoms and a poorer quality of life than men, even when they have been exposed to a similar level of risk factors (Ghouse et al., 2014; Agustí et al., 2010; Sørheim et al., 2010; Carrasco-Garrido et al., 2009). Throughout this thesis, 'quality of life' refers to the *standard of health, comfort and happiness experienced by an individual or group'* (Oxford Dictionaries, 2016e).

Increasing numbers of working age (16-65 years) women are developing COPD (Cerveri et al., 2008), with women in this age group often at important stages of their careers, and generally have the main responsibility of taking care of and supporting their families (Fletcher et al., 2011; COPD Digest, 2011). In industrialised countries*,* women of working age form an important part of the workforce (Burckhardt et al., 2005). Despite the number of women in paid employment increasing considerably over the last few decades, generally, women continue to have the principal responsibility of domestic chores and child care within the home, spending considerably more time than men performing these tasks (Scott and Clery, 2013; Gibb, Fergusson and Boden, 2013). Thus, when COPD develops in women of working age, they must cope with the disruptive effects of the disease whilst simultaneously managing their work and home lives, presenting challenges to the individual and society (Fletcher et al., 2011; COPD Digest, 2011). Throughout this thesis, a distinction has been made between formal work, termed 'work' or 'paid work' and informal work performed at home, termed 'housework,' 'domestic chores' or 'unpaid work'.

This chapter will describe the context of the study and provide an overview to the content of this thesis. A brief background to COPD follows, providing the rationale for

conducting this research study which focuses on COPD and women of working age. The objective of this research study is then defined and research questions specified. Followed by a brief summary of the conceptual framework which will guide the study, followed by the actual methods that will be used to conduct the research. Then a list of terms used throughout this thesis are defined, and information about the researcher is provided. Finally, a summary of the content of the subsequent chapters (2-8) of this thesis is given.

1.2 Significance of This Study

Previous studies that explored the impact of COPD in the areas of work and home life focused either on very severe disease symptoms, daily limitations and coping of men and women past retirement age (over 65 years) (Solem et al., 2013; DaCosta DiBonaventura, 2012a; DaCosta DiBonaventura, 2012b), or the financial consequences of COPD in the workplace, in the form of time off work due to sickness, reduced productivity or having to leave the workforce all together (Fletcher et al., 2011). The focus of this research study was not on disease symptoms, but rather to explore and understand how women, under 65 years, with COPD managed their daily lives with COPD, involving their work and home lives, so they can continue working and maintain a good quality of life. This study is one of only a few that focuses specifically on women with COPD (O'Neill, 2002; Sexton and Munro, 1988). Knowledge gained from this study, on how COPD affects the work and home lives of women under 65 years, could provide the foundations for further research and potentially inform policy makers, employers, health care professionals, and women themselves, of successful ways in which COPD can be managed, enabling women with COPD to stay at work and have a good quality of life, for longer.

1.3 Background

The Global Initiative for Chronic Obstructive Lung Disease (GOLD), consists of a committee of COPD experts that are working towards increasing awareness and improving prevention and treatment of COPD worldwide (GOLD, 2015). Members of the GOLD committee evaluate new findings relating to COPD and update the published GOLD reports which present a global strategy for the diagnosis, management, and prevention of COPD (GOLD, 2015). Reports are openly available, for free, from the GOLD website (GOLD, 2015). According to GOLD reports, the development of COPD is the result of cumulative exposure to respiratory irritants over time (GOLD, 2013; GOLD, 2015). A high level of exposure increases the risk of

developing COPD earlier, compared to those who have less exposure to risk factors (GOLD, 2013). Although cigarette smoking is recognised as the principal cause of developing COPD, various other factors have been associated with the disease (GOLD, 2015). Such factors include social deprivation and features of low socioeconomic status, such as a poor diet and occupations exposure to dust, indoor pollutants like smoke from wood and coal fires, damp, stale living conditions, passive smoking as well as smoking recreational drugs e.g. heroin and cannabis, have all been associated with COPD (British Lung Foundation, 2012a; Matheson et al., 2005; Hnizdo et al., 2004; Sezer et al., 2006; Orozco-Levi et al., 2006). Many smokers evade developing COPD, while other people that have never smoked (termed 'never-smokers') have been shown to develop airflow limitation, characteristic of COPD (Salvi and Barnes, 2009; Hagstad et al., 2012). Researchers have proposed that women are more biologically susceptibility to developing COPD (Lomas, 2006; GOLD, 2013), and reportedly develop the disease at a significantly younger age or express a more rapid decline in lung function than men (Ghouse et al., 2014; Agustí et al., 2010).

The number of women developing COPD has been increasingly, and for the first time, in industrialised countries the prevalence of COPD in women has now overtaken the number of men with the disease (American Lung Association, 2013). The rate at which COPD is developing in the female populations of certain countries is so rapid, that the spread of COPD in women has been described as a worldwide epidemic (Sin, 2007). In addition, population studies exploring the prevalence of COPD have found that after matching men and women for stage of disease, women were much younger than men, with some expressing signs of the disease in their early 40s (Silverman et al., 2000; Sørheim et al., 2010). Many women of around this age are likely to be working. This study aims to understand how such women manage their life with COPD. Although I recognise that the retirement age is changing and that people can retire before or after the official retirement age, this study uses the current working age for women, that is between 16 and 65 years old (Age UK, 2016).

1.4 Aim and Research Questions

The overall aim of this sequential mixed methods study was to explore how working women, aged under 65 years, with COPD and living in the East of England, manage their daily work and home lives.

The research questions for this study were:

1. How do women of working age perceive their COPD, and how do they view the impact the disease has on their life?
2. What are the strategies these women implement to manage work and other daily responsibilities with the disease symptoms?
3. Are the findings from a small sample of working-age women in the South of England typical of a broader range of people with COPD worldwide?

Research questions one and two are addressed in Chapters five and six, while the third research question is addressed in Chapter seven.

1.5 An Overview of the Methodology

The theoretical underpinning of this study was pragmatism and the methodology was mixed methods. Pragmatism was selected as the paradigm of choice because it is a flexible worldview, which supports the implementation of research methods that are more likely to comprehensively answer the research question, instead of restricting the researcher to certain methods that are affiliated to certain paradigms i.e. the positivist and constructivist paradigms (Creswell, 2009).

A sequential exploratory mixed methods design was used in this study, which consisted of both a dominant qualitative phase and a secondary quantitative phase. The aim of using both qualitative and quantitative research methods in this study was to comprehensively answer the research questions (1-3) and in so doing, gain an understanding of how working women, in specific, and the wider population, in general, manage their life with COPD.

The variety of methods in this study were organised into two phases, the dominant, qualitative phase (Phase One) and the secondary, quantitative phase (Phase Two), the components of which can be seen in Figure 1.
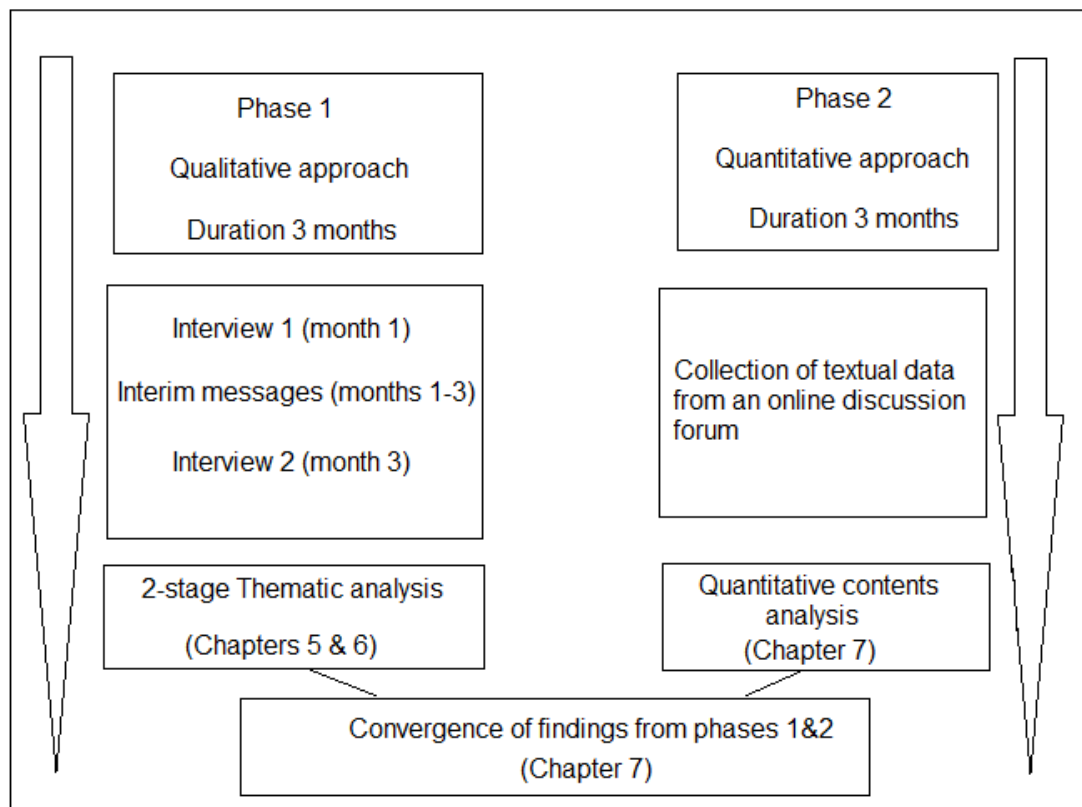
Figure 1: The research methods used in this two-phase study.

The mixed methods design utilised two Phases; Phase One and Phase Two. Phase one involved the qualitative research methods semi-structured interviews and regular 'diary-like' messages. While Phase Two used the quantitative research method of quantitative content analysis of pre-existing information on an online COPD-specific forum.

The qualitative data was collected and analysed first, followed by the collection and analysis of the quantitative data. Priority was given to the qualitative phase of the study, with the aim being to explore 'how' women of working age perceive their COPD and the impact it had on their life, and 'what' coping strategies they used to manage their daily life with the disease. Whereas the quantitative phase was secondary, and provided a means of testing transferability of the findings from a small sample of women under 65 years in the South East of England, with findings from a much larger cohort of people living with COPD worldwide. The qualitative and quantitative phases were analysed separately with the findings from each phase being converged in the interpretation stage of the study.

The two qualitative semi-structured interviews of Phase one were conducted three months apart. In between interviews there was regular (biweekly) contact with the

participant through mobile phone text messages or private messages sent on the social networking internet site Facebook (www.facebook.com). The objective of the regular written contact with participants was to capture real life data as close in time as possible to when it actually happened and in so doing, reduce the retrospective memory bias (Alaszewski, 2006). The qualitative data was analysed thematically, both longitudinally (for each participant) and cross-sectionally (across all participants). Thematic analysis required me to become familiar with the data, then code the data and construct themes. The longitudinal thematic analysis was then written up in the form of a story about the participant's life with COPD, while the cross-sectional analysis described the commonalities and differences that emerged from analysing the data for all the participants combined.

Phase Two used quantitative content analysis of pre-existing data posted on an online forum. This involved quantifying the qualitative written data by thematically analysing the data, identifying themes that appear in the text and counting the frequency the themes appeared in the data. A matrix was created into which the results for Phase Two were inserted as themes and frequency, this is shown as Table 9. A brief summary of the content of each theme is presented in Table 7. The objective of Phase Two was to confirm the findings of Phase One, and in so doing test the convergence and transferability of findings between a small cohort of working women with COPD in England, with a much larger cohort of people living with COPD worldwide.

1.6 Glossary of Key Terms in This Thesis

A definition of the following words or phrases in the context of this thesis:
- 'Woman'; an adult female person, with 'women' being the plural form (Merriam-Webster, 2016).
- 'Young (adulthood)'; the time of life between 20 and 40 years old (Cuthbertson, 2011).
- 'Middle age'; the period of life between 40 and 65 years old, when a person is 'no longer young but have not yet become old' (Collins, 2016a).
- 'Work'; a method of earning an income, it is also used to describe the place a person is employed and any activity that involves mental or physical exertion in order to reach an end result (Oxford Dictionaries, 2016a).
- 'Employed'; 'the state of being employed for a wage or salary' (Oxford Dictionaries, 2016b).
- 'Employment' is the 'state of having paid work' (Oxford Dictionaries, 2016c).

- 'Working age'; the age a person can legally work (GOV.UK, 2015a; Age UK, 2016).
- 'Housework'; the regular work done in maintaining a household, particularly cleaning and tidying (Oxford Dictionaries, 2016d).
- 'Quality of life'; the *standard of health, comfort and happiness experienced by an individual or group'* (Oxford Dictionaries, 2016e).
- 'Interim'; 'the time between two particular periods' (Cambridge Dictionary, 2016). Here 'interim messages' or 'interim data' refers to the diary-like messages written by participants within the three month time period between the first and second telephone interviews.

1.7 About the Researcher

My academic and professional background has inevitably influenced the content of this thesis. Therefore, information regarding my position as a researcher will assist the reader in understanding and contextualising the research conducted.

I come from a scientific background, with a bachelors and masters in Biomedical Science. Since graduating, I became extremely interested in women's health, especially in the areas of chronic disease and work. As a young woman myself, I am very interested in how women, not much older than myself, cope psychologically and physically with the onset of a chronic disease, and how other factors in their life influence how they manage their life with a chronic disease.

This thesis is written from a non-health specialist perspective as I do not have a nursing or medical background. I approached this research as an outsider, as I do not have a chronic disease myself, therefore I did not have any expectations about what young women with COPD would discuss and so I could bring a fresh perspective to the research.

Before recruiting participants I familiarised myself with older people living with COPD by attending various 'BreathEasy' support groups organised by the British Lung Foundation, a UK charity that focuses on respiratory health, which enabled me to talk to older people with COPD. First hand contact with people who had the disease for a long time and also reading literature about previous studies involving older people with COPD, provided some background information about what daily life with the disease was life.

Also, prior to data collection, I attended courses on qualitative research methods and training to conduct qualitative, semi-structured interviews.

1.8 Overview of the Thesis

The thesis is comprised of a further seven chapters. Chapter Two provides general background information on the chronic disease that is COPD, including a definition and physiology and prevalence of the disease. Followed by a description of causative agents and a more detailed explanation of the two most researched risk factors; cigarette smoking and genetic factors. It also presents a summary of disease burden and disease symptoms, issues around disease diagnosis and describes treatment methods including medication and surgical intervention. As woman are more susceptible to COPD than men, a separate section details the key aspects in which women are biologically more predisposed to developing the disease.

The third chapter is a review of the literature exploring what is already known about chronic disease in the workforce. The review will start by exploring previous research into chronic disease in general and work, including the challenges and benefits of working with a chronic disease and important aspects that influence whether chronically ill workers stay at work or have to stop working prematurely because of their health condition. Then previous research studies that focused on chronically ill women and work will be reviewed. Finally, the few studies that explored workers (both men and women) with COPD is reviewed, including the limitations workers experienced at work, because of their COPD, and the correlation between disease severity and employment. The final section in Chapter Three describes the conceptual model, the 'International Classification of Functioning, Disability and Health', which this study uses.

Chapter Four is the methodology and methods chapter, in which the theoretical underpinnings of this mixed methods study are described and a brief history of emergence of the mixed methods research methodology is provided. The rationale for adopting a mixed methods approach is also given, followed by a description of the study's two phase exploratory sequential mixed methods design and details of the qualitative and quantitative research methods are provided.

Chapter Five presents the findings from longitudinal analysis of qualitative data from participants in Phase One. While Chapter Six presents the findings from cross-sectionally analysing the qualitative data from all six participants. Chapter Seven reports the results from Phase Two, the quantitative content analysis of data posted

on an online, COPD-specific forum. The findings from both the phases one and two will then be converged and presented in this chapter. The thesis concludes with Chapter Eight, which highlights the main findings drawn from the study and discusses them in the context of the wider literature. Then the strengths and limitations of the study are considered, followed by recommendations for future research, policy and practise and the overall conclusion of this thesis.

Chapter 2. Placing COPD in Context

2.1 Introduction

This chapter provides the reader with a concise overview of the fundamental aspects of chronic obstructive pulmonary disease (COPD), including prevalence, risk factors, disease burden, symptoms, and diagnosis. The aim being to provide sufficient background information about the disease to make the subsequent chapters comprehensible. In this chapter, the main sources of information were reports published from the Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD) and guidelines from the National Institute for Health and Care Excellence (NICE), as they provided detailed, coherent information about COPD. Also, as the material from these organisations has been amalgamated by experts and are continuously updated with new findings from current research, these sources of information were considered trustworthy and accurate. As the objective of this study is to explore the lives of working women with COPD, where possible the chapter is directed towards women with the differences between men and women with COPD being highlighted.

2.2 Chronic Obstructive Pulmonary Disease

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) define COPD as a common and preventable disease, characterised by persistent and progressive airflow limitation, caused by a chronic inflammatory response in the airways and lungs to noxious particles or gases (GOLD, 2014; p.19).

Chronic airflow limitation, a characteristic of COPD, is produced by chronic bronchitis (small airways disease) and emphysema (parenchymal destruction), either alone or in combination (Kanervisto, Kaistila and Paavilainen, 2007; Alfonso et al., 2011). The presence and severity of chronic bronchitis and/or emphysema vary from person to person (GOLD, 2014).

Airflow limitation is usually defined as a decreased ratio of Forced Expiratory Volume in one second (FEV1) over the Forced Vital Capacity (FVC) (GOLD, 2014). FEV1 is defined as the volume of air that can be forcibly exhaled, in the first second after taking a deep breath (NHANES, 2008), whereas FVC is the total volume of air that can be forcibly and rapidly exhaled from the lungs, after taking a deep breath (Miller and O'Toole, 2003). The FEV1 and FVC are measured by a spirometry test, which

involves a device termed a 'spirometer' measuring a patient's lung function by calculating both the volume of air the patient forcibly (Miller and O'Toole, 2003; Bellamy, 2004; GOLD, 2014). The ratio between FEV1 and FVC is then expressed as a percentage, and provides a quantitative value for a patient's lung function (Bellamy, 2004; GOLD, 2014). Persistent airflow limitation that is not fully reversible is characterised by a FEV1 and a FEV1/FVC ratio of less than 0.70 (or 70%), after administration of a bronchodilator (Pauwels et al., 2004). FEV1 decreases with increased severity of airflow limitation (GOLD, 2010), as shown in Table 1. Bronchodilators are medicines that relax the bronchial muscles, causing the airways to enlarge, making it easier for air to enter and leave the lungs (American Thoracic Society, 2015) and are often prescribed for patients with COPD.

Table 1: Stages of COPD and associated airflow limitation. Adapted from (GOLD, 2010; p.9).

Stage	Severity	FEV1 (predicted)	Disease Manifestation
I	Mild	More than or equal to 80%	A cough is sometimes present, possibly accompanied by sputum production. Symptoms are often mild and go unnoticed.
II	Moderate	50-79%	Breathlessness on exertion. This is the stage at which medical advice is often sought.
III	Severe	30-49%	Further decline of airflow limitation, increased shortness of breath, reduced exercise capacity and recurrent exacerbations.
IV	Very severe	Less than 30%	Severe airflow limitation and exacerbations which can be fatal.

The pulmonary damage which results in airflow limitation develops over decades, usually because of accumulative exposure to one or more risk factors (see section 2.6), and goes unnoticed for many years, until symptoms, such as breathlessness or wheezing become severe enough the individual seeks medical advice (GOLD, 2010).

2.3 Symptoms

COPD is a heterogeneous disease, with symptoms varying greatly from person to person, as well as fluctuating significantly within the same person (Agustí et al., 2010). Breathlessness is reported to be the most burdensome symptom, present at all disease stages, and can occur during physical exertion as well as at rest (Rabe, 2006; O'Neil, 2002). Breathlessness can greatly affect an individual's daily functioning and life style (Kanervisto, Kaistila and Paavilainen, 2007).

Extreme breathlessness and dyspnoea are the main symptoms experienced during an acute exacerbation (Bailey, 2004), characterised by an acute worsening of the patient's respiratory symptoms beyond the typical day-to-day variations (Rodriguez-Roisin, 2000; Hurst et al., 2004; Celli and Barnes, 2007). Exacerbation episodes are highly traumatic experiences, and the severe struggle for breath may result in thoughts of imminent death (Rabe, 2006; Bailey, 2004).

The main causes of exacerbations are bacterial and/or viral infections, and exposure to environmental respiratory irritants, such as air pollution and extremes of temperatures (Celli and Barnes, 2007; GOLD, 2014; Bailey, 2004; Agustí et al., 2010). However, a cause is not always identifiable (Celli and Barnes, 2007). Each exacerbation causes an accelerated decline in lung function, deterioration in health status and increased risk of death (Celli and Barnes, 2007). The occurrence and duration of exacerbations varies greatly between individuals (Agustí et al., 2010; Aaron et al., 2012). Increased breathlessness has been closely associated with emotional factors (Bailey, 2004). Bailey (2004) explored the association between emotions and the experience of dyspnoea and acute exacerbations, from the patient's perspective (Bailey, 2004). Bailey found that normal emotional reactions to everyday situations, such as participating in arguments, and getting angry or frustrated, temporarily increased breathlessness (Bailey, 2004).

In addition to chronic and progressive dyspnoea, other characteristic symptoms of COPD are a persistent cough and the production of sputum, which can vary daily (Kessler et al., 2011; Espinosa de los Monteros et al., 2012). A chronic cough and sputum production may occur years before airflow limitation develops in patients with

COPD (GOLD, 2014). Conversely, significant airflow limitation may develop in the absence of a chronic cough and sputum production (GOLD, 2014). Sputum produced by COPD patients involves the emergence of small amounts of tenacious sputum following coughing bouts (GOLD, 2014). A change in sputum colour and thickness can indicate the presence of a respiratory infection and possibly the start of a bacterial infection (Stockley et al., 2000). However, sputum is often difficult to assess because patients may swallow sputum rather than expectorate it, a habit that is determined by significant cultural and gender disparity (GOLD, 2014). The presence of a chronic cough and sputum production in patients with COPD, has been associated with frequent exacerbations (Burgel et al., 2009), an increase in disease progression (Vestbo, Prescott and Lange, 1996), and premature death in patients with COPD (Pelkonen et al., 2006; Ekberg-Aronsson et al., 2005).

The frequent production of sputum has also been associated with embarrassment, anxiety, depression and fatigue in individuals, as well as urinary incontinence resulting from chronic coughing (NICE, 2016). A recent study also found that frequent sputum production was related to disturbed sleep and low sleep quality in patients with COPD (Hartman et al., 2015). Together these factors have been related to a low quality of life in patients with COPD (Scharf et al., 2010; Nunes et al., 2009).

The ECLIPSE study explored the heterogeneity of COPD in a large cohort consisting of 2163 clinically stable COPD patients, 337 smokers with normal lung function and 245 never-smokers (Agustí et al., 2010). The study design involved a baseline visit, and an evaluation of the participants three months and six months after the baseline, and then every six months over a three year period. The results showed women with COPD perceived more symptoms of higher intensity, and experienced more exacerbations during the study period, compared to than men with COPD. In this study, women also reported having a poorer quality of life than their male counterparts for a similar level of airway obstruction.

2.4 Diagnosis

The symptoms exhibited in COPD are ubiquitous among many other respiratory and non-respiratory conditions (Roberts, Smith and Partridge, 2011). For this reason, international guidelines have been produced to enable medical professionals to accurately diagnose COPD (GOLD, 2013; Bellamy, 2004). The criteria for diagnosis is based on the presence of symptoms and a history of exposure to risk factors, with diagnosis confirmed by a spirometry test (GOLD, 2013; Roberts, Patel and Partridge,

2016). Most modern spirometer devices calculate the FEV1/FVC value and compare the result against a reference value, an expected value for an individual with normal lung function of the same sex, age and height as the patient being tested, the lung function for that patient is displayed as a percentage (Pellegrino et al., 2005; Bellamy, 2004). Lung function naturally decreases with increasing age, however, airflow obstruction is considered when the FEV1/FVC value is below 70% (GOLD, 2014). The lower the FEV1 value, the more severe the airflow obstruction and COPD (Bellamy, 2004). Medical advice is typically sought when the individual has moderate disease (stage II), as the disease symptoms become more apparent (GOLD, 2010). As well as confirming diagnosis, spirometry testing is used to monitor disease progression (Bellamy, 2004). The stages of disease and their associated FEV1, % predicted values, as categorised by GOLD, are depicted in Table 1.

Although spirometry devices are present in most hospitals and primary care settings, they are being underused (Roberts, Smith and Partridge, 2011; Yu et al., 2013). This could be because of practical issues such as busy medical settings being understaffed and time restrictions to attend to patients (Moore, 2007), as well as a lack of adequate training and confidence in using the spirometry device and interpreting the results (Bellamy, 2004). All of which can result in underdiagnoses or misdiagnosis of COPD (British Lung Foundation, 2012b).

In addition, medical professionals may present a gender bias when diagnosing women with COPD, with females less likely than men to be diagnosed with COPD (Aryal, Diaz-Guzman and Mannino, 2013; Chapman, Tashkin and Pye, 2001). This may explain the underdiagnoses in women in particular (Aryal, Diaz-Guzman and Mannino, 2013; Chapman, Tashkin and Pye, 2001). The objective spirometry test can reduce or eliminate this bias, however, first, the spirometry test has to be performed (Chapman, Tashkin and Pye, 2001).

Chapman, Tashkin and Pye (2001) were the first to investigate gender bias in the diagnosis of COPD. Their study involved presenting 192 primary care physicians in North America with hypothetical cases of smokers with dyspnoea and cough, the only variable parameters were sex and age. The hypothetical male patient was significantly more likely to be (provisionally) diagnosed with COPD compared to the hypothetical female patient (64.6% vs 49%; p< 0.05), based on history and physical examination. The most common misdiagnosis of COPD was asthma. Although after the spirometry test was performed, this gender gap did decrease. More recently, Ancochea and colleagues (2013) quantitatively analysed the population burden of COPD from data collected in the EPI-SCAN study, an epidemiologic, observational study involving 11

Spanish centres, and 3,802 participants aged 40-80 years. They found 73% of participants who matched the spirometry criteria for COPD, were underdiagnosed. This was disproportionately distributed between men and women. Women (86.0%) were 1.27 times more frequently underdiagnosed than men (67.6%) (P<.05). Roberts, Patel, and Partridge, (2016) study emphasised the importance of spirometry testing to accurately diagnose COPD. Their study, which involved 445 participants who received a GP's provisional diagnosis of 'definite' or 'suspected COPD', found that following a spirometry test, significantly more women than men were found not to have COPD, refuting the GP's provisional diagnosis. The researchers suggest a difference in disease presentation in both men and women, could make accurate diagnosis of COPD in the 2 sexes difficult.

2.5 Prevalence and Incidence of COPD

Prevalence

Disease prevalence is the proportion of a population that are affected by the disease at a point in time (Epidemiology for the uninitiated, 2018). COPD is currently the third leading cause of death in the world (WHO, 2014), and presents a major burden to the individual, the health system, and society as a whole (GOLD, 2014). The future burden of COPD is projected to increase globally, as a result of aging populations and continued exposure to risk factors (Lopez, 2006b). This is in contrast to other major chronic diseases, such as cardiovascular disease, which are decreasing in prevalence (Unal, Critchley and Capewell, 2004). As COPD is known to be underdiagnosed and under-treated, the prevalence rates are only estimates, with the actual number of people living with the condition thought to be much higher (British Lung Foundation, 2012a; Pauwels and Rabe, 2004; British Lung Foundation, 2012b). For instance, 900,000 people have been estimated to have a diagnosis of COPD in the UK (NICE, 2004), however, findings from Shahab et al., (2006) study, which analysed quantitative data from the 2001 Health Survey for England, projected there to be millions of people in England, who were unaware that they were living with COPD. Hundreds of thousands of people in Spain, especially women, have also been estimated to be living with COPD, but remain underdiagnosed (Ancochea et al., 2013). This is likely to be the case in other countries.

Incidence

Disease incidence is the rate at which new individuals in a population become affected by the disease, during a specified period (Epidemiology for the uninitiated, 2018).

Studies suggest the incidence of COPD varies by country and within populations (Mannino et al., 2002; Menezes et al, 2005; Buist et al., 2007), with the highest rate of COPD being in the subpopulation of individuals aged 65 years and over (Pauwels and Rabe, 2004; Buist et al., 2007) who have typically retired from the workforce. However, increasing numbers of younger people, especially women are also showing characteristics of the disease, namely airflow limitation (Cerveri et al., 2001; Cerveri et al., 2008). Population studies exploring the prevalence of COPD have found that after matching men and women for stage of disease, women were much younger than men, with some women expressing signs of the disease in their early 40s (Silverman et al., 2000; Sørheim et al., 2010).

Despite COPD being a major public health problem, and becoming increasingly widespread, it is a relatively unknown respiratory condition (Rabe et al., 2007; Pauwels and Rabe, 2004), with the majority of people first hearing of the disease at diagnosis (British Lung Foundation, 2012a). Reasons for this widespread unawareness of COPD in the general population of the UK and other countries may be the lack of media campaigns via radio, television, newspapers and social media, which facilitate the wide-spread distribution of information regarding, the risk factors and symptoms of a disease. In comparison, nationwide awareness of other chronic conditions such as diabetes and cancer have increased, with numerous charities using such forms of media to promote the diseases (Cancer Research UK, 2015; Diabetes UK, 2016). The use of social media, sites such as Facebook, Twitter, and video sharing sites such as YouTube are not only useful fundraising and promotional tools, they also enable charities to access and engage with new audiences and facilitate information sharing and the formation of online communities of people who have all been affected by the disease (Diabetes UK, 2016). In addition, numerous cancer charities have partnered with young and older well-known faces, supermarket chains and television companies, that endorse the charities and promote fundraising events, such as the 'Race for Life' and the 12 hour, live-streamed 'Stand up to Cancer UK YouTube party' (Cancer Research UK, 2015).

Diabetes UK work with schools to raise awareness of type 1 diabetes, running a nationwide short-film competition for school children, and present awards for schools and carers, nominated by pupils and their parents for providing good (type 1) diabetes care in schools (Diabetes UK, 2016). Diabetes UK raise awareness of Type 2 diabetes by running roadshows around the country, offering free advice and testing (Diabetes UK, 2016). Such strategies have resulted in people of all ages, nationwide being made more aware of the signs and symptoms of both diabetes and cancer. In contrast, there are few awareness campaigns for COPD, all of which have been introduced relatively

recently. The British Lung Foundation (BLF) introduced the 'Love Your Lungs' campaign, with the objective to '*raise awareness and encourage early diagnosis of COPD*' by holding events in areas of the UK where the inhabitants are '*most at risk of future hospital admission with COPD*' (British Lung Foundation, 2016a)*. The BLF used a lifestyle segmentation tool to determine the location of such areas, with postcode detail, in order to target the campaign in specific communities (British Lung Foundation, 2016a). The event offers free lung screening and information about the disease (British Lung Foundation, 2016a). However, if diagnosis rates are to improve and numbers of people developing COPD is to decrease, it is imperative that awareness be raised in the whole population, especially in those with increased susceptibility to developing the disease, such as young women. It must also be highlighted here that the better known chronic diseases, diabetes and cancer (e.g. breast cancer) have relatively specific signs and symptoms, whereas the symptoms of COPD, such as breathlessness, are ambiguous and can easily be dismissed as a sign of getting older or lack of fitness.

2.6 Risk Factors

The most common risk factor associated with COPD by far, is cigarette smoking, however, there are numerous other risk factors that increase the probability of developing COPD (Alfonso et al., 2011; GOLD, 2014; Jeffery, 1998). A significant risk factor in developing countries is indoor air pollution from burning biomass fuels, used for cooking and heating (GOLD, 2014). This study, however, focuses on COPD in the United Kingdom, a developed country, where the predominant risk factors for developing COPD, as well as smoking cigarettes, include the smoking of heroin and/or marijuana (Walker et al., 2013; British Lung Foundation, 2012a), occupational exposure to (inorganic and organic) dust, gases or fumes, and external air pollution as well as a genetic susceptibility to the disease (Vogelzang et al., 1998; WHO, 2007).

Additionally evidence suggests that subgroups of the population with low socioeconomic status are at higher risk of developing COPD (Prescott and Vestbo, 1999; WHO, 2007). Socioeconomic status (SES) is a measure of a person's economic and social position in relation to other people, based on characteristics such as income, education and occupation (Office for National Statistics, 2014a). Although low socio-economic status (SES) does not itself cause COPD, individuals from disadvantaged social groups are more likely to smoke cigarettes, and to start smoking at a younger age, than people from more privileged backgrounds (ASH, 2015). In addition, prenatal exposure to cigarette smoke, lower respiratory tract infections in

childhood, poor housing conditions, outdoor and indoor air pollution, and a poor diet, are all related to low SES and can increase the chances of developing COPD (GOLD, 2015; Prescott and Vesbo, 1999). Exposure to such risk factors can accelerate the decline in lung function, above the normal rate associated with increasing age (WHO, 2007). As cigarette smoking and genetic factors are the most researched causative agents for developing COPD, they will now be discussed in further detail.

2.6.1 Smoking

Cigarette smoking is by far the most important risk factor for COPD (GOLD, 2014). Cigarette smokers present more lung function abnormalities, having an increased rate of annual decline in FEV1 and they experience more respiratory symptoms, compared to non-smokers in general (Pauwels and Rabe, 2004; GOLD, 2014). The prevalence rates of smoking in general and the ratios of female-to-male smokers vary dramatically across countries (Hitchman and Fong, 2011; WHO, 2008). For example, in developing countries the rate of male smokers is much greater than that of women (Hitchman and Fong, 2011), whereas in developed countries the rate of smoking males and females is comparable (WHO, 2008). In England, a 2013 survey reported 18.7% of adults, aged 18 and over, smoked (Office for National Statistics, 2014b). This survey found that of the respondents 24% of men, and 17% of women smoked. Other high-income countries, such as the U.S.A, Canada and Australia have similar male and female smoking rates (WHO, 2008).

This 2013 survey also revealed a vast difference in smoking in different regions within the UK, with certain areas of the North West of England had high smoking rates, for example, 30% of the population of Hyndburn Unitary Authority in Lancashire smoked, while certain areas in the South of England had much lower rates of smoking, in particular 8% of the inhabitants of Brentwood, in Essex, smoked. Employment also has an impact on smoking rates, with unemployed people (those actively seeking work) and manual workers being more likely to smoke, and smoke more cigarettes per day, than workers in other professions, such as teaching (Office for National Statistics, 2014d).

The difference in rates of female smokers between developed and developing countries may be due to the social and economic status of women and the tobacco industry's marketing of cigarettes towards women as a symbol of independence in developed countries (Amos and Haglund, 2000; O'Keefe and Pollay, 1996). Smoking among women in low- and middle-income countries, however, is predicted to increase dramatically in the following decades (Hitchman and Fong, 2011). Children of parents

who smoke have been found to have a greater risk of developing respiratory difficulties than children of non-smokers, as smoking during pregnancy affects foetal lung development (Blizzard et al., 2003). Also, a child growing up in a smoke-filled environment is more susceptible to respiratory infections and developing chronic airflow obstruction in adulthood (Breton et al., 2014; Blizzard et al., 2003), than a child growing up in a smoke-free environment.

Cigarette smoking is a gendered activity, with men and women having different rationale for taking up smoking, continuing to smoke and giving up smoking (Greaves, 2015). This will be discussed in more detail in section 2.10. The term sex here refers to the biological differences between males and females, i.e. genetics and anatomy, whereas gender refers to the characteristics that society define as masculine or feminine (Nobelius, 2004).

The cigarette companies recognised early on that women differ significantly from men in relation to smoking, and women were seen as a new client base for them to target (Hirschhorn, 2005). One example of how the Tobacco Companies viewed women can be seen in an extract from a 1976 secret research report from The British American Tobacco Company, which has been found and published;

'*Smoking behaviour of women differs from that of men.... [women are] more highly motivated to smoke.... they find it harder to stop smoking.... women are more … likely to need to smoke in stressful situations, presumably because they are less well able to deal with stress… it seems reasonable to assume that [women] will react more strongly to smoking and health pressures.... There may be a case for launching a female oriented cigarette with relatively high deliveries of nicotine....'* (Hirschhorn, 2005).

Although the female smoking rate in the UK has dramatically decreased from its peak in 1974, when 41% of British women smoked (Office for National Statistics, 2014d), Lopez, Collishaw and Piha (1994) proposed that a 30 to 40 year lag time existed, from when a population reaching a peak smoking rate, to the ensuing epidemic of smoking-related diseases, such as COPD. At an individual level, COPD takes decades to develop (Løkke et al., 2006). Additional factors, such as genetic susceptibility to COPD, the age at which a person starts smoking and how many cigarettes they smoke a day and over how many years (termed 'pack-years'), influences the time COPD takes to develop in an individual and the age at which they develop the disease (Lomas, 2006; Ringenbach et al., 2011; Lundback et al., 2003; Pena et al., 2000).

Taken together, this could explain why increasing numbers of young and middle-age women, who are current or ex-smokers are developing COPD.

A strong relationship has been established between cigarette smoking and COPD; most smokers will develop airflow limitation if they live long enough and smoke enough (e.g. continually smoke 20 cigarettes or more per day) (Lundback et al., 2003; Pena et al., 2000). However, not all smokers develop COPD (Rennard and Vestbo, 2006). COPD is also increasingly being diagnosed in people that have never smoked (Hagstad et al., 2012). A genetic predisposition to lung and airway damage offers an explanation as to the high variation in disease susceptibility between individuals (Lomas, 2006).

2.6.2 Genetic predisposition

Some individuals can be genetically predisposed to developing COPD (Brode, Ling and Chapman, 2012). The most documented genetic risk factor for COPD is a hereditary decrease in levels, or depletion of an active alpha-1 antitrypsin (A1AT) protein (Lomas, 2006; GOLD, 2013; Brode, Ling and Chapman, 2012). There are various genetically inherited mutations that have been found in the gene that encodes the protein alpha-1 antitrypsin (A1AT) (Ringenbach et al., 2011). The function of A1AT, when produced at normal levels, is to regulate the enzyme neutrophil elastase, released by white blood cells to combat an infection (Lomas, 2006). Although approximately 1% of people with COPD are reported to have alpha-1 antitrypsin deficiency, it is one of the major reasons people develop airflow limitation between the ages of 20-50 years old, which is significantly younger than those who develop smoking-induced COPD in their 60s (Ghouse et al., 2014; Lomas, 2006). Although the presence of A1AT deficiency genetically predisposes an individual to COPD, smoking cigarettes alters both the age at which it develops and the severity of the disease (Ghouse et al., 2014; Lomas, 2006). Those with severe alpha-1-antitrypsin deficiency who smoke cigarettes tend to develop more severe COPD younger than non-smokers with a similar level of alpha-1 antitrypsin deficiency (Stoller, 1997; Ghouse et al., 2014).

Furthermore, the prevalence of A1AT deficiency in women is considerably higher than in men (Silverman et al., 2000). Silverman and colleagues (2000) explored the relationship between genetics and early-onset COPD. The cohort of this study consisted of 84 probands with severe, early-onset COPD (without severe alpha1-antitrypsin deficiency) and 348 of their first-degree relatives. A 'proband' is a term used in medical genetics and describes '*the first affected individual in a family who*

brings a genetic disorder to the attention of the medical community' (Bennett, et al., 1995). Spirometric values of all first-degree relatives were comparable for males and females (Silverman et al., 2000). However, when first-degree relatives who were current or ex-cigarette smokers were analysed, females had considerably lower FEV1/FVC values, and they were more likely to exhibit significant reductions in FEV1 (<40% predicted), compared to their male counterparts. This suggests that women may be more susceptible to develop severe COPD (Silverman et al., 2000).

While A1AT deficiency is present among all ethnicities, it is much more common among Europeans, and their descendants who migrated around the world (Denden et al., 2012). Higher rates of A1AT deficiency have been found in the White Northern European population as well as the Southern Europeans of the Iberian Peninsula (Lomas, 2006; Denden et al., 2012). While it is relatively uncommon among the Black and Asian populations (Menezes et al., 2005). It has been suggested that the Vikings first brought the A1AT deficiency (mutant) genes to Great Britain when they invaded between 800 and 1100 AD and after centuries of genetic mixing the mutated genes still remain (Lomas, 2006).

2.6.3 Physiological processes in COPD

In both men and women, the incessant inhalation of harmful particles and gases, present in cigarette smoke, stimulates the body to initiate a prolonged inflammatory response, which targets the airways and lung tissue (Alfonso et al., 2011; GOLD, 2013; Jeffery, 1998). Chronic inflammation causes remodelling and narrowing of the small airways (bronchioles), characteristic of chronic bronchitis (GOLD, 2013; Camp et al., 2009). Permanent destruction of lung parenchyma may also occur, which involves the alveoli being cleaved from the bronchioles, creating large gaps in the lung tissue, typical of emphysema (Taraseviciene-Stewart and Voelkel, 2008). Damaged parenchyma significantly reduce the surface area available for gaseous exchange upon each inhalation (Jeffery, 1998). The elastic recoil of the airway is also affected, reducing the capacity of the airway to remain open during exhalation, this causes difficulties in expelling carbon dioxide-laden air from the body (GOLD, 2013). Together inflammation, parenchyma destruction and loss of elastic recoil lead to irreversible airway limitation and disease manifestations (GOLD, 2013). A1AT deficiency-derived COPD, however, has a different pathophysiology. When blood levels of the A1AT enzyme are low or negligible, neutrophil elastase destroys the connective tissue matrix in the alveoli of the lungs, creating emphysematous spaces in the lung tissue (Ghouse et al., 2014). Although the pathophysiology and areas of

lung affected by A1AT deficiency differs from the prolonged exposure to harmful particles, both can result in permanent airway limitation, and lead to similar symptoms.

A study into the epidemiology of COPD found that women are anatomically, genetically and hormonally more predisposed to developing COPD (Demeo, 2007), experiencing more frequent exacerbations and hospitalisations than men (Pardinas Gutierrez, et al., 2016). While the biological mechanisms for this are still elusive, the proposed theories will be discussed in section 2.10.

2.7 Burden of Living with COPD

2.7.1 Introduction

This section provides a brief overview of the often complex and dynamic experience of living with COPD, describing the main factors of disease burden, physical limitations, psychological aspect of living with COPD, quality of life and the strategies implemented to manage the disease. The majority of previous research studies into 'living with COPD', focused on the lives of older people with COPD, recruiting those over the age of 65 years and often with severe COPD (Williams et al., 2007; O'Neill, 2002; Fraser, Kee and Minick, 2006) or were quantitative surveys that were unable to capture the detailed experience of the study participants (Hernandez et al., 2009; Fletcher et al., 2011).

2.7.2 Disease burden

The disease symptoms and psychosocial impact of having COPD places a substantial burden on people living with it (Hernandez et al., 2009). In Hernandez and colleagues' (2009) quantitative telephone survey, which involved 389 individuals with COPD in Canada, the most common symptoms to occur ''every day'' or ''most days'' in descending order of reported frequency were coughing (56%), breathlessness (55%), sputum production (46%), and being woken by their symptoms every night or most nights (11%) (Hernandez et al., 2009). Breathlessness and limitations to physical activity have been reported to be the most distressing aspect of living with COPD (Hernandez et al., 2009; Barnett, 2005; O'Neill, 2002), affecting almost every area of a person's life to varying degrees, especially in people with moderate to severe COPD (Altenburg et al.,2013; Annegarn et al., 2012; Williams et al., 2007).

Individuals living with COPD are confronted with limitations, which can fluctuate daily and increase as the disease progresses and breathlessness worsens (Barnett, 2005; Gullick and Stainton, 2008; O'Neill, 2002; Kanervisto, Paavilainen and Heikkilä,

2007). Although people with severe COPD describe constantly being aware of their breathlessness (Gullick and Stainton, 2008; Fraser, Kee and Minick, 2006), they can experience 'good days' in which the disease symptoms and effects of the disease are minimal, and the disease is placed at the back of their awareness (Fraser, Kee and Minick, 2006). The physical limitations and symptoms experienced by people with moderate to very severe COPD, often prevent them from leaving their homes, and therefore can impact on a person's ability to participate in activities and socialise (Williams et al., 2007; O'Neill, 2002). In addition, COPD has a social impact on people's lives, which can result in life disruption, lowered self-esteem and altered social relationships (Nicolson and Anderson, 2003; Pinnock et al., 2011). All of which could lead to feelings of social isolation and depression, which reduce a person's quality of life (Williams et al., 2007).

2.7.3 Physical limitations and activities of daily living

People with moderate to severe COPD can have difficulty performing even basic daily activities (Belfer and Reardon, 2009), as any physical activity can make them breathless and extremely uncomfortable (Belfer and Reardon, 2009). For example, the basic activities of walking short distances may require those with COPD to pause and catch their breath (Gullick and Stainton, 2008), while driving was reported as unmanageable for some (Williams et al., 2007). COPD can result in a slow decline in a person's ability to exercise, functional ability for ambulatory and leisure activities as well as ability to manage their household tasks (O'Neill, 2002; Gullick and Stainton, 2008). A quantitative study measuring exacerbations and time spend outdoors found that of the 147 participants (mean age 89 years) approximately a third with moderate to severe COPD were housebound when their COPD was stable (Donaldson et al., 2002). During an exacerbation, this number increased to nearly 50% of patients (Donaldson et al., 2002). Exercise intolerance is strongly associated with physical limitations, which is a greater predictor of quality of life and morbidity than the spirometry test (Oga et al., 2003; Skumlien, et al., 2006).

The inability to exercise results in life changes, which together with disease symptoms, impact activities of daily life; from basic ambulatory activities such as eating, bathing, dressing and grooming, to instrumental activities of daily life, which involve a greater level of functioning, e.g. household maintenance, food or clothes shopping and meal preparation (Belfer and Reardon, 2009). People with COPD also reported struggling for breath while trying to multitask, for example, they found the dual action of walking and talking unmanageable (Gullick and Stainton, 2008). The adjustment or elimination of a difficult daily activity is dependent on the necessity or

desirability of the activity, the severity of disease symptoms and personal characteristics (Belfer and Reardon, 2009). Often, the first activities to be stopped are leisure activities as they are not essential to daily life, however, removing such activities can cause a decline in a person's quality of life. (Belfer and Reardon, 2009).

Breathlessness, fatigue, and negative emotions such as depression and anxiety can lead to avoidance of physical activities, which results in muscle weakness and deconditioning, which, in turn, causes any future efforts to perform physical activities to be even more difficult and unmanageable (Belfer and Reardon, 2009). This spiral of deteriorating breathlessness and inactivity frequently results in feelings of anxiety, helplessness, and lack of control of their own bodies, which further contribute to inactivity and general disability (Belfer and Reardon, 2009; Williams et al., 2011; Avşar and Kasilkci, 2010).

2.7.4 The psychological aspect of living with COPD

Psychological factors, such as illness perceptions, negative emotions and one's ability to cope with the illness, affect how a person lives with COPD and participates in day-to-day activities (Disler, Gallagher and Davidson, 2012). According to The Common Sense Model by Leventhal, the perceptions a person has about an illness directs their attempts to cope with the illness (Leventhal, Brissette and Leventhal, 2003). Various studies focusing on COPD patients in primary care (Weldam et al., 2013), attending rehabilitation (Fischer et al., 2009) and in an outpatients setting (Scharloo et al., 2007) have all shown that both illness perceptions and depressive symptoms influence quality of life. Patients with more positive illness perceptions and lower levels of depressive symptoms, had a greater quality of life than patients who had negative illness perceptions and depressive symptoms. In patients with COPD, depression (Yohannes, Baldwin and Connolly, 2003), and anxiety (Brenes, 2003) are the most commonly reported negative emotions, often accompanied by fatigue and trouble concentrating, which could affect participation in daily activities (Guell, et al., 2006),such as performing work tasks.

Other negative emotions reported in people with COPD include guilt, denial, shame and embarrassment related to their disease (Halding, Heggdal, Wahl, 2011; O'Neill, 2002; Gullick and Stainton, 2008). Those living with COPD often experience a 'loss of self' and grieve the loss of their former self (O'Neill, 2002; Gullick and Stainton, 2008), as everything that had formerly defined them as people had changed; their physical ability, spontaneous body movements, their self-image and the image they wanted to portray to others (Gullick and Stainton, 2008). The deteriorating body and the inability to control the disease trajectory can affect an individual's temperament,

resulting in them experiencing anger, frustration, irritation, aggression and hopelessness (Gullick and Stainton, 2008; Odencrants, Ehnfors and Grobe, 2005; Barnett, 2005; O'Neill, 2002).

People with COPD often blamed themselves or feel blamed by others, including medical professionals as the strong association between cigarette smoking and COPD has caused society to view COPD as being self-inflicted (Halding, Heggdal, Wahl, 2011). Feelings of guilt and blame have been found to affect an individual's self-esteem and their quality of life (Toms and Harrison, 2002; Nicolson and Anderson, 2003). In patients with severe COPD, anxiety and fear of severe breathlessness or dyspnoea can become a source of distress (Heinzer, Bish and Detwiler, 2003). One qualitative study found that after several consecutive days of severe breathlessness and physical limitations, participants had considered ending their life (Barnett, 2005). This highlights the great psychological effect of living with COPD, caused by disease symptoms and the consequent restrictions imposed on their daily life.

In addition, the invisibility of COPD often results in others assuming the individual to be healthy and capable (Barnett, 2005; Kanervisto, Kaistila and Paavilainen, 2007). This can result in a lack of understanding and support from others who may expect those with COPD to perform a task which they are incapable of doing or that triggers their breathlessness (Kanervisto, Kaistila and Paavilainen, 2007).

2.7.5 Quality of life

Quality of life, defined as a *'holistic, self-determined evaluation of satisfaction with issues important to the person'* is affected by many factors including family relationships, social interactions, financial security, job satisfaction, as well as health status (Curtis, Martin and Martin, 1997). Disease progression and factors related to the disease, such as fatigue, functional limitations, exercise intolerance and recurrent exacerbations, greatly affect the quality of life of individuals with COPD (Sprangers et al., 2000; Peruzza et al., 2003). A decrease in quality of life often results in increasing dependence on others and has been related to social isolation (Williams et al., 2007) as well as feelings of depression (Belfer and Reardon, 2009; Fraser, Kee and Minick, 2006). Improved self-efficacy (i.e. an individual's belief that they can self-manage their disease) and the implementation of successful management strategies could improve an individual's quality of life (Reardon et al., 2005). In addition, social support has been related to better disease management and greater quality of life (Mahon, O'Brien and O' Conor, 2014). However, a lack of social support among people with COPD has

been associated with social isolation, and a negative perception of their disease and their functional limitations (Williams et al., 2007).

2.8 Management Strategies

A variety of management strategies have been reported by those living with COPD, which include; resting, pacing oneself, restricting activities, using breathing techniques, avoidance, hiding their disease and taking medication (O'Neill, 2002; Gullick and Stainton, 2008). The type of coping strategies used are heavily influenced by an individual's illness perception and their personal characteristics (Leventhal, Brissette and Leventhal, 2003; Boot, van Exel and Gulden, 2009). However, some coping strategies to manage disease symptoms, can be learnt (Fraser, Kee, Minick, 2006; Avşar and Kasilkci, 2010, Cicutto, Brooks and Henderson, 2004). For example, breathing techniques of diaphragmatic breathing or purse-lipped breathing have been commonly reported by people with COPD to consciously slow down their breathing and manage frightening episodes of acute breathlessness (Fraser, Kee, Minick, 2006; Avşar and Kasilkci, 2010; Cicutto, Brooks and Henderson, 2004).

Avoidance strategies have also been reported by those living with COPD, to try and prevent the occurrence of uncontrollable breathlessness and escape embarrassment related to their disease (O'Neill, 2002; Gullick and Stainton, 2008; Sexton and Munro, 1988). Studies found that people with COPD avoid certain situations, such as social environments, which often involve respiratory irritants such as cigarette smoke and perfume, which may aggravate disease symptoms (O'Neill, 2002; Gullick and Stainton, 2008). Social events, which involve physical exertion, such as dancing, are also often avoided (O'Neill, 2002). Avoiding social contact can often lead to social isolation as they cannot participate in activities they once enjoyed (Gullick and Stainton, 2008). In addition to avoidance, some people employ strategies to hide their disease and related physical limitations, as well as by not disclosing their COPD (Halding, Heggdal, Wahl, 2011; Gullick and Stanton, 2008). Although to a certain extent restricting activity can be helpful in managing COPD, regular physical exercise has been recognised to be very important in decreasing the decline in exercise tolerance (GOLD, 2013).

Adopting ways to successfully manage COPD can reduce the occurrence of exacerbations, and slow disease progression, increase health status and functional capability, which could reduce the time absent from work, increase productivity at work and require less medical intervention (daCosta DiBonaventura et al., 2012b;

Fletcher, Albrow and Walker, 2011; Pauwels and Rabe, 2004). A discussion of strategies to manage COPD, both the stable disease and acute exacerbations follows.

2.8.1 Management of COPD; stable disease and exacerbations

Although there is no cure for COPD, there are various ways to slow disease progression, alleviate disease symptoms improve exercise tolerance and increase quality of life, as well as reducing the risk of exacerbations (GOLD, 2015). Disease management should be on an individual basis, as the presence, frequency and severity of symptoms and exacerbations vary greatly from patient to patient, as does one's life-style (GOLD, 2015). A description of a broad range of techniques used to manage COPD is provided here, for the reader to comprehend the strategies discussed by the study participants in the findings chapter later in this thesis (Chapters 5 and 6).

2.8.2 Management strategies for stable COPD

The single most effective approach to reducing disease progression is decreasing one's exposure to risk factors, thus smoking cessation for smokers is an effective management strategy (GOLD, 2015). Pulmonary rehabilitation (PR) is a source of learning and developing strategies to manage COPD, by combining exercise sessions with group discussions and advice on how to manage life with COPD (GOV.UK, 2014a; British Lung Foundation, 2016b). Groups of patients with COPD, all referred onto the course by their GP or other medical professionals, participate in physical exercise sessions, generally for a period of six weeks, led by a team of experts, usually consisting of physiotherapists, respiratory nurse specialists and nutritionists (GOV.UK, 2014a). Exercise sessions usually involve walking or cycling with some exercises to increase one's strength (GOV.UK, 2014a). In PR each participant is encouraged to do as much as they physically can, and with knowledgeable group leaders present, it is a safe and sociable environment to improve one's exercise tolerance, mobility, increase confidence and in turn, quality of life (GOV.UK, 2014a; British Lung Foundation, 2016b). Information on nutrition, living with COPD, financial aid and emotional support are also provided in PR classes (British Lung Foundation, 2016b).

2.9 Pharmacological Therapy

The treatment regimen prescribed to an individual is based on their personal requirements, assessing the severity of their symptoms, their degree of airflow limitation and the frequency and severity of their exacerbations (GOLD, 2015). The types of medication prescribed to patients with COPD include inhalers, antibiotics and steroid tablets and nebuliser treatment.

Inhalers

Inhalers are devices that deliver medication to the patient, with several different types of inhalers available to manage the symptoms of COPD (GOLD, 2015). There include short-acting bronchodilators, long-acting bronchodilators, and steroid inhalers (GOLD, 2015). Bronchodilators cause the smooth muscles in the airways to relax and open, facilitating easier breathing (GOLD, 2015b; GOV.UK, 2014a). Steroid inhalers contain of corticosteroids, which when inhaled, reduce the inflammation in the airways, improving breathlessness (GOV.UK, 2015b).

Nebulisers

Nebulisers are another method of delivering medication, and are prescribed if medication administered via inhalers prove ineffective at relieving symptoms of severe COPD (GOV.UK, 2015b). Nebulised medicine is stored as a liquid form when enclosed in a machine termed a 'compressor' and is converted to a fine spray when administered to the patient via a mouthpiece or face mask (GOV.UK, 2015a). A nebuliser enables a high dose of medicine to be administered in a single application (GOV.UK, 2015b).

Vaccinations

As respiratory tract infections can trigger acute exacerbations of COPD symptoms, which may result in pneumonia or influenza, and consequently hospitalisation, vaccinations are highly recommended for those with COPD (National Heart, Lung and Blood Institute, 2013; GOLD, 2015).

Treatment of Exacerbations

If a chest infection is the underlying cause of an exacerbation a short course of steroid tablets could be prescribed (GOV.UK, 2015b). Often COPD patients are given an emergency course of steroid tablets to keep at home, as steroid tablets are most effective in the early stages of an exacerbation (GOV.UK, 2015b). The lowest effective

dose is prescribed initially and the doctor monitors the effects, the dose may need to be increased or a longer course of steroids may be necessary (GOV.UK, 2015b).

Other Types of Treatment

Oxygen

If the oxygen level in a patient's blood is too low at rest, or if the oxygen level drops when active, oxygen therapy may be needed to increase the amount of oxygen entering the lungs and the bloodstream (British Lung Foundation, 2016c).

Alpha-1 Antitrypsin Augmentation Therapy

Augmentation therapy, also referred to as replacement therapy, is the specific therapy to treat alpha-1 antitrypsin deficiency-related COPD (Alpha-1 Foundation, 2016). The therapy uses alpha-1 antitrypsin protein (AAT) taken from the plasma of healthy human blood donors to augment (enhance) the levels of alpha-1 antitrypsin protein in the bloodstream and lungs of AAT- deficient patients with COPD (Alpha-1 Foundation, 2016). The donated AAT protein is administered weekly by intravenous infusion (Alpha-1 Foundation, 2016).

Possible candidates for the therapy are young patients with established emphysema and severe genetic alpha-1 antitrypsin deficiency (GOLD, 2015). As augmentation therapy is currently the only specific therapy for alpha-1 lung disease, and is considered ongoing and life-long (Alpha-1 Foundation, 2016). However, augmentation therapy is extremely expensive and unavailable in most countries, such as the UK (GOLD, 2015).

Monitoring

Routine follow-up of COPD patients is an essential part of managing the disease as even with the successful disease management, lung function is expected to decrease over time (GOLD, 2015). Follow-up appointments, similar to diagnosis, should consist of a discussion about the patient's symptoms, especially whether there are any new or worsening symptoms, as well as a physical examination (GOLD, 2015). An individual's symptoms and airflow limitation should be monitored to determine whether their current management strategy requires adjustment and to identify any possible complications (GOLD, 2015).

Surgery

Lung Volume Reduction Surgery (LVRS)

Lung volume reduction surgery (LVRS) is an operation in which damaged lung tissue is removed in order to enhance the function of the remaining lung tissue (NICE, 2005). Each lung can have up to a third of the diseased tissue removed, which increases lung capacity and improves the individual's breathing capability (NICE, 2005). Only patients with severe emphysema are eligible for LVRS, although the surgery is of most benefit to those whose upper lobes (of the lungs) are affected by the disease and those who additionally experience exercise intolerance (Fisherman et al., 2003). The effectiveness of LVRS is also influenced by each individual's exercise capacity and ability to withstand such an operation (NICE, 2005).

LVRS can increase a patient's lung function and decrease their breathlessness, which can improve their exercise tolerance and mobility (NICE, 2005). This also can enhance their ability to function in daily life activities, as well as improve their quality of life (NICE, 2005). However, as with all surgeries, there are risks involved, including air leakage, pneumonia, stroke, hemorrhaging and heart attack (NICE, 2005).

Lung Volume Reduction Coil Treatment

The lung volume reduction coil treatment is a minimally invasive treatment that improves disease symptoms in individuals with severe emphysema (Cleveland Clinic, 2016). The procedure involves metal coils being inserted, via the mouth, into the damaged tissue of the individual's lungs (Cleveland Clinic, 2016). The coils increases elasticity of the damaged lung reduces lung hyperinflation and improves breathlessness (Cleveland Clinic, 2016). After the coil treatment, evidence of increased exercise tolerance has been seen, with individual's walking further than before the therapy, less breathlessness and a better quality of life (Cleveland Clinic, 2016).

Lung Transplantation

A Lung transplant is an invasive operation in which diseased lung is removed and replaced with a healthy human lung from a deceased or living donor (GOV.UK, 2014b). A single or double (termed 'bilateral') lung transplant can be performed on very severe COPD patients (GOV.UK, 2014b; Todd, Christie and Palmer, 2014). A

lung transplant is only considered an option in COPD patients who meet the rigorous selection criteria, and is only an option when all other management strategies have been tried and unsuccessful (GOV.UK, 2014b; Todd, Christie and Palmer, 2014; Orens et al., 2006).

To be selected for a lung transplant the patient must have very severe COPD (i.e. FEV1 below 20%), with extreme symptom burden and fail to respond to all other medical therapies available and their projected chance of surviving the next two to three years without the transplant is expected to be less than if they have the transplant (Orens et al., 2006; GOV.UK, 2014b). Transplant candidates undergo a stringent assessment and selection process in order to increase the long-term success of the transplant (Todd, Christie and Palmer, 2014). Successful lung transplants can significantly improve lung function, following a successful single or bilateral lung transplant, with FEV1 values potentially being increased to 50-60% and 80-90%, respectively, which also improves exercise capacity (Patel, DeCamp and Criner, 2008; Studer et al., 2004). However, despite the potential benefits of a lung transplant, rejection of the transplanted lung is possible (Todd, Christie and Palmer, 2014), and while a lung transplant may increase the short-term survival of the patient, the current survival rate for long-term (over 5 years) survival in patients with COPD is very low (GOLD, 2010).

2.10 Women and COPD

Women are more at risk of developing COPD, than men, because they are a) physiologically, anatomically, genetically and hormonally more susceptible to chronic respiratory disease, b) they have a greater auto-immune response and c) they metabolise nicotine differently which makes it more difficult to stop smoking cigarettes compared to men. This section will describe this increased risk, relating to a)-c).

2.10.1 Anatomical differences between sexes

Gold and co-workers studied the effects of cigarette smoke on lung development in over 12,000 girls and boys aged 10 to 18 years in 6 areas of the United States (Gold et al., 1996). They found that cigarette exposure at an early age (as few as five cigarettes/day) actually slowed the rate of lung growth, compared to never-smokers. In addition, the effect on lung growth was fivefold greater in girls than in boys (1.09% vs. 0.20%). Lung growth occurred earlier and at a faster rate in girls than boys, thus if lung development is hindered by cigarette smoking it could prove detrimental to the female respiratory health overall. There are several anatomical differences between

male and female lungs, including the size of the lung itself and the size of the airway lumen, which are both smaller in females than males (Kim et al., 2011; Bellemare, Jeanneret and Couture, 2003). This explains why women require less exposure to cigarette smoke than men, to develop the same degree of airflow limitation and similar severity of COPD (Agustí et al., 2010).

2.10.2 Autoimmune differences between sexes

Oxidative stress is now recognised as a major influence in the pathogenesis of COPD (Kirkham and Barnes, 2013; Macnee, 2005; Macnee and Tuder, 2009). Mooney and colleagues (2001) measured the levels of autoantibody markers in 140 heavy smokers, and the findings showed women produced 50% more autoantibody than men, after adjustment for cigarettes smoked per day. This suggests that the constituents of cigarette smoke stimulate a greater autoimmune response in women than men, which could explain the accelerated nicotine metabolism demonstrated by female smokers (Benowitz et al., 2006). Although nicotine is a natural substance found in tobacco leaves (Benowitz, Hukkanen and Jacob, 2009), it is the main psychoactive component of tobacco and considered an addictive drug (Sofuoglu et al., 2012). In humans, nicotine is absorbed from the bloodstream into the liver, where it is extensively metabolism, a process which involves enzymatically modifying its structure and producing numerous active by-products, or metabolites (Benowitz, Hukkanen and Jacob, 2009), this will be discussed in more detail in the succeeding section. Generally, the purpose of drug metabolism is to increase the water solubility of the drug, which facilitates excretion from the body (Alavijeh et al., 2005). In humans, the most important metabolite is cotinine (Benowitz, Hukkanen and Jacob, 2009).

2.10.3 Nicotine metabolism and sex hormones

Nicotine is inhaled in smoke particles when a cigarette is smoked, it is then transported to the lungs, where it enters the circulation and can access the entire body (Benowitz, 2010). Within 10 seconds of puffing a cigarette, nicotine has entered the brain, and stimulated receptors in the brain, which produces the sense of pleasure experienced by the smoker, reinforcing their nicotine addiction (Benowitz, 1990; Benowitz, 2010). The individual smoker can influence, to a certain extent, the dose of nicotine inhaled with each puff, by controlling the puff volume, inhalation depth and puffing intensity and rate (Warren et al., 2014).

Nicotine is metabolised in the liver, a process mediated by the cytochrome P450 (CYP) and aldehyde oxidase enzymes (Cashman et al., 1992; Cohen et al., 2007; Benowitz, Hukkanen and Jacob, 2009). Female sex hormones, specifically oestrogen,

have been found to modify nicotine metabolism, and thus contribute to the increased susceptibility of young women to COPD (Benowitz et al., 2006). Benowitz and colleagues (2006) found female smokers (not taking oral contraceptives) metabolised nicotine and cotinine 13% and 24%, respectively, faster than male smokers (Benowitz et al., 2006). Furthermore, female smokers who take oral contraceptives have a 28% and 30%, faster nicotine and cotinine metabolism, respectively, compared to female smokers who do not take oral contraceptives (Benowitz et al., 2006). Pregnancy also enhances metabolism; pregnant female smokers metabolised nicotine and cotinine at a rate that was 60% and 140%, respectively, faster than the metabolism in the same women post-delivery (Dempsey, Jacob and Benowitz, 2002). This clear association between female sex hormones, namely oestrogen, and increased nicotine and cotinine metabolism is believed to induce the metabolising enzymes (e.g. CYP2A6) (Benowitz, 2010). Faster metabolism of nicotine, in smokers, has been associated with higher levels of nicotine dependence, compared to smokers who metabolise nicotine slower (Mwenifumbo and Tyndale, 2007; Wassenaar et al., 2011; Sofuoglu et al., 2012). Smokers who metabolise nicotine at a faster rate (than normal) have reported greater cigarette cravings after overnight abstinence from smoking, than slower nicotine metabolisers (Sofuoglu et al., 2012).

Thus, the faster nicotine metabolism experienced by female smokers, could explain their increased nicotine dependence and difficulties in stopping smoking, compared to men, who have slower nicotine metabolism. In contrast, older, menopausal and post-menopausal women, who have low oestrogen levels, were found to have significantly less risk of developing COPD than younger women, but a similar risk of developing COPD to men (Benowitz et al., 2006).

An increase in nicotine metabolism suggests a physiological and chemical reason why women continue to smoke, even after being diagnosed with COPD.

2.11 Conclusion

COPD is the third leading cause of death in the world and is associated with significant morbidity. Symptoms of breathlessness are often misdiagnosed as asthma or attributed to older age or lack of fitness. Risk factors for COPD include continuous exposure to air pollution, including cigarette smoke, and genetic predisposition, with a significant amount of younger people with COPD having a deficiency in the gene A1AT. COPD is characterised by breathlessness and limitations in daily activities, which affect people's everyday lives. The next chapter will discuss previous findings

of how individuals manage their work lives with a chronic disease in general, and COPD in particular.

Chapter 3. Literature Review

3.1 Introduction & Search Strategy

The aim of this literature review is to explore what is already known about women with COPD, and then what is known about both men and women working with COPD. Previous research has shown that the prevalence of COPD among the working age population in developed countries is increasing (Fletcher et al., 2011). It is also known that due to various factors, developing COPD can influence a workers ability to remain in employment. However, there is a clear gap in knowledge regarding the social impact of living and working with COPD, has on individuals, particularly women of working age. The focus of this study aims to fill this gap in knowledge, exploring the lived experience of women of working age with COPD.

The online research databases EBSCO HOST, CINAHL, Medline, Google scholar and Anglia Ruskin electronic journal portal were used to search for relevant peer reviewed journal articles using combinations of the key search terms; ('COPD' OR 'Chronic Obstructive Pulmonary Disease' OR 'Chronic Disease') AND ('women' OR 'female') AND ('employment' OR 'job' OR 'workforce') AND ('qualitative' OR daily living' OR 'lived experience').

As little research could be found in the area of COPD and work, I conducted a broad search of peer reviewed literature focusing on chronic disease and work in general, to put the study and subsequent findings into context. The literature review was organised into three distinct sections; chronic disease and work, COPD and work, and women who work with a chronic disease.

Relevant literature was also found by searching through the reference list of published articles found during the literature search, to expand the search area. The search was limited to literature published in the form of journals, between 1970 and 1st November 2017 and written in the English language. This literature review was not a systematic review. Papers were not formally reviewed in terms of quality. Several papers were discarded as they were deemed to be irrelevant to this study, for example; if the paper focused on the biological aspect of developing and living with COPD, instead of the lived experience of the individual, or if the focus was on the impact of occupational hazards to the development of COPD, rather than managing home and work life once an individual had developed and been diagnosed with COPD.

Due to the limited amount of literature on working age women with COPD and working with COPD in general, this chapter begins by reviewing literature on working with chronic disease in general, to provide the reader with an increased understanding of the background and context in which this study is set. In keeping with other chronic diseases, COPD is not curable, may be invisible and can result in physical limitations which require adjustments to be made in terms of lifestyle and working practices, in order to continue participating in life activities, of which work has a central role.

The focus will then shift towards what is known about working age people with COPD. Where possible the reader's attention will be drawn specifically to women working with COPD. The conceptual model used in this study will then be introduced.

3.2 Chronic Disease & the Working Age Population

Despite chronic diseases being most prevalent among the elderly population, there are increasing numbers of working age people in industrialised countries developing such diseases (Varekamp, Van Dijk and Kroll, 2013; Munir, Yarker and Haslam, 2008). Unemployment rates are higher among chronically ill individuals than those without a chronic disease (Baanders, Rijken and Peters, 2002), however, many chronically ill people continue to work and want to remain productive members of the workforce for as long as possible (Beatty, 2012; Lerner et al, 2003, de Vries et al., 2011; Boot, van Exel, and Gulden, 2009). In the UK, 1 in 5 employees (aged 16-65 years) report having at least one chronic disease (Eurowork, 2014; Munir et al., 2007). Increasing life expectancy and retirement age (Johnson et al., 2007) are projected to increase the prevalence of chronic disease in the workplace, with 1 in 2 workers estimated to have a chronic disease by 2030 (Beatty, 2012; Coalition, 2015).

Chronic disease in the workplace is recognised as causing an increase in sickness absence, decrease in productivity and can result in an individual leaving paid employment early, compared to workers without a chronic disease (Varekamp et al., 2011; Kremer, Pal, van Keimpema, 2006; Haafkens et al., 2011; Schuring, 2007; Munir, Yarker and Haslam, 2008). Such disease-related effects can cause psychological and health-related distress (Munir et al., 2007) and reduced quality of life for the chronically ill worker (daCosta DiBonaventura et al., 2012b; Orbon, 2005). Early retirement as a result of disease-related work limitations not only creates a significant financial burden for the individual and their family, but also impacts the employer and the productivity of a country (de Vries et al., 2011; Munir, Yarker and Haslam, 2008; Boot et al., 2013). It also results in the loss of skilled and experienced workers (de Vries et al., 2011; Munir, Yarker and Haslam, 2008; Boot et al., 2013). It

is important to address the difficulties faced by workers with chronic illnesses, especially COPD, in order to find ways of keeping them actively employed for as long as possible.

3.3 Paid Work in the Context of Chronic Disease (Pros, Cons and Barriers)

The majority of studies focusing on work, in the context of chronic disease have found that staying in work is beneficial. The schedules and structures involved in a work role have been found to help preserve normal life patterns in individuals with chronic disease, acting as a distraction from disease-related anxieties (de Vries et al., 2011). In addition, being a member of the workforce has also been shown to increase a person's self-confidence and social status and provides a forum for social contact (de Vries et al, 2011). Work can also provide a sense of satisfaction, the opportunity for self-development, and financial security (de Vries et al., 2011). Subsequently, a vacuum can be created in the lives of some chronically ill workers who prematurely leave the workforce because of their condition (Liedberg and Henriksson, 2002), with financial losses impacting their (and their family's) lifestyle (de Vries et al., 2011). Studies show male and female workers with COPD have a lower quality of life than their non-chronically ill colleagues (Orbon et al., 2005; daCosta DiBonaventura et al., 2012a). However, those who stay at work despite their COPD have been found to have a higher quality of life than those with COPD who leave employment, despite both groups having similar airflow obstruction (Orbon et al., 2005). This suggests workforce participation has a positive influence on the lives of people with COPD.

However, there was some evidence that staying at work could be detrimental to those with chronic disease, especially COPD (Kremer and van Keimpema, 2006; Fletcher et al., 2011; Sin et al., 2002). Although, this depended greatly on the type of work and the severity of the disease; with physical work or work involving persistent exposure to high volumes of respiratory irritants, such as fumes and dust, exacerbated disease symptoms and perhaps accelerated disease progression (Kremer and van Keimpema, 2006; Fletcher et al., 2011; Sin et al., 2002). Furthermore, there is evidence that chronically ill workers are sometimes presumed to be incompetent and their condition and symptoms are often misunderstood or not taken seriously by colleagues or Management (Barnes et al., 2008; Crooks, 2007; Wynne-Jones et al., 2011).

Despite the many benefits of staying at work, some of which have already been described, those who stay at work with a chronic disease often have to make adjustments in other areas of their lives to continue being able to attend work (de Vries et al., 2011).

Disease-related work limitations have been reported to be a barrier to staying at work (Lerner et al., 2003; Beatty, 2012; Toye et al., 2016). The term 'work limitations' here relates to the concept of disability (Lerner et al., 2003), which The National Institute of Medicine defines as:

"… the expression of a physical or mental limitation in a social context—the gap between a person's capabilities and the demands of the environment" (Pope and Tarlov, 1991, p. 81).

The origins of workplace limitations are multifactorial and involves the interaction between a person with a health condition and their environment, which may trigger or aggravate symptoms and limit their functional capability (Blanc, Chan-Yeung and Malo, 1999). The extent of work limitations reflects the degree of disease-related difficulty an employee experiences in performing work tasks (Lerner et al., 2003). Consequently increasing levels of work limitations have been related to higher absence rates and lower work productivity (Fletcher et al., 2011; Fletcher, Albrow and Walker, 2011; Lerner et al., 2003). Reduced productivity at work could limit future career opportunities and if adjustments are not successfully introduced, a high degree of work limitations can result in chronically ill employees prematurely leaving paid employment (Fletcher et al., 2011; Fletcher, Albrow and Walker, 2011; Lerner et al., 2003). Interestingly, only a weak relationship has been found between the underlying disease physiology and the level of work limitations (Livneh, Lott and Antonak, 2004), suggesting that other factors may be significant in the level of work limitations experienced. Psychosocial factors in the workplace have been found to be important, for example, the relationship between the worker and their colleagues and managers, the perceived level of support at work and an individual's degree of work autonomy may impact on the level of work limitations a chronically ill worker experiences (Lerner et al., 2003).

The majority of research exploring challenges faced by chronically ill workers, especially women, in the workplace, has focused on workers with musculoskeletal disorders. Crooks (2007) research study focused on the working women's experience of managing musculoskeletal disease in the workforce and strategies they used to stay at work. The study involved performing in-depth, semi-structured interviews on

18 Canadian women who had developed musculoskeletal disease (arthritic in nature) after entering the workforce. The participants' ages ranged from 26 to 69 years, with the average being 44 years. Findings from this research study provided further insight into the numerous challenges chronically ill women experience in the workforce and ways in which they manage to stay at work, which are described below.

Barriers to staying at work, reported by chronically ill women include high work volume and an employer's lack of knowledge about their disease (Crooks, 2007; Burckhardt et al., 2005). Disease factors such as the time since onset, disease symptoms, recurrent exacerbations, the nature of the work and the amount of physical activity required can all influence a chronically ill worker's level of limitations (Crooks, 2007; Burckhardt et al., 2005). Furthermore, the invisibility of many chronic diseases can mean others perceive a chronically ill workers who exhibits disease symptoms or limitations at work, to be incompetent (Barnes et al., 2008) or dishonestly taking time off work when claiming to be sick (Crooks, 2007; Wynne-Jones et al., 2011).

Working women who manage invisible chronic diseases at work have reported experiencing scepticism from colleagues and superiors who doubted their debilitating symptoms and disease severity, which sometimes led to social judgements being made of the chronically ill worker, such as being lazy, a hypochondriac an attention-seeker or a wimp (Crooks, 2007; Burckhardt et al., 2005; Vickers, 2001). These false perceptions means that there is a lack of understanding when a person with a chronic disease may require work enablement such as leaving work early to attend medical appointments (Vickers, 2001; Crooks, 2007).

The daily fluctuation of symptoms and their severity means the degree of work disabilities in people with chronic disease is constantly changing (Henriksson, Liedberg and Geedl, 2005). This compounds the difficulty others (work colleagues and managers) have understanding a person's disease as one day the person can perform a task, whereas the following day the same task could be impossible (Crooks, 2007). Social barriers in the workplace were found to be more disabling than physical barriers by working women with musculoskeletal disease (Crooks, 2007). Due to the negative connotations associated with being chronically ill, female workers may experience more social pressures to hide their limitations and appear able-bodied, compared to men with a chronic disease (Crooks, Chouinard and Wilton, 2008; Stone, 1993; Peters, 1993).

COPD shares many of the aspects of other chronic disease in terms of the benefits and barriers to work, especially the incurable nature of the illness, its episodic severity

resulting in fluctuating symptoms, its lack of visibility and the unfavourable social judgements it can engender. Reviewing the literature on chronic disease in general suggest that staying in work is beneficial but that barriers to staying employed exist. However this literature does not explore the effect of COPD in particular, in the context of paid work. The next section will explore further chronically ill workers in general and specific aspects of their participation in the workforce.

3.3.1 Staying at work

De Vries and colleagues (2011) studied why and how 21 Dutch workers (9 male; 12 female) with chronic non-specific musculoskeletal pain stayed at work. They found personal characteristics, which included disease perception and a worker's motivation to work were important factors and prerequisites for successfully remaining in employment (de Vries et al., 2011). The need to stay at work appeared to encourage motivated workers to find ways to stay at work (de Vries et al., 2011). Chronically ill workers who left work could still be motivated to stay at work, but were unable to make the necessary adjustments (Hansson, Boström and Harms-Ringdahl, 2006; Berglind and Gerner, 2002).

3.3.2 Personal characteristics

Personality characteristics have been found as factors associated with chronically ill employee's determination to stay at work (de Vries et al., 2011; Boot et al., 2008). Evidence for this was found in workers (an aggregate of male and female participants) with chronic musculoskeletal pain, who reported personal characteristics such as perseverance, ambition, positive thinking, openness/communicative, assertiveness and self-confidence as factors that influenced their level of work limitations (de Vries et al., 2011).

The most extensive evidence in this area comes from Boot, van Exel and Gulden's (2009) Q-methodology study, which investigated the different ways employees with asthma and COPD adapt to their limitations at work. They found that within a population of 34 employees with asthma and COPD (14 male: 20 female, average age 49 years) with asthma and COPD (20:14 respectively), it is possible to differentiate different profiles in adapting to the disease consequences at work. Each of the 4 adaptation profiles they found, represented a different group of patients who required different strategies to manage their disease. The first adaptation profile, the 'adjusted worker', found a way to adapt to their limitations, for example, to reduce their limitations at work, they reduced their work pace. The next profile was the 'cautious worker', workers in this profile worried about their health and had not accepted their

disease-related limitations, focusing on their limitations rather than on their current capabilities. The third profile was the 'eager worker', with workers in this profile appearing to have the least limitations compared to workers who fitted into the other profile groups. 'Eager workers' were highly motivated to stay at work. Lastly the fourth adaptation profile was 'worried workers', with workers in this profile group reporting the greatest functional limitations and were emotionally preoccupied with their chronic disease. The 'worried workers' adaptation profile consisted solely of workers with COPD. Although worried and cautious workers may still manage to stay at work, their level of work limitations is expected to be higher, while their work productivity and their quality of life lower than workers with the characteristics of the other profiles (Boot, van Exel and Gulden, 2009). Similar findings were also seen in male and female workers with chronic pain (de Vries et al., 2011). Emotionally focused coping strategies have been related to poorer adjustment and more distress than strategies that are problem-focused, with the individual perceiving greater control over their disease and fewer functional limitations (Marcos et al., 2007; Livneh, Lott and Antonak, 2004).

In summary, we know that work in general, and the structure, social contact and financial benefits associated with work, can have a positive effect on workers living with chronic disease. We also know that there are several factors associated with staying at work despite having a chronic disease, such as personal characteristics, which influence the strategies individuals use in order to manage their limitations and continue working. However, we do not know the challenges working age women with chronic diseases, particularly COPD, face on a daily basis and the impact their home commitments have on their ability to manage their disease at work.

3.3.3 Disease perceptions

Studies on adaptation to chronic disease have shown that there often is a considerable discrepancy between the level of disease-related dysfunction as reported by patients and the underlying pathology of their disease (Boot et al., 2008). In previous studies, both males and females aged between 15 and 64 years, with the same disease and severity reported different physical, emotional, and social limitations related to their disease (Boot et al., 2008; Bekke-Hansen et al., 2014). The concept of disease perceptions originate from Leventhal's theoretical 'Common-Sense Model' (CSM) of health behaviour (Leventhal, Nerenz and Steele, 1984), which hypothesised that in order to understand and manage the challenges experienced when living with a chronic disease, individuals create their own beliefs of their disease. The CSM suggests that health-related behaviours and health-related outcomes, such

as quality of life, are heavily influenced by the patient's own beliefs or representations of the disease (Leventhal, Nerenz and Steele, 1984; Leventhal, Leventhal and Contrada, 1998).

How an individual perceives their disease depends on various factors such as their gender, age and education level, as well as one's perceived self-efficacy, their disposition e.g. optimism/pessimism and their perceived level of social support (Aalto et al., 2005; Grace et al., 2005). This thesis uses the term 'self-efficacy' to describe the extent to which individual's believe they are capable of performing specific behaviours in order to attain certain goals.(Bandura, 1994). Self-efficacy governs the thoughts, feelings, level of motivation a person has and the behaviour they display.' (Bandura, 1994). People with high self-efficacy, who were confident in their capabilities approach challenging situations with a positive 'can do' mindset and do not take setbacks as a reflection on their capabilities (Bandura, 1994). Whereas people with low self-efficacy tend to shy away from challenging situations as they doubt their capabilities in tackling difficult task, and view any setbacks as being due to personal deficiencies (Bandura, 1994). People with low self-efficacy are more prone to stress and depression than those with high self-efficacy (Bandura, 1994).

Also, a person's previous disease history has been found to be more strongly associated with their perception of disease than their current disease severity (Yu et al., 2004). Negative disease perceptions, such as believing that a disease, for example, may be lengthy, severe, and uncontrollable and has been associated with poorer functioning and increased pain in people with arthritis (Hampson, Glasgow and Zeiss, 1994). Such negative perceptions are more prevalent in chronically ill people who have left the workforce due to disease-related work limitations, than in those who stay in paid work (Boot et al., 2008).

Additionally, the disease perceptions of significant others, such as the partner, employer or healthcare professional can affect a chronically ill person's experience with the disease (McCluskey et al., 2011). Research exploring general beliefs and attitudes about health and work in individuals claiming limitations benefit in the UK and their partners concluded that support and encouragement from partners is very important in promoting work participation (DWP, 2011a; DWP, 2011b).

Disease perceptions have been strongly related to the level of work limitations experienced and self-reported health of chronically ill employees (Boot et al., 2008). In Boot et al.'s (2008) study, which consisted of both men and women aged 15-64 years, (363 were employed and 189 were unemployed). Those participants who were

fully work disabled and had left paid employment because of their disease, believed the consequences of the disease were more severe than the chronically ill participants who remained at work. This may be because such individuals avoided situations where they could experience limitations, which may result in increased absence from work, more problems returning to work following a period of absence, and eventually, greater work limitations (Boot et al., 2008). Those employed may have found jobs in which they have sufficient job control opportunities, whereas those in the work disabled group may not have succeeded in finding a work environment in which they were able to function with their chronic disease (Boot et al., 2008).

In another study, Boot et al., (2009) conducted one of the few studies that explored ways in which workers with COPD or Asthma adapted to limitations and signs of adequate or inadequate adaptation. The trajectory of these diseases are distinct. This study had a high proportion of females participating (20 females, 14 males), with a mean age of participants being 49.6 years, 20 with asthma, 14 with COPD. Average years since diagnosis was 21.8 years average work hours per week 32.9 hours. As reported above, the study identified four adaptation profiles; the eager, the adjusted, the cautious, and the worried workers, providing an insight into the different ways in which workers with asthma and COPD cope with their illness at work. However, the study pooled results together from both male and female participants. The eager group consists of asthma patients only, and all workers in the worried profile reported that they had COPD. The other two profiles consisted of both Asthma and COPD patients. The inclusion of both COPD and Asthma may have affected the study findings. The findings of this study may also be limited by possible information bias due to the reporting of socially accepted behaviour and attitudes (Althubaiti, 2016). This study also had no information about the disease severity, however, previous research has shown that within a population of workers, disease severity is not the main determinant of their ability to function at work (Orbon et al., 2005; Montes de Oca et al., 2012; Fletcher et al., 2011). Nevertheless, it is possible that differences in adaptation profiles can, at least, partially be explained by differences in perceived limitations of workers, which could result from differences in disease severity. Furthermore, this study did not include information about the job title or work context, thus, it cannot be ruled out that differences in the work context of the participants could have accounted for the differences found between the profiles.

3.3.4 Support at work

Perceived support from colleagues and managers positively influenced chronically ill (male and female) workers ability to manage their disease at work (Munir, Yarker and

Haslam, 2008; Wynne-Jones et al., 2011). Researchers found that the ability of chronically ill female workers to stay at work was significantly influenced by high levels of support and understanding from their superiors and colleagues at work, as well as from their family and friends (Liedberg and Henriksson, 2002; Assefi, et al., 2003; Reisine, et al., 2003; Löfgren, Ekholm and Ohman, 2006). Although support and understanding from work colleagues and superiors is an important aspect of chronically ill women staying at work, the invisibility of most chronic diseases makes it difficult for others to understand (Liedberg and Henriksson 2002; Henriksson, Liedberg and Geedl, 2005; Sandqvist, Scheja and Eklund, 2008). However, a lack of support from managers, can have the opposite effect (Munir, Yarker and Haslam, 2008). A possible reason for chronically ill workers receiving little support could be that managers are unaware of their chronic disease as they have not disclosed it (Munir, Yarker and Haslam, 2008). When disclosure had been made, some managers reported that high pressures to meet attendance and performance targets and their limited knowledge of chronic diseases and its impact within the workplace resulted in them providing little support to the chronically ill worker (Munir, Yarker and Haslam, 2008).

3.3.5 Adjustments

Adjustment latitude refers to the opportunities people have to reduce or adjust their workload when ill (Johansson and Lundberg, 2004). Adjustment latitude governs the extent functional limitations affect an individual's work ability (Johansson and Lundberg, 2004). A high adjustment latitude means an employee has a high level of control over their work situation, such as being able to decide their work content, work schedule, workplace, and work pace, all of which may enable workers to navigate around intermittent disease exacerbations, thereby reducing their need to take sick leave (Hultin et al., 2013; Hultin et al., 2010; Johansson and Lundberg, 2004; Alexanderson and Norlund, 2004). On the other hand, a low adjustment latitude at work refers to little or no control over the work situation, which can increase stress and consequently aggravate disease symptoms and increase sickness absenteeism (Johansson and Lundberg, 2004; Liedberg and Henriksson, 2002). Though Hultin et al. (2013) found low adjustment latitude actually seemed to discourage sick leave instead of encouraging it. The authors suggested this unexpected discovery could be because a high workload and low level of adjustment latitude could possibly motivate workers to attend work when ill.

In Liedberg and Henriksson's (2002) study exploring work limitations in women with fibromyalgia, a lack of control over the work situation was found to be mainly reported

by women in service roles. In the same study, the well-educated women were found to be in work positions where they could control their work content, work schedule, pace of work and workplace, which enabled better management of their condition, compared to women with a lower level of education. For example, they could go home in the afternoon if they feel unwell, rest, and complete the work tasks when they felt better.

As the degree of adjustment latitude accessible to workers varies between socioeconomic groups, occupations, workplaces (Johnson et al., 2007), the possibility of having control over the work situation is not available to every chronically ill worker (Hultin et al., 2013).   Together, adjustment latitude and workplace support can facilitate the implementation of necessary work adjustments (Leijten et al., 2013).

Work adjustments permit chronic diseases to be accommodated in the workplace, adjusting the balance between work demands and work capacity (Wynne-Jones et al., 2011; Henriksson, Liedberg and Geedl, 2005). Previous studies focusing on chronically ill women at work, have found that the successful implementation of work adjustments, which consider the specific needs of individual workers, are vital for reducing the rate of sick leave and keeping chronically ill women productive and satisfied at work (Henriksson, Liedberg and Geedl, 2005; Sandqvist, Scheja and Eklund, 2008).

Like adjustment latitude, although successfully implemented work adjustment can reduce the need to take time off work, they are not available to everyone that need them (Driessen et al., 2010). If the worker discloses their chronic disease and requests work modifications to be made, it is up to the manager to implement these changes, however managers are sometimes unsure of how to make the adjustment or unaware of their legal responsibilities to the ill employee (Wynne-Jones et al., 2011). In addition, a chronically ill employee may not be fully aware of the work adjustments available to them, nor of their employer's responsibility to provide suitable adjustments (Baanders et al., 2001). A lack of knowledge of organisational policies, such as modifications to work, can act as barriers to the effective implementation of work adjustments (Munir, Yarker and Haslam, 2008).

The type of work adjustments vary depending on the type of chronic disease and nature of the work role (Boot et al., 2013). Reported work adjustments include reducing the ill workers workload, flexibility of working hours and workplace, adjusting work content, retraining for a more suitable job role and adjustments made to work equipment (de Vries et al., 2011). Chronically ill working women reported that

retraining did not always correspond to the ill workers ability level, knowledge or interests, and could include tasks that were too challenging for them (Liedberg and Henriksson, 2012). Tangible work adjustments may be easier and quicker to implement (Munir et al., 2005). Adjustments to working hours were more often reported by employees with psychological disorders, while modifications to work equipment were more likely to be received by workers with musculoskeletal disorders (Boot et al., 2013). However, a Canadian cohort study of 401 male and female workers with musculoskeletal injuries, found that offering and accepting work adjustments were related to workplace factors and age, rather than disease-related factors (Franche et al., 2009).

The successful application of work adjustments by the employer has been shown to not only reduce absenteeism, but also increase a workers productivity and their quality of life and reduce hospital admissions (Boot et al., 2013). Women working with musculoskeletal diseases suggested possibilities of job-sharing and working from home, would help keep chronically ill workers at work, as this could provide more control over working hours, and the work tasks would still be done (Crooks, 2007). In addition, working from home saved energy spent on the daily commute and eliminate the need for chronically ill women to 'keep up appearances' at work (Crooks, 2007).

However, not all attempts to adjust working conditions are successful, and failed attempts can discourage employees from asking for further efforts to accommodate their condition, despite reasonable work adjustments forming part of some company's organisational policies and being a legal requirement in the UK (Wynne-Jones et al., 2011). Crook (2007) conducted in-depth interviews with 18 women who developed musculoskeletal disease while employed. Although some women wanted to continue working for the same employer, they required specific adjustments to be made to accommodate their particular limitations. A few women described how their employer had made an uninformed attempt at implementing unsuitable, generic changes to their work situation without consulting them as to what specific modifications were needed. Without consulting the chronically ill worker regarding their specific limitations and needs, any adjustments made will be unsuccessful as they will fail to lessen the work limitation. Other female workers in this study reported wanting work adjustments but considered it was inappropriate to request them because of their work position, or the type of work they did. Those who were unsuccessful in receiving suitable adjustments decided to leave employment. However, several female workers with musculoskeletal disease had a high level of autonomy over their work situation and described their ability to manage their own work adjustments which enabled them to remain productive at work while effectively managing their condition. One woman

modified her work schedule as she was in a position where she could set her own meetings and appointments to accommodate her preferred working hours, while another woman was able to make her working day more flexible.

Implementation of work (place) adjustments increase the chances of a worker with COPD staying at work (Kremer and Wevers 2000; Kremer, Andries and Wevers, 1997). However, the adjustments made at work are not always sufficient, resulting in many workers with COPD reportedly wanting further adjustments to be made (Kremer, Pal and van Keimpema, 2006). In addition, the progressive nature of COPD means interventions at work must be continually reviewed and altered when necessary to continue meeting the needs of changing limitations (Kremer, Pal and van Keimpema, 2006).

In a study exploring employment and work disability in patients with COPD in Holland, female participants left the workforce at a younger age than male patients (Kremer, Pal and van Keimpema, 2006). This supports the findings that women develop COPD at a younger age than men, and also experience the disease differently (Boot et al., 2008; Bekke-Hansen et al., 2014), highlighting the need for further research focusing on COPD on working age women. Further, those who stopped working prematurely, because of COPD, reported the implementation of adequate adjustments in their last job, could have enabled them to continue working for longer (Kremer, Pal and van Keimpema, 2006).

Some chronically ill women manage their disease and their work role by not only reducing the amount they work per day, but by putting in a rest day during the working week, taking unpaid days off work, using paid holiday time or taking regular sick leave to cope with their disease in the work situation (Liedberg and Henriksson, 2002). A reduction in or more flexible working hours can enable women to use their remaining work capacity to continue functioning in a work role (Henriksson, Liedberg and Geedl, 2005), as it can help accommodate the constantly fluctuating ability levels experienced by those who have a chronic disease. In addition, flexible working hours allow the worker to decide the hours they work depending on their ability that day, working less hours on days when they feel unwell (Crooks, 2007). However, flexibility in the working day and work content is not permitted in all work environments (Crooks, 2007). For women who have little control over their work situation, making adjustments is more difficult and depends on the discretion of the employer (Crooks, 2007). In certain work situations re-allocating the work of a chronically ill employee was difficult as everyone in the workplace already had a high workload (Liedberg and Henriksson 2002). Also, making adjustments to the chronically ill workers work tasks

3.3.6 Attendance management and presenteeism

Taking time off work due to sickness, termed 'absenteeism', is not only a financial burden to employers, chronically ill employees and their families (Munir, Yarker and Haslam, 2008), it also causes psychological and health-related distress (Munir et al., 2007). In an attempt to reduce workplace absenteeism, attendance management policies have been introduced by some organisations (Grinyer and Singleton, 2000; Whitaker, 2001). Such policies have been effective at reducing absenteeism associated with acute disease or illegitimate days-off work (Chatterji and Tilley, 2002; Goetzel et al., 2004). However, for workers managing a chronic disease, stringent, inflexible work attendance policies can increase the numbers of workers attending work despite feeling unwell, termed 'presenteeism' (Burton et al., 2006; Dew, Keefe and Small, 2005; Beatty, 2012).

Munir, Yarker and Haslam's (2008) mixed methods research study is the most extensive research study conducted to date that focuses on the effectiveness of attendance management policies for chronically ill employees in the UK. Four different organisations took part in this study; 2 from the private sector (manufacturing) and 2 from the public sector (public administration and transport). Occupational health staff, human resources staff, attendance managers, health and safety managers, line managers, and trade union representatives, of each organisation were interviewed. In total 58 participant interviews were conducted; 36 being with female and 22 being with male participants, aged 25-57 years. Questionnaires, which examined sickness absence management in the organisations, were randomly sent out to employees from each organisation. They found all 4 organisations had strict policies regarding the number of short-term absences allowed. Exceeding this number could result in a warning or disciplinary action being taken, possibly forcing a worker to disclose their chronic disease to employers to justify their absences (Munir, Yarker and Haslam, 2008).

Other research also found that to avoid disclosure of their condition, some employees may refrain from taking time off work when unwell (Munir et al., 2007; Munir, Yarker and Haslam, 2008; Wynne-Jones et al., 2011). Attending work despite feeling unwell

can cause high levels of psychological and health-related distress (Munir et al., 2007), and can affect disease management and exacerbate disease conditions over the short- and long term (Munir, Yarker and Haslam, 2008). Conversely, taking approved time off work can improve a chronically ill worker's long term health and their ability to stay productive at work for longer (Munir, Yarker and Haslam, 2008). In Munir and colleagues (2008) study, only half of the chronically ill employees had disclosed their disease at work.

The decision to work when unwell could be influenced by other work related factors, such as the accumulation of work tasks during a periods of absence, problems finding replacement staff, burdening colleagues with additional work pressures to meet deadlines and how their manager and colleagues would perceive them e.g. such as a 'good' or a 'bad' worker (Hultin et al., 2013; Munir, Yarker and Haslam, 2008; Munir et al., 2007, Aronsson, Gustafsson and Dallner, 2000; Wynne-Jones, et al., 2011; Barnes et al, 2008, Main, 2008). Additionally, attending work despite feeling unwell may be encouraged as presenteeism is often regarded as an organisational and social 'norm' (Wynne-Jones et al., 2011, Munir, Yarker and Haslam, 2008).

3.3.7 Disclosing a chronic disease

Disclosure of their disease to an employer are required if suitable adjustments are to be made (Wynne-Jones et al., 2011). Voluntary disclosure of a chronic disease is dependent, however, on psychosocial factors at work and the work environment (Munir, Yarker and Haslam, 2008). Despite experiencing difficulty performing work tasks and needing help and support, both emotionally and in the form of work adjustments, some chronically ill employees delay disclosing their disease for a variety of reasons such as having an unapproachable manager, feeling they would be perceived as being unable to do their job well, fear of losing their job or of being stigmatised or discriminated against (Wynne-Jones, 2011; Munir, Yarker and Haslam, 2008). A lack of disclosure acts as a barrier to implementing adjustments at work (Munir, Yarker and Haslam, 2008). Also, after a worker discloses their chronic disease managers and organisations need to have suitable resources available to provide adequate support to the worker (Munir, Yarker and Haslam, 2008). The implementation of suitable work adjustments can reduce the rate of absenteeism and improve the workers' productivity, as well as improve the management of their disease (Munir, Yarker and Haslam, 2008).

3.3.8 Psychosocial factors at work

The work environment is made up of physical and psychological work demands, job control, workplace social support, job satisfaction and organizational climate (Hultin et al, 2010). Although a worker may experience disease-related limitations in performing physical tasks, adjustments can be made or the task could be changed for one that is more suitable to the workers capabilities (Tillett et al., 2015).

However psychosocial factors in the workplace, such as the perceived level of support and understanding from work colleagues or managers, impact one's ability to stay at work and are more difficult to adjust (Baker-Mcclearn et al., 2010). An understanding and supportive manager is expected to effectively implement adjustments to keep a chronically ill worker productive at work for longer, while at the same time avoid work-related worsening of their condition (Tillett et al., 2015). Having a supportive manager also increases a chronically ill workers belief that they can manage their disease at work (Munir et al., 2009; Munir et al., 2007). Whereas, unsupportive employee-manager relationships can exacerbate work limitations and cause psychological distress (Munir et al., 2007).

COPD is increasingly being diagnosed in people of working age (16-65 years) (Sin et al, 2002), and like most chronic diseases, it is progressive and debilitating by nature, limiting an individual's ability to function in daily life, which includes one's performance in the workplace (Hernandez, et al., 2009; Fletcher et al., 2011; Kremer and van Keimpema, 2006). Compared to non-respiratory chronic diseases, COPD has a greater impact on absenteeism, perceived inability to perform work tasks and perceived work disability (Eisner et al., 2008).

3.3.9 Work and home life

It is widely acknowledged that work and home life are interrelated, thus in order to manage a chronic disease in the workplace, the condition must also be managed successfully outside of work (de Vries et al, 2011). In addition to work adjustments, ways in which male and female workers with musculoskeletal diseases stayed at work involved self-managing their condition both at home and at work by listening to their bodies, working within their limits, re-prioritising their life, reducing their workload and increasing their functional capacity (de Vries et al., 2011; Wynne-Jones, et al., 2011). In de Vries et al's., (2011) study, male and female workers with chronic musculoskeletal pain increased their functional capacity by exercising regularly and resting more and reduced their workload by delegating tasks, asking for and accepting help from others and reducing their travelling distance to work (de Vries et al., 2011).

People living with chronic diseases have also reported using a wide range of coping strategies, including physical activity, meditation, medication, reprioritising tasks, resting and avoiding certain activities, to manage work and home life despite debilitating symptoms and without exacerbating their condition (Liedberg and Henriksson, 2002; Löfgren, Ekholm and Ohman, 2006; Crooks, 2007). Those who learn to accept their condition use more effective and well-adjusted coping strategies (Raymond and Brown, 2000).

Although such research into working age women with chronic diseases highlight the challenges and coping strategies used by women with musculoskeletal diseases in the workplace, very little is known about how women of working age, especially women with COPD, manage their work and home-life commitments. The next section will focus specifically on COPD and work.

3.4 COPD and WORK: Staying at Work

3.4.1 COPD and work

The majority of previous research into COPD has focused on the impact of the disease on daily life, particularly in older people (both men and women, over 65 years) (Gabriel, 2014; Stureson and Bränholm, 2000; O'Neill, 2002; Avşar and Kaşikçi, 2010; Steindal et al, 2017; Rodriguez Gonzalez-Moro et al., 2009). However, limited research focusing on COPD and the working age population explored the financial burden of the disease (Fletcher, 2011), daily life with COPD without focusing on work status (O'Neil, 2002, Avşar and Kaşikçi, 2010; Barnett, 2005), how (male and female) workers with COPD manage their work life, without taking into account their home life (Fletcher et al., 2011; Burckhardt et al., 2005). This literature has not focussed on females and where females are included in the sample studied, they are a minority and the findings are frequently reported whilst combining genders (Avşar and Kaşikçi, 2010; Chang, 2016). Where findings are reported according to gender, this is highlighted in the section below.

3.4.2 Severity of COPD and employment

A 2013 Telephone Surveillance Survey conducted in the United States found the prevalence of COPD ranged from 2.6% among those aged 18–34 years to 12.3% among those aged ≥75 years, highlighting the onset of COPD in those of working age (Wheaton et al., 2015). Although data on the gender of those of working age with COPD is indistinct (Wheaton et al., 2015).

The presence of COPD in the working age population can result in COPD-related work disability, which can cause workers to leave paid employment prematurely (Yelin et al., 2006; Sin et al., 2002; Kremer and van Keimpema, 2006). However, many people diagnosed with COPD continue to work (daCosta DiBonaventura et al., 2012a). Work environments which involve regular exposure to airborne irritants such as cigarette smoke or dust, likely to exacerbate respiratory symptoms and have been connected to work cessation in those with COPD (Kremer and van Keimpema, 2006). Also, disease severity has been found to be an important factor in determining the degree of work disability in people with COPD (Fletcher et al., 2011; Sin et al., 2002), with evidence suggesting those with moderate and severe COPD (defined by GOLD stage) have greater work disability, are less productive at work and are more likely to leave paid employment compared to workers with mild COPD (Fletcher et al., 2011; Sin et al., 2002; Kremer, Pal and van Keimpema 2006).

Sin et al.'s (2002) population-based study, aimed to determine the relationship between severity of COPD and workforce participation in the U.S, using data from the Third National Health and Nutrition Examination Survey (NHANESIII). Data was collected from 12,436 participants, of which 46.5% were males, and 8.6% reported to have COPD. The average age of participants was 37.9 years. They found that self-reported COPD was associated with a significant (3.9%) decrease in workforce participation, with more severe disease severity having a greater impact on work loss than mild severity. They also found 18% more men with COPD were in paid employment compared to women with COPD (Sin et al., 2002), proposing the greater/differing impact COPD has on working-age women compared to men.

However, the authors acknowledge that because the survey was cross-sectional in nature, they cannot be certain that severe COPD caused decreased work participation or whether loss of work caused more severe COPD (Levin, 2006). This quantitative study lacked data on workers with COPD who worked part-time, and it did not consider (unpaid) work performed in the home, or factors other than disease, that could influence a person's ability to stay at work with COPD.

In disagreement to Sin et al., (2002) findings, research by Orbon et al., (2005) and Montes de Oca et al., (2012), found disease severity to be the same in men and women with COPD who were in paid employment and their unemployed counterparts, suggesting that factors other than disease severity influence employment status. This is supported and developed by other researchers who found the ability of workers with COPD to stay at work is affected by additional physical and psychosocial factors, not only the worker's disease severity (Kremer and van Keimpema, 2006; Fletcher et al.,

2011; Orbon et al., 2005). For example, how individuals with COPD manage their condition influence the degree of work disability they experience, with low levels of disease management causing higher levels of work disability and increased hospital visits (daCosta DiBonaventura et al., 2012a). Whereas successful disease management and the implementation of suitable adjustments at work and workplace support could result in workers with COPD being actively employed for longer (Munir et al, 2007).

Regarding females with COPD and work, Sin and colleagues (2002) found less women with COPD were in paid employment than men, which was supported by the findings of Kremer, Pal and van Keimpema, (2006). As reported above, Kremer and colleagues (2006) conducted a cross-sectional study in Holland, which found that the female participants with COPD stopped working at a younger age than their male counterparts. The study that aimed to explore work experiences and problems of people with COPD, to develop more effective guidelines for preventing work disability and work loss, involved 617 patients of working age (between 45 and 60 years, mean age 54.3), of which 43% of which were female and only 52% of the total participants were employed at the time of the study, 42% stopped working and 6% never worked. Data was collected via a quantitative questionnaire on respiratory health and work history.

A third of those who left the workforce after developing COPD reported the implementation of work adjustments in their last workplace could have enabled them to continue in active (paid) employment, which supports other studies into chronic disease and employment (Munir et al., 2007, de Vries et al, 2011). Notably, 73% of the participants had additional health problems to COPD, which makes it difficult to attribute these results solely to COPD, yet it could be more representative of the working age population living and working with COPD, of which many could be living with multiple health problems.

Fletcher and colleagues (2011) conducted a cross-country, cross-sectional survey to increase the understanding of the impact of COPD on employment and to establish its wider potential costs in a working age population. They estimated the impact COPD had on work in the preceding 7 days by using the Work Productivity and Activity Impairment Questionnaire (WPAI). To assess the overall impact on productivity, the WPAI generated 4 scores: absenteeism (hours of work missed due to illness), presenteeism (impact of illness on productivity while at work), work productivity loss (combined impact of absenteeism and presenteeism) and activity impairment (regular activities).

Four hundred participants were selected from each of the study countries; Brazil, China, Germany, Turkey, the U.S and the UK, with a total of 2426 men and women with COPD, aged between 45 and 67 years, responding to the questionnaire.

Of the 70% of those who were not employed at the time of questioning, 26% reported they had given up work because of their COPD, with the mean age of early retirees being 58.3 years (range 45-67 years). Fifty three percent of those respondents who retired early were female, which further supports findings from other studies that COPD impacts female participation in the workforce more than male participation (Sin et al., 2002; Kremer, Pal, and van Keimpema, 2006). In addition, 52% of those who retired from work prematurely had moderate disease and 40% had severe disease, which supports other research that reported increasing disease severity has a negative impact on work participation (Sin et al, 2002). Although the percentage of people with severe disease still in active employment (9%) is significantly less than those with less severe COPD, the fact that there were respondents with severe COPD still participating in active work is extremely encouraging and begs the question, what other factors are involved in enabling these people to still work, other than disease severity.

This study also highlighted the economic impact of COPD on those workers who retired prematurely because of their disease, with the average lifetime earnings losses being estimated to be £200,000 per individual.

This study is one of the few that have investigated the impact of COPD on the working age population, both males and females. However, it purely focused on work participation, as it was designed as a hypothesis-generating exercise to identify the factors likely to influence the economic burden of the disease. Here the authors describe the observed effects of COPD on: income, employment, work productivity, healthcare utilization and quality of life. The study does not include activities outside of work, which could have influenced the respondents work status. This study also pooled data from the different countries, with the different countries having substantial variation of disease severity and data from the males and females. The different countries have different healthcare systems and the paid work (or previous paid work) of each study respondents in the different countries could have varied greatly. This study offers an insight into the effect COPD has on workforce participation over several countries, however, further work is needed to really understand the impact the disease has on the work and home lives of working age people, especially women, who have been found to leave work earlier than men, due to COPD. Women also have different responsibilities which society has placed on them, in addition to

workforce participation, which makes their experience of living and working with COPD unique and incomparable to the experience of their male counterparts.

The literature search found no previous research that considered the effects of COPD on people of working age, in the context of their activities outside the workplace as well as inside the workplace, i.e. the holistic effect COPD had on their life.

The literature search found studies that focused on the effect of COPD on employment only, without considering activities outside of the workplace (Fletcher et al., 2011; Kremer, Pal, and van Keimpema, 2006), or the experience of living with COPD, while overlooking work status (Avşar and Kaşikçi, 2010).

Avşar and Kaşikçi (2010) conducted a phenomenological qualitative study exploring how 14 participants (11 men, 3 women) live with COPD, in Turkey. The participant's had a large age range, from 55-81 years, with a mean of 67 years. Although the study had participants of working age, there is no mention of the participant's work status. Similarly, Barnett's (2005) phenomenological study of patient's experiences with COPD did not mention the work status of the participants, nor did it state basic, demographic data of the study participants, such as whether they were male or female and their age.

Furthermore, Rodriguez Gonzalez-Moro et al., (2009) assessed the impact of COPD severity on physical disability and daily living activities in general. The study involved conducting two epidemiological observational cross-sectional descriptive studies with 1596 patients with moderate COPD and 2012 patients with severe or very severe COPD in the routine clinical practice in Spain. Despite the authors offering no definition of what is meant by 'work' in this study, the findings demonstrate 44.6% of participants with moderate COPD and 64.7% of participants with severe/very severe had reduced their work time as a result of their COPD. The number of participants in this study who continued to participate in the workforce is not stated. Also, the vast majority of participants with moderate (88%) and severe/very severe COPD (87.3%) were male. The results for males and females have been pooled together, making it difficult to distinguish the findings by gender. Moreover, all the participants were older than 67 years, with the age range of those with moderate COPD (defined by GOLD stage) being 67.3-68.3 (mean age 67.8 years) and with severe/very severe COPD being 69.2-70 years (mean age 69.6 years). Considering the age of all participants, which is over the national retirement age set by the Spanish Government, which was 65 years at the time this paper was published, is it supposed that not all participants were in paid employment at the time of the study. Also, if 'work' here does refer to the impact of COPD on paid employment, due to the age of the participants, difficulty

performing tasks could be due to other factors, such as comorbidities etc. Nevertheless, this is one of the few studies found in this literature search that considers the impact of COPD on daily life activities, such as home and work life. However, due to the lack of clarity on those participants who were in paid employment, the mean age, and narrow age range of the participants and the low proportion of women who participated in the study, it is unclear if the findings transfer to women in paid employment.

In addition, several studies found in the literature search had significantly more male than female participants (Chang, 2016; Rodriguez Gonzalez-Moro et al., 2009), while few focused solely on women with COPD (O'Neill, 2002; Steindal et al., 2017). However the studies explored the experience of women living with COPD in general, and either had participants of (or older than) retirement age or simply overlooked the effect of COPD on female work participant. In many cases, participants had a high mean age (greater than 65 years) (Gabriel, 2014; O'Neill, 2002; Avşar and Kaşikçi, 2010; Steindal et al, 2017; Rodriguez Gonzalez-Moro et al., 2009). This is of importance as the experience of an individual of working age (18-65 years) living and working with a COPD is expected to be very different to that of someone who is older and retired, due to additional activities and family or social responsibilities expected of them. Similarly, it is recognised women experience COPD differently to men (Boot et al., 2008; Bekke-Hansen et al., 2014), perceiving more severe disease symptoms and having different social and cultural roles to men.

In summary, the literature suggests that workplace adjustment is important to allow people with COPD to remain in employment. There is a suggestion that the ability of men and women to remain in work with a diagnosis of COPD may differ but the findings are conflicting. The existing research is also deficient in several areas. It lacks evidence on the combined effect of work and home life on people with COPD, either because it focuses on only work or only home activities, or because it focussed on a population beyond the age of retirement.

Existing research is also sparse in terms of the experiences of working-age women. The next section looks specifically at existing research on women and work.

3.5 Women and COPD

In the literature search, there were few studies that focused on women with COPD. However, none of these studies explored the impact of COPD on young and middle aged (working age) women. O'Neill's (2002) qualitative study explored how 21 women

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in two pulmonary rehabilitation clinics in the North Eastern United States recognise and respond to symptoms of COPD. The participants had a wide age range (45-81 years, with a mean age of 67 years). Despite a few of the participants being of working age, only one participant was still in employment, while most were retired (15 participants) or disabled (five participants). Despite the women in this study being most vocal when asked to discuss the effects of their illnesses, most discussions revolved around losses; loss of jobs, family and social relationships, and for the younger participants', loss of intimacy. However, the study did not go into detail about work and about potential ways of staying in employment. In addition, as all participants were recruited from pulmonary rehabilitation clinics, it could be assumed that the information they received during the rehabilitation program possibly enriched these women's representations and influenced their choice of coping strategies. However, women who have had no experience in a rehabilitation program may present other findings.

In another study that focused on COPD and women, was a qualitative study focusing on women's experiences of living with COPD in Norway (Steindal et al., 2017). The nine study participants were aged between 63-87 years, with a mean age of 72 years, which meant the majority were older than retirement age. Due to the older age of participants, the study focused on their experiences of living with COPD at home, and did not refer to work. The study findings were limited to limitations involving housework, and being unable to participate in social activities. These two studies focusing on women with COPD highlight the dearth of knowledge into how the increasing numbers of women of working age, developing COPD, manage their life as a whole, this includes work and home life.

3.5.1 Women and work

During the past fifteen years, the number of women, with and without children, participating in the workforce has increased significantly (Office for National Statistics, 2011), with women forming an important part of the workforce, in industrialised countries (Burckhardt et al., 2005). Women value participating in paid employment as it can form a part of their identity and gives them financial independence (Liedberg and Henriksson, 2002; Henriksson, Liedberg and Geedl, 2005). Consequently, many women who exit the workforce grieve over the loss of their identity and part of their self-worth (Liedberg and Henriksson, 2002). In a study of working and non-working women with fibromyalgia, those who continued working had a significantly greater quality of life than those women who left work because of their disease (Henriksson, Liedberg and Geedl, 2005). Reasons for differences in quality of life could be due to

the impact leaving the workforce has on financial status, social networking and self-esteem (a sense of one's own value as a person), and lack of distraction, which can result in a heightened awareness of health problems. All of which can impact quality of life (Crooks, 2007; Burckhardt et al., 2005; Henriksson, Liedberg and Geedl, 2005; Liedberg and Henriksson, 2002).

Although the majority of a working woman's life may be occupied by paid work, the working woman is also typically responsible for maintaining the household, and caring for children and elderly relatives, termed 'unpaid work', which also consumes her time and energy (Liedberg and Henriksson, 2002). Time Use surveys from various countries have reported that women spend more hours than men performing 'unpaid work', and that this gender difference is present across all types of employment, including full-time employees (Australian Bureau of Statistics, 2006; Fisher et al., 2007; Lader, Short and Gershuny, 2006). For women in general the high demands of both work, domestic chores and family responsibilities are difficult to balance, however for women with a chronic illness, they can have the same responsibilities as well as trying to manage their chronic disease (Liedberg and Henriksson, 2002).

Responsibilities outside work strongly influence a woman's ability to continue working with a chronic disease. A decrease in their working hours would mean a reduction in pay for those who have to reduce their total working hours (Henriksson, Liedberg and Geedl, 2005; Liedberg and Henriksson, 2002). Marital status may influence the decision to continue working and the ability to adjust working hours, as married women generally share their financial responsibilities with their partner, while unmarried women may be totally dependent on their own salary.

A longitudinal study followed 94 young women, aged between 18 and 39 years, for a year, after being diagnosed with fibromyalgia and found that in these women, work limitations were evident (Burckhardt et al., 2005). Sixty percent of the women were employed at the time of diagnosis, 6 months after diagnosis this had decreased to 46% of the women in employment (Burckhardt et al., 2005). All the women who had given up work had done so due to difficulties associated with their fibromyalgia (Burckhardt et al., 2005). Between 6 and 12 months post diagnosis this had decreased again to 41%, indicating a downward trend in those continuing to work (Burckhardt et al., 2005). However, this study did not consider the interaction of work and home life. As previously mentioned, work and home life are interrelated and so activities or management strategies chronically ill workers, particularly women, implement at home, are likely to have a knock-on effect. This could have influenced the ability of the women in Burckhardt et al.'s study to continue working with

3.5.2 The second shift

As already mentioned, although women's involvement in the workforce has increased, women continue to have the main responsibility of domestic chores and child care within the home (British Social Attitudes, 2015; Gibb, Fergusson and Boden, 2013). It has been suggested that women are having to perform a 'second shift' of paid employment and unpaid work (Hochschild, 1997). Hochschild states that *'most women work one shift at the office…and a 'second shift' at home'* (Hochschild, 1989, p.4). The 'second shift' refers to the domestic and family commitments society mainly places on the woman, such as maintaining the home and caring for children (Henriksson, Liedberg and Geedle, 2005; Liedberg and Henriksson 2002; Vickers, 2001).

Since 1983, the NatCen's British Social Attitudes survey has conducted annual surveys asking approximately 3,000 members of the British population about life in Britain (British Social Attitudes, 2015). As part of the 2012 survey gender roles in domestic chores and caring roles were explored, using random probability sampling to send questionnaires to British households (Scott and Clery, 2013). The results of the survey were that men reported spending 18 hours a week performing domestic chores and looking after family members (8 hours on housework: 10 hours caring), while women reported spending 36 hours a week on these activities (13 hours on housework: 23 hours caring) (Scott and Clery, 2013). When they compared these findings to a similar survey they conducted in 2002, they found there had been little change in the gender distribution of domestic chores and caring roles between couple households (with partners living together). With women in Britain, still spent more time performing these tasks, than men (Scott and Clery, 2013). This is similar to findings from a New Zealand study into gender differences in employment and housework in a birth cohort of 30 year olds, which found women spent considerably more time than men in domestic chores and child care (Gibb, Fergusson and Boden, 2013). In Britain, it was more likely that women took on the roles of food shopping, household cleaning, caring for family members and meal preparation, than men, although the latter two tasks were likely to be performed by both partners rather than only by the women (Scott and Clery, 2013).

Women sharing their time and energy between work and domestic chores can result in an increased struggle to balance their work and family life (Henriksson, Liedberg

and Geedle, 2005; Scott and Clery, 2013). Evidence suggests that the demands of the 'second shift' can affect a chronically ill woman's ability to recuperate her energy after returning home from work (Henriksson, Liedberg and Geedle, 2005). In order to continue working, some chronically ill women must renegotiate their role in the home, which often involves delegating tasks to their partner or children or leaving the domestic chores undone (Liedberg and Henriksson, 2002; de Vries, 2011).

The previous section has outlined what is known about chronic disease and work in general, about COPD and work in particular, and highlighted the gaps with regard to COPD in women, and COPD in the context of work-life and home-life.

The next section introduces the conceptual model which has guided the exploration of the experience of working-age women with COPD in this research.

3.6 Conceptual Model

Various models have been developed to explore aspects of living with chronic disease, 2 models in particular were considered for use in this study, the 'Common Sense Model of Disease Representation' (CSM) and the 'International Classification of Functioning, Limitations and Health' (ICF).

The CSM is a theoretical framework which proposes that an individual's disease representations or 'lay' beliefs about disease enable them to make sense of their symptoms and also direct any coping actions (Hale, Treharne and Kitas, 2007). The CSM has been used extensively in adults with chronic disease to understand self-management, principally medication adherence (Sonny and Insel, 2016, Leventhal, Brissette and Leventhal, 2003). The CSM model has previously been used in COPD research (Kaptein et al., 2008), and research specifically exploring how women with COPD recognise and respond to their disease symptoms (O'Neill, 2002). This model was considered unsuitable as a framework for this study, as the focus of this study was on how women with COPD manage work participation and applying the model to work participation was problematic as the model focuses on the emotional perception of the disease.

The second model, the 'International Classification of Functioning, Disability and Health' (ICF) was developed by the World Health Organisation (WHO) in 2002, and '… *provides a framework for the description of human functioning and disability and for the documentation, organisation and analysis of this information'* (WHO, 2013). The ICF can be used as a method of classifying the level of function or dysfunction associated with a health condition and also as a conceptual model (WHO, 2013). The

use of ICF as a method of classifying and coding heath conditions, involves the quantitative measurements of functioning and disability of individuals or patients (WHO, 2013). The ability to objectively classify and code a health condition creates a standard language by which the international community and the different professionals involved in managing an individual's health condition, can communicate (WHO, 2013).

As a conceptual model, ICF integrates the two major models of disability; the medical model and, crucially, the social model, forming a 'bio-psycho-social' model (WHO, 2013). The ICF model groups' information into several parts, with the first part focusing on functioning and disability (body functions and body structures, activities and participation), while the second part involves contextual factors (environmental and personal factors) (WHO, 2013). Terms used in the model are defined in Table 2. In the ICF model, disability and functioning are regarded as outcomes of interactions between health conditions (i.e. disease) and contextual factors (i.e. environmental and personal factors) (WHO, 2002), however, the interaction between the domains is bidirectional and the relationship is complex, dynamic and often unpredictable (WHO, 2013). Domains embody meaningful groups of body functions, actions and participation in life situations, enabling a more holistic understanding of the experience faced by a person with a health condition to be captured (WHO, 2013). Also, this model facilitates a better understanding of the effect contextual factors have on functioning as well as a greater awareness of participation and social interaction among individuals with a health condition (Jelsma and Scott, 2011). Human function is classified in ICF as being on three levels; *'functioning at the level of the body or body part, the whole person and the whole person in a social context'*, with dysfunction at any one of these levels resulting in disability, termed *'impairments, activity limitations, and participation restrictions',* respectively (WHO, 2002). ICF also allows the integration of data from both quantitative and qualitative sources (WHO, 2013), facilitating its use in mixed methods research.

Although the ICF model is increasingly being used in chronic disease research from the biomedical and physiotherapy perspective (Stucki, et al., 2004a; Stucki, et al., 2004b; Jelsma and Scott, 2011), with researchers predominantly using the model's coding function as a diagnostic tool to quantitatively measure functioning of patients with chronic disease, including COPD (Jobst et al., 2013), to date few studies have used the conceptual model in the social context. Furthermore, no research could be found that applies the ICF model to explore the factors that affect individuals with a chronic disease, in particular COPD, participating in work, despite its use in such areas being previously recommended (Forhan, 2009).

This study aims to address this gap by focussing on the social context of the ICF model in regard to COPD in working age women.

The gap found in the literature review related to the lived experience of women of working age with COPD. There was also a dearth of knowledge regarding how environmental factors and personal factors influence work participation in working age women with COPD. The ICF model was considered a suitable model to use as the conceptual framework for this study, as it recognises the different factors involved in living with a chronic disease, including work participation, as it considers the biological aspect of disease, as well as contextual, non-biological factors, and how such factors individually and collectively effect participation in life activities. From the literature review it was apparent that the severity of disease (and other biological factors) did not really explain why some people (including women) work while living with a chronic disease, while others do not. Thus, it was important to investigate these other factors to gain a more holistic understanding of the work and home lives of working age women with COPD.

It was originally hoped that the study would include quantitative, biological measurements, in the form of participant's Spirometry values, which the ICF model allows. However, while conducting the study it became apparent that collecting such quantitative data was not possible. Reasons for this included participants not being told the actual value of their Spirometry test by medical professionals, or they were unable to remember the exact value of their most recent test result.

The ICF model captures many features related to life with a health condition; biological disease, limitations in performing activities and participation in life activities, as well as the contextual factors that might influence these (WHO, 2002). However, in its original form all domains are given equal importance. This study focused on the effects COPD had on working women's life, particularly their work life, thus in order to focus on work participation, the model had to be adapted for use in this study, illustrated in Figure 3. The figure shows a large boxed area, which depicts the domains of interest in this study, with the size of the boxes and arrows within this area being relative to the importance given to these domains. As the physiological disease condition was not a focus of this research study, it was shown outside the area of interest (depicted by a central 'box').

Table 2: Definitions of terms used in the ICF model. Adapted from (WHO, 2001, p.130; WHO, 2002, p.11).

Definition of terms in the ICF model (in the health context)

Functioning is a broad term for body functions, body structures, activities and participation. It represents the positive aspects of the interaction between an individual (with a health condition) and their contextual factors (environment and personal factors).

Disability is a broad term for impairments, activity limitations and participation restrictions. It represents the negative aspect of the interaction between an individual (with a health condition) and their contextual factors (environmental and personal factors).

Body function- the physiological functions of body systems (including psychological functions).

Body structures-anatomical parts of the body such as organs, limbs and their constituents.

Impairments- problems with body function and structure such as significant abnormality or loss.

Activity- the performance of a task or action by an individual.

Activity limitation- difficulties an individual may have in performing activities.

Participation- involvement in a life situation.

Participation restrictions- difficulties an individual may experience in involvement in life situations. Derived from one or more limitations.

(External) Environments factors- the physical, legal and social structures which include social attitudes, workload, adjustments and perceived support received at work and at home. These act as either barriers to or facilitators of the person's functioning.

(Internal) Personal factors- characteristics of an individual, such as biological sex, age, coping styles, social background, education, professional, past and current experience, overall behaviour pattern, character and other factors that affect how disability is experienced by the individual.
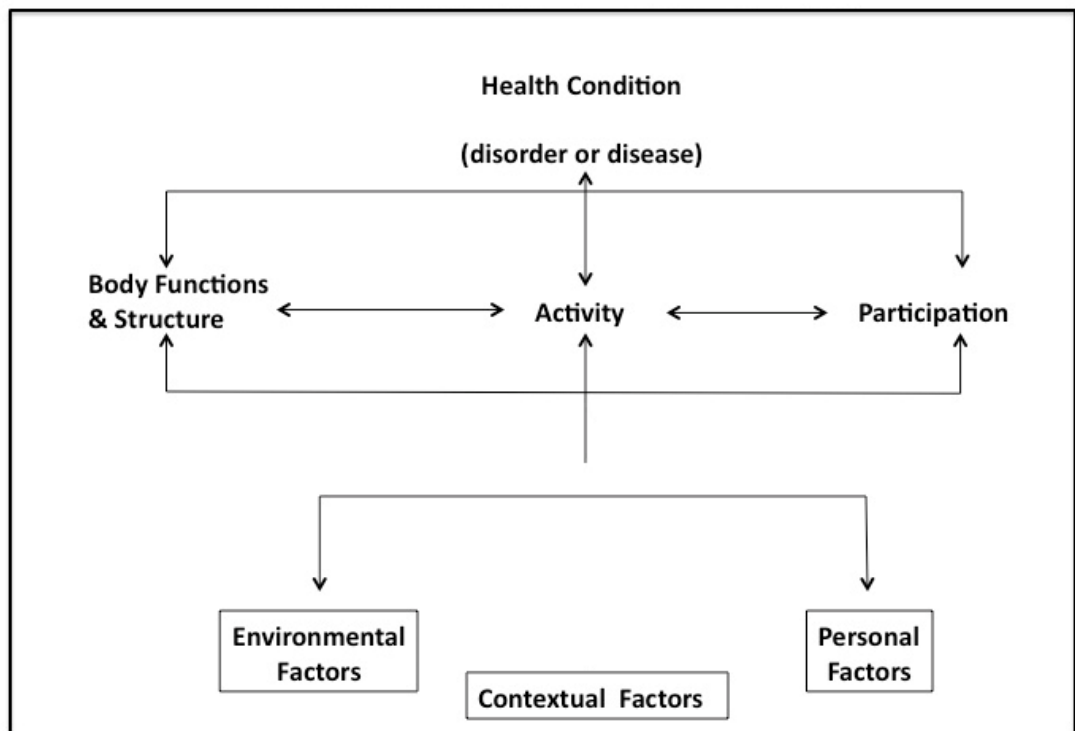
Figure 2: The original ICF model. Taken from (WHO, 2002; p10).
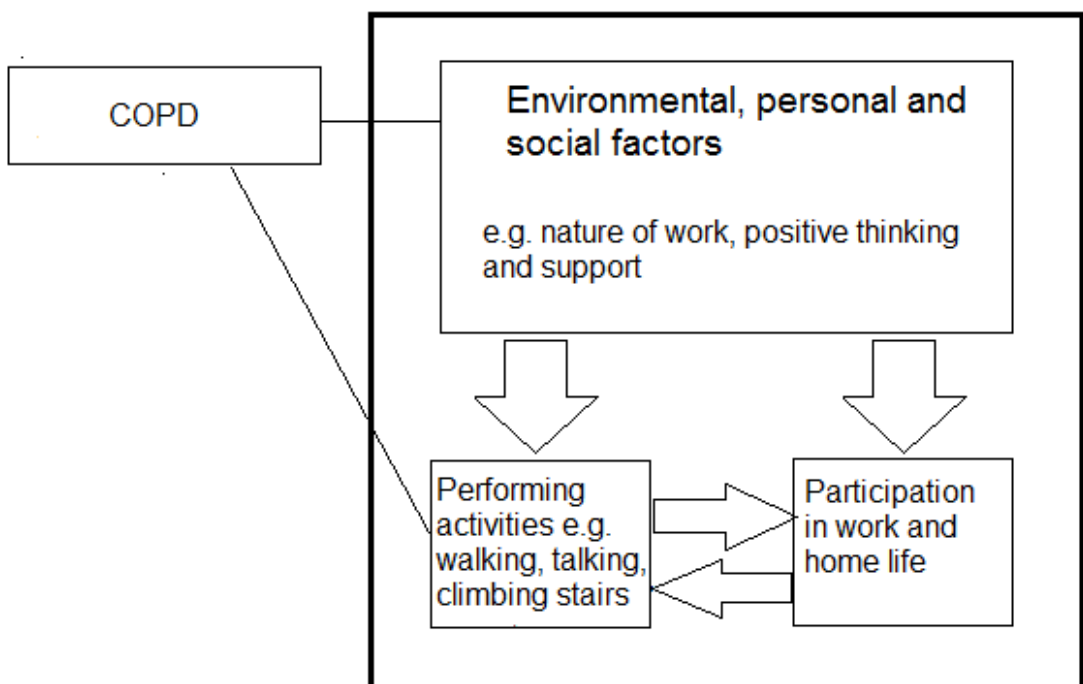
Figure 3: The adapted ICF model used in this study.

3.7 Conclusion – What is Known and What is Unknown in Regard to COPD and The Working Age Population.

It is known that COPD has a significant financial impact on the working age population, with those who continue to work, being concerned about their future prospects in the workplace, including their potential career progression and future earning power (Fletcher et al., 2011). Twenty to forty percent of people with COPD are expected to leave work early because of the chronic disease (Kremer, Pal and van Keimpema, 2006; Chapman, Bourbeau and Rance, 2003; Britton, 2003). From the published literature available on COPD and work, it is clear that factors other than disease severity, affect the management of COPD and the impact it has on the lives working age people. Workplace adjustments are needed to keep people at work and those who stay at work with COPD report a higher quality of life than those who leave the workforce because of COPD. Adjustment latitude and support are important to make adjustments to the work. Various strategies to manage work with chronic disease have been reported, such as reducing the workload, flexibility of working hours and workplace, and adjusting the content.

The studies conducted previously on COPD focus on one part of life, whether it be daily activities in general or the effect of COPD on employment status, none considered the effect of COPD on a working age person's life as a whole. This is especially significant in women working with COPD as they are mostly responsible for performing the second shift of maintaining a household and caregiving, as well as participating in paid work. The increasing numbers of working age women developing COPD, and the different social roles women have been given compared to men, means it is ever more important to specifically explore the coping strategies women use to manage COPD and stay at work for as long as possible. This research project aimed to address this gap in the literature by focussing on the whole-life experiences of women of working age, with COPD.

Chapter 4. Methodology

4.1 Introduction

As the current study aimed to explore complex, previously unexplored matters, mixed methods was considered the most suitable approach. To facilitate the collection of a wide range of rich data, this study was divided into two Phases; Phase One and Phase Two. Phase One involved the researcher performing two qualitative telephone interviews and collecting interim messages, over a three month period, while Phase Two involved the researcher quantitatively analysing the content of text written on an internet forum, over a three month period (Figure 4). Although the objectives of this study have already been stated, they will be repeated here to remind the reader at this stage, as the philosophical framework and thus the methodology were determined by the aims of the research.

4.2 Study Aim and Research Questions

The overall aim of this mixed methods study was to explore how working women, aged under 65 years, with COPD and living in the East of England, manage their daily work and home lives.

The research questions for this study were:

1. How do women of working age perceive their COPD, and how do they view the impact the disease has on their life?

2. What are the strategies these women implement to manage work and other daily responsibilities with the disease symptoms?

3. Are the findings from a small sample of working-age women in the South of England typical of a broader range of people with COPD worldwide?

4.3   An Overview

The pragmatist paradigm and mixed methods (MM) methodology guided this research study. Pragmatism was selected as the paradigm of choice because it is a flexible worldview, which supports the implementation of research methods that are more likely to comprehensively answer the research question, instead of restricting the researcher to certain methods that are affiliated to certain paradigms i.e. the positivist

and constructivist paradigms (Creswell, 2009). The variety of methods in this study were organised into two Phases, the components of which can be seen in Figure 4.

4.4　Research Paradigms and Philosophical Underpinnings

A paradigm is described as the way in which we view the world (our 'worldview'), *'complete with the assumptions that are associated with that view'* (Mertens, 2003, p139). In the context of scientific research, researchers affiliated to each paradigm hold distinct philosophical beliefs and values about how to conduct research, (Greene, 2006; Crotty, 1998; Teddlie and Tashakkori, 2009; Creswell and Plano Clark, 2011). It is recognised that there are multiple paradigms, the three paradigms to be considered here are positivism, constructivism and pragmatism. This study was informed by the pragmatist paradigm that merges both the positivist and constructivist paradigms, which remained true to their philosophical underpinnings.

A paradigm features three philosophical aspects, these are: epistemology (human knowledge and knowledge acquisition), ontology (nature of reality) and methodology (how the inquirer should go about finding out) (Teddlie and Tashakkori, 2009; Greene, 2006; Guba and Lincoln, 2005), the research methods of each paradigm are also included here.

Positivism

Positivist researchers adopt an objective epistemology, in which the researcher impartially discovers the absolute knowledge of an objective reality (Scotland, 2012). The positivist ontological position is one of realism (Scotland, 2012), which assumes the research findings are independent from the values of the researcher (Teddlie and Tashakkori, 2009; Scotland, 2012), and the researcher is solely an observer with the aspiration to expose the 'objective Truth', the one and only reality that exists for the quantitative researcher (Crotty, 1998; Guba and Lincoln, 2005). Quantitative research aims to confirm or verify a specific, pre-existing theory, based on what is already known about the phenomenon under study (Teddlie and Tashakkori, 2009). In the positivist paradigm quantitative research methods are used and can include structured questionnaires from which statistical data is collected and analysed (Teddlie and Tashakkori, 2009).

Constructivism

Constructivist researchers take a subjective epistemological stance, and a relativist ontological viewpoint (Scotland, 2012), considering reality to be subjective and constructed from the individual mind, with there being as many realities as there are individuals (Scotland, 2012; Crotty, 1998). As meaning is constructed, constructivists consider that the researcher and the participants have to actively work together in order to create a deep understanding of, and interpretation of the realities of the phenomenon under investigation (Teddlie and Tashakkori, 2009). Constructivist research acknowledges and embraces the fact that the researcher will undoubtedly use their personal values and experiences throughout the data gathering and data analysis processes (Teddlie and Tashakkori, 2009). Constructivists recognise the unique subjectivity of each researcher, which is influenced by their previous experiences, training and a natural bias (Patton, 1999). The constructivist paradigm uses qualitative research methods which are exploratory in nature (Teddlie and Tashakkori 2009), and works within inductive logic ('from the bottom up'), from *'individual perspectives to broad patterns and, ultimately, to theory'* (Creswell and Plano Clark, 2007; p22).

Qualitative researchers collect, analyse, interpret and present subjective data which may be in the form of words, images or text (Teddlie and Tashakkori, 2009). Frequently used methods of data collection are interviews using semi-structured or open-ended questions, participant diaries, participant observation, or audio-visual materials (Teddlie and Tashakkori, 2009). Qualitative data analysis is frequently performed by categorising the data into patterns or themes (Teddlie and Tashakkori, 2009), this will be described in more detail later in the chapter.

Pragmatism

Pragmatism, the most widely supported philosophical underpinning aligned to mixed methods research (Teddlie and Tashakkori, 2009; Johnson and Onwuegbuzie, 2004), accepts there can be singular and multiple realities co-existing. In so doing, pragmatism supports the used of positivist and constructivist worldviews in the same study (Creswell and Plano Clark, 2007). The focus is on solving practical problems in the 'real world' (Creswell and Plano Clark, 2007, pp. 20-28). In the pragmatist epistemological stance both subjective and objective approaches are valued to reveal the answers (Andrew and Halcomb, 2006; Creswell and Plano Clark, 2011; Teddlie and Tashakkori, 2009). In a mixed methods study, each individual method used stays true to its respective worldview, which guides the methodological approach (Creswell and Plano Clark, 2011).

The overarching philosophical stance of this mixed methods study was pragmatism, with the dominant qualitative phase (Phase One) of the study being underpinned by a constructivist position, using an inductive approach to collect and analyse qualitative data. The secondary, quantitative phase (Phase Two) was based on an objective, positivist viewpoint and a deductive approach was used to collect and analyse data for the quantitative content analysis.

4.5   The Emergence of Mixed Methods Research

The decades of conflict between the quantitative and qualitative research traditions, with researchers from each tradition declaring superiority over the other, sparked the emergence of mixed methods research in the 1960s (Tashakkori and Teddlie, 1998). There were researchers and philosophers from both the quantitative and qualitative traditions who supported or opposed mixed methods research (Tashakkori and Teddlie, 1998). A zealous paradigm debate began, which Tashakkori and Teddlie (1998) termed the 'Paradigm Wars' (Tashakkori and Teddlie, 1998). The 'wars' involved opposition from purists on both sides debating the mixing of quantitative and qualitative methods in a single study is not viable as the two methodologies are incompatible (Johnson and Onwuegbuzie, 2004; Glogowska, 2011). The argument against mixing methods was thus termed by many as the 'Incompatibility Thesis' (Teddlie and Tashakkori, 2009).

The successful application of mixed methods research in research projects have aided in discrediting the 'Incompatibility Thesis' (Teddlie and Tashakkori, 2009). The emergence of the 'Compatibility Thesis' provided substantial evidence for combining divergent paradigms, and a reasoning that has led to many researchers' advocating a peaceful coexistence and the notion that certain types of research question are better suited to be answered by the most appropriate method (Teddlie and Tashakkori, 2009). The 'Compatibility Thesis' marked the end of the paradigm debate for most, enabling MM researchers to refocus their attention on developing the mixed methods tradition (Teddlie and Tashakkori, 2009).

Since the turn of the millennium, mixed methods research has developed dramatically, being used in a broad range of research disciplines, with various articles and books being published, and the 'Journal of Mixed Methods' being introduced in 2007 (Greene, 2008). Various researchers, namely Creswell, Plano-Clark, Teddlie, Tashakkori, and Onwuegbuzie have really pushed mixed methods research as a methodology and research design in its own right (Creswell and Plano Clark, 2011;

Fetters, Curry and Creswell, 2013; Teddlie and Tashakkori, 2012.; Wisdom et al., 2012). However, the concept of mixing both quantitative and qualitative methods in one research inquiry has occurred since the beginning of the 20th century (Johnson, Onwuegbuzie and Turner, 2007; Johnson and Onwuegbuzie, 2004). Although such research lacked the mixed methods research label (a term created years later), the sense was there (Johnson and Onwuegbuzie, 2004). A key example of early mixed methods research is Thomas and Znaniecki's classic study 'The Polish Peasant in Europe and America' (Lopata, 1996).This study incorporated a broad selection of data including diaries, statistics and a written autobiography, to portray the lives of the millions of Polish people who immigrated to America between 1880 and 1910 (Brannen, 2009; Lopata, 1996). This study intended to comprehend the cultural background of the immigrants, from their own perspective. Thomas and Znaniecki's use of subjective data in this study defied the conventional ways of viewing the nature of data, at this time (Brannen, 2009; Lopata, 1996).

4.6   The Rationale for Employing Mixed Methods Research in This Study

Mixed methods research was considered the most appropriate methodological approach to address the research questions in this study. The rationale for using a mixed methods research design was based on the concept that using both qualitative and quantitative research methods and converging them would provide a more detailed understanding of the research problem, than is a single research method was used (Andrew and Halcomb, 2012). This was a mixed methods research study, in which there were two phases, a dominant qualitative and a secondary quantitative phase. The first and second research aim of this study was qualitative in nature, as the research questions posed were exploring 'how' young women reported their experiences of living with COPD and anticipated a descriptive response of 'what' coping strategies are employed by these women in order to continue with their day-to-day activities. The qualitative phase methodologically reached data saturation; meaning that after interviewing all six participants, no new themes emerged. The third research aim of this study was to find out whether the findings from Phase One were typical of the international female perspective of living with COPD. Thus Phase Two was conducted to demonstrate transferability of findings from Phase One, from a sample of women in the East of England.

Since the objective of this study was to explore the disease experience of a previously unstudied group (working women with COPD), pragmatist and the associated

philosophical stances and a mixed methods approach were considered to be appropriate to guide this study.

4.7   Combining Research Methods

Creswell and Plano Clark (2011) described four important design characteristics that outline mixed methods research studies. The first being the extent to which qualitative and quantitative data converge, that is, does one data set inform the other or are the data sets collected independently of one another? (Creswell and Plano Clark, 2011). The second design characteristic is the sequence for collecting data. In a concurrent (also termed simultaneous) design, the collection of both the qualitative and quantitative data sets occurs at the same time (Creswell and Plano Clark, 2011). Although this could reduce the data collection period, it could be resource intensive, and the researcher cannot allow the collection of one data set to influence the collection of the other data set (Halcomb and Andrew, 2009). Whereas, a sequential design consists of qualitative and quantitative data sets being collected separately, with findings from one type of data collection, such as telephone interviews, informing the collection of the subsequent data set, for example, a survey (Halcomb and Hickman 2015). In sequential designs, the data collection period takes longer than it does in the concurrent design (Halcomb and Andrew, 2009).

The third design characteristic is that the relative priority given to qualitative and quantitative data can vary (Creswell and Plano Clark, 2011). Research which is exploratory in nature usually gives priority to qualitative data as little information is already known about the phenomenon under study (Halcomb and Hickman, 2015). While, in explanatory research, in which researchers search for complementarity, quantitative data is frequently prioritised (Andrew and Halcomb, 2006).

The fourth and final design characteristic is that timing of data convergence that is when qualitative and quantitative data is combined (Creswell and Plano Clark, 2011). The convergence of aspects of both qualitative and quantitative approaches at any stage throughout the research process is a possibility within mixed methods research; from the philosophical stance underpinning the research to the data collection, analysis and interpretation stages (Halcomb and Hickman, 2015). A single philosophical viewpoint or worldview, consisting of only one epistemological, ontological and axiological view, could be chosen to underpin the whole mixed methods research study (Creswell and Plano Clark, 2011). However, another option is to combine multiple philosophical stances within the design of the mixed methods

research study (Creswell and Plano Clark, 2011). This is done by keeping the different research methods with their associated philosophical worldviews (Creswell and Plano Clark, 2011). In this way, the mixed methods research study can hold both a constructivist (qualitative) and positivist (quantitative) philosophical stance (Halcomb and Hickman, 2015). However, this research approach only uses mixed methods as a data collection method, with each methodological approach being guided by its associated worldview (Creswell and Plano Clark, 2011). In this study, the pragmatist worldview guided the entire research process, and as this study was predominantly qualitative, the vast majority of that pragmatic stance was influenced by constructivist (qualitative) views.

4.7.1 Data integration

The term 'triangulation' describes the use of two or more different methods, principally qualitative and quantitative methods, at any stage of the research process, including collection, analysis and interpretation of the data, in an investigation of the same research interest (Hussein, 2015; Fielding, 2012). Triangulation originated from navigation and military tactics which involved using numerous reference points to locate an object's exact position (Smith, 1975). In this way, multiple viewpoints allowed for greater accuracy (Yeasmin and Rahman, 2012). Triangulating different methods and types of data was first used in social research by quantitative researchers (Jahoda, Lazarfield and Zeisl, 1976). After the publication of Campbell's paper describing the use of 'triangulation' by means of convergent validation, triangulation become established in qualitative research (Campbell and Fiske, 1959; Fielding, 2012).

There are various areas of a research project that can be triangulated in the investigation of the same research phenomenon, including methodological approaches, theoretical perspectives, data sources, investigators and analysis methods (Hussein, 2015; Yeasmin and Rahman, 2012). Methodological triangulation is the most frequently used (Yeasmin and Rahman, 2012). The decision of which triangulation method is most suitable for a particular study, is determined by the objectives of the research study (Yeasmin and Rahman, 2012). The triangulation techniques are not mutually exclusive and multiple triangulation methods can be used in a single study (Yeasmin and Rahman, 2012). As already mentioned, each method has its own strengths and weaknesses, however, by merging two or more data sets, observers, theories or methodologies the intrinsic biases or weaknesses and the problems associated with studies that use one method, one researcher or one theory can be overcome, to provide a coherent understanding of the research area (Andrew

and Halcomb, 2009; Yeasmin and Rahman, 2012). The convergence of different research methods and data sets via triangulation, enables mixed methods to offer researchers the potential to gain a deeper understanding (from qualitative data) and a broader outlook (offered by quantitative approaches) of the research area (Yeasmin and Rahman, 2012; Fielding, 2012). This is of significant interest when researching an unexplored research area (Yeasmin and Rahman, 2012). Another reason to use triangulation is to increase the credibility and validity of the overall research results by converging two or more research methods, which allows the researcher to gain a more complete view of the social realities or research area being investigated (Yeasmin and Rahman, 2012). The three possible outcomes of triangulating data from different research methods are convergence/confirmation, inconsistency (not confirming but not contradictory) and divergence/contradictory divergence (Yeasmin and Rahman, 2012). Various methodologists have used triangulation methods to confirm one set of results with another, often by validating findings from the qualitative approach with results from the quantitative approach, providing the researcher with more confidence in their results (Yeasmin and Rahman, 2012). In this study, the rationale for triangulating qualitative and quantitative data was to validate the findings from the (main) qualitative phase (Phase One) of the study, with the findings of the quantitative phase (Phase Two), see section 6.24.

4.7.2 How to integrate data

Although the integration of qualitative and quantitative data sets is a fundamental aspect of analysis and conceptualisation in mixed methods research (Fielding, 2012; Maudsley, 2011), with the broad aims being 'illustration, convergent validation (triangulation) and the development of analytic density or 'richness'' (Fielding, 2012; p1), details on how to integrate the two data sets has been generally neglected in the literature (Andrew, Salamonson and Halcomb, 2008, Zhang and Creswell, 2013). Although Creswell and Plano Clark (2011) define the four characteristics of a mixed methods design (outlined in the Methods section 4.9), and Zhang and Creswell (2013) describe three separate techniques for mixing data in mixed methods research, they do not provide detailed methods in which to combine qualitative and quantitative data.

For the benefit of the reader, the three techniques described by Zhang and Creswell (2013) to mix data are; integration, connection and embedding (Zhang and Creswell, 2013), with integration incorporating data at the interpretation phase of the research process, after qualitative and quantitative data have been collected simultaneously and analysed independently (Zhang and Creswell, 2013). Connection involves the collection and analysis of one data set being based on the findings of the other data

set (Zhang and Creswell, 2013). While the 'embedding' approach involves the analysis of one data set which is embedded within the other data set, this generally consists of a minor qualitative element nested within a predominantly quantitative study (Zhang and Creswell, 2013). These methods of mixing data are not mutually exclusive and different methods of mixing could be combined within the design of some projects (Zhang and Creswell, 2013). This research embedded a small quantitative element into a wider qualitative project.

In addition, Fielding (2012) states that *'effective data integration requires a well-considered approach that knows when to synthesize some findings (because they are equivalent and commensurate) and when to respect and investigate contradictory findings (because the contradiction reflects epistemologically based differences that cannot be resolved empirically, only conceptually)'* (Fielding, 2012; p1). For the novice researcher, the lack of information on exactly how to integrate the two sets of data proves extremely challenging as they may not have the knowledge and experience needed in conducting qualitative and quantitative research, let alone know when to *'synthesize'* or *'respect and investigate'* findings. Further, the lack of guidance extends to courses and training, as although training in how to conduct mixed methods was sought, no courses in any shape or form were found. This is definitely something that needs addressing as mixed methods research becomes increasingly popular and to ensure the standard of research is high. Although, saying that, providing guidance on how to mix the plethora of possible combinations of qualitative and quantitative methods that could be used in mixed methods research could prove difficult.

4.8   Methods

4.8.1 Introduction

This section will discuss the rationale for choosing the specific mixed methods design, and describe the methods employed in both phases one and two. Convergence of data from both phases will then discussed, followed by the issues of ethics and rigour.

This mixed methods study consisted of two phases; a dominant qualitative phase (Phase One), and a secondary quantitative phase (Phase Two), shown in Figure 4. For clarity the two phases will be discussed separately, Phase One will be discussed in sections 4.9 and Phase Two in section 4.10.

Phase One		Phase Two
a) Qualitative interview 1	+	a) Quantitative content analysis
b) Interim data collection		
c) Qualitative interview 2		
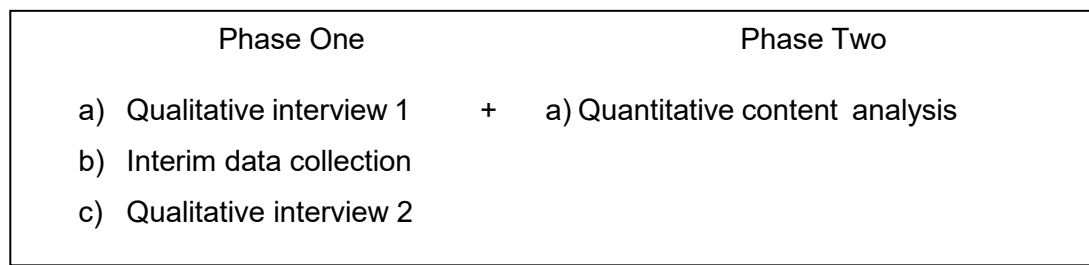
Figure 4: The two-phase research design

4.8.2 Choosing a mixed methods design

This section provides the reader with an insight into the types of mixed method designs available, before the research design of this study is presented.

There are no fixed protocols for designing a mixed methods study, however, there are a variety of different types of mixed method research designs available (Creswell and Plano Clark, 2011). The choice of design should be informed by the methodological stance and the objectives of the research study (Creswell and Plano Clark, 2011). There are three basic mixed methods designs, which are 1) exploratory sequential; 2) explanatory sequential; and 3) convergent (Fetters, Curry and Creswell, 2013). In sequential designs, the collection and analysis of the quantitative and qualitative data occur one after the other (Teddlie and Tashakkori, 2009; Fetters, Curry and Creswell, 2013), with the purpose being to have one phase of the study build on the other (Fetters, Curry and Creswell, 2013). Whereas in the convergent designs the quantitative and qualitative data are collected and analysed within a similar time period (Teddlie and Tashakkori, 2009; Fetters, Curry and Creswell, 2013), with the purpose being to compare the results of the two methods (Fetters, Curry and Creswell, 2013).

In an exploratory sequential design, the qualitative data is collected and analysed first and then the findings inform the following quantitative data collection (Onwuegbuzie, Bustamante and Nelson, 2010). Whereas, in an explanatory sequential design, the quantitative data is collected and analysed, with the findings subsequently informing the collection and analysis of qualitative data (Ivankova, 2006).Other aspects which can vary in mixed methods studies is priority given to the components and the point of merging the two components. Sometimes priority is given to one approach over the other (e.g. the qualitative phase is given priority over the quantitative phase or vice versa) (Creswell and Plano Clark, 2011). However, sometimes both Phases can be

given equal importance (Creswell and Plano Clark, 2011). In addition, the point at which the two components are mixed can occur at various points in the study; mixing can occur at the planning, data collection, data analysis or reporting stages of the study (Andrew and Halcomb, 2009; Bryman, 2006; Tashakkori and Creswell, 2007; Teddlie and Tashakkori, 2009; Creswell and Plano Clark, 2011; Fetters, Curry and Creswell, 2013).

4.8.3 The research design of this study

As the research design is '*directed by and extends from the research question*' (Tashakkori and Teddlie, 2010; p 340), the design chosen for this study was an exploratory sequential mixed methods design, which used both qualitative and quantitative approaches in order to gain a comprehensive understanding of how working women, in specific, and the wider population, in general, live with COPD.

First, the qualitative data was collected and analysed, and then the quantitative data was collected and analysed. Priority was given to the qualitative phase of the study, with the aim of exploring how working women, with COPD, manage their work and home lives. The objective was to find out what challenges these women face in their daily lives and coping strategies they have developed. Whereas the quantitative phase was secondary, with the purpose of providing a means of testing convergence between the qualitative data, from a small cohort of working women in England, with a much larger, cohort of women living with COPD internationally. The point at which the Phases were merged was at the interpretation stage of the study, shown in Figure 4. The methods employed in Phase One of this mixed methods study were two semi-structured telephone interviews and regular (biweekly) contact with the participant through text message and private messaging on the social networking internet site Facebook (www.facebook.com). The method employed in Phase Two was quantitative content analysis of pre-existing data posted on an online forum. A detailed description of each method will follow.

4.9   Phase One: Women's Voices

4.9.1 Introduction

Phase One of this mixed methods study was guided by the theoretical and epistemological stance of the constructivist, and employed qualitative methods to answer the following questions posed in this research study:

1. How do young women perceive their COPD, and how do they view the impact the disease has on their life?
2. What are the strategies these women implement to manage work and other daily responsibilities, while living with disease symptoms?

4.9.2 Design

This phase involved the collection of qualitative data from participants over a three month period. Data collection methods in Phase One were semi-structured telephone interviews, two interviews (a baseline interview and a three month follow-up interview) and diary-like messages using mobile phone text messages or private messages on the social media site Facebook (facebook.com). During the three month period between the first and second telephone interview, I sent prompt messages to each participant every two weeks, using either text message or private messaging on Facebook (depending on the preference of the participant) asking generic questions such as 'how are you' or 'how have you been recently' as well as more specific questions relating to events individual participants discussed in the first interview or mentioned in a previous message.

4.9.3 Setting

The study focused on women who lived in the East of England which included the counties of Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Kent, Surrey, Berkshire, Buckinghamshire, East Sussex, Hampshire, Surrey and West Sussex. The study also included boroughs in the East and South East of London; Barking and Dagenham, Bexley, Greenwich, Hackney, Havering, Lewisham, Newham, Redbridge, Tower Hamlets, Waltham Forest, Southwark, Croydon, Lambeth and Bromley.

4.9.4 Population and sample

Of the 64 million people living in the UK (Office for National Statistics, 2014c), three million of whom are thought to be living with COPD (British Lung Foundation, 2012b). As there are approximately 13 million women of working age (16 to 65 years) in employment (Office for National Statistics, 2014c), there is a high probability that some of these working women, under the age of 65 years are living with COPD.

However, rough statistics of how many young, working women are living with COPD are impossible to gauge. There are many possible reasons for this, including; under diagnosis or misdiagnosis of the disease in young women, and the lack of knowledge about COPD and disease symptoms result in many individuals dismissing signs of the disease and not seeking help (British Lung Foundation, 2012b; Fletcher et al.,

2011). In addition, those young women who are diagnosed with COPD are difficult to locate; the Hospital respiratory wards (in Essex) contacted to recruit participants for this study stated they very rarely have young, working women with COPD coming through their doors. Also, such women are very rarely found attending Pulmonary Rehabilitation classes, reasons for this could be that the classes are run during working hours (Monday to Friday, 9am-5pm), and so to attend, a working woman would have to take time off work, and depending on the type of work and the relationship between the employee and manager, taking time off to attend a rehab class could be very difficult. In addition, it is also likely that during the recruitment process there were more individuals that fitted the inclusion criteria, however, for their own reasons, such as the embarrassment of having the disease, they did not want to partake in the study.

Six women were recruited, at the time of conducting the study, all the women lived in London and the South East of England. Of the six, five women were in paid employment (four worked full time and one worked part time), and one of the women left employment relatively recently, because of her COPD symptoms. The age of the women ranged from 36 – 58 years, with the mean age of the participants being 44 years old. Three of the women lived alone, the other three women lived with their partners. Four of the women had children, two of which had their children living with them. The age of the children differed considerably, from a few months old to teenage and adult children, who were more independent. Table 3 below, shows the demographics of each participant, numbered one to six, for anonymity.

Table 3: Demographics of research participants

Participant	Age	Partner?	Children?	Nature of Job?	Time since diagnosis
One	44	Yes	Yes (teenagers)	Desk-based	weeks
Two	41	No	No	Desk-based and physical	years
Three	36	No	No	Self-employed	days
Four	39	Yes	Yes (baby)	Self-employed	months
Five	48	No	No	Physical	years
Six	58	Yes	Yes (adults)	Desk-based	years

4.9.5 Ethical considerations in this study

Ethics principles are tools for making reasoned judgement and form the foundations for decision making during the various stages of the research process (The British Psychological Society, 2014). There are seven ethical principles that guide ethical practise, these are; beneficence, non-maleficence, fidelity, justice, veracity, confidentiality and respect for autonomy (van Denend and Finlayson, 2007). These principles will now be considered, with overlapping principles being considered together.

The ethical principle of beneficence refers to the obligation of the researcher to make sure the research study is of benefit to the patient (Polonsky and Waller, 2010). Although the potential to cause harm, such as emotional, physical, social or economic harm (Burns and Grove, 2010; Polonsky and Waller, 2010), to a person can sometimes be unavoidable, the researcher should make sure that the potential benefits of the research outweigh the possible risks to the research participant (e.g.

emotional, physical, social or economic harm) (Gelling, 1999), and the research participant should always be thought of as more important than the research protocol, even if this means the data has to be invalidated (Tarling and Crofts, 2002). In addition to research being beneficial to the individual research participant, research should also benefit society in general (Parahoo, 2014).

The ethical principle of non-maleficence relates to the participant no being harmed as a result of participating in a study (Garity, 1995). While the ethical principle of justice involves the researcher treating participants fairly (Parahoo, 2014) and always placing the needs of the participants before the study objectives (Gelling, 1999). This study involved only interviews, consequently physical harm was therefore extremely unlikely. I protected the participant's autonomy by ensuring that they were fully informed of the aims and process of the study, and were made fully aware that they could withdraw from the study at any time. I also protected the participant's confidentiality. Although this study involved discussing potentially sensitive and possibly distressing aspects of the participants' lives, I was alert to signs of distress and had taken steps to ensure that participants knew they did not have to discuss anything they did not want to discuss.

The benefits of achieving a better understanding of the experiences of women, such as the study participants, and how they negotiate their lives with COPD, include raising awareness among medical professionals and employers of possible challenges these women face, highlighting areas where support and interventions are needed. Consequently, facilitating women with COPD to successfully manage their disease, which can result in them staying at work and continuing to live a satisfying life. This would not only have a multitude of benefits for the individual woman with COPD, but it would also reduce the financial burden COPD currently places on the employer, the health system and the government.

The ethical principle of veracity relates to the responsibility of the researcher to tell the truth about the research study (Garity, 1995), even if it dissuades potential participants from participating in the study (Parahoo, 2014). In this study, information about the study was provided in the form of the 'Participant Information Sheet', before they signed the consent form, and verbally at the beginning of each telephone interview.

Fidelity relates to the building of trust between the researcher and the participant (Parahoo, 2014). The participant entrusts themselves to the researcher, who then has the responsibility to safeguard the participant in the research context (Garity, 1995). In order to build a relationship of trust the researcher has to inform participants of the

potential risks associated with the research study before gaining informed, non-coercive, voluntary consent to take part in the study (Polonsky and Waller, 2010; ESRC, 2015). This study complied with the ethical principle of fidelity by sending potential participants a 'Participant Information Sheet' together with a 'Consent Form', in which they were made aware that they could approach the researcher with any queries, or decide to withdraw from the study, at any time throughout the study period and that any data collected from them will be withdrawn and not be used in the study. All six women interested in participating in this study reported reading the information sheet and gave informed consent to voluntarily take part in the study, and all six participants remained in the study for the entire duration of the study period.

Respect for autonomy refers to the researcher not trying to control or influence the participant and enabling them to maintain their freedom of choice (Gillon, 2003). In this study, the researcher frequently informed the participants that their participation in the study was voluntary and that they could leave the study at any time, without the need to provide a reason.

The principle of confidentiality refers to the researcher not disclosing information considered to be private or sensitive that the researcher has revealed (Burns and Grove, 2010). In this study, confidentiality was maintained by the researcher protecting the participant's identity by using pseudonyms and concealing any identifiable information by taking special care with published quotations and taking care when storing the data, for example, the data was stored in locked drawers and on password protected computers.

The application of ethical research practise lies with the individual researcher, their willingness to acknowledge their ethical and moral responsibilities and their capacity to recognise ethical issues when they arise, consider the implications and act accordingly (Guillemin and Gillam, 2004; Orb, Eisenhauer and Wynaden, 2001). Additional characteristics of an ethical researcher are to respect the participant, as a fellow human being, and treat them in a humane, non-exploitative way, while at the same being mindful of the research objectives and their role as a researcher (Guillemin and Gillam, 2004; Orb, Eisenhauer and Wynaden, 2001). In this study, I, the researcher, was very aware of my ethical and moral responsibilities to all the women who participated in the study. The ethical considerations that applied to Phase One of this study, have been discussed, the ethical issues that related to Phase Two of this study are considered in section 4.10.3.

4.9.6 Ethical principles in phase one

Ethical principles were applied throughout Phase One. Before recruiting participants, the study applied for and received ethical approval from the Hatfield Research Ethical Committee on 11th July 2014, shown in Appendix 3. Reference number 14/EE/148. The recruitment phase involved inviting individuals to participate by advertising the research study on (COPD-specific) group pages on Facebook. For this the researcher created a professional, researcher account, which had the sole purpose of broad casting the study, and recruiting participants onto this study. The profile page clearly showed the researcher's first and second name, the fact that they were a PhD student and their research area, the affiliated University and a recent picture were also clearly visible. In addition, the recruitment messages clearly stated the purpose of the study, the inclusion criteria and contact details, for individuals who were interested in the study to contact the researcher voluntarily. Thus, throughout the recruitment phase the researcher was mindful of transparency, in relation to the study and of themselves, as they were aware that recruiting participants online involved a risk of the user portraying themselves as somebody whom they are not.

Individuals who contacted the researcher, received detailed information about the study, regarding the purpose, methods and proposed uses of the research, what was expected of them if they participated in the research, and details of any risks or benefits of taking part (ESRC, 2015). It also included the contact details of the research supervisor and the complaints procedure that was in place. A consent form was also sent to interested individuals, who were requested to read the information sheet and sign and returned the consent form.

During the data collection phase, participants were made aware of telephone interviews being recorded, and their consent was sort at the beginning of the first interview (in addition to receiving the signed consent form), and each participant was also reminded that their participation was voluntary and they could withdraw from the study at any time. The difficulty in foreseeing ethical dilemmas in qualitative interviews are recognised (Orb, Eisenhauer and Wynaden, 2001). Whenever personal information was willingly disclosed during the semi-structured interviews, the researcher was intentionally empathetic and respectful to the participants. No distress was shown by the participants regarding the topics discussed. However, due to the nature of the disease, one participant did have to stop the interview due to breathlessness, the interview was terminated, and the conversation was via Facebook private messaging. In this way data could still be collected without causing undue distress to the participant. All data was stored on a secure, password protected

laptop, and as the researcher transcribed the data, access to the participant's data was restricted. The identity of the participants was protected by using pseudonyms.

4.9.7 Recruitment

The inclusion criteria for participation in this study involved being; female, diagnosed with COPD, under the age of 65 years and at the time of recruitment, were currently in or had recently left (in the last five years) paid employment. Individuals had to live in the South East of England and be fluent in English. Working women, under the age of 65 years old, with COPD were difficult to find. Advertising and recruiting in the predictable settings of Hospital Respiratory Departments and British Heart Foundation Support groups (termed 'Breath Easy groups') within Essex, did not present with many patients who fitted the inclusion criteria. Most of the patients in such settings were older than 65 years and retired from paid employment. As the majority of internet competent adults regularly use the social media site Facebook (Moreno et al., 2013) and numerous groups have been set up specifically for people with COPD, this was considered a useful advertising and recruitment tool. The specific COPD Facebook groups act as a platform for advice, support and communication with others who have COPD or their relatives.

In order to recruit using Facebook, a professional Facebook account was created, with a recent picture of the researcher as the profile picture, clearly stating my PhD research status and a brief summary of the research topic, which were considered important aspects of online recruitment to provide potential participants with transparency and reassurance that the study is genuine.

After creating a professional account, terms such as 'COPD', 'Chronic Obstructive Pulmonary Disease' and 'alpha-1 antitrypsin deficiency' were typed into the search tool. Many (over 10) groups existed, some of which were international, while others were focused on the UK, for example 'COPD Scotland' and 'alpha-1 UK support group'.

Due to the lack of response from recruitment attempts in local Hospitals, it was decided to advertise the study on all the COPD- related Facebook groups, in order to get an idea of the extent of COPD in younger women in general.

A recruitment post, including details of the study, inclusion criteria and contact details of the researcher was posted on the walls of all COPD-related Facebook groups that were found at the time of recruitment (October 2014). It must be noted that some groups had a 'closed' group status, which meant that I had to 'join' the group, and

sometimes had to explain my reason for wanting to join the group to the group administrators, in order to post on their 'wall' or message board. The ability to post messages in 'closed' groups depended very much on the administrators of the group (who acted as the gatekeepers), with some being extremely helpful and supportive of the research, while others stated the group was a space for individuals with COPD to share information between themselves, and research was not welcome. Therefore, recruitment messages for the study were only posted on the pages of COPD-related groups in which the administrators agreed to allow research. In order to maximise the number of people viewing the recruitment post, the same post was re-posted weekly over a three month period. This was necessary because with each new message added, old messages move down the page and so old messages are easily missed on an active Facebook group page where people add multiple messages on a daily or even hourly basis.

Many people expressed interest in the study, a number of whom fitted the inclusion criteria of being under 65 years old and working, however either lived in a different country or another part of the UK. Although this meant they would not participate in the study, it brought to light the fact that there are working women with COPD in their 30s and 40s in areas of the world such as Australia, Scandinavia, America and Scotland. Posting on Facebook group pages was sometimes met with hostility, and a few times the researcher was not allowed to 'join' a COPD-related group from privacy reasons.

During the three month period, women, who fitted all the inclusion criteria, sent me private messages on Facebook, expressing interest in the study. These women were sent a Participant Information Sheet (Appendix 1) and a Participant Consent Form (Appendix 2) via email, Facebook private message or ordinary post. All women signed the consent forms and returned and then a mutually convenient time and day was arranged for the first telephone interview to be conducted.

4.9.8 Data collection

Interviews

As mentioned, the dominant phase in this study, Phase One, involved each of the six participants receiving two semi-structured telephone interviews. For each participant the two interviews were conducted three months apart, and between February 2015 and September 2015, with each interview lasting between 20 and 75 minutes. The length of the interview depended on the participant, with some having more to say than others. The interviews were conducted at a mutually convenient time, which for

most women was outside of work time, however for one interview was conducted during a participant's lunch break, while in her office. The interviews were recorded using a Dictaphone (with the participant's permission) and transcribed verbatim. A qualitative research interview has been defined as '*an interview, whose purpose is to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena*' (Kvale, 1983; p174). As interviews can provide detailed descriptions of the phenomena being investigated they are a popular form of conducting qualitative research (Britten, 1995). There are several ways of conducting qualitative interviews, including face-to-face and by telephone (Opdenakker, 2006). Each type of interview has its advantages and disadvantages, which must be considered before being employed (Opdenakker, 2006).

Face-to-face interviews have the advantage that nonverbal data, such as facial expressions and body language, and contextual data, e.g. physical features of the interviewee and details of their environment can be collected (Opdenakker, 2006). However, intonation of speech and nonverbal dialogue, such as coughing or breathlessness can compensate for not being able to see the interviewee (Opdenakker, 2006). Telephone interviews facilitate interviewing individuals who are geographically dispersed, without the inconvenience of travel or cost to the researcher (Sturges and Hanrahan, 2004). However, both parties do require a telephone signal (Carr, 2001). As researcher and participant do not physically meet, there is a reduced risk, in relation to safety, for both the interviewer and interviewee (Carr, 2001). Interviews conducted on the telephone also permit more anonymity than face-to-face interviews (Sweet, 2002), and because of this the interviewee may feel more comfortable discussing personal information (Novick, 2008). A drawback of both types of interview is that interviewees (and interviewers) can be distracted by their surrounding environment (Sturges and Hanrahan, 2004). Both face-to-face and telephone interviews can be recorded, with the permission of the interviewee (Opdenakker, 2006).

The reason telephone interviews were performed in this study, as opposed to face-to-face interviews, was due to difficulties scheduling face-to-face interviews into the already busy lives of the participants. Telephone interviews were more convenient for the participants, as they could cancel and rearrange the interview at short notice. Before conducting qualitative interviews, the researcher went on a training course specifically focused on developing questions for- and the performing of- a qualitative research interview.

In addition to the mode of conducting a qualitative interview, there are various ways of structuring qualitative interviews, being; structured, semi-structured and in depth interviews (Britten, 1995). In structured interviews the interviewer must plan the entire interview in advance, and ask structured, pre-determined questions (Britten, 1995). While in semi-structured interviews, which are centred on a loose structure, the interviewer asks open-ended questions about the topic being investigated (Britten, 1995). The semi-structured interview is flexible in that deviation from the subject matter can result in a more detailed description of the research topic (Britten, 1995). While in depth interviews are less structured than the other two interview types, and cover few topics, but in detail (Britten, 1995). Semi-structured in depth interviews was the chosen approach for this study. The researcher is considered a key research instrument in the interview process (Patton, 1990), which requires considerable skill to guide the interview and obtain detailed information about a topic. The qualitative interviewer aims to '*go below the surface of the topic being discussed, explore what people say in as much detail as possible, and uncover new areas or ideas that were not anticipated at the outset of the research*' (Britten, 1995). A vital part of the interview process is that the interviewee understands what is being asked, and that the interviewer understands the meaning given by the interviewee in their reply, instead of depending on their own assumptions (Britten, 1995). Other factors that could influence an interview, both positively and negatively, is how the researcher (interviewer) is perceived by the participant (interviewee), which can be influenced by characteristics such as class, race and sex and social distance on the interview (Novick, 2008).

The interviews, although three months apart for each participant, were staggered, depending on when the participant was recruited. Thus, some participants were interviewed in February and again in May, while others were interviewed in June and September, and some were in between these time periods. The interview dates for each participant are shown in Figure 6.

The purpose of the first interview was for the researcher to build a rapport with the participant and gather demographic information about each participant. The aim of the second interview was twofold; i) once a rapport was developed and the interviewee was more at ease, they could elaborate on what they said in the first interview and ii) to see how the situation had evolved over a three month period. In the second interview, the researcher asked questions derived from topics that emerged after transcribing the first interview and interim data.

The terms researcher and interviewer, and participant and interviewee are used interchangeably. The interview schedule consisted of a list of the core themes and

questions to be covered by the researcher in the interviews. The questions were used as a loose guide during the interview, as it was more important that each interviewee comprehend the question and understand what was being asked, rather than use standard and rigid questions for all participants. The interview schedule is shown in Figure 5 and Appendix 6.

Interview Schedule

General demographic information will be asked at the beginning of the study, during the first face-to-face interview. Information about the following will be gathered:

Age, occupation, how many hours they work and in what capacity (standing all day, sat at a desk, working outside etc.), their ethnic background, their highest level of education, who is the main breadwinner in their household, if they have children and if so, how many.

The following themes (1-3) are extracted from the research questions and will form the basis of the semi-structured interviews. A-c) are examples of the open-ended questions that participants will be asked during the interviews.

1.   **Explore the experiences of young, working women with COPD**. The participants will be asked questions such as;

a) Can you tell me about when you first found out you had COPD?

To understand how their life has changed since developing this disease.

2.   **Explore the experiences of these women managing their symptoms in combination with their family and working life?**
a)   Can you tell me in what way COPD affects your family life?
b)   And you're working life?
c)   And how you cope with both family and work life?

3.   **Explore how and to what extent young women with COPD cope with periods of acute disease exacerbation, and the affect this has on their family life**
a)   Can you tell me about times when you have a 'flare-up' of your condition?
b)   What are the after effects of an exacerbation on you personally/ on your job and on your family life?

Figure 5: The interview schedule guide for the telephone interviews.

4.9.9 Diary use as a research method

Diaries are the frequent reporting of events and experiences in daily life (Bolger, Davis and Rafaeli, 2003). A research diary is a method of self-reporting, which is commonly

used to explore ongoing experiences (Bolger, Davis and Rafaeli, 2003). This research method facilitates the investigation of 'social, psychological and physiological processes, within everyday situations' (Bolger, Davis and Rafaeli, 2003; p2), and capture the 'little experiences of everyday life that fill most our working time and occupy the vast majority of our conscious attention' (Wheeler and Reis, 1991; p340).

Benefits of using diary methods is that events and experiences that happen in life, can be captured as it is lived (Bolger, Davis and Rafaeli, 2003). As participant diaries are a form of collecting data in real time, they reduce the bias associated with retrospective reporting of an event or experience, by minimising the amount of time that passed between an actual experiences and reporting this experience (Bolger, Davis and Rafaeli, 2003).

Research diaries can obtain reliable person-level information, as well as data on intrapersonal change over time, this can be compared for individual participants and provide interpersonal differences in change over time (Bolger, Davis and Rafaeli, 2003).

4.9.10 Diary messaging in this study

The purpose of the diary messaging (referred to here as 'interim data') was to capture data on the challenges working women face because of their disease, and the coping strategies they employ. Diary messaging was performed between interviews one and two, and aimed to collect data between interviews, in real time. The diary design involved the researcher contacting the participant every two weeks over a three month period, via private messaging on Facebook or text message. The message from the researcher was intended to act as a reminder that a diary entry was due. The decision to use Facebook and text message as the modes of diary entry was another attempt to make it easier for people to respond. The use of Facebook and mobile phones as research instruments was an effort to reduce the burden on the participants, as the majority of young and middle-aged people are regular users of Facebook and/or their mobile phones (Moreno et al., 2013; Carr, 2001). The time interval between each diary entry was two weeks, which was considered to be not as burdensome as daily or weekly diary entries for the participants, yet could still capture real-time data with minimal retrospective bias. Though, admittedly the reporting of experiences a few weeks, days or even hours after they occurred may succumb to retrospective memory bias. The study had to balance data collection with the wellbeing of the participant. As the participants of this study were working women with COPD, who already had busy lives, this study wanted to gain an insight into their lives, without proving burdensome.

In the Facebook or text message, the questions asked to the participants related to their recent health status, and the implications this had on their work and family life. An advantage of using Facebook or text message compared to more traditional methods of conducting diary entries; such as pen and paper or voice recorded, was that the researcher received the diary entry instantaneously. The researcher could then reply and ask the participant for more detail regarding something in that diary entry. The diary entry could be written at a convenient time for the participant, and could only take a few seconds, or minutes to complete. Other advantages were that each diary entry was automatically date and time stamped, which made organising the data easier for the researcher, and images and internet links could be easily included in the diary entry, as well as words. Combining data from both interviews and diary-type interim data enabled the development of a more holistic understanding of how COPD impacted on the everyday life of working women, and vice versa, how daily life affected the health of working women with COPD.

4.9.11 Data Analysis

Data analysis in Phase One involved performing a two-way analysis, shown in Figure 6. All the data collected from each individual participant (i.e. data from interviews one and two and interim messages) was viewed as a participant 'case', meaning there were six participant cases in total. Each participant case was analysed using the framework analysis model, which suggested using two-way analysis; categorising each case and then analysing across all six cases thematically (Gale et al., 2013). A preliminary analysis of each case was performed and four common categories materialised, these were; 'on being diagnosed with COPD', 'work and COPD', 'COPD and home life' and 'adjusting work and life'. Each individual narrative is presented in Chapter 5.

Then, once each case had been analysed using framework analysis, all the cases were analysed collectively using thematic analysis to search for themes and subthemes across the cases. The second stage of analysis was guided by 'The Six Phases of Thematic Analysis' (Clarke and Braun, 2013). Common findings were: 'knowing I have COPD', 'working with COPD', 'home life: relationships and responsibilities' and 'towards leading a normal life', presented in Chapter Six.

The reason for conducting a two-way analysis was to ensure the whole story of the participants lives with COPD, was captured, both from the individual perspective and from the viewpoint of a group of women (with different experiences and life situations).

Participant	Interview One	No. of Interim Messages written by each participant	Interview Two
One	March 2015	15	June 2015
Two	March 2015	19	June 2015
Three	March 2015	9	June 2015
Four	March 2015	30	June 2015
Five	June 2015	11	September 2015
Six	June 2015	17	September 2015

Figure 6: The two-way analysis of qualitative data in Phase One.

4.9.12 Categorising individual cases

The Framework analysis model, is a pragmatic approach to data analysis that was developed in the 1980s by social policy researchers (Ritchie, Spencer and O'Connor, 2003), and is becoming increasingly popular in healthcare research (Swallow et al., 2011; Tierney et al., 2011). The Framework model is situated within an extensive family of analysis methods often called thematic analysis or qualitative content analysis (Gale et al., 2013). These analysis methods recognise commonalities and differences in qualitative data, by detecting patterns between concepts, to draw descriptive and/or explanatory conclusions about the phenomenon under investigation (Gale, et al., 2013). Framework analysis involves several stages that systematically reduce the original qualitative data (i.e. interview transcripts), to make the analysis of individual cases more manageable (Gale et al., 2013).

The stages of performing framework analysis in this study was guided by (Gale et al., 2013). These were;

Stage One: Transcription

Interviews were recorded and transcribed verbatim. This enabled me to immerse myself in the data.

Stage Two: Familiarisation

I became familiar with each interview and 'diary-like' interim message sent from each participant.

Stage Three: Coding

Once familiarised, I carefully read the transcript and interim messages line by line, and gave words or phrases that related to the research question a paraphrase or label ('a code'). As Phase One was qualitative and thus took an inductive approach, 'open coding' was performed, in which anything that could be of relevance in the data was

coded. Coding line by line facilitated a holistic sense of what the participant said, and provided the opportunity to see things in the data that could usually go unnoticed because it is not expressed clearly or does not 'fit' with the rest of the story.

Stage Four: Developing a working framework of analysis

After several transcripts were coded, I met with my supervisors to discuss the labels used and we agreed on codes to apply to all following transcripts. A working analytical framework was created by grouping codes together into categories and then clearly defining them.

Stage Five: Applying the analytical framework

The working analytical framework was then used by applying existing categories and codes to the transcripts.

Stage Six: Charting data into the framework matrix

In order to reduce the volume of qualitative data, the data from each participant was summarised by category and then placed into a matrix. A matrix is the 'intersection' of two groups, displayed as rows and columns (Miles, Huberman and Saldana, 2014). The aim of creating a matrix was to condense large amounts of data and display them in a table format, enabling the data to be easily viewed and facilitating detailed analysis and comparison with similar data (Miles, Huberman and Saldana, 2014). There are no fixed standards in creating a matrix, rather, the construction of a matrix is a creative, yet organised task, with no 'correct' matrix, but the matrix constructed should help provide the researcher with realistic answers to the questions they are asking in their research study (Miles, Huberman and Saldana, 2014). This is presented in Table 6.

Stage Seven: Data interpretation

Throughout the analysis process I made a note of ideas and initial interpretations of the data collected from each participant, which were discussed with my supervisors. Using categories and subcategories data from each participant was interpreted to create a case or their story.

4.9.13 Thematic analysis

The second stage of framework analysis involved thematic analysis on all six cases to detect commonalities and differences between participant's experiences of working and living with COPD. I used Braun and Clarke's (2006) six phase approach to thematic analysis. Essentially, thematic analysis is a *'method for identifying and*

analysing patterns in qualitative data' (Clarke and Braun, 2013; p3), which can offer rich insights into complex phenomena (Braun and Clarke, 2006).

The steps I took in the thematic analysis process were similar to those already mentioned in framework analysis and were as follows:

Firstly, I familiarised myself with the data, which involved immersing myself in each participant's story; reading and rereading transcripts of interviews one and two and the diary-like interim messages for each participant.

Secondly, I went through each story and coded the data, that is, I created short labels for significant features that appeared in all the data that related to the research question. The coding process and coding of the data were discussed with all three supervisors, which resulted in certain codes proving inert in regard to the research questions and study objective. After reflecting on all the data, I focused on and established codes that were significant to the study objective. A sample of thematic coding is presented in Appendix 7.

Thirdly, once all data was coded, similar codes (or codes referring to similar things) were grouped together in an attempt to start developing themes. A theme was classed as data that captured something significant, relative to the overall research question (Braun and Clarke, 2006). I then went back to the beginning, read through the data, to continue the theme development process that is, determining significant patterns that reoccur throughout a participant's narrative. Fourthly, I checked the themes were appropriate in relation to the coded data and the data as a whole, making sure the themes told an interesting story about the data. All the themes were reviewed by myself and my supervisors, with some themes being removed and some being added. Fifthly, the themes were then given names that reflected the content of the theme, which sometimes was a phrase quoted by the participant in the text, and researcher also described the crux of each theme. It was sometimes difficult to give a theme a name and also clearly describe what issues the theme represented. The last stage was to write up the findings, which involved interweaving the analytic narrative with graphic data extracts, in order to present the reader with a comprehensible and credible story derived from the accounts of the participants.

Determining important patterns in pages and pages of text was particularly difficult, and required a thorough knowledge of the data, this involved me writing numerous drafts of possible themes and what the theme was about. I conversed frequently with my supervisors throughout the construction, reviewing, and defining and naming themes, as well as the writing up phase, of the thematic analysis process, which

helped guide me throughout the process, as well as increase the credibility and confirmability of the results.

4.10 Phase Two: International Dialogue

4.10.1 Introduction

Phase Two of this study involved conducting a quantitative content analysis method, guided by the positivist philosophical position. Data was collected from pre-existing text posted on a COPD-specific forum, on the health-focused internet site 'Patient' (http://patient.info/). The purpose of performing quantitative content analysis was to support the findings of Phase One, the dominant, qualitative phase, by answering the third research question, which was;

3. Are the findings from a small sample of working-age women in the South of England typical of a broader range of people with COPD worldwide?

4.10.2 Setting and population

The word-based (qualitative) data, which referred to the broad subject matter of 'living with COPD' were collected from the COPD-specific online forum. As the data was posted online, accessible by anyone with the internet, the authors of the text could be located anywhere in the world. As the internet is widely available and the prevalence of COPD is increasing worldwide, affecting billions of people internationally, one would expect the COPD-specific forums and blogs to have participants located in different countries around the world. Comments on blogs may be from people living with COPD, or relatives or friends of someone with the disease. Only data posted online that was written in English and referring to 'living with COPD' was collected and analysed.

4.10.3 Ethical considerations in phase two

The ethical considerations for Phase Two differ significantly from those for Phase One of this study, as Phase Two did not involve recruitment of or contact with human participants, but it did involve using information posted on internet sites. The data used in the quantitative content analysis phase (Phase Two) of this study was already publically available and the author of the text was made unidentifiable, the ethical issues of attaining informed and voluntary consent was not applicable. Quantitative content analysis is an observational research method, meaning I collect the data without having any interaction with the individual who posted it on the websites

(Moreno et al., 2013). There is little guidance on the specific ethical issues attributed to using social media internet sites as a research tool (Moreno, et al., 2013). Despite there being some debate around using data from social networking sites and online forums in research, the purpose for creating such internet sites was to share information with others (Moreno et al., 2013). There have been several legal battles in the United States regarding the privacy of the data Facebook users publish, in such cases, the courts concluded that as the individual knowingly posted the materials onto a social networking website and made the information publically available, privacy could not be expected (Moreno et al., 2013; Naaman, Boase and Lai, 2010).

Ethical approval for Phase Two of the study was sought and granted by the Faculty (of Health, Social Care and education) Research Ethics Panel (FREP) of Anglia Ruskin University (Appendix 4), with the condition that I regularly posted a message on the internet forum or social media group page informing users of the site that data collection was being carried out and they could inform me if they didn't want information they posted to be used in the study. The posting of this 'opt out' message caused controversy between users of COPD-specific Facebook groups and I decided not to use any of the data from these sites. Further, some online forum websites also did not want any of the posted data to be used for research, however although the administrators of the health-focused website 'Patient' (patient.info) did not want a regular post being posted on their site, they did allow use of data as long as the author and content of the data remained confidential and anonymous. This highlights the diverse opinion of using data from the internet in research. Difficulty in gaining permission to use data from certain sites restricted the amount of data collected and analysed as well as the time allocated for data collection.

4.10.4 The use of social media in research

Although ethical approval was given by Anglia Ruskin University to conduct quantitative content analysis of data from internet forums and social media sites, accessing such information proved unexpectedly challenging. In accordance with the ethical approval granted, a statement was written to inform group users that data posted on the site could be used for research purposes, and the information would remain confidential and anonymous. The administrators of two health-focused internet forums; Patient (patient.info) and COPD Foundation (COPDfoundation.org) were contacted, asking them if this statement could be regularly posted on their sites. Neither site wanted the statement on their forum; COPD Foundation did not want information from their forum used for research purposes, despite already having ethical approval, while Patient gave permission to collect data from their forum as long

as the data remained confidential and anonymous. Correspondence from both sites are presented in Appendix 5. The statement was also posted onto multiple COPD-specific groups on the social media site Facebook (Facebook.com). Soon after posting, the statement received a few 'likes', and positive comments such as 'thanks for caring', which were encouraging. However, the statement did receive negative comments, which were extremely rude, and abusive, with a personal attack being launched on me, the researcher. A response was posted explaining the aims of the research study, but received further abuse. This highlighted the negative aspect of using social media for research purposes, as the internet gives a voice to 'trolls'. A 'troll' in the context of the internet and social media is someone who deliberately causes conflict online (Collins, 2016b). Such people can be exceptionally abusive and irrational, and it would have been futile to continue. There is no policing of such social media groups and it only takes one troll to extinguish interest shown by the other (potentially hundreds of) groups users, in the study.

4.10.5 Quantitative data collection- content analysis in general

Content analysis is a flexible method for systematically analysing messages in any kind of communication, including spoken, print or electronic communication (Kondracki, Wellman and Amundson, 2002; Cavanagh, 1997). Content analysis can be either a qualitative or a quantitative analysis method (Kondracki, Wellman and Amundson, 2002), which approach to employ in a research study lies with the theoretical and practical interests of the researcher and the objective of the study (Weber, 1990).

Quantitative content analysis involves quantising qualitative data by simply counting instances that themes or patterns appear in the data (Bazeley, 2012). Counting themes or patterns in data can be used to enhance findings from qualitative data (Bazeley, 2012). Essentially, the coding process organises the content of the messages in a way which facilitates the identification, indexing or retrieval of content appropriate to the research questions (Shepherd and Achterberg, 1992). As a result content analysis is a content-sensitive method of data analysis (Krippendorff, 1980). Content elements can be words, phrases, topics, theories or concepts (Berg, 1998). Once the data sample has been identified, these components undergo either quantitative or qualitative analysis (Kondracki, Wellman and Amundson, 2002). Quantitative analysis involves quantifying qualitative data, by counting the frequency certain words of content appear in text, in order to explore the usage of words or content (Kondracki, Wellman and Amundson, 2002; Hsieh and Shannon, 2005). Quantitative content analysis is often applied to retest existing data in a new context

(Catanzaro, 1988). While qualitative analysis is usually employed to examine the hidden meanings in the data sample, which can lead to theory development (Kondracki, Wellman and Amundson, 2002). Although there are no systematic rules for applying content analysis, the key concept of all content analysis is that the many words of text are categorised into smaller content groups (Weber, 1990).

4.10.6 Content analysis in this study

Phase Two of this study involved using quantitative content analysis to analyse a large sample of textual data collected from messages publically posted on an online, COPD-specific forum. As already mentioned, the difficulty in gaining permission to use data posted in online groups and forums resulted in a limited amount of data being collected and analysed, and reduced the time scale of the second phase of this study. The objective of the quantitative phase was to confirm the findings of the qualitative phase, via triangulation; to see whether themes that emerged in the small cohort of working women in the East of England, could be transferred to a wider population of women living (and working) with COPD.

Phase Two involved me reading the messages posted over a three month period (from December 2015 to February 2016) on an online COPD forum 'Patient' (www.patient.info). I extracted main (primary) posts relating to 'living with COPD', and comments to these posts (secondary posts) written by women, filtering the messages by the pseudonyms used on the forum, which were mainly gender-oriented. If the gender was unclear, I did not collect the data. The data was then thematically analysed the data in the same way I performed the thematic analysis in Phase One. The themes collated in Phase Two were guided by pre-formed categories developed from the findings from Phase One.

I then returned to the original messages and counted the frequency these themes and subthemes appeared in the data over this time period. A matrix was created, presenting the themes and subthemes from Phase Two and their frequency in the forum messages. Then the themes and subthemes constructed in Phases One and Two were compared to see whether they were similar (different or not mentioned) in both Phases, in other words, whether what the participants during the qualitative interviews and diary-like messages similar to what international women with COPD wrote on online COPD forums. The themes constructed in Phase One covered the key interests of this research study, which was, how working women manage life with COPD. Thus the same themes were used for Phase Two. All messages posted on the forum from male users, during this three month period, were excluded from the data collection process. Messages posted by men (or posted by someone who could

potentially be a man), or about a man living with COPD were excluded from Phase Two of this study, as the focus of this study was on the lived experience of working age women with COPD, including messages from or about men with COPD would contaminate the data and affect the rigour of the study and trustworthiness of the findings. Removing the 'male-related' data meant there were no implications to the aims of the study, and it was no longer a limitation of the research project. . This was achieved by filtering the user pseudonyms by gender, only messages from users with clearly female pseudonyms were collected and analysed. In addition, posts written by women that were about men with COPD e.g. 'my husband has COPD', were also excluded from Phase Two.

Counting the frequency themes and subthemes occurred in the data facilitated the findings from the large sample to be summarised (Rose, Spinks, Canhoto, 2015), keeping the content of the data and the author anonymous; a key requirement for gaining approval to collect the data from the website. In addition, frequency counts enabled common themes to be easily and clearly identified, and the main features of the data content to be described (in a generic manner) (Rose, Spinks, Canhoto, 2015). The ability to gain an overview of data on 'living with COPD' on a large scale, was essential to answering the third research question and testing the transferability of the findings from Phase One.

The reason data was collected from an internet site, as opposed to other sources, was because the increased use of social media has changed the way people communicate and interact with others (Naaman, Boase, and Lai, 2010). Facebook and other sites have become a platform for a plethora of virtual social support groups (Mo and Coulson, 2008) and people living with an disease are more inclined than others to join such support groups, as they search for normality and acceptance, they seek advice from others and start to understand their condition (Davison, Pennebaker and Dickerson, 2000). The quantitative analysis of qualitative data involved me becoming familiar with the data, and then giving each sentence or phrase a short label or code and grouped the codes into themes, as with the analysis of data from Phase One of this study. I went through the data and counted the frequency each theme occurred in the entire body of collected data. I then created a table with the themes that emerged from the data, and the number of times they occurred. I had no contact with the authors of the messages, and they remained anonymous, as Phase Two of the study was interested in the prevalence of themes, not who said/wrote them or specifically what they said.

4.11 Data Convergence

Data from both Phases One and Two were analysed separately and converged in the interpretation stage as shown in Figure 7. The findings of this convergence are presented in Table 9 (p.178).
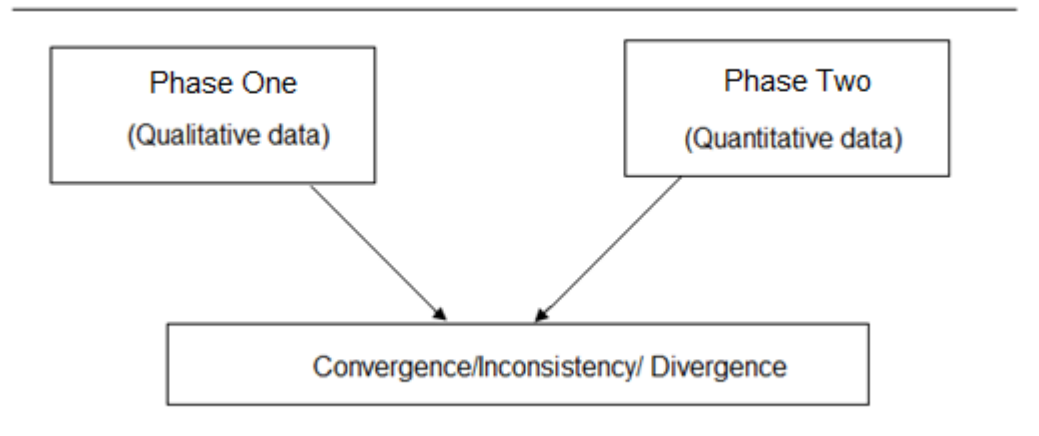
Figure 7: The possible outcomes of triangulating data from Phases One and Two.

If triangulating data from both qualitative and quantitative research methods results in convergence, the credibility of the qualitative data would be enhanced, however if divergence occurs it will lead to an interesting discussion and set the questions for future research (Teddlie and Tashakkori, 2009). In addition, the quality of a mixed methods triangulation study is dependent on the transparency and detail of reporting how the Phases of mixed methods analysis were performed and inferences and conclusions were reached (Creswell and Plano Clark, 2007).

4.11.1 Problems converging the data in this project

In this study I intended to triangulate both quantitative and qualitative data in Phase One, however, collecting accurate quantitative data from all participants was not possible. This meant using triangulation to converge different data collected from the same sample of participants in Phase One was not possible.

Phase Two of this study provided a quantitative element, however as a different data collection method was used on a different sample it cannot truly constitute triangulation. The implementation of qualitative interviews and diary entries in Phase One, combined with quantitative content analysis in Phase Two, could be more

4.11.2 Potential negatives of mixed methods research

A challenge in performing mixed methods research is that it requires a more extensive range of research skills and knowledge in both qualitative and quantitative research methods, than if either method was used alone (Halcomb and Andrew, 2009; Halcomb and Hickman, 2015). Therefore mixed methods research is usually performed by research teams and rarely conducted by a single researcher (Bowers et al., 2013). The practical implications of using a mixed methods research design include the need for additional resources and the increased financial costs involved in collecting two sets of data rather than one (Halcomb and Andrew, 2009). Further, the time needed to complete collection, analysis and interpretation of the two data sets could prove problematic when performing mixed methods research, especially when the research is conducted in fulfilment of a postgraduate degree (Halcomb and Andrew, 2009). In a sequential mixed methods design, insufficient time to analyse the first data set, could result in the second data failing to address significant issues emerging from the first data set (Halcomb and Andrew, 2009). In addition, data management could be more difficult in a mixed methods research design, as the data set created from gathering both qualitative and quantitative data, is larger and more complex than the data set that would be collected in a study that was purely qualitative or quantitative (Andrew and Halcomb, 2009). The resulting data set becomes more complex when the integration of qualitative and quantitative data occurs within the analysis stage of the study (Halcomb and Hickman, 2015). The level of complexity affects the amount of time needed to analyse the data, and for the researcher, a variety of skills are required to manage the data, as well as resources necessary to store the data (Halcomb and Hickman, 2015).

4.11.3 Rigour in mixed methods research

Although mixed methods research is becoming increasingly popular, there is no clear definition of how to demonstrate rigour in mixed methods studies (Halcomb and Hickman, 2015). Rigour should be demonstrated using the criteria required when conducting individual qualitative or quantitative research studies, in addition to the specific requirements from mixed methods research (Creswell and Plano Clark, 2011). The integration of qualitative and quantitative data, at any stage of the research process, is an important aspect in establishing rigour in mixed methods research

(Glogowska, 2011). Rigour can also be demonstrated in a mixed methods research study by the researcher providing the reader with a clear description of how they performed analysis of the data and thoughtful, justified explanations why the decisions made all through the research process, irrespective of the exact method applied (Lavelle, Vuk and Barber, 2013).

In the context of this study, rigour was established by the qualitative and quantitative phase being combined at the interpretation stage of the study, and as a result of providing a detailed description of how I thematically analysed the qualitative data in both Phases 1 and 2. Regarding rigour and researcher biases, I did not have a chronic disease, which meant I did not have any expectations of what was going to emerge in either phase of this study. However, as a young woman, of a similar age to some of the participants, I could relate to some of the age- and gender- related concerns they described. Although I was aware that a rapport between herself and the participants were necessary to facilitate richer data to be collected, I was also conscious of maintaining a boundary between being a researcher and their friend. An additional measure to increase rigour, and reduce researcher bias on the research findings, throughout the research process, work was read by my supervisory team.

4.11.4 Trustworthiness in phase one

The ability to assess the quality of all research is important in keeping the standard of research high (Yardley, 2000; Emden and Sandelowski, 1998). However, as qualitative and quantitative research methods have different philosophical assumptions and research objectives, the same criteria cannot be used to assess the quality or integrity of both (Morrow, 2005). Trustworthiness of a qualitative research study is essential to evaluate the worth of the research (Guba, 1981; Emden and Sandelowski, 1998). Guba (1981) produced four constructs that establish trustworthiness, these are;

1) Credibility
2) Dependability
3) Transferability
4) Confirmability

These are parallel to the quantitative terms of internal and external validity, reliability and objectivity, respectively.

Credibility

Credibility (comparable to internal validity) refers to the consistency of the findings with reality (Lincoln and Guba, 1985). Credibility is one of the most important elements in establishing trustworthiness (Merriam, 1998). In this study credibility was established by; established qualitative research methods being used, in the form of semi-structured interviews and quantitative content analysis (Shenton, 2004). As well as by familiarising myself with the data sample prior to data collection (Shenton, 2004), this was done by reading the literature of women with chronic disease and workers with chronic disease, as well as conversing with men and women (over 65 years) who had been clinically diagnosed, and were living with COPD, and with COPD specialists.

Credibility was also established by having regular debriefing sessions with my supervisors (Shenton, 2004), and keeping a reflective commentary of the research process, especially the data analysis stage (Morrow, 2005, Shenton, 2004). In addition, background information about me, as a researcher is included in this thesis, to ensure credibility of me as the researcher (Patton, 1990). A thorough description of the phenomenon under investigation, has also been provided to enhance the study's credibility (Shenton, 2004), as this information enables the reader to evaluate the findings from this study, in the context of the actual situation (Morrow, 2005). Further, in the final chapter, the discussion, the study's main findings have been compared with findings from previous research, which promotes credibility of this study (Shenton, 2004). However, due to time restrictions involved with a doctoral research study, it was not practical to ask participants to check the accuracy of the transcripts of their interviews, which is another form of enhancing the credibility of a research study (Shenton, 2004).

Dependability

Dependability (comparable to reliability) refers to consistency in techniques of conducting the research and analysing the data of how the research is conducted (Gasson, 2004). In this study, I have written a detailed description of the data collection process and the methods that were used to analyse the data, which can enable the work to be repeated by researchers in the future, although the same results may not be obtained (Morrow, 2005; Shenton, 2004). Providing such information also enables readers to examine if correct research practices have been followed (Shenton, 2004). To further enhance the dependability of this study, an evaluation of

the research design and how the overall research process was conducted, is provided in this thesis, under strengths and limitations described in the concluding chapter, Chapter Eight (Shenton, 2004).

Transferability

Transferability (comparable to external validity or generalisability) is the extent to which findings of the study can be generalised and relate to research being conducted in a different context (Morrow, 2005). To achieve transferability in this study, I have provided demographics of the participants and details of the data collection methods used in this study (Shenton, 2004). As a recap, data collection in Phase One involved telephone interviews (one and two) and diary-like interim messages, for each of the six participants. Each interview varied in duration, from 20 minutes to 75 minutes and the number of diary-like interim messages participants wrote was diverse as was the content and detail of what the women wrote in the messages. The small sample size and lack of statistical analysis in the qualitative phase (Phase One) of this study, means the qualitative data in this study, and as a whole, is not generalisable, in the traditional sense (Morrow, 2005).

Confirmability

Confirmability (comparable to objectivity) focuses on the recognition that no research is objective (Morrow, 2005). Confirmability focuses on the matter that '*findings should represent, as far as is (humanly) possible, the situation being researched rather than beliefs, pet theories, or biases of the researcher*' (Gasson, 2004, p.93).

To enhance the confirmability of this research study, a detailed description of the methodology and a clear description of how the data analysis was performed, as well as the rationale for choosing one approach over another, have all been included in this thesis (Shenton, 2004). In addition, the limitations that existed in this research study have been recognised and reported in this thesis (Shenton, 2004).

4.11.5 Rigour in phase two

Rigour in quantitative research is determined by assessing the quality of the research (Muijs, 2011). Research of poor quality can cause the results to be inaccurate or invalid (Claydon, 2015). The quality of a research study can be determined by peer reviewing the research to determine the rigour of the research methods (Claydon, 2015). Peer reviewing is a process in which the research is revised by a researcher's colleagues (typically in the same research area) (Sense about Science, 2006). This research study was peer reviewed by all three of my supervisors.

The quality of quantitative research is also associated with the concepts of validity and reliability (Peat, 2002). Validity refers to the precision of data-collecting instruments; whether they measure what they are supposed to measure (Peat, 2002; Carter and Porter, 2000), whereas reliability is concerned with the degree of consistency in measuring values (Carter and Porter, 2000). Validity can be categorised into two distinct types; internal validity and external validity (Peat, 2002). Internal validity refers to the reliability of the research methods; whether they are accurate and repeatable (Peat, 2002) and the extent to which the results of the study truly reflect reality (Carter and Porter, 2000), i.e. are caused only by the phenomenon being studied, rather than the consequence of extraneous variables (Peat, 2002; Carter and Porter, 2000). External validity is the degree to which the findings from a study can be generalised, and applied to and across wider populations (outside the sample from which they were derived), settings and times (Peat, 2002; Johnson and Christensen, 2004).

In this study, threats to validity and reliability of the quantitative content analysis include researcher bias, as during the data collection stage, I selected messages that I considered related to 'living with COPD'. I also analysed the data, which involved reading and re-reading the data and searching for any words or phrases that related to 'living with COPD'. As different people use different terms to mean the same thing, I had to be flexible with the terms used in categorising the content of the text. This involved looking at the overall meaning implied by the text, instead of focusing on individual words in the text.

In addition, the reliability and validity of the data were subject to the transient factors affecting the writers of the text, for example, their disease severity and the time since diagnosis, as well as the mood they were in when they wrote the text and posted it on the online forum. The size of the sample, that is, the number of forum messages analysed, was smaller than expected as the data collection period had to be dramatically reduced to three months (from the planned 12 month period) due to delays in gaining ethical approval for Phase Two of this study, and the time limit to complete this doctoral investigation.

The reduced amount of data collected, due to the shorter data collection period, could have affected the results for Phase Two of the study, and thus, the convergence with findings from Phase One, as the data collected was only a small sample, which could have been less representative of how women living with COPD internationally, manage their disease. In addition, details regarding the demographics of the author and time of day the message was posted were not always available.

4.12 Conclusion

The chapter started with a definition of a research paradigm and an overview of the three main paradigms, their associated philosophical stances and related methods were then described and compared. This was followed by this study's aims and research questions and a rationale as to why the pragmatist paradigm, that underpinned this study, and the associated mixed methods methodology, which guided this research study, were chosen. A detailed description of the emergence of mixed methods research is given. The mixed methods methodology is described in detail, including strategies on how to integrate two (or more) data sets and its application to research and the data integration process is also described. A clear description of the research design leads the reader into a thorough explanation of the research methods involved in each of the two Phases of the study, which includes details of the ethical considerations to be taken into account and reflections on how they relate to this study. This chapter also presented the methods used for data collection and data analysis in each phase are of the study. The following two chapters will exhibit the findings from Phase One.

Chapter 5. Findings of Phase One: Individual Experiences of Working and Living with COPD

5.1 Introduction

This chapter presents the findings from the Phase One stage of this study. Data for this phase was collected from each participant, through interviews one and two and diary-like interim messages. Data collection captured a three month period of time of a participants experience of living with COPD. The multiple data sets for a participant were aggregated and considered together for that participant. In Phase One the data, therefore, is presented separately for each participant. Categories and subcategories were generated from this experience. These categories were compared among the participants and four similar categories were identified for each participant: 'On Being Diagnosed with COPD', 'Work and COPD', 'COPD and Home Life' and 'Managing the Disease'. While there were similarities there was also variation between the subcategories for some of the participants. The categories and subcategories that emerged within each of the six participants' experience are presented in this chapter. The categories and subcategories for participants' narrative are presented in Table 5. Pseudonyms have been used to protect the identity of each woman.

Table 4: A description of the main categories.

Categories	Description
On Being Diagnosed with COPD	This was about being diagnosed with COPD; thoughts and feelings post-diagnosis and inter-actions with health professionals.
Work and COPD	This was about living with COPD's work life and her chronic health condition.
COPD and Home Life	This was about the influence of COPD on the women's home lives, or vice versa.
Managing the Disease	This described the ways in which the women managed their disease symptoms, to continue working and living their lives.

Table 5: The categories and subcategories for participants' narrative.

Participant	Categories	Subcategories
Laura	On Being Diagnosed with COPD	Realising something wasn't right and reacting to the diagnosis
	Work and COPD	Attendance and work environment
	COPD and Home Life	Daily life, support: family and friends
	Adjusting Work and Life	Pacing herself, planning ahead, physical activity and breathing technique, reprioritising and making life easier
Sarah	On Being Diagnosed with COPD	Realising something wasn't right, emotional impact of COPD, maintaining control, feeling judged and having to justify herself
	Work and COPD	Challenges to her work role, just as good as everyone else and support at work: manager and colleagues
	COPD and Home Life	Daily life, while I'm still good, support and socialising and relationships, intimacy and starting a family
	Adjusting Work and Life	Pacing herself, avoidance, positive thinking, physical activity and pushing herself, other strategies to manage her COPD and reprioritising
Fern	On Being Diagnosed with COPD	Realising something wasn't right and reacting to the diagnosis
	Work and COPD	Challenges to her work role
	COPD and Home Life	Daily life, support: family and friends and starting a family
	Adjusting Work and Life	Recognising limits, positive thinking, healthy lifestyle, self-education and adjusting goals
Georgina	On Being Diagnosed with COPD	Realising something wasn't right and reacting to the diagnosis
	Work and COPD	Challenges to her work role
	COPD and Home Life	Daily life, motherhood, informing family and support: family and friends
	Adjusting Work and Life	Recognising limits and pacing herself, positive thinking, avoidance, healthy lifestyle, reprioritising and other strategies to manage her COPD

Natalie	On Being Diagnosed with COPD	Realising something wasn't right, emotional impact of COPD, asking for help and hoping for a miracle,
	Work and COPD	Challenges to her work role
	COPD and Home Life	Daily life, socialising, relationships, support: family and friends
	Adjusting Work and Life	Recognising and managing her limits, emotional coping, hiding her COPD and healthy lifestyle
Sally	On Being Diagnosed with COPD	Realising something wasn't right and emotional impact of COPD
	Work and COPD	Challenges to her work role and work as a benefit
	COPD and Home Life	Daily life and support: family and friends
	Adjusting Work and Life	Disclosure, acceptance, recognising limits and pacing herself, making adjustments and self-education.

5.2 Laura: Participant One

Laura was 44 years old, she worked part time in a desk-based role. She lived with her husband and two teenage children. Laura had been diagnosed with COPD just before the participating in the study. Laura had never smoked.

Category One: On Being Diagnosed with COPD

There were two subcategories, which were; 'realising something wasn't right' and 'reacting to the diagnosis'.

Realising something wasn't right

Having asthma, Laura was used to acute periods of mild breathlessness, however, she first became aware of unusually severe breathlessness during a walking holiday. A few months after noticing her breathing difficulties, Laura visited her GP who reluctantly referred her to a respiratory consultant. A spirometry test was performed and the results confirmed a diagnosis of COPD. The diagnosis caused a range of emotions, including shock, anger, depression, isolation, and frustration.

Reacting to the diagnosis

Laura described experiencing a range of emotional responses her diagnosis including shock, anger, depression and isolation. Laura described a sense of utter shock at being diagnosed with COPD, as at 44 years old, the thought of having such a

progressive, incurable and life-changing condition was difficult for her to understand and accept.

'I was just shocked, absolutely shocked. I couldn't believe it, I was in total shock really. I honestly thought [the doctor] was just going to turn around and say to me ... my asthma was playing up and there was different medication I could take. But I knew that when he said I had [COPD], I knew it was a life changing condition. I am still trying to get my head around it.' (Laura Int1)

Laura also described feelings of anger at developing the disease as she had deliberately tried to lead a healthy lifestyle and had never smoked a cigarette, yet she developed this chronic lung condition.

'[I am angry] that I am in this position. I have never smoked, never. I mean, I have never had a cigarette in my mouth… and I always said to myself, I will never smoke because I don't want anything to happen, you know, to my lungs … and this is how I've ended up, it doesn't make sense.' (Laura Int1)

The diagnosis of COPD had also caused Laura to experience feelings of depression and being alone.

'It has really been hard, I can't explain it. Last week I felt really down, like really down, I couldn't pick myself up...' 'I think sometimes… Although it's common, it's not common in people that I know, sometimes you feel so alone...' (Laura Int1)

Category Two: Work and COPD

This category contained the two subcategories 'attendance' and 'work environment'.

Attendance

Laura reported that having COPD affected her attendance at work, with her taking time off when unwell or attending hospital appointments.

'…There is always a reason why I am off work. Like when I was in hospital, then I would have been off… so I have had quite a lot of time off recently.' (Laura Int1)

Laura also had to take time off work to attend pulmonary rehabilitation classes, which ran during her working hours. Unlike hospital appointments, her employer did not consider rehabilitation classes to a legitimate reason to have time off work, and told Laura she had to make the time up or take the time as part of her annual holiday allowance. However, Laura considered attending these classes to be an essential part of learning to manage her everyday work and home life with COPD. The prospect of

having to lose her holiday time distressed Laura as it meant she had less time off work to relax and spend time with her family.

'These sessions that I am having, these rehab sessions, basically, [work] are making me take it as holiday. They said to me 'you can make the time up, ' so I said that I would, but it is going to be a struggle to make my time up, it means I've got to work as well as going to the rehab course, I've got to make the time up.' (Laura Int1)

Work environment

Laura had stated the walk from the car park to her desk was very strenuous, to the extent that she had to stop and rest before reaching her work building and this meant she could start work feeling 'out of breath'.

'…getting from the car in the car park [into work] I was finding quite difficult, and I was really out of breath.' (Laura Int1)

When Laura was at work, during the winter months the work environment was cold and draughty, with the only heat coming from a fan heater, and this affected Laura's breathing. Laura told her colleagues that she did not want the heater on. The heater subsequently became a source of conflict in her workplace.

'..At work, I sit at reception, and it's quite open, and the doors are opening all the time and it's quite cold. And in winter it gets very cold, and we have to, we don't have heating in reception, we have heaters, but they are … fan heaters. And the fan heater, I must admit, I cannot have it on me because it affects my breathing, because I suppose it gets dusty and it just blows all the dust everywhere. So I find it hard in the winter, also I have a lot more colds in the winter…the last couple of months [the heater] has been causing problems at work. Some of the girls were moaning because I wouldn't have the heater on. The heater doesn't agree with me.' (Laura Int1)

Category Three: COPD and Home Life

This main category contained three subcategories; 'daily life', 'support at home: friends and family' and 'on being a woman'.

Daily Life

COPD significantly affected Laura's home life and her ability to do certain day-to-day tasks which she used to do routinely. Specific challenges Laura faced included general physical activities such as cleaning her whole house in the same day, climbing the stairs, hanging heavy items like a duvet and making the bed.

'…going up and down stairs, like my stairs at home, I find it really difficult, normally I go up and down the stairs and take the washing backwards and forwards to each bedroom and stuff like that. I can't really do that anymore… like normally I can do the house from top to bottom on my day off, but unfortunately now, it's come to a point that I can only do one room at a time... It's things like that that I am used to being able to do that I can't do anymore.' (Laura Int1)

Support: friends and family

Laura described her family and friends as being very supportive, which helped Laura both physically and psychologically.

'My mum and all my sister-in-law's have been really good. Before I had my cleaner coming, they used to help me indoors and that as well. They have all been really good, I think I am really luckily, I have lots of family and I've got lots of friends, so I am really lucky in that way.' (Laura, Int2)

Her husband was also supportive, showing his support by reminding her to keep within her limits. For example, if she felt unwell, and pushed herself to perform a task at home, her husband would notice she was becoming increasingly short of breath and would remind her to rest or would help by taking over the activity.

'It's quite good, cos at the moment, [my husband] … can tell when I am not feeling well, cos sometimes I don't say anything, but obviously he can hear when I am out of breath, and he will say to me, 'what are you doing?' and I will say 'I'm just, you know, peeling the potatoes', and he will say, 'well why don't you just come and sit down and have a rest and do it in a minute.' And I say to him 'well why don't you get up off you your backside and you do it', and that's what he does.' (Laura Int2)

On being a woman

As Laura considered the activity of shopping to be a part of her gender identity and her inability to go shopping like she used to, affected her perception of herself as a woman.

'…You know what… I really miss? I love shopping, like all women do… I can't go out shopping like I used to. I could go from the car into the shop, but very, well, as quick[ly] as I can, and pick up a few bits. But to do a weekly shop for me is too much, I physically can't do it.' (Laura Int1)

Category Four: Adjusting Work and Life

In this category, there were five subcategories, which were; 'pacing herself', 'planning ahead', 'physical activity and breathing technique', 'reprioritising' and 'making life easier'.

Pacing herself

Since being diagnosed with COPD, Laura managed to perform different tasks by pacing herself and taking breaks, which prevented exacerbations of her symptoms. Laura found this adjustment to a slower pace of life extremely difficult and sometimes pushed herself past her limits, which had consequences.

'I try and just get on with it and just plod along and then realise that I'm gonna come down with a bump, and that's what happens. But I've still not learnt to pace myself, because I'm not that way, you know, I'm still getting used to everything.' (Laura Int2)

Laura also avoided certain activities that she knew would make her short of breath, such as climbing the stairs and talking whilst physically exerting herself.

'If I am not feeling well, I won't do stuff, I realise that I can't do it…I've learnt to shut up…It's not that I don't want to talk, it's that if I am doing stuff, I find it hard to do both.' (Laura Int2)

Planning ahead

Planning ahead helped Laura manage certain aspects of her condition while at work and at home. For instance, in the first interview Laura reported struggling with her phlegm production as she was too embarrassed to expel it. She realised swallowing her phlegm did not help her condition. In the second interview she had learnt to plan ahead and carry tissues with her at all times, which meant she could discreetly expel the phlegm.

Laura also tried to plan ahead when carry items up and down the stairs at home. To avoid climbing the stairs multiple times she would wait until various items needed taking upstairs and then she would carry several things at the same time, to reduce the number of times she had to walk up and down the stairs.

Physical activity and breathing technique

Another way Laura managed her COPD was by doing regular exercise in the form of going to the gym several times a week, as she found this improved her lung capacity and breathlessness.

'…I do try and exercise a bit more, cos I realised having this [COPD], that the more you exercise, the better your lungs are… I try and go to the gym at least twice a week… I do the treadmill and I do the bike and I just do some leg exercises.… I feel better for [going to the gym], because it gives me a bit more energy, also I do think that it definitely does help with my chest, you know, I really do.' (Laura Int2)

Laura had also learnt to use a breathing technique to manage periods of extreme breathlessness, which involved breathing out through the nose instead of the mouth.

Reprioritising

Although Laura used to be an active and independent working woman, mother and wife, COPD limited her abilities. During the study period, which occurred weeks after her diagnosis, Laura had re-evaluated and prioritised aspects of her life, in order to allocate time and energy on things she considered important.

'…I think it sort of put other things into perspective [being diagnosed with COPD], because you just never know what's round the corner, you know.' (Laura int2)

'It has been really difficult for me to adapt, but I've had to adapt to it, so that I can do things still that I wanna do. You know, I didn't have a choice but to adapt to the whole situation.' (Laura Int2)

Laura described how she learnt to combine work, socialising and home life. In the first interview, Laura described trying to rest as much as possible when she was at home to be fit for work the following day. However, she said this was often difficult as she also had housework to do, which consumed her energy. By employing a cleaner, she didn't have to worry about doing the housework, and could use her time differently; by socialising with family and friends and going to the gym. The fact that someone else was taking care of her housework took the pressure off her and she didn't worry about what she had to do at home.

'[Delegating housework has] definitely helped me, because it means that I can do other things, like if I want to pop out for a bit, I can. Because I found that if I was trying to do all that, all the things, all the housework and everything, then sometimes I didn't have energy to be able to do other things. And I just decided that it was more important that I got help round the house and I am able now, if I wanna go out for a coffee with friends, I can, if I am feeling OK…' (Laura Int2)

In the second interview Laura explained how she approached her manager and requested adjustments to be made to the form of heating the workplace. Her manager agreed to change the heater to accommodate her disease.

'I've spoken to my manager, and basically, the fan heater is no good for me, because it dries the air out and makes me cough, so he is going to get [an] electric radiator for the winter.' (Laura Int2)

Laura also informed her manager about her difficulty walking from the car park to her work desk. This resulted in her being granted permission to park closer to the building, and consequently, a shorter distance to walk.

Laura emphasised that reprioritising meant makings changes to her family role as a mother. She had been used to putting everything and everyone before herself. After she was she had been diagnosed with COPD she considered it was time to put herself first and do the things she needed, and wanted to do, in order to have a good quality of life.

'When you are a mother, everything around you comes first, and you leave yourself last. But I am having to learn now, that this is not always the case, and it shouldn't always be like that, I need to look after myself more than I need to look after them, because they are getting older, they should be looking after themselves. I decided that it is now my time, and that this time is for me, and I need to do this, to help me get better, or not get better, but to be able to live a better life. Things are never going to get better.' (Laura Int 2)

She also no longer worried about preparing delicious evening meals for her family, as it was no longer a priority. Laura knew that if she felt unwell or was taken to hospital because of an exacerbation, her teenage children could prepare something to eat, whether it be by heating frozen food or making beans on toast.

Making life easier

As Laura's breathlessness had made daily activities challenging, she frequently described introducing changes that would make her life easier, for instance, by asking others for help.

In the second interview, Laura had learnt to say when she 'would rather not' do certain things, she knew would aggravate her symptoms, instead she had started asking other people for help. At first she found asking for help very difficult because she was used to doing everything herself, but with practise it became easier to do. The will to look after herself motivated her to request adjustments at work, employ a cleaner and delegate household chores.

'At first I found it really awkward and difficult [asking for help] because I never ask anyone for anything, I do everything myself. But I've had to learn that when I need

help, I need to ask for help, and I am doing that now, I ask for help if I need it, but it has been hard for me to do that, because, as I say, I do everything.' (Laura Int2)

Within the study period, Laura had learnt to make changes to doing the family's weekly food shop to accommodate her disease, as her breathlessness meant she could not sustain her previous shopping habits. Shortly after being diagnosed, the task of food shopping had become too much for her and the task had shifted to her husband. However, by making changes she was able to reclaim a role she perceived challenging her gender identity that is the role of grocery shopping. To do this Laura changed where and how she shopped. Laura went to a much smaller supermarket, which was easily accessible from the car park and started buying heavy and bulky items from the supermarkets online shop and having the items delivered straight to her kitchen and were put away by her children.

There was a marked transition in how Laura perceived her condition in the first interview and then in the second interview, which subsequently influenced how she managed her life. By the second interview it was clear she had learnt to successfully manage her condition, which increased her confidence that she could have a good quality of life despite having COPD.

'..I'm managing OK, yeah, yeah, I am managing better than I thought I would. I think you learn to surprise yourself…' (Laura Int2)

'I don't know [what I thought would happen]. I just thought things were gonna get worse … You know, you read all these horror stories. I thought it was just gonna get worse, but it has definitely got better. And I think you learn to live with it more … So yeah, it's been OK.' (Laura Int2)

Summary

In the short time Laura had been diagnosed with COPD, she had experienced various limitations and changes to her everyday life at her work and home life. During the three months study period Laura had discovered ways of making adjustments to her work and home life to accommodate her COPD, making her life easier. The practical strategies Laura implemented resulted in her positively managing her COPD, which enabled her to stay at work, maintain her home and have what could be considered a good quality of life.

5.3 Sarah: Participant Two

Sarah was 41 years old, single, had no children and lived alone. She worked full time in a job that was both desk-based and sometimes physically demanding. Sarah was diagnosed with COPD several years prior to involvement in this study. She had alpha-1 antitrypsin deficiency and she smoked for a short time.

Category One: On Being Diagnosed with COPD

This category included five subcategories, which were; 'realising something wasn't right', 'emotional impact of COPD', 'maintaining control', 'feeling judged' and 'having to justify herself'.

Realising something wasn't right

Sarah was aware of her increasing breathlessness years before seeking medical advice. However, she dismissed her breathlessness as being caused by anxiety and stress related to having a busy job. Sarah realised how bad her breathlessness had become when she was drying herself after a shower. This prompted her to visit her GP.

Sarah visited her doctor and requested a referral to see a respiratory specialist. The specialist performed various tests including the spirometry test and an alpha-1 antitrypsin test. The results confirmed Sarah had COPD and alpha-1 antitrypsin deficiency. As Sarah had been diagnosed a few years prior to participating in the study, she could not recall her initial reaction to her diagnosis.

Emotional impact of COPD

Sarah could describe how living with COPD made her feel as she described it as having an emotional impact on her life. Sarah was sometimes anxious about her amount of breathlessness, which subsequently made her more short of breath. Her heightened awareness of her own breathing made her anxious that other people also noticed her breathing difficulties, especially in the workplace.

'*Sometimes I think my anxiety levels about my actual condition are actually quite dominant as to how I am feeling. Like some mornings I can get up and I don't think about it and then other times it's the first thing on my mind and I wonder how short of breath I am going to be walking to the train station.' (Sarah Int1)*

Having COPD also caused Sarah embarrassment.

'*It's embarrassing to say that you can't breathe properly…' (Sarah Int1)*

Embarrassment affected how she managed her disease. Sarah described that although she had a high risk of developing chest infections (related to having alpha-1 antitrypsin deficiency), embarrassment prevented her from wearing a protective face mask in situations where the risk of developing an infection was high, like on an aeroplane.

'[on an aeroplane] I don't wear a mask or anything like that, because I, I guess I'd feel embarrassed to wear it and wouldn't really want too much attention, kind of drawn to myself, you know.' (Sarah Int2)

In addition, Sarah described feeling angry for not knowing she was genetically prone developing COPD, stating that if she knew, she would never have smoked.

'If you knew you had an underlying issue you would never put a cigarette to your lips.' (Sarah Int1)

Maintaining control

Sarah was an independent woman who liked to be in control of her life. Sarah considered that a person could chose the extent to which COPD impeded their life. She often talked about how she tried not to allow COPD to take over her life, or her thoughts.

'I think you have to decide how much you allow it to affect you. You have to make a decision, in a way, who is going to win … I think I don't really try and, what's the word, I don't let it, I don't mean affect me, because it does affect me, but I just try and lead a normal life as possible, like I still do all the same things as all my friends and everything.' (Sarah int2)

Despite trying to keep control of her life, Sarah felt anxiety when she was in control of her COPD.

'It can be, I suppose, quite disheartening and stressful, because it's like, I don't know, you have a problem with your ankle or something, it's every day, you know...it's like living with… a constant level of an anxiety disorder, it's like you are constantly aware of it, you know. You can try and manage it, but you are never going to change it or get rid of it.' (Sarah Int2)

Feeling judged

Sarah described how she felt stigmatized and judged by others for having previously smoked and being diagnosed with a chronic respiratory condition. Sarah also found that these assumptions about COPD and smoking were also made by medical professionals.

'The minute you say you have got COPD, naturally [people] think 'Oh Gosh, she must have smoked her head off', and that's the label you get… even in the medical profession, people outside chest physicians don't actually know what alpha-1 antitrypsin is. They have heard of it, but they think it is some sort of… made up disease.' (Sarah Int1)

Although Sarah felt stigmatised, her genetic predisposition to developing COPD made the diagnosis easier for her to accept.

Having to justify herself

Sarah considered the invisibility of her condition, and the fact that she looked well, resulted in others expecting her to have the physical stamina to do things women she felt who were her age did, like dancing at parties. When Sarah didn't meet their expectations, she felt like she had to justify herself. Sarah refer to an example when she was at a party, and she was sat watching other people dancing.

'[The woman] came up to me about three times and she was like 'this is [a party] … aren't you going to get up and dance' and I said 'not to this song', thinking she is going to go and leave me alone. But I think she had a bit to drink so she came back again, and I was thinking 'my God', you know, so in the end I had to go into detail. I said 'look I am just not able to dance' and she was like 'oh it doesn't matter… you can just…' I don't know what she said, like put one foot in front of the other, something ridiculous, and I was like 'no with my lungs you can't, so should we leave it there now.' I said 'you go knock yourself out, you dance away, I can watch you'…you know when you have situations like, it's like you feel like you are having to explain yourself...' (Sarah Int2)

Category Two: Work and COPD

There were four subcategories that related to work, which were; 'changing her work role', 'challenges to her work role', 'just as good as everyone else' and 'support at work: manager and colleagues'

Changing her work role

Around the time Sarah was diagnosed with COPD, a less demanding work role became available within the same organisation. She took the job. She described how her current role was less stressful and less physically demanding, compared to her previous managerial role. On reflection, she considered her previous work role to be unsustainable in the long term as she would have found it increasingly difficult to function with her progressive breathlessness. If she had not changed jobs, she would

have had to leave her old job anyway, as she would have been unable to meet the job demands.

'I think that if I was in the role that I was in before, which was a couple of months before I was actually diagnosed, my breathing was certainly a lot worse then ... I certainly noticed the stress I was feeling at work was just exacerbating the situation. But that was before I was diagnosed.' (Sarah Int1)

'[My current job] comes with its own stresses, but the demand isn't immediate… It hasn't got the same sort of high intensity or energy that you need to do the job... yes it can be busy, and yes I can be in a bit of demand, I guess, but it is nothing in comparison to [my previous work role]... So yeah, [changing jobs has] definitely helped me.' (Sarah Int2)

In her current work role, although Sarah could perform the majority of the work tasks, she found certain aspects of the job made her particularly short of breath, such as walking and talking to people.

'If I am talking a lot I can get short of breath. I find myself having to pause to take a breath… obviously walking around [at work], I can walk around, but there are times... it's quite variable, I get short of breath. But not to the point where I need to take an inhaler.' (Sarah Int1)

Challenges to her work role

Sarah was in a supervisor role at work and she found that her breathing, in addition to physical tasks, was affected by stress. She described becoming increasingly stressed and consequently increasingly breathlessness while reprimanding staff members. Her own awareness of her breathing, led her to believe other people were conscious of it, which could lead to possible feelings of vulnerability, as her breathlessness could be seen as a sign of weakness that could undermine her position of authority.

'I can definitely feel like I would have to, I wouldn't say start hyperventilating, nothing as dramatic as that, but I would have to take a breath [when reprimanding a colleague]. I have noticed that I am having, like a sharp inspiration of breath, I don't know whether it's psychosomatic or if I actually need to do it, but I know that I am doing it, and the person that I am having the confrontation with, knows I am doing it as well, because it is so obvious.' (Sarah Int1)

Sarah felt that the limitations she experienced with COPD undermined her authority in the workplace. To avoid episodes of breathlessness and reduce exposing her

struggle for breath, she had become more selective in approaching staff members under her supervision.

'…*Now I have to almost pick my fights, is it worth bringing that up? Is it worth the stress of having that conversation with that person, about whatever it is that they have done? And sometimes it is [worth it], and I still do it, but then you have to weigh up how you're going to feel afterwards.' (Sarah Int1)*

Just as good as everyone else

Apart from having difficulties with a few tasks at work, Sarah considered herself to do her job as well as everyone else. She gave the impression that it was important how others, especially her manager, perceived her as a worker, as well as for herself to believe she was still a capable employee.

'…*I do the same as everybody else. Apart from manage the [team] now, which is what I am not able to do anymore. But, you know, my manager knows that I still perform to the same level, as in mentally and what I actually do… it hasn't slowed my mind down, or I don't allow it to encroach on my life so much that I am not able to concentrate.' (Sarah Int1)*

Support at work: manager and colleagues

Everyone at work were aware of her disease to some extent, and her colleagues showed support by doing tasks they knew she found too to undertake. Sarah's manager was supportive and understanding and allowed a certain amount of flexibility in Sarah's work schedule so she could attend pulmonary rehabilitation classes.

Sarah, however, wrote in her interim data, that when she was struggling to keep up with the work load, the support of her manager and colleagues could only go so far, as the work still had to be done.

'*[My work colleagues] have their own stresses and just want the job done. Also people can't really relate to how it feels to be short of breath.' (Sarah interim)*

Category Three: COPD and Home Life

There were four subcategories in this category, which were; 'daily life', 'while I'm still good', 'socialising and support' and 'relationships, intimacy and starting a family'.

COPD had affected her basic activities such as walking and running for the train, as well as activities she did for pleasure, such as dancing and being intimate with a partner. She also needed much more time to recover her breath after physical exertion.

Daily life

Sarah had always been an active person, and tried to remain active by walking everywhere, however, she recognised that she had become increasingly breathless during physical exertion and she noticed the time required to catch her breath had increase significantly over the past year.

'*I manage to walk pretty much everywhere, but I did notice maybe in the last six months that I have been a lot more short of breathe….My recovery period [after any exertion] has doubled in the last year. So for instance, if I am running to catch a train, so I am running for maybe 30 seconds, I am OK while I am running, but the minute I stop and I sit down on the train it can take me anything up to 8 minutes to recovery, whereas before it would take me maybe two, three minutes.' (Sarah Int1)*

Sarah cleaned her apartment herself, however she found certain routine tasks difficult. A clean home was important to Sarah and so she pushed herself to do it regularly. She stated that when she was no longer able to clean herself, she would have to pay someone to do it, as it could not go undone. Sarah, however, had already employed a gardener as she could no longer maintain her garden due her physical limitations.

While I am still good

During the study period, Sarah had three holidays abroad planned. One of the trips was something Sarah had always wanted to do and she wanted to go while she was still physically able, as her future health and physical capabilities were unknown.

'*…my biggest thing, the reason I chose to do [this specific holiday] this year, [is] because it is somewhere I always [have] wanted to go to, but I figured, I don't know how I am going to be in a couple of years. So I thought, if I am going to go, I want to go while I am good*.' *(Sarah Int1)*

Socialising and support

Dancing had always been Sarah's passion, she used to regularly go out dancing for enjoyment as well as dancing at social events. She recalled being able to stay on the dance floor all night before having COPD, but now she became short of breath after half a song. Her lost ability to dance had a significant impact on Sarah's life, as dancing was not only an important part of social events, like weddings and parties, but it was a way of relaxing and enjoying herself.

'*If somebody asks me to dance, forget about it. I might do half a song or a song, yeah, maybe a full song at a push, depending on what type of music it is… I have gone from somebody who could stay on the dance floor all night, to half a song...' (Sarah Int1)*

'[Now] I can dance, I can stand there and move, but that's not actually dancing, you know.' (Sarah Int2)

Sarah had a large circle of friends and a family network, the majority of whom had been very supportive. Sarah frequently socialised and holidayed with friends who knew about her condition. Her friends supported her by performing activities that were within her limits, for example, walking at a slow pace. If they unintentionally started to walk faster, they would realise and slow down again for Sarah.

'I have to say my friends are very supportive and they all know what the situation is and they themselves sometimes forget… if they are walking ahead of me, or there are three maybe four of us and two or three might start to pick up pace and obviously I can't really keep up with them… they would notice and they would slow down.' (Sarah Int1)

When referring to holidays she went on with friends, there was a sense of ease as her friends knew and understood her condition and did not pressurise her to push herself beyond her limitations.

If she was invited out during the working week she had to consider if she had the energy to go out after work and whether she would be sufficiently rested to go to work the next day. Sarah considered her lower energy levels were the result of a combination of things, not exclusively due to COPD. When Sarah did go out with friends, she found the basic activities of walking and talking made her breathless. To continue socialising, she used strategies to manage her breathing, such as walking at a slower pace and letting the other person do the talking.

'I am definitely more tired… some people might suggest going out during the week… to the movies… dinner or … a drink. Whatever it is, I know myself I have to decide whether I have the energy for it or not, because I have to be up the next morning at half six. Probably my stamina isn't the same… I don't think it is as cut and dry as being down to the COPD, I think it's lack of sleep, being over 40 and having a chronic condition.' (Sarah Int1)

At times, however, all plans of going out had to be cancelled, because Sarah was too exhausted to do anything such as when she had a 'chest infection'.

Relationships, intimacy and starting a family

Sarah was a young woman, who was single during the study period. When Sarah was diagnosed with COPD she was in a relationship, however one of the reasons her previous relationship ended was because her boyfriend wanted to have children and start a family. As Sarah was already experiencing difficulty breathing, the thought of

carrying extra weight of a baby frightened Sarah as she knew this would make breathing even more difficult.

'… [I] already struggle [with breathing] at the weight that I'm at, never mind going almost full-term with a baby, that's just not, not going to be easy for me.' (Sarah Int2)

The physical symptoms of COPD, and the constant awareness of her breathlessness affected Sarah going on dates and finding a partner.

'…I think it limits me because something as simple as walking and talking with somebody, it can be quite obvious that I am short of breath...' (Sarah Int2)

Sarah also described how her severe breathlessness affected her having sexual intercourse and worried that this might be problematic in a new relationship if it did not meet the partners expectations.

COPD also affected Sarah's choice in potential boyfriends. For instance, Sarah recalled when she went on a blind date with a man who had a long stride and walked very fast, when they walked together Sarah was finding it very difficult to keep up with him. She considered this level of activity unsustainable.

'I went on a date with a guy, it was a bit of a mistake really, but he, it was quite funny, because he was incredibly tall and I am obviously not that tall, and he was like, for every one of my 10 steps, he was like taking 2 steps, and I was thinking 'shit, I'm not going to be able to keep up with him, this is seriously like being with a giant'…by the time we got to the restaurant, I honestly felt like I was going to collapse, like he was just striding ahead...he couldn't help it because that's just how he walks, but I felt like I had sprinted or something...I had to go to the bathroom and kind of gather myself, until I was able to go back and have a conversation with him.. luckily he was quite chatter, so I kind of let him carry on...I didn't fancy him anyway, so it was a bit, thinking to myself, 'gosh, it's good that [I don't fancy him], I don't think I could sustain that level of activity just walking around.' (Sarah Int2)

Sarah made the decision to delay telling a potential partner about her COPD, which could be due to feelings of shame or embarrassment, fear of being judged and not wanting to 'scare' the other person away.

'The reason I don't want to say something so early on is, maybe it is a bit deceitful, I don't know, but I think if someone wants to be with you, they like you, that shouldn't matter anyway. But I think if you start telling people quite early on, then they don't really have time to get to know you, so people can pass a judgement quite quickly.' (Sarah Int2)

Category Four: Adjusting Work and Life

Sarah described using six strategies to manage her condition, each of which formed a subcategory. These were; 'pacing herself', 'avoidance', 'positive thinking', 'physical activity and pushing herself', 'other strategies to manage her COPD' and 'reprioritising'.

Pacing herself

By pacing herself, Sarah was still able to do things such as walking with friends, clean her apartment and perform physical work tasks without becoming too breathless. A slower pace meant that to be punctual, Sarah had to leave more time to get somewhere.

'*I have to leave earlier, because I don't want to rush, because if I have to rush then I get stressed and when I am stressed my breathing becomes more of a problem for me… I am somebody who likes to be on time anyway, so this is nothing new. If I say I am going to do something, I am going to do it and I am going to be on time… I will always leave early to make sure that I am not, either going to let somebody down or going to be late or end up having to rush.*' *(Sarah Int1)*

Sarah was conscious of her breathlessness when talking, and considered she spoke at a fast pace. To reduce her breathlessness when speaking, she was learning to speak slower, especially at work.

'*I am trying to teach myself to speak slower, because I naturally, I think, speak quite quickly. I find that if I am speaking very fast, then I feel more short of breath.*' *(Sarah Int2)*

Avoidance

Sarah avoided talking about her disease. She explained that she didn't like to talk about her problems in general, especially not her chronic lung condition. This dislike of voicing her difficulties was a way of Sarah managing life with her disease. Putting her experience into words made it real

'*I suppose if people do probe it and push it, especially with my family and if they do push it a bit too far with me, I can get quite snappy about it. I do find it irritating. 'I don't want to talk about it, why do you keep asking me?' Whenever I have had problems in my life I have always sorted them out myself anyway, so that's part of my character anyway. Other people like to talk things through, I perhaps don't so much.*' *(Sarah Int1)*

Not only did Sarah not want to dwell on her condition, she also didn't want to worry her younger siblings. If someone persistently inquired about her disease, she became irritated.

'If I was to... say what's going on to my family, to my younger siblings, I don't want them to worry unnecessarily… I would rather let them think everything is absolutely fine, and it works well for me as well because that's how I manage it.' (Sarah Int1)

In keeping with her avoidance strategies, Sarah described ways in which she managed to conceal her COPD from others. She said she didn't particularly want to go around hiding it, and found some incidences when it was very difficult to mask her breathing problem.

'I am quite good at masking it for a period of time…I can really push myself if I know I'm not going to have to push myself for a long period of time. But if I know I'm in for a longer journey with a person, as in a walk, then I know I can't pull it off, so I have to start off on a slower pace.' (Sarah Int2)

Positive thinking

Sarah used positive thinking to help her manage 'bad days', when she struggled for breath more than normal. Sarah could tell it was going to be a bad day in the morning, as days when she struggled for breathe while drying herself off after a shower were indicative of her being more breathless than normal, for the entire day.

'My bad days I suppose, I can kind of tell pretty much straight away in the morning I know if it's going to be a bad day, because once I have my shower, you know, some days I don't feel short of breath after my shower…actually drying off, I can feel that some days I feel more short of breath. So I kind of think 'Oh, it's going to be one of those days when I will struggle a little bit more'. (Sarah Int2)

Physical activity and pushing herself

Although initially Sarah avoided physical activity, as she did not want to experience the increasing breathlessness that accompanied it. However, with time, she had started to become more physically active and considered exercise an important part of managing her breathlessness. In an effort to become more active, she started walking and climbing a few flights of stairs at work and kept pushing herself to gradually increase the amount of exercise, for example she started climbing 2 flights of stairs at work and aimed to eventually climb all 5 flights of stairs, to her office.

'I have started to try and do two flights of stairs and then… the next week [I will] try and do three. I am still only on three at the moment. I work on the fifth floor and there

are like two stair wells between each floor, so you're talking, maybe 37 steps... so you do 37 and 37...but I do have to stop on the third 37.' (Sarah Int1)

Sarah strongly believed that if she strengthened her legs, her breathing would improve. With this in mind, she pushed herself to be active, walking most places and setting herself goals to gradually increase her stamina.

'When you have any problems with your breathing... your [leg] muscles are quite tired. So as best I can, I try to exercise my legs a bit. So even if it does mean I have to drag myself out of the house and walk around… to do a brisk enough walk so I can feel it on my legs. Because if your legs aren't strong, your lungs are going to have to work that bit harder…I am pretty sure the more you do, the more I will be able to manage to go all the way up to the [5th floor]. I think, yeah, I can definitely sort of manage in time.' (Sarah Int2)

In the second interview, Sarah recognised her efforts to increase her leg strength had been beneficial. She described going on holiday and being able to walk up gradients without having to take as many breaks as she might have done if she had been less active.

Additional strategies to manage her COPD

In addition to exercise, Sarah used breathing techniques and music as strategies to assist her manage her COPD. The breathing techniques were used by Sarah to reset her breathing and calm herself down when she found herself struggling for breath.

'If I can just get myself into a headspace where I feel calm enough, I tend to just sort of, not hold my breath, but just stop trying to breathe in and out so much, almost like hyperventilating. If I stop and hold my breath, then it tends to balance itself out. Then I start [breathing] again.' (Sarah Int1)

Another strategy Sarah used to manage her symptoms was to try and not focus on her breathing, for instance, listening to music. This shifted the focus off her breathlessness whilst walking up a hill and made the task less difficult.

'What I try to do is have my music on so I am not concentrating on the actual act. I find it easier to just distract myself to get to the top of the hill without considering what I'm actually doing.' (Sarah Int2)

Reprioritising

After being diagnosed, Sarah had re-evaluated the things she wanted to do in her life, and planned to do them sooner rather than leaving things for later. For example, she now thought twice about confronting work colleague, which would

cause her stress, and tried to worry less about things. She had also planned to go on various holidays before the end of the year, one of which being a destination she had always wanted to go to.

'I suppose having any type of chronic condition makes you re-evaluate or prioritise the things you want to do in your life…' (Sarah Int1)

Sarah described trying to reduce her stress and anxiety levels by trying to worry less about things.

'Since I have been diagnosed, I just think, I suppose I think in general, is that worth worrying about. Like before I was always a bit more of a people pleaser, especially socially or with family or friends. I would always go that extra mile, and I still do to an extent, but I just think, 'no, I can't do that', and whether people accept it or they get upset about it... that's their issue.' (Sarah Int1)

In the second interview, however, Sarah's job was as busy and stressful as ever, she acknowledged that it was always going to be like that, and so she had to learn to cope with the stress.

'I think it's about learning to manage, you know, stress levels a bit better... I've had to learn over the past couple of years to not let things get to me, because I think in a way I am probably somebody who kind of, what's the word, maybe a little bit of a perfectionist. I like things either done in a certain way or whatever, so if things aren't quite right, it does sort of stress me out a little bit. But yeah, I have just had to learn to let go of certain things... really.' (Sarah Int2)

She also considered actively looking for ways of managing her stress, for example by attending yoga classes to help her relax.

Not knowing how fast her disease would progress and how long her ability to be independent would last, Sarah tried to live her life one day at a time and tried to not plan too far ahead.

Summary

COPD significant affected Sarah's life, although she tried to remain in control of her life. Sarah had not requested work adjustments to be made, but had learnt to ask for help when performing certain tasks she struggled undertaking. The strategies Sarah implemented to manage her condition in and outside of work, for example working within her limits and pacing herself, enabled her to stay at work and maintain her independence outside of work.

5.4 Fern: Participant Three

Fern was 36 years old, had no partner or children and lived in shared accommodation. She was self-employed mostly worked from home in a desk-based role, however, she sometimes had to commute to the office. She was diagnosed a week before participating in the study. She was found to have alpha-1 antitrypsin deficiency and previously smoked cigarettes and marijuana. Fern was a keen sportswoman.

Category One: On Being Diagnosed with COPD

This category consisted of two subcategories, which were; 'realising something wasn't right' and 'reacting to the diagnosis'.

Realising something wasn't right

The first time Fern noticed problems with her breathing was during an intense running session, when she became breathlessness and started wheezing. The sports trainer noticed Fern wheezing and advised her to see a doctor. Fern initially went home and researched the symptoms for herself, and thought she might have exercise-induced asthma. A few weeks later, she visited her GP, who performed various tests and asked her to note any changes in her breathing. When there was no change in her breathing, she went back to her doctors' surgery and the respiratory nurse performed a spirometry test and blood tests, which confirmed Fern had COPD and alpha-1 antitrypsin deficiency. At the time of the study.

Reacting to the diagnosis

Fern accepted she had COPD and instead of blaming herself for smoking when she was younger, she took responsibility for her actions.

'*I don't know how I feel, I am not beating myself up about it. Yes, if I had known I wouldn't have smoked. If I had known that I had that genetic condition, whatever, those genes, then I wouldn't have smoked, but I didn't know, so I have no regrets. I take responsibility for what I have done…I don't know what the progression of the disease will be like, I am not really sure what to expect. So I am OK with it really.'* (Fern Int1)

Physical activity was a key component of Fern's life. Being diagnosed with COPD, however, made Fern feel very protective of her lung health and prevent further damage. Consequently, she made the conscious decision to limit her extreme physical activity.

However, reducing her activity resulted in feelings of frustration when she perceived her fitness level to not be improving at she had expected it to.

Fern was very self-conscious of her breathlessness and wheezing when she was running and of was concerned how others perceived this symptom. This made Fern feel that she was being judged as unfit.

'… *before [being diagnosed] I was just like 'God, I must be really unfit [due to wheezing and breathlessness] and everyone is going to think that I am really unfit…obviously that is not the case.'*

However, after being diagnosed Fern researched the disease and equipped with more knowledge, Fern had become less self-conscious of her breathing. Fern accepted she should go at a pace she was comfortable with and just tell other runners to go ahead. This made her calmer, reducing her respiratory symptoms.

'*If I am running with other people, I get anxious that I am holding them back…I get stressed and I don't breathe properly and they have to drop back and make a conscious effort. This was all before I was diagnosed as well. [since being diagnosed I] just make an effort to be a bit calmer, now I just tell them 'I'm not going to run with you, you go on and I'll catch you up later.' (Fern Int1)*

Category Two: COPD and Work

This included the subcategory *'challenges to her work role'.*

Challenges to her work role

As Fern's work role was mainly sedentary, desk-based and not physically demanding, Fern felt that COPD had not affected her functioning at work. However, when Fern had to work outside her home, the journey to the office, made her breathless. The commute from home to her office was a 20km round trip, and she often cycled.

'*[My COPD] hasn't really affected [my work]. I mean, it would only really affect my journey in...' (Fern Int2)*

As her workplace and work hours were flexible, she was more able to make adjustments to her lifestyle to accommodate her disease. For example, when she ran in build-up areas, the air pollution affected her breathing. She decided to avoid the air pollution by running outside of the city a few times a week, which was only possible because she was self-employed and could manage her own work schedule.

'*Because I'm self-employed, yes, [it is possible to go outside the city to run], but I mean, if I was in a 9-5 job, no, I don't think it would be [possible] at all.' (Fern Int2)*

Category Three: COPD and Home Life

This category contained three subcategories, which were; 'daily life', 'support: family and friends', and 'starting a family'.

Daily life

Fern had mild COPD and was still able to do most daily activities without any effect on her breathing, however, when she did intense cardiovascular exercise like running or cycling rapidly, running uphill or climbing stairs, she became breathless and wheezy.

'*I can do anything, there is nothing really in my day-to-day life, apart from the running. There is nothing that really causes me any problems. Walking, yeah, if I hammer it up the escalator … or cycle too fast, they are probably the main things.*' *(Fern Int1)*

Fern's mild COPD did not limit her performing housework, which she was able to do on her own, without any problem.

Support: family and friends

Fern considered her family and friends to be supportive, although they didn't understand the disease or the effects it had on her life, in the present and in the future.

'*I mean, they don't really 'get it'. I mean, my friends don't, you know, you explain to them that the end point could be that you are shuffling around with a can of oxygen attached to you, but I don't think they really. I mean, obviously you wouldn't, it's not their problem, you don't normally think about that. But I mean, yeah, they are supportive.*' *(Fern Int2)*

Starting a family

As Fern had alpha-1 deficiency which had caused the development of COPD, she was conscious of the increased susceptibility her future children would have of developing the disease.

'*[Being diagnosed with COPD] makes me think about having kids, but I am not sure it would change that, because I would just tell them they couldn't smoke. Get them tested and say 'you are not allowed to smoke, ever!''* *(Fern int1)*

Category Four: Adjusting Work and Life

Fern described five ways in which she managed her disease, each of which formed a subcategory. These were; '*recognising limits*', '*positive thinking*', '*health*y lifestyle', 'self-education' and 'adjusting goals'.

Recognising limits

Since being diagnosed, Fern was conscious of looking after herself and her lungs in the longer term, although she was still determined to push herself and pursuit new challenges, she was now aware that pushing herself too much could affect her health in the short- and long-term. She explained that she knew her limit and she pushed herself to a certain point, but not past that point, as she thought it wasn't worth the discomfort and possible harm to her lungs.

'*I could go out and run a 5km and completely smash it and just put up with the wheezing, or I could just go out and if I [am] pushing myself hard, I tend to drop back now… I can push it for a little bit, but you know, it's just so uncomfortable that I just don't want to... Yeah… it's knowing that limit really, it's still pushing, but knowing where you're comfortable doing that, you know, there is just no point in killing yourself all the time.' (Fern int2)*

Fern tried to protect her lungs and limit disease progression by avoiding or reducing her exposure to things that she knew affected her breathing, such as air pollution, stress, cold and wet weather and running very fast.

'*In terms of my lifestyle, I try and avoid pollution a lot more now, like way more than I ever did. I don't really do long runs in [the city] and if it's really hot and the air is really smoggy, I try and avoid, I avoid built up areas and I find myself going outside of town a lot more, at weekends and stuff … I've been thinking about the longer term, how to do that… [During the winter I] don't want to risk getting cold and wet, so I might just go and hide in the gym. Get strong over winter then emerge in the Spring and do more running.' (Fern Int2)*

Positive thinking

Fern described herself as a positive person. Her positive attitude enabled her to manage her diagnosis, and she said her positive thinking had possibly stopped her from becoming depressed.

'*I don't think there has been any worsening in [my disease], but I am feeling reasonably positive, I guess. There doesn't seem to be any point in kind of worrying about it really*.' (Fern Int2)

Healthy lifestyle

Fern considered she lead a healthy life prior to being diagnosed with COPD; eating healthily and exercising regularly. As already mentioned Fern was an exercise enthusiast, with physical activity playing a very large part in Fern's life. Post diagnosis

Fern decided to continue all her activities, however she did decide to go at a slight slower pace, which alleviated her breathlessness and wheezing. She also described how exercise had improved her symptoms, as cycling at a steady pace had actually helped her breathing.

'It's made quite a big difference since I have been cycling, I think … just not getting out of breath, I used to be more breathless.' (Fern Int1)

Fern noticed that chemicals in cleaning products also affected her breathing. On the days when the cleaner came to clean communal areas of the house, Fern closed her bedroom door and isolated herself to avoid inhaling the respiratory irritants found in cleaning products.

Self-education

Fern strongly believed in taking responsibility for one's own health and she viewed self-education as way she could manager her COPD. This personal responsibility was demonstrated by her informing herself about the disease, preparing questions to ask the lung specialist and taking her own measures to minimise her disease progression, and not depend on others to manage her disease for her. At the first interview, described how she persuaded the respiratory nurse to give her the spirometry results to take home, so she could investigate what the results meant, from there she did further research around the causes, symptoms and outcome of the disease. With her increased understanding of the causes and symptoms of the disease, she wanted to also educate her family and friends.

'I am a big believer that people have to take personal responsibility for themselves. I think a lot of people are like 'oh well, it's not my fault and I am not going to change my life' and whatever…I still believe that I have to do my best to make sure it doesn't progress as much as it could do.' (Fern Int1)

In the second interview, Fern was asked what motivated her to inform and educate herself about the condition. She said:

'[Educating yourself is] all you can do! … I want to feel that I am doing the best for myself, and if the only way to do that is to find stuff out and act on it [then that is what I will do]...' (Fern Int2)

Adjusting goals

An additional way Fern managed her disease was to adjust her ambitious goals. Fern was determined to continue being extremely active, yet she was aware that certain physical activities, like running fast, increased her COPD symptoms and could cause

further lung damage. Fern decided to make a compromise by adjusting her fitness goals, which meant instead of aiming to run fast over a relatively short distance, her objective had changed to maintaining a steady pace over a longer distance. Running at a slower pace did not cause Fern to wheeze, which meant Fern was able to run slower, for longer, without the fear of impairing her future health.

'…Now I do quite a lot of [strength exercises] because … I need to be able to do cardiovascular exercise into the future. There is no point in me tearing around now, if I am going to end up, my knees and breaking myself, so rather than running fast, I think, well try and get my body stronger, making sure my running form is good and learn a bit more, just so I can do it into the future in a more sustainable way. That's probably been the biggest change.' (Fern Int2)

Summary

The combination of having mild COPD and a flexible, non-physically demanding job role meant Fern's performance at work was unaffected by her condition. However, her breathing was affected by her extreme physical activity, which was her passion. In order to manage life with the disease, in the short time since diagnosis, Fern had learnt to accept her condition and tried to protect her lungs from further harm. She was conscious of her long-term health and adjusted her goals to limit the breathlessness while still enjoying her life.

5.5 Georgina: Participant Four

Georgina was 39 years old, married and had a young child. She was self-employed and often worked from home in a desk-based role. Sometimes, her work role also involved travelling to meet clients in different locations. Georgina had been diagnosed six months prior to participating in the study. She was found to have alpha-1 antitrypsin deficiency and had previously smoked.

Category One: On Being Diagnosed with COPD

This category contained three subcategories, which were; 'realising something wasn't right', 'reacting to the diagnosis' and 'informing family'.

Realising something wasn't right

Georgina first noticed her increasing breathlessness during her pregnancy. Her concerns were dismissed as being a normal part of pregnancy. After giving birth she continued to experience breathlessness, which doctors diagnosed as asthma. When

she was treated for asthma, her symptoms continued, which made her doubt her breathlessness was caused by asthma. She then made an appointment to see her GP, but before the appointment date she developed a chest infection.

'I was short of breath … when I was pregnant, that's the first time I noticed it. Everyone put it down to being pregnant…I thought it would get better… everyone [was] like 'we think its asthma or something'…so then I had an asthma spray, it kind of helped, but I still made an appointment with the GP. But you know, things take time and then I had a chest infection before I even had my appointment … and that was really bad…' (Georgina Int1).

When she saw her doctor, they performed a spirometry test, which showed a low level of lung function. The chest infection was thought to have influenced the spirometry results, so the tests had to be repeated a few weeks later. The test were repeated but the results remained the same, showing severe airway obstruction. Georgina was then referred to a respiratory specialist, who tested her alpha-1 antitrypsin levels and confirmed she was deficient in this protein.

'… I did a spirometry [tests] and they said it was very low, which is very strange as I am operating completely normal, you know, on very little air…and then I had all the tests done… [which had to be repeated because of my chest infection], and we redid the [tests] and unfortunately the results were exactly the same and then they were worried, obviously cos of my age and the severity of the COPD then they transferred me to [a specialist]. After we did blood tests, he called me back in and said it was alpha, and since then I've done the spirometry and it went up [slightly].' (Georgina Int1)

Reacting to the diagnosis

Georgina had been relatively recently diagnosed with severe COPD at the time of the study and was still coming to terms with her condition. She described how developing COPD at a young age, caused her emotional distress. The implications of having a genetic predisposition to the disease was also upsetting, as it potentially affected her daughter.

'Obviously the thought of it first of all. Because it's not just COPD, its alpha-1, I know eventually I will need a lung transplant and that's obviously quite upsetting. And also I have a daughter and she is a carrier for sure, I hope she doesn't have it, but she is definitely a carrier, which she has to be careful of smoke generally, of any kind, or any substances and also potentially of her losing her mum at a very young age, that is one of my major concerns really.' (Georgina Int1)

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Georgina was also in denial. On one hand she wanted to be aware of the treatment she could require in the future, however, she had not fully accepted she had the disease or the consequences associated with the diagnosis.

'I know [the need for a lung transplant] will come eventually but I don't wanna say I'm preparing myself because I don't wanna get ready for it, but I do wanna be ready just in case, if you know what I mean. You might call it denial. I am not avoiding it but I would rather not go there.' (Georgina Int1)

Georgina also described feeling frustrated at how COPD was managed within the UK National Health System and the time period she had been waiting to see a specialist.

Informing family

Georgina waited until she received the results from her alpha-1 antitrypsin deficiency test before telling her family of her condition. She thought if her COPD was solely caused by her smoking cigarettes, her parents would judge her and consider the disease to be self-inflicted. Whereas, if she had a genetic susceptibility to developing COPD, they would react differently.

'I wanted to really make sure it was the alpha-1 that's causing it. I used to smoke but not that much. I didn't want to particularly go and tell my parent, who hate smoke and always have done, that I used to smoke, so it was one of those moments, but anyway, it was obviously alpha-1.' (Georgina Int1)

After telling her parents, initially her family were in shock. Following the news, her siblings were tested for the gene.

Category Two: Work and COPD

This category included the subcategory 'challenges to her work role'.

Challenges to her work role

Georgina's work role was mainly desk-based, checking emails and calling customers, which she did from home. Georgina reported that her functioning at work had not been affected by COPD. However, she said this was mainly because of the nature of her work: if her work had been more physical, then she would have found it more difficult to perform work tasks.

'[It has not affected my work] yet. But it's also because I am on the phone, I sit down and talk, so it's not really, my work is not physical. If I had to lift boxes, then yes it would.' (Georgina Int1)

Sometimes her work commitments involved meeting clients face-to-face, in a restaurant for example, for a working lunch. If there were stairs involved, Georgina said her physical limitations made it difficult to climb up or down. Georgina found this embarrassing and she used strategies to hide her difficulties so no one would noticed.

'*I do sometimes go and see clients and sometimes the restaurant is on the second floor, or in the cellar, then I do struggle to get up the stairs, you know, no one actually notices it, I kind of hide it quite nicely.*' (Georgina Int1)

She considered working for herself was less stressful than working for someone else, it enabled her to manage her condition better than if she had a manager and had a rigid work schedule and having to commute to a workplace.

'*I run my own business, I don't get that stress that other people would get from their bosses or something, because I don't have a boss. So luckily I don't get that, I think if I was working in an environment doing the same job as I am doing, but not working for myself, like I used to, I think I would probably get stressed.*' (Georgina Int2)

Despite having a flexible work schedule and working from home, Georgina was unable to rest during the day because she had other responsibilities and tasks to complete.

'*[I cannot rest in the day] because I have a child, so I can't, and if she is going to the child minder I need to use the time to get everything else done, like washing and the housework as well as my job, at the same time.*' (Georgina Int2)

Category Three: COPD and Home Life

There were three subcategories that related to Georgina's home life, which were; 'daily life', 'motherhood' and 'support: family and friends'.

Daily life

Georgina described the main impact COPD had on her life was that it restricted her physical activity, affecting basic day-to-day functioning such as walking, running, talking, climbing stairs and carrying heavy objects. However, as a mother of a young child, Georgina could not avoid doing these activities, for example, running after and carrying her daughter.

'*Now [my daughter] is approaching the terrible twos, it is more difficult because she is throwing tantrums and I have to pick her up and carry her, and now she is heavier, so that is more challenging really, because obviously I have to carry her upstairs now. These days, when she throws a tantrum I cannot just let her lie in the lift floor, I need*

to get her upstairs somehow… and she runs in the opposite direction from me as well now… so I have to run after her. Luckily she is not as fast as me, but I am out of breath after that.' (Georgina Int2)

Georgina made regular international trips to visit family and friends. She sometimes found the experience of travelling independently very difficult, due to her physical limitations and her breathlessness.

'… travelling with a child is hard enough, but if you are actually, physically limited with breathing and stuff, you know, …sometimes you have to take the child, carry the child up and you have to carry your suitcases and stuff and that's quite challenging if you travel on your own, because obviously my husband, he can't always come. So that kind of thing worries me the most, that kind of travelling on my own, being on my own doing this kind of thing… you can't just tell a child 'No, I can't carry you,' she won't have that, that would cause a tantrum.' (Georgina Int1)

A significant limitation in Georgina's life was the loss of spontaneity that was associated with COPD. Prior to her diagnosis she didn't have to think about taking medication or planning her day around her capabilities, she could just get up and go. She mourned the loss of her former, spontaneous self.

'At this stage, today, I would like to go horse riding, I would like to climb a mountain, or go travelling without having to worry about taking medication or waking up in the morning, not having to take medication… the days when I didn't have to take anything, I would just [get] up and go.' (Georgina Int2)

Her physical limitations also meant Georgina had to accept that she could no longer do the extreme sports she used to enjoy, such as skiing, snowboarding and scuba diving. This upset Georgina, as it not only placed limits onto her previously limitless life, but it also affected her future plans with her family.

'… I used to go snowboarding in the winter, I can't do that, so I can't teach my husband or my daughter how to snowboard…or ski, which is quite annoying. Scuba diving, I definitely can't go scuba diving anymore.' (Georgina Int2)

Georgina found most house chores difficult, such as carrying the shopping, taking the rubbish out and hanging the washing out to dry. She explained that she still did these tasks, but at a slower pace, or her husband would do them when he was at home.

Motherhood

Georgina was diagnosed with COPD when her baby was only a few months old. Her disease-related limitations had made the role of being a mother more challenging.

Georgina considered that as her daughter was getting older, parts of motherhood were now getting easier, while other aspects were becoming more difficult.

'*In a way [motherhood] is getting easier because [my daughter] can do a lot of things, like walking upstairs herself, and walking downstairs, so I don't actually have to carry her, unless she throws a tantrum. In fact, she prefers walking up the stairs, so…99% of the time it is actually easier because she can do things on her own, or I can say to her 'can you bring me this', and she brings it to me, whereas before I couldn't do that. The opposite is when she throws tantrums and then it's getting more difficult, so there are pros and cons.' (Georgina Int2)*

Georgina also experienced fatigue, a symptom of her COPD, which reduced her impetus to do activities with her daughter, which frustrated Georgina. However, her husband would take her daughter to do activities.

'*If I didn't have [COPD], I probably would be more, not as tired, because I do get quite tired, and probably would be more active, more pro-active even, you know. I do take her to the children groups…I still do that, but sometimes I feel I should just take her outside, you know, [a] nice day, I should take her outside and sometimes I'm like I can't be bothered, you know. And that is actually, that annoys me in a way. But it's OK because my husband takes her out.' (Georgina Int2)*

Support at home: family and friends

Georgina described her family and friends as being very supportive. Her husband showed support by helping with household chores now and again. He also cooperated with his wife's coping strategies, for example, by using his spray deodorant in another room, away from Georgina, as this affected her breathing. Georgina described one friend was particularly supportive, as she educated herself about COPD and organised a private yoga class in Georgina's house.

'*I've got some friends that are extremely [supportive], one of my friends, she is really supportive, she has just found this yoga guru who comes and does private classes and she has organised for him to come to my house…to do a private session about breathing with yoga, and things like that, so yeah, she has been brilliant. She has been reading up, the moment I told her what I've got, she knew more about it than I did, I was like 'wow'. Yeah, great, everyone has been great so far.' (Georgina Int2)*

Category Four: Adjusting Work and Life

Georgina described 8 different ways she managed her disease, each of which formed a subcategory. These were; 'recognising limits and pacing herself', 'positive thinking', 'healthy lifestyle', 'reprioritising', and 'other strategies to manage her COPD'.

Since being diagnosed with COPD, Georgina had made changes to her life to accommodate her disease. For example, Georgina purposely ate healthier and avoided air pollutants, she took her inhaler before activities and rested when she felt unwell. She had also recently discovered yoga, breathing exercises and deep tissue massages as ways to ease her breathlessness.

Recognising limits and pacing herself

Despite having chest infections and being breathless, Georgina reported never having had an acute exacerbation. She considered this was because she recognised her limits, and when she felt she was going over her limit she would slow down or stop what she was doing. She gave an example of when she ran to catch a flight once, and she became extremely short of breath. She realised she was near her limit and just stopped to recover her breath.

'…once I had to run after a, well run to catch my flight, with a child attached to me, so that was pretty much, yeah that was bad, but it wasn't super bad, I mean because I just stopped, I just thought 'if the plane goes, it goes and I won't be on it, never mind'. You know, you have to kind of stop and, why am I trying to kill myself here, running like crazy when I know I can't.' (Georgina Int2)

By staying within her limits and pacing herself, Georgina managed to still do difficult tasks, such as climbing the stairs and performing household chores.

Due to her demanding work and home schedule including having a young child, Georgina barely had time to herself to just rest. Though when she had a chest infection and felt extremely tired, instead of pushing herself to carry on as normal, she sent her daughter to the child minders for a longer time period than usual, to give her time to rest and recover.

'I actually had a chest infection recently…and then I was super tired and so from this week [my daughter] was at the child minders for three days in a row…so I basically slept for three days, which was amazing because it's something I haven't done in a long time.' (Georgina Int1)

Also, when Georgina's daughter ran away from her, Georgina had to chase her, which made her breathless. Georgina had learnt that once she had caught her daughter, she could recover her breath by holding her daughter and resting to cover her breath.

'I just have to hold her so she can't go anywhere, whilst I catch my breath.' (Georgina Int2)

Positive thinking

Georgina considered herself a positive person, which helped her manage feelings of depression after being diagnosed with COPD.

'I…need to stay positive, because I think that is one of the main things that many people they just get dragged down. And I think you need to stay positive and then I'm not gonna, it's not gonna happen.' (Georgina Int2)

Healthy lifestyle

Post her COPD diagnosis, Georgina had intentionally worked towards becoming healthier, both by eating healthier but also by exercising regularly, in an attempt to reduce the progression of the COPD.

'I am definitely healthier than I was before the diagnosis … I eat healthy, I don't drink alcohol, I don't smoke, funnily enough…The healthier I am, the healthier I am gonna be longer, I presume...' (Georgina Int2)

Georgina considered being more active would increase her exercise tolerance, maintain or increase her daily level of functioning and her quality of life, and also prepare her body for a possible lung transplant.

'I've been reading that if it were to come to a lung transplant you need to make sure your legs are strong and obviously your heart and cardio.' (Georgina Int2)

Georgina was also considering buying an exercise bike to be able to strengthen her legs, and as a result, improve her breathing, from home. She also walked her daughter to the park for exercise.

'Taking [my daughter] to the park everyday which is lots of exercise for me [as] I have to run after her!!' (Georgina interim)

A healthier lifestyle also saw Georgina trying to protect her lungs and so decided to avoid irritants and things that she knew affected her breathing, such as pollution and spray deodorants, and cleaning products.

'Since the diagnosis I don't want to be in touch with chemicals as much...I am aware of that and that's why I would rather not [clean my home] myself… I avoid everything, all the pollution as much as I can. If someone next to me smokes, I will cross the road or I will avoid it, I can't stand it, I hate it, it's funny. I do try to avoid it ...' (Georgina Int2)

Reprioritising

In the second interview, Georgina explained that she had learnt not to worry about her home being a mess and her husband was supportive of this.

'…I don't care if the place is a tip, my husband, luckily, has been quite good with that...' (Georgina Int2)

Placing housework lower down on her list of priorities, took the pressure off her to try and keep a tidy home, as well as run a business, look after her daughter and manage her chronic disease.

Other strategies to manager her COPD

In the diary-like interim messages and the second interview, Georgina described using alternative strategies to manage her breathing, these included using a breathing aid, doing yoga and yoga breathing and having deep tissue massages. Georgina bought a device to strengthen the respiratory muscles, which she thought was effective at easing her breathlessness.

Georgina had also been practising yoga at home, using an application (app) on her tablet computer. Each session lasted about 30 minutes, which she practised a few times a week.

'I've started doing yoga on my [tablet computer], you know, there are some apps you can download for breathing with yoga, so I have started doing that at home now…I have noticed that through stretching, a lot of stretching, obviously I am stretching all the muscles that are really tight around my ribcage and that has really helped [my breathing].' (Georgina Int2)

In addition to yoga, Georgina had recently discovered having deep tissue massages, once every few weeks, were very effective in helping her breath.

'I have had massages and that helps…I've found a really good massage therapist...he does acupressure and deep tissue combination, and that is incredible, that is really, really good.' (Georgina Int2)

Summary

Georgina's day-to-day work life was not affected by COPD. However, the disease-related physical limitations, such as walking and climbing up or down stairs effected all aspects of her life, including work related meetings, performing household tasks and looking after her young child. Initially she hid her difficulties from others, but as time went on she had learnt to accept her condition, work within her limits and ask for help. She had discovered various ways to alleviate her breathlessness, which she felt had helped her to maintain a good quality of life.

5.6 Natalie: Participant Five

Natalie was 48 years old, living alone and had a grown-up son. Before being diagnosed with COPD, Natalie had a full-time job which was physically demanding. However, due to her COPD-related limitations, she could no longer perform the work tasks required and had to leave her job. Natalie had been diagnosed with COPD several years before participating in the study after a period of smoking heavily both cigarettes and marijuana.

Category One: On Being Diagnosed with COPD

This category contained four subcategories, which were; 'realising something wasn't right', 'emotional impact of COPD', 'asking for help' and 'hoping for a miracle'.

Realising something wasn't right

Before Natalie was diagnosed with COPD, she experienced a couple of major life traumas. This period of Natalie's life was very emotional and she was trying to deal with everything on her own. She turned to smoking to help her cope with the stress, anxiety and grief, and at she claimed that at one point she was almost chain smoking.

Natalie first went to her doctor with the symptom of breathlessness. A spirometry test was performed, which confirmed she had COPD. At the time of the study, Natalie had been diagnosed for a few years when recruited into this study.

Emotional impact of COPD

Natalie experienced various emotions associated of living with COPD, which were depression, anxiety, frustration and embarrassment.

Natalie blamed herself for her heavy smoking habit, which led to her developing COPD.

'It is my fault my lungs are like this, it is all my fault I've got emphysema. When I got through [the traumatic events], I would go to the doctors and receive tablets and I was stressed… [and] I would just smoke...' (Natalie Int1)

Natalie reported that directly after being diagnosed, she felt severely depressed and anxious, to the point of feeling suicidal. However, since then she had developed various management strategies to reduce feelings of depression.

'…to be honest, [COPD] can really get you down, it can <u>really</u> get you down.' (Natalie Int1)

Natalie's inability to perform basic tasks and her slower pace frustrated her. She compared her physical abilities to people much older than her and who were much fitter than her.

'I do feel slightly shit because some of these older people are better than I am. I do have a bit of a problem with the fact that I am young, younger, really.' (Natalie Int1)

Natalie was very embarrassed that she had COPD, hiding her disease from her friends and people she knew.

'I try and hide it, I try and hide it, that's the bottom line. Lots of people don't know I've got it, I try and hide it [because] I am ashamed and I am embarrassed.' (Natalie Int1)

Despite having severe physical limitations, she put off applying for a blue disability badge for the car, which would permit her to park much closer to buildings of interest, for example the supermarket, or shops in general, so she would not have to struggle walking to get somewhere. She did not want to consider herself as disabled, although due to her severe breathlessness and physical restrictions, she was disabled.

'I haven't managed to get myself a blue badge yet, I am trying to hold off, I am not proud of this what I've got.' (Natalie Int1)

In the second interview, Natalie was embarrassed that she could no longer maintain her garden, and felt embarrassed and defeated that she had to ask for help.

'I feel embarrassed and I feel beaten that I have had to have someone come in and do it.' (Natalie Int2)

Natalie was used to her breathlessness when she was alone at home. However, when she went out in public, she was very conscious of how others perceived her, especially when she rushed to do something, which caused her to be severely breathless. She described several examples of incidences when she struggled for breath in public places, which made her very embarrassed and self-conscious.

'It doesn't pay to rush, you just stand there looking like an idiot, I've called myself a goldfish because most of the time I am like aha, aha, aha…when I am out of breath, yeah, Goldfish quite a bit actually.' (Natalie Int1)

'I get a rush to go for a wee, which is a pain … I am gasping for breath and I need a wee, it's awful. It's even worse when you are out and that happens, in a public place.' (Natalie Int1)

Natalie often received comments from strangers about her breathlessness, which only highlighted her deteriorating lung health.

'…I have to go to the library to use a computer...I always get in there, [and they say] 'you're really out of breath'. I get it from people all the time, strangers that don't know me. 'You alright, you alright, you're out of breath, been rushing?' and it's like 'Oh God'… [Comments about my breathlessness] just sort of drives it home really.' (Natalie Int2)

Embarrassment and feeling self-conscious sometimes acted as a barrier to Natalie attending the COPD-exercise classes, as she felt uncomfortable being the youngest one in the group and yet the most breathless.

'I haven't been to class for the last three weeks, cos… basically I couldn't face it, because honestly, the last time I did go, I mean, I am the youngest one there and yet I get more out of breath and I go bright red in the face, which is horrible…You get all them old people, you know, and you are worse than them, it's like ahhh.' (Natalie Int2)

Natalie was also conscious of her red-faced appearance after exercise and how impacted on her confidence.

'But now after [the exercise] class and that, I'm OK as long as I don't see it, but obviously I get in the car and catch sight of myself in the mirror, and I think 'oh my God', and I seem to be the only one that looks like that…It really gets to me that one, I put on a foundation, but it makes no difference…It just doesn't help my confidence, it's not helping my confidence at all, that side of things.' (Natalie Int2)

When Natalie did go for a walk she was aware of her slow pace, which she thought would make people see her as weak and vulnerable.

'Now it just takes me ages, just getting up and walking down [to the river] and that, I just, oh God, oh, I'm looking around, whether they are like, 'oh, we have a naff one here.' (Natalie Int1)

Her slow pace also affected her social life, as Natalie turned down offers to go on social walk with friends as she was too self-conscious of how they would perceive

her, and didn't want to hold them back. This consequently resulted in Natalie becoming isolated.

Natalie lived in a rural part of England, with few neighbours. She also used to enjoy evening walks by the river. Now, because of her severe breathlessness and only being able to walk at a slow pace (a 'plod'), she thought other people saw her as weak and an easy target. She felt vulnerable, a feeling that she had never experienced before, despite living in the middle of nowhere for many years.

'…Anyway, I realised that to a wolf they would clearly see my weakness. I'd always felt so strong and able, yet realised I could not fight and run away if needed to.' (Natalie Interim)

Asking for help

Natalie was fiercely independent and felt uncomfortable asking people for help. She described always looking after others, she was not used to needing others to help her.

'I am a carer, I am a carer, I don't want [people] caring for me'. (Natalie Int2)

She considered asking for help was associated with older, decrepit people, not a woman in her 40's.

'…Apparently this is what old people feel like, you know, it's really not a nice feeling, having to rely on other people…I just think it might be time, it might be worse for me because I'm younger.' (Natalie Int2)

Hoping for a miracle

Natalie was hoping for a miracle that would see her lung health dramatically improve and she would be removed from her current situation, in which her severe breathlessness limited everything she did, and she could once again lead an active life and go back to working with children.

'At the end of the day I am only 48, I don't see why my body can't heal...I do believe in miracles and that sort of thing.' (Natalie Int1)

At the time of the study, Natalie was being assessed to have coil reduction therapy. The possibility of having the therapy was a great source of hope for Natalie, and she was noticeably very excited to see the consultant and of reclaiming a normal life of work and home life responsibilities such as having a dog..

'If I can get this operation, and it's successful, I might be able to, it might just give me my lungs back, that's what I'm hoping. And then I can get back, I really miss working with children actually.' (Natalie Int2)

'…I might be able to get a dog, now wouldn't that be wonderful...I've got little dreams.' (Natalie Int2)

Natalie's high hopes of having the coil reduction therapy, and it removing her from her current situation, emphasises the cataclysmic effect COPD can have on a young woman's life.

'[People with COPD] are so decrepit because of our lungs. Give us a chance- we can sort that out for you…I think that sums up how bad it is really.' (Natalie Int1)

Category Two: Work and COPD

This contained the subcategory 'challenges to her work role'.

Challenges to her work role

Natalie used to work full-time with children, in a very physically demanding role. Natalie's symptoms and disease-related limitations resulted in her leaving her job:

'You need a lot of energy to work with children, yeah, [I] can't do that [now].' (Natalie Int1)

Natalie indicated that she is an expressive person, and found that in addition to physical exertion, any kind of emotion (e.g. excitement, happiness and sadness) could cause her to become short of breath. The combination of emotion and a fast pace made Natalie's breathlessness even more severe.

'[I couldn't go back to working with children because] I wouldn't trust myself with [the children], cos you have to move quick[ly]. And also, something I've found, you see, is if there is a lot of emotion and quickness there, oh God, I'm stuffed, I'm absolutely stuffed. I cannot get the oxygen, so I would not trust myself to be working with children at all, I really wouldn't.' (Natalie Int2)

Natalie indicated that while she missed working she was unable to re-enter the workforce in a different work role, as she lacked the skills required.

'..I am no good with paperwork, I'm no good with computers either, I'm ashamed to say. No, I am a kind of hand-on girl, really.' (Natalie Int2)

Category Three: COPD and Home Life

There were four subcategories in this category. These were; 'daily life', 'socialising', 'relationships' and 'support at home; family and friends'.

Daily life

Natalie was breathless doing basic day-to-day activities, such as walking, talking, climbing stairs, cleaning her house, maintaining her garden and food shopping. Household tasks such as hanging out washing and making a bed increased her breathlessness.

'Even just making my bed, making my bed is really a challenge. A duvet, it's funny, you would never think of, but just trying to get your duvet in your duvet [cover], Oh my God, major hard work, major. It takes ages, takes ages to do….' (Natalie Int1)

Rushing whilst doing any activity further exacerbated Natalie's breathlessness, so she tried to do everything at a slow pace.

'Even going shopping, parking the car in [the supermarket] car park …for me, I have to stop before I even get to the shop.' (Natalie Int1)

Natalie was stated she was unable to keep her house tidy and maintain her garden, which had become burdensome. Her physical limitations meant her house was untidy, and as she could not afford to pay a cleaner or gardener, she considered moving to a smaller house with a smaller garden.

'My house is a wreck, apart from you can walk in and come into the kitchen, but the rest of the house, I haven't really got on top of it. I haven't got the ability to get on top of it… I haven't really got the money to pay anyone to do it, so yeah, because of my condition, I am looking to move.' (Natalie Int1)

Socialising

Natalie's social life had been greatly affected by her chronic respiratory condition. This was because emotions such as excitement and happiness, as well as physical exertion such as walking, walking and talking and dancing, which were key elements to socialising, exacerbated her breathlessness. In order to avoid worsening her breathlessness, Natalie tried to avoid such emotions and physical activities, which meant she avoided social situations and had become withdrawn from her friends and from society.

'I have kind of become slight[ly] reclusive...I can't even get excited, I can't dance, I used to dance a lot. I can't dance anymore, things like that…I won't go to parties anymore, I won't go. If I can't get up and enjoy myself, then I won't go.' (Natalie Int1)

Natalie referred to her physical state as a metaphorical 'stagnant pool', feeling like she was stuck and not moving forward with her life. She also explained that her social life revolved around attending the exercise classes, which specifically catered for people with COPD. She felt comfortable exercising there, as everyone in the class understood her condition, her symptoms and her limitations.

'I think [the stagnant pool is] trickling a bit now since I've met [the exercise instructor]. I am just trying to step out into the world and that … [The exercise class] is a lifesaver actually. Absolute lifesaver.' (Natalie Int1)

'I must admit, the only social thing I do is [the exercise] class, because they all understand...I feel comfortable because we are all in the same boat.' (Natalie Int1)

Relationships

The physical and psychological limitations related to COPD, made Natalie unwilling to look for a partner or start a relationship.

'There is one man in class who breathes as bad as me and he is waiting for a transplant, and he is 60 and he said he is single, relationship wise, he is single, because he couldn't, he goes, 'because I can't enter a relationship being this way' and I said to him, yeah, I know, I am exactly the same, [I just can't]. (Natalie Int2)

Support at home; family and friends

Natalie didn't have a close family unit, she has one adult son, who didn't live with her and she saw occasionally. Natalie did not tell her elderly mother had that she had COPD.

No family unit and few friends meant Natalie had little support and had to manage living with her COPD by herself. However, the few people she had told about her condition, she said, had been supportive.

'I only have a small handful of friends, but yeah, they do seem supportive, yeah.' (Natalie Int2)

The main support Natalie received was from the exercise class and the class instructor, who not only supported Natalie but also encouraged her to push herself within her limits.

'In [the exercise] class we start off with a warm up and then we do 5 minutes walking. If I [am] with one of the guys, if we are talking, I am terrible, of cause I say to [the instructor] 'I can't walk and talk', and she is really positive...and she goes 'oh no, you gotta talk', and I go 'yeah, I'll talk'. But it's bloody hard, I am really out of breath.' (Natalie Int1)

Category Four: Adjusting Work and Life

This category contained four subcategories, which were; 'recognising and managing her limits', 'emotional coping', 'hiding her COPD' and 'healthy lifestyle.

Recognising and managing her limitations

As Natalie lived alone, she had to do the essential activities, such as going food shopping and cooking, on her own. Natalie had to find ways of making difficult housework and shopping tasks easier for herself. For example, when she went food shopping, she sourced a shopping trolley as soon as possible and used it to lean on whilst walking to the store, around the store and back to her car, which alleviated her breathlessness and meant she could still independently buy her provisions.

In order to still eat well even on 'bad' days, when her breathlessness was worse than usual, she planned ahead. When she went to the supermarket, she would bulk buy fresh, ready-made soup and store them in the freezer. By doing this, even when she felt unwell or found cooking a struggle, she could just defrost a soup and heat it up.

'I buy [.... soups] when they are on sale, [they] go in my freezer, yeah, they are kind of like a backup after a bad day. Yeah, you just take it out of the freezer in the morning, you know, you manage to do that.' (Natalie Int2)

Natalie had learnt to manage her COPD breathlessness, by pacing herself when doing basic daily tasks, such as walking and cleaning her house and gardening. Natalie learnt to recognise her limits by trial and error, and tried to stay within her limits to avoid exacerbating her breathlessness. Natalie gave an example of the traumatic experience as a result of her going over her limit.

'...the last time I did try and cut my lawns, my heart beat was almost coming out my chest and I was having so much trouble breathing and I just thought, this is no good, this is not physically helping me at all...it frightened me a bit, cos of the way my heart was going...and I really couldn't breathe, so somebody cuts my lawn for me now.' (Natalie Int2)

After this experience, Natalie knew she could no longer maintain her garden herself, and had to accept help from a friend.

Emotional coping

Several very traumatic events occurred in Natalie's life over a similar time period, coinciding where COPD diagnosis. Natalie described had she had felt suicidal at that time and realised that she had to cope with everything on her own and pick herself back up. Natalie discovered the Emotional Freedom Technique (EFT) which helped her cope with negative thoughts and depression. EFT is a form of psychological acupressure, which involves tapping on meridian points while voicing positive affirmations. This technique is reported to work by releasing emotional blockages within the body's energy system, optimising mental health and potentially healing physical disease. Natalie was able to perform the technique on herself when needed. Compared to how she was before using the technique, she said she was emotionally in a better place, experiencing less depression (which she termed 'downhill').

'I can go downhill, but I don't go downhill for long now, I won't allow myself, I start tapping on my meridian point, it kind of does clear things- really good technique.' (Natalie Int1)

Hiding her COPD

Natalie was extremely embarrassed when she was severely breathless in public, as well as by her physical limitations, which caused Natalie to try and hide her disease from others by avoiding certain situations and 'secretly' taking her inhaler. This affected Natalie's social life as she avoided going for walks with friends and withdrew from social activities and events.

'I don't have many friends...they all want to go for walks [in summer]… I always decline because it's just too embarrassing. I won't hold them back, you know.' (Natalie Int2)

Healthy lifestyle

Natalie tried to adopt a healthier lifestyle to give her body what it needed to perform better, which she considered was the only thing she could do to help herself. For instance, after being diagnosed, Natalie had stopped smoking, started cooking home-made meals and taking amino-acid supplements (recommended to improve lung health), she also considered exercise to be important in keeping healthy.

'One thing I am trying to do is cook ... I am just trying to give my body what it needs to help it perform better. I don't notice any difference but I feel like I can at least try and do something, you know.' (Natalie Int1)

She intentionally ate certain foods because of their known benefits for the body, for example she tried to eat a lot of garlic and onions, because they cleansed the body.

Summary

Natalie's COPD and severe breathlessness every aspect of Natalie's life, and was the reason she left paid employment at age 44 years. Natalie had discovered various strategies to manage basic daily activities, however she had little support and some of her management strategies, such as hiding her disease from others and avoiding socialising resulted in her feeling lonely. Little support and negative feelings of depression, vulnerability and loneliness, impacted on Natalie's quality of life.

5.7 Sally: Participant Six

Sally was 58 years old, married and had three grown-up children, none of whom lived with her. She worked full-time in a desk-based role. At the time of the study, Sally had been diagnosed with COPD for over a year. She had never smoked and was found to have alpha-1 antitrypsin deficiency at the same time as she was diagnosed with COPD.

Category One: On Being Diagnosed With COPD

This category consisted of the subcategory, which were: 'realising something wasn't right' and 'emotional impact of COPD'.

Realising something wasn't right

Sally first recognised she had breathing problems when she suddenly started experiencing progressively worsening pain and was struggling to breathe. She went to her doctor, who did not know what was wrong with her. Desperate to find the cause of her pain and breathlessness, she went to the Accident and Emergency Department of her local Hospital. Despite having a pulmonary scan and being given an explanation of what was causing her symptoms, Sally wanted a second opinion.

'..[A few months before being diagnosed with COPD], I started experiencing some horrific pain, it just got worse and worse, I found breathing difficult. I battled to talk, yeah, my voice went… after seeing doctors and they couldn't find anything, I went to A and E, and they did a scan…I wasn't happy with the explanation they gave. The pain they thought I had pulled a muscle, which I knew I hadn't ...' (Sally Int1)

Sally used her private health care from work, and saw a private consultant, who performed genetic tests which showed Sally had alpha-1 antitrypsin deficiency, a diagnosis of COPD followed.

Emotional impact of COPD

Due to shortness of breath, Sally was no longer able to do certain activities which she used to enjoy, for example singing aloud to music. She found this very frustrating. In addition, she described the frustrated and frantic feeling she experienced when, during a long period of breathlessness, she was physically unable to communicate with people around her.

'When I am going through a particularly long episode, it drives me absolutely demented, because it is so difficult to get someone's attention, to talk to someone...' *(Sally Int1)*

In an interim message, Sally described sometimes feeling frustrated at how the invisibility of her COPD caused a lack of understanding from others, especially medical professionals.

Category Two: Work and COPD

This category contained two subcategories, which were; 'challenges to her work role' and 'work as a benefit'.

Challenges to her work role

Sally said when her disease was stable, it did not affect her ability to perform at work, as her job role was mainly desk-based and not physically demanding. Though, the sudden and sporadic occurrence of exacerbated breathlessness, as well as extreme tiredness could limit her performance at work. Sally's employers permitted a certain amount of work flexibility, allowing Sally to work from home, which enabled her to manage her disease, while completing job tasks, as and when she felt able to.

'… [There are] the odd days when I am really, really tired and I really battle, so I work from home then. I am able to do that, which is really helpful… the company that I work for currently allows me to work from home periodically, so that's what I normally do…' *(Sally Int1)*

If Sally experienced an exacerbation in the workplace, she would take her inhaler, which indicated to her manager and colleagues that she was having an exacerbation.

'I have had episodes [at work] where I can be absolutely fine, and within about 20 minutes, my voice absolutely goes and I am struggling to breath… so I go flushed and red and [my boss and colleagues] know that normally I use my [inhaler], so they know that there is a problem.' *(Sally Int2)*

If her exacerbation continued after taking her inhaler, she had to leave work and go home for the rest of the day, which could mean missing scheduled appointments or meetings. After an exacerbated, Sally might need to take a few days off work to recover. As there was no one to do her work when she was not there, the workload accumulated and waited for her when she returned to work.

Work as a benefit

The flexibility to work from home helped Sally continue to work despite feeling extremely tired, however, she tried not to work from home as she enjoyed the interaction with her colleagues. Going to the workplace distracted her from worrying about her health condition and prevented her from going into a 'black sunk' of depression.

'It's very relaxed when I work from home...but I don't do it unless I have to because I miss the interaction with other people. I also find that if, I find it better to come into work if I can, because it takes my mind off things, and, I don't go into a black sunk, as it were. I prefer to be around people, I think it's helpful.' (Sally Int1)

Category Three: COPD and Home Life

In this category, there were two subcategories, which were; 'daily life' and 'support: family and friends'.

Daily life

Although Sally described experiencing severe breathlessness and frequent exacerbations, she purposely tried to continue doing things she enjoyed, such as going to the theatre and going for walks with her children, as it was very important to her to still try and enjoy life to the full. In order to continue doing these activities Sally paced herself and took rest breaks when needed, but she was determined that COPD was not going to stop her living her life how she wanted to.

'I meet up with my children, and do quite a lot of stuff with my children, we go to the theatre, I do a lot of craft work, we travel as much as we can… I enjoy life.' (Sally Int1)

Sally also explained that being short of breath sometimes made house chores and food shopping difficult, as she found it tiring.

'If I am feeling well then I am absolutely fine, but if I am having a flare-up, I battle [with housework] and …it does take quite a lot out of me.' (Sally Int1)

Support: family and friends

Sally's husband and children were very supportive. They all knew about her disease and understood her physical limitations. Her husband helped do tasks around the house, and Sally frequently went out with her family for walks or evenings out to a restaurant or to the theatre, with her family going at her pace, recognising when she needed breaks and stopping to rest.

'My husband is very supportive, so he will do whatever needs to be done.' (Sally Int1)

Her work colleagues and employer were also very supportive, facilitating flexible working hours and workplace.

Category Four: Adjusting Work and Life

Sally described various ways of managing her disease, which resulted in five subcategories relating to disease management. These were; 'disclosure', 'acceptance', 'recognising limits and pacing herself', 'making adjustments' and 'self-education'.

Disclosure

Sally had told her family, her employer and all her colleagues about her condition, which made it easier to manage as, if she felt unwell, everyone was aware of her COPD, and she received support, at work this involved her employer allowing her to work from home.

'..Once I explained it to them, then they were able to understand…' (Sally Int1)

In the second interview Sally said:

'Obviously, as the disease has progressed, my work and my family obviously know what's going on so there is less having to explain now as it gets sort of beyond that stage.' (Sally Int2)

Acceptance

Sally seemed to have accepted her condition, and learnt to recognise her limitations and work within them, which enabled her to continue enjoying her life. Sally explained that when she had an acute exacerbation, the only thing she could do was to rest to allow her body to recover and regain its strength/energy.

Recognising limits and pacing herself

Sally recognised her limits. She paced herself accordingly and took breaks when needed, which enabled her to still lead an active life, despite her severe breathlessness.

'..the things that [me and my family] do are always within my limits, so we can still go out in the evenings, you know, go out for dinner, enjoy going for a walk where I can, a nice walk and things like that.' (Sally Int2)

After experiencing a period of extremely variable symptoms, in an interim message Sally described trying to do things at a slower pace, to reduce the possibility of an exacerbation.

'.. [I have] have been trying to take things slowly.' (Sally Interim)

Sally tried to be sensible and keep within her physical limitations, however, her desire to live life to the full and accomplish certain things before she died, motivated her and sometimes that desire caused her to push herself past her limit. She was aware that going past her limit would have consequences.

'… I know that I shouldn't push myself and I do. Simply because I just get fed up with not being able to do something and I am determined to do it, and I am worried that I will regret it the next day then I have to take it a little bit easier. Anyway, the majority of the time I am sensible and I am within my limits, I just try and enjoy life to the full and keep trying to tick things off my bucket list.' (Sally Int2)

Making adjustments

Other ways in which Sally managed life with her disease was to make adjustments. Sally often felt tired when cooking, so she introduced a chair into her kitchen and had started sitting during kitchen activities. This made the tasks easier and less taxing for her.

'I use a chair now in the kitchen, if I am doing a lot of baking or something, because I can find that quite tiring.' (Sally Int1)

Sally tried to have a healthy lifestyle by eating healthily and keeping physically active by walking. Rest was also a key way Sally tried to manage her life with COPD and to prevent exacerbations. This could involve talking time off work.

'…there is nothing I can really do [to recover from an exacerbation] except rest, breathe and rest, and sleep…sometimes I have quite a bad [exacerbation], then I might just take a couple of days [off work] just to sleep through it...' (Sally Int1)

As she had experienced numerous exacerbations during the study period and in an attempt to stabilise her symptoms and conserve her energy levels, Sally decided to regularly work from home. This enabled her to still complete work tasks and continue working full-time, as well as enabling her to manage her disease.

'…at the moment I am trying to work from home at least one day a week, just to try and keep well. If I get tired it does affect me, because my resistance seems to be lower. At the moment I am just trying to, where I can, work from home one day a week. It just makes it a little easier that way…' (Sally Int2)

As stress triggered her shortness of breath, Sally also tried to avoid stressful situations, to circumvent an exacerbation. Working at home was a way of also minimising stress.

Self-education

Sally had no formal training on how to manage her COPD, as she had not been referred to a pulmonary rehabilitation course. However she had learnt ways of improving her breathing from searching for and reading information herself.

'I read [about the breathing technique] somewhere…but I can't remember where. I read it somewhere that it gets extra oxygen into your lungs and it kind of does help me.' (Sally Int2)

She found a breathing technique that involved elongating her torso by raising her arms above her head and taking slow, deep breaths. When Sally used this technique, she found it helped to alleviate her breathlessness.

Summary

Sally described experiencing severe breathlessness and fatigue, which affected her attendance at work and her ability to perform household tasks. The support and understanding Sally received at both work and home enabled her to stay in full-time employment as well as live a satisfying life. Sally's approach to life, her thirst for an enjoyable and fulfilling life meant that she did not let COPD stop her doing activities she wanted to do, she just went at a slower pace and took rest breaks.

5.8 Conclusion

This chapter presented the findings that emerged from the first stage of qualitative data analysis in Phase One, which involved analysing data from each participant (longitudinally), using framework analysis to observe the categories and

subcategories that arose in each participant's individual narrative. The subsequent chapter will present the findings from the second stage of qualitative data analysis, which occurred in Phase One. This involved gathering all the data together and performing cross-sectional analysis on the narratives from all the participants, using thematic analysis.

Chapter 6. Findings of Phase One: Cross-Sectional Thematic Analysis

6.1 Introduction

This chapter presents the findings from the second stage of qualitative data analysis, which involved thematically analysing stories from all participants collectively. The 4 common themes that ran across each participant's story were: 'Knowing I Have COPD', 'Working with COPD', 'Home Life: Relationships and Responsibilities' and 'Towards Leading a Normal Life'. The themes and subthemes are presented in Table 6.

Table 6: The themes and subthemes that emerged from thematic analysis of all six participant's stories collectively.

Themes	Subthemes
One. Knowing I Have COPD	Seeking a diagnosis and diagnosis bias Who to tell Stigma, assumptions and being judged Hoping for a miracle Emotional rollercoaster and facing assumptions of others
Two. Working with COPD	Renegotiating work Just as good as anyone else Finding ways to adjust
Three. Home Life: Relationships & Responsibilities	Support Asking for help Socialising Stigma, Avoidance and hiding disease Dating and romantic attachments Mothering
Four. Towards Leading a Normal Life	Reprioritising Recognising limits and setting new goals Getting fit Self-education Reclaiming the female role

6.2 Theme One: Knowing I Have COPD

This theme was about the participant's experience of being diagnosed with COPD and the impact the diagnosis had on them. The subthemes were *'seeking a diagnosis and diagnosis bias', 'who to tell', 'stigma- assumptions & being judged', 'hoping for a miracle'* and *'emotional rollercoaster and facing assumptions of others'*.

Seeking a diagnosis and diagnosis bias

This subtheme referred to the participants being aware of the change in their health that led them to seek medical advice. This caused concern in participants, with most visiting their doctor straightaway. However, Sarah dismissed her severe breathlessness as being stress- and anxiety- induced and delayed seeing a doctor for several years. When participants saw their doctor, many of the participants described their doctor as dismissing their concerns, and being unwilling to refer them to a respiratory specialist. This could have been because of general expectations among medical professionals that COPD effects 'older' people, and mainly males, creating a diagnosis bias towards working age women who present with symptoms of COPD.

Due to the unwillingness of their GP, and a potential diagnosis bias towards these apparently healthy- and young- looking women, several of the participants had to be extremely persistent and forceful in persuading their GP to refer them to a respiratory specialist. The specialist subsequently diagnosed them with COPD.

'I noticed my breathing was getting worse ... I went to the doctors and basically I wasn't treated very [well] at the doctors. This is one of the problems, I actually asked them to refer me to a respiratory consultant, which they did, but they didn't really want to…I had to sit at [the doctors] desk until he had [filled out the referral form]. I threatened not to leave until he referred me.' (Laura Int1)

After being diagnosed, Laura decided to change her doctor. She found the new doctor much more helpful and it led to her being referred to pulmonary rehabilitation.

Some participants started to present symptoms of COPD at a most unexpected and atypical time. Georgina's COPD first became noticeable when she was pregnant with her first child.

'I was short of breath … when I was pregnant, that's the first time I noticed it. Everyone put it down to being pregnant. After I had the baby, by caesarean, which was quite lucky, I don't think I could have pushed her out, [my family thought it was] asthma…so then I had an asthma spray, it kind of helped, but I still made an appointment with the GP. [It took a while to see my doctor] and then I had a chest infection before I even

had my appointment… I [had] a spirometry [test] and they said it was very low…. [I then had] a chest X-ray and that was hyper inflated so everyone [thought] it was due to the chest infection, we had to do the [test] again in six weeks see if everything clears up. And we redid the [test] and unfortunately the results were exactly the same and then they were worried, obviously cos of my age and the severity of the COPD then they transferred me to [a respiratory consultant].' (Georgina Int1)

Who to tell

Some participants had told their family, friends and employer about their diagnosis, while others were much more selective at who they disclosed their COPD to. Georgina told her close family she had COPD, but to other people she knew, she deliberate oversimplified her condition by telling people she had asthma. She did not mention her condition to work clients.

'…if its people I know, I just tell them I've got asthma, I don't really say it because it's too much to explain, some people are acquaintances. My friends know, everyone that needs to know, knows, but people that are just acquaintances [like work clients] I am not going to go through the whole story…' (Georgina Int2)

Natalie was embarrassed by her diagnosis and didn't tell many people she had COPD.

'*I try and hide it, I try and hide it, that's the bottom line. Lots of people don't know I've got it, I try and hide it [because] I am ashamed and I am embarrassed.'* (Natalie Int1)

Stigma, assumptions and being judged

Working age women with COPD, who participated in this study described the presence of stigma, assumptions and being judged, since being diagnosed with the chronic respiratory disease. The term 'stigma' here, is used to '*refer to an attribute that is deeply discrediting…that makes [the person] different from others... [and] less desirable- in the extreme, a person who is quite thoroughly bad… or weak. [they] are reduced in our minds from a whole and usual person to a tainted, discounted one*.' (Goffman, 1990, p12).

The stigma associated with a diagnosis of COPD related both to physical disgust or pity (sputum, breathlessness, genetic abnormality) and assumed character defects such as a heavy smoking habit.

There was a definite stigma attached to having COPD, as the disease is strongly perceived to be caused by cigarette smoking. Awareness of this stigma influenced

some participants disclosing their disease to others. For example, Georgina waited until the results of her genetic test before telling her parents she had COPD, as she thought they would blame her. However, as Georgina's test results confirmed she had alpha-1 antitrypsin deficiency, disclosing her disease to her parents was easier, as she received support rather than blame.

Some participants also faced assumptions, and consequently judgements, being made by others. Sarah described how a stranger interrogated her for not dancing at a social event. While her consultant was also surprised as she looked 'too well', considering her spirometry test results. From these results, the consultant assumed she would be less active than she was, and possibly much older, than a woman in her 40s. Assumptions were increased by the invisibility of COPD.

'…I look a lot younger than 41, people think that I am in my early 30s, so straight away there is an assumption. And if you look at me and I am just sitting down, I look like there is absolutely nothing wrong with me whatsoever…one of the consultants …called out my name…obviously he looked at my notes before I went in about my lung function and when I approached him, you know, I can go fairly speedy at times, when I'm ready, so I was like on top form that day, like flying along, and when we got into the room, he was like 'Gosh', he said 'you look remarkably well and very spritely considering your results'... (Sarah Int2)

Several participants feared being judged for having COPD and were also embarrassed at having the disease and the related symptoms. This caused some participants to hide their disease from others.

'…I am quite good at masking it for a period of time …' (Sarah Int2)

'…I do struggle to get up the stairs, [when I'm with work clients] no one actually notices it [because] I kind of hide it quite nicely.' (Georgina Int1)

'I try and hide it... Lots of people don't know I've got it…I am ashamed and I am embarrassed. I just don't put myself in a situation where [others] can see [me struggling for breath]. I take my [inhaler] secretly.' (Natalie Int1)

The physical limitations that result from having COPD were also difficult to accept and embarrassing for some participants.

'I feel embarrassed and I feel beaten that I have had to have someone come in and [mow my lawn].' (Natalie Int2)

Other participants described being judged. Some participants judged themselves, and judged by others, as because of their age, they were often in contradiction of social expectations.

'[People with COPD are] so decrepit because of our lungs'. (Natalie Int1)

'…some of these older people [with COPD can do more than I can]. I do have a bit of a problem with the fact that I am young, younger, really.' (Natalie Int1)

6.3 Theme Two: Working with COPD

The subthemes were '*renegotiating work', 'just as good as anyone else' and 'finding ways to adjust'.*

Participants described having to renegotiate their work situation, which included renegotiating relationships within the workplace. Several participants described situations in which their COPD had affected interactions with their colleagues. Laura voiced her issue with the fan heater in the workplace, which created tension in her workplace between her and her usually supportive colleagues.

The employed women who described difficulties at work, consciously made adjustments to accommodate their COPD, which enabled them to stay at work. Each woman found different aspects of work difficult and thus required different adjustments to be made. Renegotiating work depended on various factors, for example, the nature of the work role.

Laura had requested adjustments to be made to alleviate the disease-related difficulties she experienced at work, being the distance she had to walk from the car to her desk and the fan heater which aggravated her symptoms. Her employer allowed her to park closer and changed the fan heater for an electric one.

Sarah found the physical aspects of her job made her struggle for breath and either delegated tasks to her colleagues or she do the task at a slow pace.

Sally found her concentration and extreme tiredness affected her work. She also experienced acute exacerbations in the workplace. In order to manage her condition and stay in paid employment, her employer allowed her to work from home. She then performed her work when she felt able.

Fern and Georgina, the 2 self-employed participants considered their work not to have been affected by their COPD. This could be because of the type of work and the fact they both worked from home.

Georgina stated:

'[COPD has] not yet [affected my work]. But it's also because I am on the phone, I sit down and talk, so it's not really, my work is not physical. If I had to lift boxes, then yes [COPD would affect my work].' (Georgina Int1)

Natalie could not renegotiate her physically demanding work role, so she had to leave.

'[I left work because] I was struggling…because of the [disease] symptoms.' (Natalie Int1)

In addition, her education level and training affected her ability to re-enter the workforce in a less-physical role.

'If I was on the phone, sitting down, I might be able to, that's about it, cos seriously I have problems with day to day, that's the trouble. I am no good with paperwork, I'm no good with computers either. I'm ashamed to say. No, I am a kind of hands-on girl, really… I'm a carer…' (Natalie Int2)

Just as good as everyone else

The sub-theme 'just as good as everyone else' was the frame of mind that they were able to perform the same as anyone else, even those that did not have a chronic disease.

In this study Sarah, a determined, independent, career-driven, woman, spoke of how she tried to was still more than capable of performing in the workplace, the same as her colleagues. She did not want to be perceived as being incapable or different to others because of her chronic condition.

'[Apart from the few things I struggle with]… I do the same as everybody else [at work]…my manager knows that I still perform to the same level, as in mentally and what I actually do. You know, it hasn't slowed my mind down, or I don't allow it to encroach on my life so much that I am not able to concentrate…' (Sarah Int1)

The participants who worked for employers (as opposed to being self-employed) described receiving support from colleagues and managers. Supportive employers allowed suitable adjustments to be made to accommodate the participants COPD. Implementing suitable adjustments enabled the work to be completed without compromising the participant's health.

'…the odd days when I am really, really tired, and I really battle… I work from home... I am able to do that, which is really helpful. I am in an administrative role… and the

company that I work for … allows me to work from home periodically, so that's what I normally do. Sometimes I have quite a bad flare-up, then I might just take a couple of days just to sleep through it, apart from that I'm OK.' (Sally Int1)

'… [Work] were very good…they let me have every Wednesday off [to attend pulmonary rehabilitation classes], so that was really helpful.' (Sarah Int2)

However, there was a limit to the support, as colleagues had their own work to do and managers had objectives to meet, for example, attendance targets.

'[People at work know about my COPD] but they have their own stresses and just want the job done.' (Sarah interim).

'These … [pulmonary] rehab sessions, [my employer is] making me take it as holiday. [My manager] said to me 'you can make the time up, ' so I said that I would, but it is going to be a struggle to make my time up, it means I've got to work as well as going to the rehab course… I had 2 weeks off sick 2 weeks ago, and I was meant to be on holiday, so I had three days holiday left, so they asked me to take those today and next week as holiday basically, which I am not happy about.' (Laura Int2)

The employed women who described difficulties at work, consciously made adjustments to accommodate their COPD, which enabled them to stay at work. Each woman found different aspects of work difficult and thus required different adjustments to be made. Renegotiating work depended on various factors, for example, the nature of the work role.

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6.4 Theme Three: Home Life; Relationships & Responsibilities

This theme described how participants managed their home lives with COPD, including their relationships and responsibilities. The sub-themes were *'support', 'asking for help', 'socialising',* ==*'stigma*==*, avoidance and hiding disease', 'dating and romantic attachments'* and *'mothering'*.

Support

All participants, except Natalie, described received a lot of support from family and friends, with the participants who lived with partners, receiving more support than the participants who lived alone. Support was both emotional support and practical, receiving help completing household tasks. Participants who had domestic help from their partners had more time and energy to do other things, such as socialise and manage their disease, both of which positively influenced their ability to stay at work.

Natalie was the only participant who lacked a family unit and had few friends, choosing to disclose her COPD to very few people, consequently she perceived little support.

Asking for help

Some participants had learnt to ask for help when they found tasks difficult. Sarah asked work colleagues for help in completing work tasks that increased her breathlessness. While at home Sarah and Natalie had to ask for help maintaining their

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garden and Laura, Georgina and Fern al had cleaners to come and clean their homes. Laura also asked her teenage daughters to help her perform household tasks such as hovering and preparing family meals, which formed part of her reprioritising her life to manage her disease while still trying to lead a normal life.

Socialising

Socialising with friends was found to be an important part of how participants successfully managed their life with COPD. Most women had an active social life. After diagnosis, Laura reprioritised her life to make more time to see her friends, which she enjoyed, and considered it to be important in balancing her work and family responsibilities.

However, many participants described experiencing difficulties performing basic physical activities, such as walking and talking, which could impact their social life. Most participants had developed different strategies to manage these difficulties and continued to have an active social life. For example Sarah and Sally went out with people who knew about their COPD and their limits, which made the need to stop and rest less embarrassing and took the pressure off to go beyond their limits.

'My family, obviously they all understand what's happening and that's when they do understand now. So if we go out for a bit, and we have done a little bit of walking, I say 'I actually need to sit down now, I can't carry on'. They are quite understanding about it…' (Sally Int2)

Sarah continued to go for walks with friends that understood that she had to walk at a slower pace, and managed her trouble walking and talking by letting her friends talk, while she listened.

'…From the social aspect, if people say 'oh we are going to go for a long walk in the countryside', I generally let them do most of the talking and they know that if I am not answering, they know I can't do both.' (Sarah Int1)

However, Natalie was the only participant who avoided all social situations, such as meeting up with friends to go for a walk, as she expected to struggle for breath, which would embarrass her. As Natalie had chosen not to disclose her COPD, the few friends she had did not know or understand about her disease, meaning they were not able to show her support.

'I can't go walking with friends, because I know I just can't. You avoid, you have to avoid situations. I can't walk and talk, I can't walk far without having to stop and catch

my breath anyway. I couldn't say I will go for a walk with a friend because it will just ruin their walk… I have kind of become, slightly reclusive...' (Natalie Int1)

Avoiding socialising was Natalie's unsuccessful attempt at managing her disease, as she had become isolated and lonely, with a poor quality of life. This was enhanced by her being unemployed and not having the social contact work offers. At the time of the study Natalie had recently joined a privately run exercise class, created especially for people with COPD. This had become Natalie's only social contact as she didn't feel judged or embarrassed, as everyone attending the class had COPD.

'…The only social thing I do is [the COPD-specific exercise class], because [everyone] understand[s]…I feel comfortable because we are all in the same boat.' (Natalie Int1)

Hiding the disease

To try and reduce embarrassment and receiving judgement from others, some participants decided to hide their diagnosis from their friends and family. This was done by either not disclosing their condition or by using strategies to hide their symptoms and limitations.

'I try and hide it, I try and hide it, that's the bottom line. Lots of people don't know I've got it. I try and hide it, I am ashamed and I am embarrassed…I just don't put myself in a situation where they see it. I take my puffer secretly.' (Natalie Int1)

'[I only told my parents very recently that I had COPD] because I wanted to really make sure it was the alpha 1 [deficiency] that's caused it. I used to smoke but not that much. I didn't want to particularly go and tell my parents who hate smoke and always have done, that I used to smoke…' (Georgina Int1)

'[If I tell someone I have a breathing problem] just tell them I've got asthma, I don't really say [it's COPD] because it's too much to explain... My friends know, everyone that needs to know, knows, but people that are just acquaintances I am not going to go through the whole story...' (Georgina Int2)

If Georgina had to meet business clients in a location with stairs, which she found difficult to navigate, she would go behind her clients, so they did not see her struggle. In doing so she managed to hide her disease from them.

Dating and romantic attachments

The formation of new relationships had to also be renegotiated. Two single women in the study stated their COPD prevented them from going on dates, causing difficulties establishing relationships with potential partners. This was due to the invisibility of the

disease and the possible lack of understanding from potential partners, and the possible expectations of the other person might have. The women were also conscious of their severe physical limitations which affected basic activities, such as walking, as well as intimacy, and significant embarrassment. COPD also affected participants having children. This is an age- and gender- specific impact of COPD, as it only affects women of childbearing age (under 65 years).

Sarah was in a relatively new relationship when she was diagnosed with COPD. The stress of the diagnosis and her reassessment of her ability to have child contributed to the breakdown of the relationship.

 '… [COPD] limits me [finding a partner] because, something as simple as walking and talking with somebody, it can be quite obvious that I am short of breath… but then, I think when it comes to other things, like physical things… it is obvious that you are going to be more short of breath… I am not just talking about in the bedroom, just in general, like just feeling short of breath…' (Sarah Int2)

Although Sarah described being obviously breathless performing basic physical activities such as walking, and also during intimacy, she decided not to tell a potential partner at the start of their relationship, to avoid being rejected and judged because of her condition. She knew that when the relationship was more established, telling the other person of her COPD would be difficult.

'But I think the difficulty will sort of be… when I meet somebody that it's a bit more of a, well, it's a relationship, then that's when, you know, I'll have to come clean and say what's actually happened… But I think if you start telling people quite early on, then they don't really have time to get to know you so people can pass a judgement quite quickly and think…' (Sarah Int2)

The physical and emotional effects of COPD had completely prevented Natalie from looking for or starting a relationship. Several participants were single at the time of the study and they explained that the search was made more complicated by the fact the women had COPD. Their symptoms and limitations as well as the emotional aspects of the disease, such as embarrassment and fear of being judged, stigmatised and possibly rejected, made dating difficult. One participant stated she would continue looking for a partner, but she would wait a while, until the relationship became more established, before disclosing her illness. While COPD prevented Natalie from starting a new relationship.

'I can't enter a relationship being this way… [I] just can't…obviously blokes don't realise my condition when they meet me, but no, I can't, just can't [start a relationship with my COPD].' (Natalie Int2)

Mothering

The traditional mothering role of maintaining the house and caring for children, had to also be renegotiated. Laura's teenage children were expected to do more to help around the house, such as cleaning and cooking the family meals. However, Georgina, who had a very young child had experienced challenges in caring for her daughter, as she required running after, lifting and carrying, things Georgina found caused her to struggle for breath. In addition, being diagnosed with COPD and discovering she had alpha-1 antitrypsin deficiency, after having her child, caused Georgina to worry she had passed the genetic predisposition to COPD onto her daughter. She also worried about the impact her future health would have on her daughter.

'…It's not just COPD, its alpha-1 [antitrypsin deficiency], I know eventually I will need a lung transplant, and that's obviously quite upsetting… [My daughter] is a carrier for sure, I hope she doesn't have it, but she is definitely a carrier, which she has to be careful of smoke generally, of any kind, or any substances. And also potentially … losing her mum at a very young age that is one of my major concerns really.' (Georgina Int1)

Sally had grown-up children and her relationship with them had changed since developing COPD, as they had learnt to respect her limits and also were very concerned at their mothers deteriorated health.

Several participants were frightened of the future, as although medical professionals could not provide information on their future health, they recognised their symptoms had worsened considerably in the past few months.

'I think if you were to think, right, I am only 41, my lung function test is really quite bad, if I stabilise and stay as I am, there is always the natural progression or deterioration of your lungs as you get older, so no one knows what the road ahead is going to deliver… the worst case scenario, it's not a very pleasant thing to even think about. So you know, on that level I think it's easier to not really think about it. At the moment I am lucky because I am able to have a social life with my friends, I am able to go on holidays, I don't require oxygen at the moment, which, again, that for me would be another huge psychological issue.' (Sarah Int1)

'…I do think [my family] are concerned and worried about [my COPD] and how my health has deteriorated in the past number of years, I think overall, I know I can't do as much as I used to do, but I do try.' (Sally Int2)

'There is a very good chance that my lung function will deteriorate [over time]… [and] I know eventually I will need a lung transplant, and that's obviously quite upsetting.' (Georgina Int1)

Most participants had accepted COPD was part of their life and they had found ways to adjust to their condition, or at the time of the study they were finding ways to adjust, in order to lead a normal life.

6.5 Theme Four: Towards Leading a Normal Life

This theme included the subthemes: *'reprioritising', 'recognising limits and setting new goals', 'getting fit', 'self-education' and 'reclaiming the female role'.*
Reprioritising

Many of the strategies participants described in this study to manage their COPD, such as planning ahead, keeping within their limits and pacing themselves have been reported by older people (over 65 years) living with COPD. However, a significant management strategy used to help working women (under 65 years) manage their busy lives is reprioritising. Before developing COPD, all the participants in this study worked and had the main responsibility of maintaining their homes and caring for children, as well as enjoying activities women under 65 years typically enjoy, such as socialising and dancing. After being diagnosed with COPD many participants had reprioritised their lives to manage their disease, and do what is important to them as well as what they enjoy. Laura, for example, within months of being diagnosed with COPD had accepted she had the disease and decided to get help doing the housework; she employed a weekly cleaner and delegated tasks such as cooking to her teenage daughters. The important things in her life had changed from being cooking a delicious family meal and her tidying the house, after work, to spending time with her husband, going to the gym and socialising. She had decided to spend more time doing what she needed and wanted to do to help her manage her COPD and have a satisfying life. Her successful disease management outside of work, helped her inside of work.

However, Natalie is an example of when prioritises are not adjusted to accommodate the disease. After years of living with the disease, she finally accepted that her struggle to mow her lawn had become too great and she felt she was pushing her

body past its limits. She decided she needed help, but then felt like a failure for not being able to do it herself. She was even considering moving to a smaller house with a smaller garden so she didn't have to maintain it. She tried to do everything she had done prior to developing COPD. When she struggled to complete these tasks, she would not find ways of adjusting, she would avoid doing them. This proved an unsuccessful way of managing the disease.

Recognising limits and setting new goals

All participants spoke of learning to recognise their limits and work within them. The youngest participant, Fern, who was passionate about running and liked to challenge herself, had decided to set herself new goals. When she ran fast, she became abnormally breathless and started wheezing, after being diagnosed, to limit disease progression yet continue running, she decided to run slower but over a longer distance.

Getting fit

All participants had started eating healthier and participate in regular physical activity after being diagnosed with COPD. Most started with a small amount of exercise and gradually increased the distance, intensity or time. Physical activity, although difficult at first, was described by all participants to ease their breathlessness, especially riding a bike and yoga (movements and breathing technique). For several participants getting fit was especially important as they expected to need either a lung transplant or coil reduction therapy in the not so distant future.

Self-education

Fern and Sally had described using their own initiative to investigate COPD and informed themselves of possible ways of managing the disease. As neither had been referred to pulmonary rehabilitation classes, this was an important way of learning how to manage the disease.

'[Educating yourself is] all you can do… I want to feel that I am doing the best for myself. And if the only way to do that is to find stuff out and act on it. You know, I am not one of those people who is like 'oh I am ill, therefore I am not gonna run and the doctors will sort it out'.' (Fern Int2)

Reclaiming the female role

This subtheme was about identifying certain responsibilities as being the "perceived female role". One participant, Laura, described how shortly after being diagnosed with

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COPD, she had to renounce her role of doing the family's weekly food shopping, as she was physically unable to walk around the store or carry heavy bags. This role had to shift to her husband, which challenged how she perceived herself as a woman.

However, during the three month study period, Laura had found idiosyncratic strategies to accommodate her disease and reclaimed her 'womanly role' of food shopping, which included shopping in smaller stores, with accessible parking, and order groceries online to have delivered to her home.

6.6 Conclusion

The themes that emerged were strongly related to age and gender. The unexpected onset of COPD in all six participants (aged 36 to 58 years), created a momentous disruption to their current life and their future plans. Some women found ways of managing their disease, so they could continue working and were able to find the disease was not only unexpected, but required adjustments to be made regarding how these women perceived themselves, and how they performed daily activities.

Chapter 7. Results from Phase Two and Data Convergence

7.1 Introduction

The purpose of Phase Two, which consisted of performing quantitative contents analysis, was to support the findings of the qualitative interviews in Phase One, the dominant, qualitative phase, by answering the third research question, which was;

4. Are the findings from a small sample of working-age women in the South of England typical of a broader range of people with COPD worldwide?

This chapter presents the findings from Phase Two; the quantitative content analysis and then converges the findings from both phases of this study which are presented in a matrix.

7.2 Main Findings of Phase Two

As already mentioned, Phase Two involved collecting data from messages posted on a COPD-specific, online discussion forum on the website 'Patient' (http://patient.info/). A total of 343 messages (consisting of 39 primary and 304 secondary messages or 'comments') were posted onto the forum during the data collection period from the 1st December 2015 to 28th February 2016. Each message, also termed 'post', was analysed, coded and grouped into themes and subthemes. The number of times each theme and subtheme occurred in the collective data, was counted, in so doing the qualitative data became quantified. A brief overview of the content of each theme and subtheme is presented in Table 7.

Table 7: A summary of the content of theme and subtheme.

Themes and subthemes	Summary of content
Symptoms	Common symptoms of COPD, such as breathlessness, coughing, wheezing, phlegm production, fatigue, sleeplessness. Several messages described the consequences of symptoms, such as urinary and flatal incontinence.
Symptom Triggers	Factors that activated breathlessness, such as air pollution, the weather and stress
Smoking	Some individuals described finding it difficult to stop smoking post diagnosis
Emotional Aspect of Disease	The emotional aspect of the disease included comments that described their anger and at developing the disease. Also, symptoms could be extremely embarrassing and individuals mentioned anxiety, panic and frustration, at their inability to do basic tasks, which could lead to depression and feelings of isolation. A few recently diagnosed women were scared at how quickly their disease could progress, and were scared for the future as they had young children.
Changed Personalities	Two messages included women describing how the disease had changed their personalities, as they had gone from being lively, cheerful and fun people to becoming frustrated and irritable as a result of their disease-related limitations.
Diagnosis	Misdiagnosed or delayed diagnosis
Impact on Life Delayed routine	Morning symptoms delayed the individual leaving the house.
Difficulty doing basic tasks	Individuals mentioned struggling with basic daily tasks such as hoovering and walking upstairs. Although some could do most basic tasks they found it very difficult and had to do it all slowly.
Affected social life	Unable to be away from home overnight as symptoms were unpredictable and variable.
Difficulty travelling	Requiring oxygen made it difficult to leave the house and go on holidays.
Home Life Responsibilities	Difficulties performing housework.
Afraid of future for young children	Young women with COPD spoke of their fear for the future as they had young children.
Support	Support from family and friends.
Lack of Support	Having no physical, mental or financial support. Having to manage life with COPD and the implications, alone.
Relationships	Describing relationships with family, friends and medical professionals.

Work	
Difficulties staying at work	Some women said it was sometimes difficult to stay at work because of symptoms such as fatigue.
Adjustments to stay at work	To manage to stay at work, women discussed having to change their working hours; starting work later or going from full-time to part-time to accommodate health condition.
Managing to stay at work full-time	Some women managed to remain at work with COPD, some until their official retirement age.
Motivation to stay at work (financial status)	Financial status and financial commitments as well as family status (single parent) motivated a few women with COPD to stay at work.
Fears of unemployment	A young woman recently diagnosed was worried about her future ability to work and sought advice from individuals who had lived with COPD for longer.
Struggle to stay at work	Some women described being forced to leave work because of their disease-related work limitations related to COPD.
Disease Management Medication	Advice or queries about medication. Some reported specific medication significantly relieved their symptoms.
Problems with medication	Some said their medication made no noticeable difference or they experienced adverse side effects.
Alternative (non-pharmaceutical) treatment	Using lemon tea to reduce phlegm production
Pulmonary Rehabilitation	Some individuals described attending pulmonary rehabilitation classes.

Table 8 (p.176) depicts the themes and subthemes that emerged in the messages international women posted in the forum during the three month data collection period, and how often (the frequency) they appeared in the text. The total number of times themes and subthemes emerged in all the data collected is also shown. Due to each message potentially containing several themes and subthemes, the total frequency all themes and subthemes appeared in the data (455) is higher than the total number of messages (343) posted in the forum during the data collection period.

While Table 9 (p.178) represents the convergence of findings from Phases One and Two. Table 9 shows the comparison of the themes and subthemes of each of the two Phases, with the frequency they appear in Phase Two being stated. The level of comparison is shown in the third column as 'similar', 'different' or 'not mentioned'.

As shown in Table 9, convergence of the data from Phases one and two was incomplete, and although no themes or subthemes appeared to be 'different', some key themes described in Phase One, did not appear in the forum messages in Phase Two, are denoted in the table as 'not mentioned'. Phase Two showed that some of the main themes, collected from the qualitative sample, were transferable to a larger international set of women with COPD. However the data from message forums also differs from that gathered from the qualitative interviews in that interviewees in Phase One spoke more about personal, emotional experience. This could be because participants in Phase One felt more comfortable discussing personal or sensitive information, for example, their inability to meet expectations and their limitations, during one-to-one interviews, whereas they would be less willing to post such information on a public forum, visible to all forum users. Phase Two demonstrated that the findings are transferable in a limited sense, and also that qualitative one-to-one interviewing provides rich, personal and emotional data which did not appear in online message forums. Such themes include issues around staying at work with COPD and renegotiating relationships since developing the chronic disease. Thus some themes from Phase One data collection were not reinforced by findings from Phase Two.

Table 8: The frequency themes and subthemes occurred in the forum messages

Themes and subthemes	Frequency theme and subtheme were mentioned in the forum messages
Symptoms (e.g. breathlessness, coughing, wheezing, phlegm production, fatigue, sleeplessness)	45
Triggers	10
Trouble with diagnosis	5
Emotional Aspect of Disease	7
Impact on Daily Living	
Difficulty doing basic tasks	10
Affected social life	1
Difficulty travelling	2
Pulmonary Rehabitation	5
Hospitalisation	1
Work	
Difficulties staying at work	3
Forced to leave work due to COPD	2
Adjustments to stay at work	2
Motivation to stay at work	3
Fear of having to leave work because of symptoms	1
Managing to stay at work full-time	4
Home Life	
Anxious of future with young children	4
Support from family	1
Live alone and have to manage alone	1
Relationships	
Family	2
Friends	1
Medical professionals	1
Disease Management	
Smoking (giving up)	2
Medication	18
Problem with medication	4
Alternative treatment	6
Acceptance	2
Making adjustments	3
Pacing themselves	3
Pushing themselves	2
Avoidance	6
Breathing techniques	2
Asking for help	1
Healthy lifestyle	
-healthy eating	1
-regular exercise	5
Planning ahead/reprioritising	2
Living each day as it comes	1
Positive thinking	1
Focusing on abilities and not limitations	1

Recognising limits	1
Rest	1
Determination	4
Searching for and/or giving advice or support on the forum	280
Total	455

Findings from Phases One and Two of this study were converged using a matrix, presented in Table 9. In this study, the data from both Phases One and Two were converged using a matrix formed of three columns (Table 9). The first column presents the themes and subthemes found in Phase One, while the second column presents the themes and subthemes found in Phase Two, with the frequency the themes occurred in the text shown in brackets. The third column compares the themes and subthemes in both phases and states whether they were similar, different or not mentioned. In the table below, the term 'similar' refers to the content of the theme or subtheme in Phase Two corresponding to the content of the theme of subtheme in Phase One. Whereas the term 'different' in the context of Table 9, refers to the content of the theme or subtheme in Phase Two not corresponding to that of Phase One. While 'not mentioned' means the content of the theme or subtheme that emerged in Phase One, did not appear in the data collected in Phase Two.

Key findings from:		
Phase One Qualitative data	**Phase Two Quantitative data (frequency occurred in text)**	**Similar/Different/ Not mentioned?**
Difficulty being diagnosed	Trouble with diagnosis (5)	Similar
Psychological aspect of COPD	Emotional aspect of the disease (7)	Similar
Inability to meet expectations (their own and of others) Feeling judged		Not mentioned
Limitations in General	Impact on daily life (13)	Similar
COPD and Work Limitations at work Forced to leave work Work adjustments Managing to stay at work Support at Work	Forced to leave work (2) Adjustments to stay at work (2) Managing to stay at work (4)	Not mentioned Similar Not mentioned
COPD and Home life Limitations at home Family life Motherhood Social life Dating Starting a family	 Anxiety about having the disease while looking after young children (4)	Not mentioned Not mentioned Similar Not mentioned
Management Strategies Acceptance Making adjustments Pacing themselves Pushing themselves Avoidance (of triggers or activities) Breathing techniques	 (2) (3) (3) (2) (6) (2)	Similar

Asking for help	(1)	
Healthy lifestyle		
-healthy eating	(1)	
-regular exercise	(5)	
Planning ahead/ reprioritising	(2)	
Taking each day as it comes	(1)	
Positive thinking	(1)	Similar
Focusing on abilities and not limitations	(1)	
Recognising limits	(1)	
Rest	(1)	
Determination	(2)	
Taking Medication		
-prescribed medication	(18)	
-non- prescribed/alternative	(6)	
Educating oneself about COPD		
Hiding disease		
Working from home		Not mentioned
Alternative ways to manage breathlessness (e.g. yoga, massage)		
Disclosure		Not Mentioned

There were 20 individuals, all women, in total that posted at least one message onto the online forum over the three month data collection period. Messages posted by individual users of the forum using male or gender neutral usernames/pseudonyms, or the content of the message referring to them being male, were excluded from the data collection process. Some women were more active in writing messages than others. From the content of posts, the international location of women with COPD posting on this online forum could be established; with some women living in the UK, Australia, North America, Canada and China. This shows the diversity of the international perspective of women living with COPD. The age of women posting messages on the forum also differed, with several stating they were of working age, had young children or had grown- up children or were retired. However it must be noted that the ability to communicate in the English language may have limited the users to the forum.

After data was collected and analysed from pre-existing messages in an online forum, it became apparent that conducting semi-structured interviews (in Phase One) was a richer form of data collection (in this study). Data collected from interviews was more detailed and participants were more open to speaking about personal experiences and emotions, compared to the data posted online, which was predominantly seeking support and advice, for example, were their symptoms normal and what should they do.

In the quantitative phase, there was data posted by women with COPD, about their ability to stay at work, expressing their fears for the future earning capacity, their financial status and their anxiety of having COPD while having to look after young children, which was similar to the findings of the qualitative phase. Such findings from both the qualitative and quantitative Phases of this study converge, demonstrating that there are women, similar to those who participated in this study, who have COPD and experience difficulties at work, and they have to found strategies to manage their disease, while meeting other responsibilities in their life, like work.

The purpose of Phase Two was to test the transferability of the findings from Phase One. In so doing, Phase Two showed which important issues, described by a small sample of women (under 65 years) with COPD, in the East of England, were also reported by the wider, international community with COPD. Here, convergence showed that some issues described by the six participants in Phase One, were also reported by individuals with COPD internationally. However, other key issues, such as the impact COPD had on a person's work and home life and strategies used to manage the disease in the work and home environment in particular, although reported in Phase One, were not mentioned by the international community using the online forum.

Chapter 8. Discussion, Conclusion and Recommendations

8.1 Introduction

This mixed methods study provided a three month snapshot view of how young and middle-age women with COPD managed their complex lives with the disease. The main findings from this study provide new and valuable insights into the wide-ranging effects COPD has on the work and home lives of working women under 65 years old. This final chapter begins by outlining the principal findings from this mixed methods study and their contribution to the existing literature. The International Classification of Functioning, Disability and Health (ICF) conceptual model will then be presented and the findings will be placed in context of the model, clearly defining the study's contribution to enhance this model. The strengths and limitations of this study will then be considered and the chapter concludes by suggesting recommendations for future research, policy and practise, followed by the main conclusions of the study.

The research questions posed in this study were:

1. How do women of working age perceive their COPD, and how do they view the impact the disease has on their life?

2. What are the strategies these women implement to manage work and other daily responsibilities with the disease symptoms?

3. Are the findings from a small sample of working-age women in the South of England typical of a broader range of people with COPD worldwide?

8.2 Key Findings

The key findings from the study were:

1. In Phase One of this study, stigma, defined as a spoiled identity, was significant to how these women perceived their disease, and how they viewed the impact COPD had on their lives. Judgment and blame were also subthemes, and came from themselves and from others.

2. The first phase of this study found that none of the working age women fitted the classic stereotype of the older, male smoker with COPD. This generated a bias among

medical professionals, which led to a delayed diagnosis in the young and middle age women in this study. Not fitting the stereotype of someone with COPD also resulted in surprise from other people once the diagnosis was revealed to them.

3. Phase One found that there were strong assumptions about how these women looked, and what society expected their capabilities to be, compared to what their actually capabilities were.

4. In both Phases One and Two, despite all women being shocked at their diagnosis, with time most women accepted COPD as being a part of their new life and had successfully developed strategies to manage their symptoms and physical limitations, reducing the impact COPD had on their lives. However, some women were unable to accept their diagnosis and were overwhelmed by the thought of having this chronic disease and the associated implications to their current and future life. One woman perceived COPD had a deleterious impact on her life, as since developing COPD she had had to leave paid employment and her social life had been severely affected, both of which she explained were due to her physical limitations caused by her disease. In such instances self-judgment and self-blame were perceived to be greater than the other women who had accepted COPD as part of their lives. Self-judgment and self-blame did not aid in developing successful strategies to manage life with COPD.

5. In Phases One and Two women in this research used a variety of strategies to manage work and their other daily responsibilities, including the housework that forms part of the 'second shift'. Common strategies involved disclosing their COPD to their employer, work colleagues, family and friends, requesting and receiving adjustments at work and reprioritizing their lives.

6. The findings of the smaller qualitative sample were partially reflected in the wider international sample.

In the context of existing literature

The women who participated in this study perceived their COPD, and the impact it had on their lives, very differently to one another. Most women were learning to adjust their lives to accommodate their COPD, while others were unable to perform basic daily tasks and consequently could not participate in daily life activities. Various factors were found to influence the perception of COPD and the perceived impact COPD had on their lives. Such factors included their experience of stigma, regarding responsibility for the condition and its physical effects, and overturning the

expectations of others, including medical professionals, regarding the life stage at which the women were diagnosed with COPD. In addition, the level of support they perceived at work and at home, the nature of the work role, their ability to adjust difficult tasks and the woman's personal characteristics e.g. whether they were positive or negative thinker, were all found to influence their perception of COPD and its impact on their lives.

All participants in this study reported being shamed by their diagnosis of COPD. The overarching theme to capture the different experiences of shame experienced by these women is stigma, with subthemes being, judgement and blame, resulting from the assumption that COPD is caused by smoking. Stigma is a social construction that defines individuals based on distinguishing characteristics (Dinos et al., 2004). Stigma occurs when society then labels such individuals as tainted, less desirable or handicapped (Goffman, 1963). Consequently, stigma can devalue individuals and lead to feelings of guilt and shame (Williams, 1987). Adverse judgement could also arise from the invisibility and visibility at different moments in time, with exacerbations and physical limitations exposing their disease to others.

Assumptions about the stereotypical COPD sufferer caused diagnosis bias, resulting from the assumption that COPD was caused by smoking, because the women were younger than expected, looked 'well', and being a woman.

8.3 Stigma

As already stated, 'stigma' here refers to 'an attribute that is deeply discrediting…that makes [the person] different from others...' (Goffman, 1990, p12). Stigmatisation, or the valuing and devaluing of individuals within a society are caused by social judgments relating to sociocultural values and beliefs (Johnson, 2007). Stigma may come from medical professionals, family, friends or strangers and can effect an individual's illness experience (Johnson, 2007).

8.3.1 Stigma associated with smoking

Although the literature recognises a numerous causes of developing COPD (Fromer, 2011), medical professionals strongly associate COPD, with cigarette smoking (Halding, Heggdal, and Wahl, 2011; Johnson et al., 2007; Simpson and Rocker, 2008), with those who develop COPD automatically being stigmatised as smokers and having developed a 'self-inflicted' respiratory disease (Albrecht, Walker and Levy, 1982). However, stigma associated with smoking has already been mentioned by few individuals with COPD (O'Neill, 2002) and detail as to how patients are stigmatised

and the consequences of stigmatisation in those with COPD is lacking. A comparable relationship has been made between heavy cigarette smoking and lung cancer (Chapple, Ziebland and McPherson, 2004).

An interview study of 45 men and women aged between 40 and 90 with lung cancer from across the UK, found individuals with lung cancer experienced stigma and blame from their medical professionals, for smoking (Chapple, Ziebland and McPherson, 2004). This assumption resulted in patients, who had never smoked or had stopped smoking years ago, feeling frustrated at automatically being labelled a smoker and consequently held responsible for developing lung cancer. Younger lung cancer patients were more likely to be blamed and held responsible for developing what was seen as a 'self-inflicted' disease than older patients. The authors suggest this could be because medical professionals considered that older people became addicted to cigarettes at a time when smoking was socially acceptable and before the risks were widely known.

Other forms of stigma and judgment were also made by others, such as family members and strangers, with some participants fearing disclosing their disease to family members, for fear of being blamed for developing a self-inflicted disease. The presence of such stigma and blame, especially from influential people in these women's lives, influenced the level of perceived support, access to healthcare, psychological effects and management of COPD and the individual's quality of life.

The stigma associated with disease can also be influenced by whether the disease is considered to be self-inflicted (Johnson et al., 2007). When an individual is perceived to have control over the onset of the disease, they could experience a greater negative reaction from others, than if the disease was caused by factors outside of the individual's control (Weiner, Perry and Magnusson, 1988). This was found to be the case in this study, as several women had never smoked and many were found to have genetically inherited alpha-1 antitrypsin deficiency, which predisposed them to COPD, which was in contradiction of the widespread presumption that COPD is only caused by smoking. The genetic factor could have resulted in the development of the disease at a much earlier age than those without alpha-1 antitrypsin deficiency. For those women who did use to smoke, having a genetic factor made the diagnosis easier to deal with as it meant the blame for developing COPD, shifted from them and their smoking habit, to their genetic inheritance, something they had no control over. Having alpha-1 antitrypsin also made disclosure to family and friends easier, as instead of receiving a negative reaction related to stigma and blame, they received support and empathy.

8.3.2 Judgements associated with invisibility and visibility of disease

Other types of stigma associated with COPD, reported in the literature include stigma related to the visible effects of illness, such as severe breathlessness and functional limitations (Johnson, et al., 2007; O'Neill, 2002; Berger, Kapella and Larson, 2011). In this study, this type of stigma was caused by judgements. The participants of this study reported feeling embarrassed and judged by close friends as well as strangers, this was because of their inability to conform to expectations of physical activities, such as daily tasks at work and at home, as well as social activities, like dancing. Participants also experienced embarrassment and judgement associated with disgust, for example, when they were in public places and had erratic and severe periods of breathlessness, or had a productive cough, in which the coughing as well as expelling the sputum were causes of disgust and judgement from others.

This was found to affect relationships at work, with family members and with friends/partners, either causing relationships to be renegotiated or avoided. Avoidance could result in social isolation, which in turn, could influence quality of life. Such judgements could be perceived as greater in these young and middle-age women, compared to older women with COPD, due to the sense of having to comply with the expectations others had of the capabilities of women their age. This is the first time such judgement has been described in young and middle-age women, who are working and living with COPD.

Stigmatisation of patients with COPD, from medical professionals acts as a barrier to accessing guidance in self-management, as well as the emotional support and social inclusion, shown to be associated with a positive doctor-patient relationship (Halding, Heggdal, and Wahl, 2011). Having regular access to guidance of symptom management, has been found to increase a patient's confidence in self-managing their COPD (Simpson and Rocker, 2008). Patients who felt psychological supported by their physician were more likely to successfully manage their disease in their daily lives (Bourbeau and Johnson, 2009).

In this study several participants had never smoked and felt frustrated at the automatic assumption that they were smokers. The other participants had smoked to varying degrees prior to their diagnosis of COPD. Both non-smokers and smokers felt unfairly judged by medical professionals, who could be unsympathetic to their concerns and made hurtful remarks regarding the severity of their lung condition. Thus the assumption of COPD being solely a smokers' disease and an older person's disease, affected how medical professionals behaved towards the young and middle age

women on this study, which acted as a barrier to diagnosis and also influenced their access to treatment.

In this study, diagnosis bias was found to be present among medical professionals as they assumed the development of COPD is solely caused by heavy cigarette smoking, despite several of the women never having smoked. Such diagnosis bias has been reported in few studies into COPD (O'Neill, 2002). This could be a result of research focusing on the lived experience of older people (over 65 years) with COPD. If the perspective of medical professionals is similar for COPD as it is for lung disease, older patients may not experience the same level of blame that younger people with COPD are exposed to. It could also be because older people are expected to become ill, while younger people are not.

In addition, if young and middle-age women with symptoms of COPD are not diagnosed, because of such stigma from medical professionals, this could influence their work lives, as they would still experience the progressively worsening symptoms and physical limitations, but would not have a clinical diagnosis to make their condition 'real'. This could affect the authorisation of time-off work due to feeling unwell, necessary adjustments being made, and general support and understanding to manage their symptoms at work, if they have not been acknowledged by medical professionals, as having COPD.

8.3.3 Assumptions associated with age

Prevalence rates of COPD are rarely divided by gender or age groups (Fletcher et al., 2011). Despite there being a significant increase in COPD developing in people under 65 years, especially in young and middle-age women (Fletcher et al., 2011), this study found many medical professionals still assumed COPD solely develops in older people (over 65 years). This was the first study to my knowledge that highlighted the assumption associated with age of onset in young and middle-age women who presented with symptoms of COPD. The younger age of the women in this study, and the invisibility of their disease (their 'well' appearance), resulted in their health concerns not being taken seriously, which formed a barrier to diagnosis and subsequent treatment. Although international guidelines have been published, outlining the risk factors, symptoms, and the protocol for diagnosing and treating COPD (Fromer, 2011; GOLD, 2015), false assumptions made by the physician, could prevent such guidelines being followed. This could result in a false diagnosis being made and inadequate treatment being given to the patient. Such assumptions made by medical professionals of younger women with COPD provides a novel contribution to the literature.

8.3.4 Assumptions associated with gender

In addition to age, individuals can experience assumptions associated with gender that is, related to the cultural norms and values relating to the distinct roles and behaviours of men and women in a given culture (WHO, 2016). Research into women with chronic diseases found that women can experience false assumptions from medical professionals (DiGiacomo et al., 2015). A study by DiGiacomo and colleagues (2015) found women felt disempowered when interacting with medical professionals, with their health concerns being dismissed. Participants considered a source of their disempowerment was the male dominance in the medical profession, especially in specialty fields. Disempowerment referred to not seeking a second opinion and difficult communicating with medical professionals. The study found that women sometimes did not feel confident to ask questions during consultations, and accepted the medical professional's opinion. This was dependent on the doctor-patient rapport and the individual women's characteristics. Women's interaction with medical professionals was affected by a range of factors, including doctors attributing their concerns to mental health issues and their fears of being labelled, (for example, as a hypochondriac), which meant their health concerns were often dismissed or made insignificant, causing them to feel frustrated. However, the determination of these women to find out what was wrong with them, led them to persevere and pressurise their physician to refer them to a respiratory specialist, or seek a second opinion. If they had settled for what the medical professionals had initially told them, they probably would not have received a diagnosis of COPD and consequently would not have received adequate treatment, while their disease, symptoms and physical limitations became progressively worse. This is the first time such damaging assumptions in women with COPD has been described. Such assumptions are harmful, because they are false.

In this study, diagnosis bias was found to be present among medical professionals as they assumed the development of COPD is solely caused by heavy cigarette smoking, despite several of the women never having smoked. Such diagnosis bias has been reported in few studies into COPD (O'Neill, 2002). This could be a result of research focusing on the lived experience of older people (over 65 years) with COPD. If the perspective of medical professionals is similar for COPD as it is for lung disease, older patients may not experience the same level of blame that younger people with COPD are exposed to. It could also be because older people are expected to become ill, while younger people are not.

Such negative experiences of interacting with medical professionals could result in a reluctance to seek further help, affecting how they perceive their illness, which in turn, effects self-efficacy of disease management (Chapple, Ziebland and McPherson, 2004). In this study, for those women who had a support network and were determined to seek help, the bias of medical professionals appeared to have much less of an effect on how they perceived their COPD. However, for women who lacked a support network and felt vulnerable, medical bias could lead to feelings of depression and low self-worth, which made them reluctant to return for treatment.

8.4 Working with COPD

Of the six women who participated in this study, five were working (four full-time, and one part-time), two were self-employed and worked from home, while the other three women worked for organisations. One participant had to leave work because of her COPD. This study found that working age women to stay at work with COPD depended on various factors. The nature of the work role and the individual's ability to make adjustments at work (i.e. their adjustment latitude) were the two significant factors found in this study to influence the ability of women with COPD to stay at work.

8.4.1 Nature of work – employment and housework

In this study, the nature of the work role and the work environment, that is whether the role was physically demanding or sedentary, affected the women's ability to perform the work tasks and consequently, stay at work. Most women had sedentary, desk-based work roles and reported few difficulties in performing their duties at work. In this study, work roles that were not too physically demanding appeared easier for the woman to manage their work tasks and their disease symptoms, than work roles that were very physically demanding and required great amounts of energy. One participant, Sarah, had a very stressful and physically demanding, managerial job at the time of her diagnosis. She was fortunately able to negotiate her work to a role that was less physically demanding and less stressful. In this way, she was able to continue performing her work tasks and manage her COPD, which enabled her to stay at work full-time (40 hours a week). However, when the work role could not be restructured and changing to a less physically demanding job was not an option, the participant, Natalie, was forced to leave her job shortly after being diagnosed with COPD. Coincidently, Natalie perceived her disease and related physical limitations as being greater than the other participants, who were able to stay at work. This is in agreement with previous research into women working with limited systemic sclerosis,

that found a correlation between work ability and perceived well-being; the greater the work ability, the better the participants perceived their health and well-being, and the lower work ability, the poorer they perceived their wellbeing (Sandqvist, Scheja and Eklund, 2008). They also found that participants had a greater ability to perform work tasks in jobs that were less physically demanding. The researchers suggest the positive association between ability to perform work tasks and well-being could be bidirectional, with greater wellbeing promoting performance at work and staying at work could improve well-being.

In addition, Natalie lacked the skills required to re-enter the workforce in a less active capacity, consequently, she remained unemployed. As she was not offered any retraining, she could remain unemployed long-term, with little chance of ever working again. This prospect caused her great distress, as, in her 40's she was a long way from the official retirement age and she was already deprived of the many benefits associated with working, such as financial independence, life structure and purpose and social interactions. This finding has great implications for women with COPD, who could be forced to leave work because of their inability to continue performing the work tasks. Quality of life, self-esteem and social contact were all found to be affected by leaving the workforce years too early, as a result of a chronic illness. Future research into keeping women with COPD participating in the workforce for longer could involve exploring training options to teach such women transferable skills to change to less physical, desk-based work roles.

Despite the objective disease severity of each participant in this study being unknown, from the symptoms participants reported, disease severity seemed to not be an important factor in performance at work. This disagrees with previous research into COPD, which found disease severity to be associated with work status (Fletcher et al., 2011; Sin et al., 2002). However, as this cannot be confirmed, more research could be done to explore this further.

In addition to having a sedentary work role, factors that influenced employment status included having a supportive work environment, being motivated and determined to stay at work and the ability to implement suitable work adjustments. Support and understanding from managers and work colleagues were important in perceiving COPD to be manageable in the workplace. Supportive managers were found to be more likely to implement requested adjustments to aspects of the work environment, which enabled these women to still performing work tasks, while managing their COPD. The women who successfully managed to stay at work also described having a strong support network outside of work. This correlates with previous research that found perceived support from colleagues and managers positively influenced the

ability of chronically ill workers to manage both work tasks and their disease at work (Munir, Yarker and Haslam, 2008; Wynne-Jones et al., 2011). In particular, the ability of chronically ill female workers to stay at work has been found to be significantly influenced by high levels of support and understanding at work, as well as at home (Liedberg and Henriksson, 2002; Löfgren, Ekholm and Ohman, 2006).

Emotional and physical support from family and friends was important in managing COPD in their home lives. Family members helped complete household tasks, while supportive friends helped these women maintain an active social life. In this way, a high level of perceived support was found to reduce the perceived impact of COPD on these women's lives, both at work and at home. This resulted in greater self-efficacy (belief in their own abilities) in managing their COPD and thus perceived COPD to have little impact on their life. In this study, women who had high levels of support appeared to have a good quality of life. These findings concur with other studies that show support to be of high importance in people managing chronic disease at work (Wynne-Jones et al., 2011; Baker-Mcclearn et al., 2010; Munir et al., 2009; Munir, Yarker and Haslam, 2008) and at home (Mahon, O'Brien and O' Conor, 2014; Backman et al., 2007), however, this is the first time they have been described in working women with COPD.

8.4.2 Ability to make adjustments

Previous studies focusing on chronically ill women at work, have found that the implementation of specific work adjustments, are important for keeping productive and satisfied at work (Henriksson, Liedberg and Geedl, 2005; Sandqvist, Scheja and Eklund, 2008). Research exploring challenges experienced by women working with musculoskeletal disease (Crooks, 2007; Liedberg and Henriksson, 2002) found women working predominantly in service roles reported having a lack of control over the work situation, with the implementation of necessary adjustments being dependent on the discretion of the employer (Crooks, 2007; Liedberg and Henriksson, 2002). Whereas well-educated women were found to be in work roles in which they had greater work autonomy, being able to control their work content, work schedule, pace of work and workplace, which enabled better management of their condition, compared to women with a lower level of education (Liedberg and Henriksson, 2002).

This has also been found in this study. Young and middle-age women with COPD experienced breathlessness which could be triggered by any activity, for example, physical or stressful tasks. The working participants needed to make adjustments to their work role in order to conserve energy and negotiate tasks they found difficult, like activities that involved a lot of talking and walking. One participant, Natalie, had a

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very fast pace and physically demanding work role. She experienced the most difficulties in performing her work tasks. The self-employed participants, Fern and Georgina, who worked from home described the least difficulties performing work tasks, while the women who worked for organisations described experiencing difficulties performing tasks specific to their work role.

Fern and Georgina both reported to have a high level of education, had a great deal of control of their work schedule and work content, which together with working from home enabled them to balance their workload with their capabilities and disease symptoms.

Whereas Laura and Sarah, who worked for employers all had to disclose their disease and request adjustments to be made by their employer/manager. The ability to make certain adjustments not only depended on the employer but also on the work role, with the women who worked in service roles, facing customers, being unable to work from home, however their managers did make tangible adjustments such as allowing closer parking and facilitating a regular day off to attend pulmonary rehabilitation classes. However, despite perceiving support at work, certain adjustments that may have been required were dismissed as impractical. For example, Sarah considered in her busy work role, that the ability to reduce her work load by re-allocating her work to her colleagues was not possible as everyone in the workplace already had their own high workload. This was practical barrier to making needed adjustments to the workload was found in women working with fibromyalgia (Liedberg and Henriksson, 2002). Although this is the first time it has been described in working women with COPD. However, after diagnosis Sarah had made her own individual adjustments to her work role in order to remain in the workforce for longer. She had changed to a more suitable job role, one which was less stressful and less physically demanding. In her current role she also asked colleagues to perform work tasks that triggered breathlessness. Natalie, in the very physically demanding work role, appeared to have a very low level or no general adjustment latitude. It was unknown if she had disclosed her COPD to her employer, but the fact that she generally tried to hide her disease from others suggested her employer could have been unaware of her chronic disease and breathing problems. Her severe breathlessness performing most work tasks and her inability to adjust her work situation to make her role more suitable to her capability resulted in Natalie leaving her work role. This supports the finding by Hultin et al., (2010) that a low adjustment latitude is associated with a high rate of sickness absence. These findings builds on this, showing that a low level of adjustment latitude can result in increasing difficulty performing work tasks, while simultaneously negatively affecting disease management. As a result, an inability to make

adjustments to the work role can result in the chronically ill worker exiting the work role and the workforce completely.

Sally, who had an office job, without regular contact with customers, described how her employer had been very supportive and understanding of her COPD. As she experienced frequent breathlessness and fatigue at work, which made performing work tasks extremely difficult, she was allowed to work from home on a regular basis. Being able to work from home was a very important factor in her managing to stay in full-time employment despite her seeming severe COPD, as she was able to rest when she felt unwell, and complete work tasks at her own pace, when she was feeling better. Working from home enabled her to accommodate her disease and continue participating in the workforce. However, the one disadvantage she described about working from home was the lack of social contact she enjoyed in the office setting. This supports the finding that working women with fibromyalgia reported social contact at work to be an important source of work satisfaction (Liedberg and Henriksson, 2002).

This is in agreement with research into the ability of workers (male and female) with chronic nonspecific musculoskeletal pain to stay at work, which found that the ability to make adjustments was an important factor in workers staying at work (de Vries et al., 2011). They found that adjustments at work enabled workers with chronic nonspecific muscular pain to stay at work. Adjustments were made at different levels: by changing jobs, by retraining for a more suitable work role, and by organizing their work in terms of flexible working hours, more flexible work, having more appropriate work content and shorter working hours. The ability to work from home has also been suggested by women working with musculoskeletal diseases as a way to stay at work while managing their disease, as it enabled more control over working hours, and enabled the work tasks to still be completed, while the workers were able to self-manage their disease (Crooks, 2007). The results of work adjustments in my study, support the findings from previous research (de Vries et al., 2011; Crooks, 2007; Liedberg and Henriksson, 2002), and contribute to knowledge into factors affecting women with COPD staying at work.

In addition to work adjustments, in order to successfully stay at work, the women with COPD in this study had to make adjustments in their life outside of work. The study found strategies to manage their COPD and alleviate their breathlessness involved increasing their exercise capacity by exercising regularly. Participants also reprioritised their lives, to reduce their workload and conserve energy and make time to have a social life, which was important to them. They recognised and tried to stay

within their own limits and used strategies to reduce their workload, by delegating tasks and accepting help from others in completing tasks such as housework and childcare.

Reducing demands outside of paid employment formed part of this strategy. Women living with partners could delegate housework to partners and teenage children, however, women who lived alone had to find strategies to manage the difficult household chores on their own. Strategies included pacing themselves and taking rest breaks. Some participants also employed professional help to clean their home and maintain their garden, which had become too difficult for them, consuming their energy and exacerbating their breathing. These findings supports research into strategies to self-manage disease in workers with musculoskeletal pain (de Vries et al., 2011). However, this is the first time such strategies have been reported to manage COPD in working women.

8.5 Home Life: Relationships and Responsibilities

Support and a social life were found to be an important part of managing, both physically and emotionally with having COPD. COPD was also shown to act as a barrier to initiating new relationships and starting a family.

8.5.1 Support and isolation

Previous research has reported the importance of social support in the successful management of COPD. Quantitative research into COPD in a Turkish cohort found that a positive relationship exists between family support, self-efficacy and successful self-management of COPD (Kara and Mirici, 2004). Kara and Mirici (2004) found that 96.7% of a cohort of patients with COPD reported moderate to moderately high levels of loneliness. However, such studies have either had mainly male cohorts or much older participants (Kara and Mirici, 2004; Williams et al., 2007), than those in the current study. De Torres and colleagues reported women with COPD had lower quality of life than men with COPD, and suggested psychological suggested or sociocultural factors were involved in their impaired quality of life (de Torres et al., 2005; de Torres et al., 2006). Therefore the findings from the current study adds to such findings, offering the young and middle-age working woman's perspective of support and isolation while living with COPD. In this study, women who received support from either family or friends, or both, seemed to successfully manage their COPD, managing to maintain a work and home life. Whereas a complete lack of support appeared to negatively impact self-efficacy and management of COPD.

8.5.2 Social life

Barnett (2005) found that moderate to severe COPD impacted on an individual's social life and their role within the family. Although in Barnett's study the age and gender of the participants was unclear. Findings from the current study suggest COPD could negatively affect a young and middle-age woman's social life, as the variability of symptoms and frequent chest infections meant social plans had to be cancelled. However, most women in this study, were determined to maintain their social life despite reporting moderate to severe COPD symptoms, as it was a highly valued part of their life. In order to maintain a social life, strategies were used, which included disclosing their condition to their friends, to facilitate support and understanding behaviours from their friends. Some women also reprioritised their life, for example by delegating housework, to make more time and conserve energy to be able to participate in social activities. Having supportive friends and a good social life helped balance the emotional effects of COPD.

The majority of women experienced breathlessness with any physical exertion, the impact this had on their social lives varied. For some women, maintaining their social lives was vital, and they re-prioritised their lives to apportion their time and energy to be able to still see their friends. However, one participant, Natalie, was embarrassed and ashamed of having COPD and the resulting physical limitations. She anticipated being stigmatised and viewed as disabled, by others when out in public or in a social situation and used strategies to avoid such experiences. Strategies included concealing her COPD from the few friends she had and avoided social outings. This avoidance strategy resulted in Natalie becoming isolated and a social recluse. The avoidance of physical exertion due to anxiety around increased breathlessness, led to a decline in exercise tolerance and deconditioning, which reduced her Natalie's confidence in leaving the house. Social isolation in individuals with COPD has been associated with depression (Kara and Mirici, 2004). Taken together such factors can lead to a lower quality of life.

Berger, Kapella and Larson (2011) suggested relationship distance was related to the likelihood of experiencing stigma. Less stigma was expected in close relationships (i.e. partners and close friends), whereas stigma was more likely in interactions with strangers, who could react to the visible evidence of COPD. This suggests that support from close family and friends could buffer the negative effects of stigma in individuals with COPD. This was found in the current study; with women who perceived a high level of support perceiving and being effected less by stigma than those who had little or no support. In this study, a low level of support and high level

of perceived stigma resulted in the development and implementation of unsuccessful management strategies, such as avoidance, which resulted in isolation and a decline in quality of life.

A decrease in social interaction has been found to be a potential strategy of avoiding potentially stigmatising situations, as well as pragmatic adaptations to physical limitations by individuals with COPD (Berger, Kapella and Larsson, 2011). Findings from this study agreed with such findings.

Self-blame negatively affected her perception of COPD and the impact it had on her life, as well as the emotional effects of COPD and the strategies she developed to self-manage COPD in her life. Natalie used avoidance as a frequent management strategy, however, this resulted in social isolation. Natalie was the only woman to describe feeling ashamed and blamed herself for developing COPD. This could be because she was the only woman who had a history of heavy cigarette smoking and did not report having alpha-1 antitrypsin deficiency. It was not mentioned that she received the genetic test. Natalie also perceived being stigmatised and blamed by medical professionals for smoking and developing a self-inflicted disease. This could have resulted in Natalie blaming herself or increasing the level of self-blame. Blaming behaviour from others, including medical professionals, associated with smoking and developing a self-inflicted disease has been previously reported in older men and women with COPD (mean age 70 years old) (Berger, Kapella and Larsson, 2011).

8.5.3 Burden

Most women in this study described being constantly aware of their breathlessness. For some, Natalie and Fern, a continuous awareness of their symptoms and physical limitations led to feelings of being a burden on others. A sense of being a burden could affect the sense of self-worth (Berger, Kapella and Larson, 2011), and acted as a barrier to socialising. Interestingly, anxiety of burdening others occurred in women with mild COPD (FEV1/FVC 70%) and perceived moderate to severe COPD.

The efforts made by the women in this study to avoid experiencing stigma support and add to those found by Berger, Kapella and Larson (2011), as such strategies were implemented by young and middle-age women with COPD. Such efforts involved attempting to minimise the visibility of their disease, by taking their inhaler covertly, avoiding becoming breathless in public, where possible. This could mean avoiding activities that were expected to cause severe breathlessness, which circumvented receiving unwanted attention and experiencing stigma and judgement by others. Several women also attempted to avoid being stigmatised by strangers by

informing them they had respiratory problems, which was intended to remove the ambiguity from the situation.

In Williams et al's., (2007) study, 'holidays' and 'going out' were found within the context of social participation, with participants having difficulties going away on holiday, especially if they had to travel on an aeroplane, due to their dependency on oxygen therapy. Despite such difficulties, holidays were important to almost all participants. However, this study explored what was important to both men and women over 64 years and who had been living with moderate to very severe COPD for several years. In the current study, despite describing moderate to severe COPD, most participants were still able to go on holidays and travel abroad without too much difficulty related to their COPD. A major factor influencing holidays, in addition to physical limitations, was financial restrictions, as the participant who had left her job and consequently had no income, was unable to go on holiday and leave her normal life for a few days. Holidays and travelling were positive and important life activities to all of these women, as several were not originally from England and had to travel by aeroplane numerous times a year to visit family and friends in their country of origin. For Sarah in particular, going on holidays with friends and going to destinations that she had always dreamt of seeing was very important to her. Aware of her progressing disease, she wanted to travel and continue to holiday while she was still good, as her future ability to travel and be independent was uncertain.

Going out and socialising was also important to these women. Most women made adjustments to their life, such as reprioritising certain activities, to accommodate their COPD while successfully managing to maintain a social life. Laura actively reprioritised her life to be able to maintain an active social life; delegating housework to be able to go out with friends. This is significant as the socialising reported in previous COPD research, was among older individuals aged 64 – 83 years (Williams et al., 2007), and was very different to the socialising activities associated with young and middle age women. Most participants were determined to maintain their social lives as they were considered very important aspects of their life, with positive social interaction and support helping them manage the negative emotional effects of COPD. However, for one participant, her physical limitations, self-blame, fear of being stigmatised and judged as incapable by others, and not wanting to inconvenience or burden others, resulted in her being socially isolated.

8.5.4 Relationships and mothering role

This study found that the onset of COPD in young and middle-aged women effected relationships, both maintaining established relationships and forming new

relationships, and the role of these women within their families. Family relationships and roles within the family have also been reported to be effected by the onset of COPD (Williams et al., 2007). Difficulties in performing certain daily activities could act as a barrier to participating in home and family life (Williams et al., 2007). However, the research conducted by Williams et al., (2007) was in individuals over 64 years, and focused on the home and family life of those in this age group. The current study adds to this, as it focused young and middle-aged women, and their home lives, which differ significantly from those of older people, as they are more likely to have younger children to care for and mother. In addition, women of this age are also more likely to have work lives to manage, which was also a focus of the current study. Previous research found women with COPD associated their ability to perform housework with their role as a wife and mother, suggesting the personal meaning attributed to domestic activities could have more weight than the activities themselves (Williams et al., 2007). In the current study, one participant, Laura considered her physical disability in performing the weekly food shop, when first diagnosed with COPD, resulted in a loss of her womanly role. She was determined to regain this role and soon found strategies to take back the role that had temporarily shifted to her husband. Some women employed cleaners and gardeners to keep their homes and gardens tidy, while several participants admitted to being more relaxed about housework, as it was no longer a top priority, it was often not performed and the home was left untidy.

This study also found COPD impacted dating and initiating new relationships. Despite reports that the presence of COPD affected intimacy in relationships (O'Neill, 2002; Williams et al., 2007), the effect COPD has on dating and starting new relationships has not previously been reported. Several single women in this study described that difficulties in dating were not only related to physical limitations in performing basic activities, such as walking and talking, but were also associated with the psychosocial aspect of living with the disease, such as disclosure of the illness, fear of being stigmatised and rejected because of their COPD and fear of being a burden or holding other back.

8.5.5 Motherhood

The timing of disease onset influenced the impact COPD had on the lives of these women. Developing COPD during child-bearing years was shown to impact their decision to have children, which negatively affected relationships. Also, knowingly having alpha-1 antitrypsin deficiency made some women anxious of passing COPD onto their children. Research has shown that the presence of sickle cell disease in

young women impacts their major life decision to have children (Smith-Whitley, 2014). However this study was the first to show the underlying genetic susceptibility of COPD disrupting major life decisions, such as child birth, in young and middle-age women. The implications of this could be that childless, and possibly single, women could lack both support and satisfaction in their life, especially as the disease progresses. Young and middle age women diagnosed with COPD and alpha-1 antitrypsin deficiency could benefit from genetic counselling and support, to help them understand and manage the implications of their condition on their decision to have children.

When the onset of COPD occurred after women had already had their children, the disease affected the woman's mothering role. Previous research found that a young woman's mothering role was affected by the development of arthritis (Backman et al., 2007). However, disease-related difficulties to the mothering role have not previously been reported in women with COPD. Further qualitative research over a longer period of time, is needed to gain a more detailed insight into the difficulties young women with COPD face when they have to fulfil their mothering role as well as manage their disease.

In this study the age of the children was an important factor in the level of difficulties the women experienced and how they managed, as younger, more dependent children could be more physically demanding than teenage or adult children who were more independent. The fluctuating symptoms of breathlessness and fatigue meant their abilities to perform tasks, related to caring for their children, varied on a daily basis. Furthermore, an inability to perform typical motherly duties caused feelings of inadequacy and guilt. These results are broadly consistent with the findings of Backman and colleagues (2007). This is the first study, to my knowledge, to examine the effects of COPD on women with young children. This study highlights the significant impact COPD can have on the lives of women who wanted children and those who were raising young families.

Also, the participant's personal characteristics were found to affect how they perceived COPD and the impact it had on their lives. Women who accepted their COPD, had an optimistic outlook, and were determined to 'get on' with their lives as normal, successfully adjusted their life to accommodate COPD. Whereas women who refused to accept their diagnosis, and experienced negative emotions such as self-blame and shame (for having the disease), and a hopeless, pessimistic outlook, employed unsuccessful strategies to manage their COPD, and considered COPD to have a great impact on their lives.

8.5.6 Strategies women use to manage their COPD

A variety of challenges were reported by participants, depending on their individual work situation. Challenges included difficulty walking from the car to the work building, completing physically intense work tasks and the effect of sudden symptom exacerbations and fatigue on work performance. Disclosure was an important part of actively managing COPD at work as it enabled participants to receive support from managers and colleagues and request adjustments to be made to areas of their work life they found difficult and which affected their ability to perform work tasks. The implementation of successful work adjustments, such as asking colleagues to perform their difficult work tasks and being able to work from home when feeling unwell, facilitated continued participation in work and helped with managing their COPD.

Perceived support and understanding shown in the workplace varied between employers, and for workers who had little work autonomy, support from the same employer was shown to vary depending on the situation and type of adjustment required. Also, the implementation of specific adjustments was dependent on the manager's discretion as well as organisational policies.

In order to stay at work, COPD had to be successfully managed in their home life. A variety of strategies were employed to manage COPD at home, with the most successful strategy being reprioritising life. Reprioritising involved actively making adjustments to their home life, by altering the mothering role and domestic tasks, proportioning their time and energy, to spend more time socialising and looking after themselves, in an attempt to leading a satisfactory life, while successfully managing COPD.

In this study, of the six participants in Phase One, several women clearly displayed different levels of self-efficacy. For example, one woman, Laura, exhibited high self-efficacy as shortly after the shock of being diagnosed with COPD she had learnt several strategies to manage her work and home life with COPD, such as ordering shopping online, parking closer to her work and employing a cleaner at home. Such initiatives gave her more time and energy to do things she enjoyed and felt she had to do to maintain her health, such as seeing friends and going to the gym. Whereas, Natalie presented low self-efficacy, in which she was demotivated to do things around the house and go for walks, she spoke of feeling 'beaten' by the disease and her strategies for managing with her limitations often involved not participating in the activities she found difficult, which caused a sense of isolation and severe depression. Although the study participant's self-efficacy varied greatly, it is a significant factor in successfully managing COPD both at work and at home. This study found that although some of the participants benefitted from attending BreathEasy support

groups, further support, especially emotional support and guidance, particularly aimed at young and middle age women with COPD was lacking. Further, BreathEasy groups need to be held at a time convenient for working women, as currently they are held during the day, a time when working women are usually at work and would have to take time off work to attend, which in itself can have repercussions from the employer. In addition, BreathEasy groups need to specifically target women of working age, with a group of similar aged women in the group, and age-appropriate information (e.g. potential challenges and management strategies for daily work tasks, shopping, socialising, having relationships, dating, sex, child bearing, raising a young family etc.) being disseminated throughout the duration of the course. The provision of a crèche would also allow single, working mothers with COPD, or those unable to arrange childcare, to attend the course, which they would otherwise be excluded from. Implementing the above recommendations would not only be of great benefit to the women diagnosed with COPD but would create a 'safe' environment in which they could socialise with women who understand.

Studies focusing on the successful management of other chronic, debilitating conditions, such as Fibromyalgia and arthritis, have demonstrated the positive influence self-efficacy can have in coping behaviours and one's ability to function (Henriksson, Liedberg and Geedl, 2005; Liedberg, and Henriksson, 2002; Löfgren, Ekholm and Ohman, 2006, Tillett et al., 2015).

Research investigating the effectiveness of treatment for reducing fatigue severity in patients with Chronic Fatigue Syndrome, evaluated whether multidisiplinitary rehabilitation treatment, which involved a combination of different interventions including cognitive behavioural therapy, was more effective than cognitive behavioural therapy alone in patients with Chronic Fatigue Syndrome (Vos-Vromans et al, 2016). Vos-Vromans and colleagues (2016) found that the severity of fatigue was significantly more reduced in patients receiving the multidisiplinatary rehabilitation treatment compared to those receiving cognitive behavioural therapy alone. Once the course of treatment ended, the reduced level of fatigue was sustained until 52 weeks of follow-up in patients who received the multidisciplinary treatment, however, during this period, the mean level of fatigue of the patients receiving cognitive behavioural therapy alone, increased. The fact that multidisciplinary rehabilitation treatment had a greater and more sustained effect on the symptoms of Chronic Fatigue Syndrome than cognitive behavioural therapy alone, may well suggest that multidisciplinary rehabilitation treatment could also be highly beneficial in the treatment of other chronic diseases, such as COPD.

Other studies also found having regular rehabilitation sessions, which include physical education, as soon as possible post diagnosis, follow-up sessions, and one-to-one counselling with a psychologist, increase a patient's self-efficacy to successfully manage their chronic condition (Zangi et al., 2015, Schreurs et al., 2011; Goudsmit, Ho-Yen, Dancey, 2009; Vos-Vromans et al., 2016).

As the study also found many young and middle age women with COPD are regular users of the internet and social media sites such as Facebook, interventions using such (digital) methods of communication and sharing the personal experiences of others in managing COPD, could be welcomed. Research into asthma management have shown the practicality of using an interactive PC/laptop/tablet/smartphone compatible website created with extensive input from adults living with asthma, to provide experience-based information (Newhouse et al., 2016). The aim of the research was to support the subjective perception of self-efficacy and self-management of asthma, and improve the patient's health status (Newhouse et al., 2016). The researchers noted that the study participants were experienced in managing their condition and had their asthma well controlled, they were also comfortable and confident using the internet (Newhouse et al., 2016). Thus, although they were willing and able to take part in the study, outside of the study they were not likely to be searching online for health information or connection with other people living with asthma, in order to support their own asthma management (Newhouse et al., 2016). The study demonstrated that the creation of a facts and figures' website of asthma management is feasible, however, future work is needed to determine the best methods to maximise engagement and adherence, and to identify which individuals with asthma are most likely to benefit from such an intervention, for example, this intervention may be best suited to those who are newly diagnosed or experiencing a change in symptoms (Newhouse et al., 2016).

It can also be suggested from the findings of the current study, that a COPD-specific Facebook group, guided by a (COPD-specialist) Medical Professional, would be a useful way of sharing information and helpful resources on management techniques as well as offering peer support, all of which would help increase an individual's self-efficacy of managing COPD. An application (or app) downloadable for free to a device (smart phone or tablet), providing COPD-specific advice on management techniques, could also be useful. Further, a support group specifically for young and middle age women to discuss issues and receive support from others living with COPD would be a great benefit to some of the participants in this study, especially those who lack a support network and social life. Such a support group could either be physical or

online, which would enable women living with COPD to meet other women locally also living with COPD, or women with COPD living far apart for example, a woman in the East of England, and a woman in Canada, to have contact. This physical distance and the fact these women may never meet in person, could allow a rapport to develop, possibly leading to the sharing of personal and sensitive information with someone who may relate, something these women may not feel comfortable sharing with anyone else. This rapport and sensitive information sharing was experienced in this study with the study participants and myself, the researcher. Several participants felt a great sense of relief in being able to share such sensitive information.

In addition, interventions, such as an online course for family members, friends, employers and work colleagues would increase their knowledge and understanding of COPD, positively influencing the way they perceive the symptoms and limitations of a young or middle aged women with COPD. The course could include factual information, real life experiences of working age women living with COPD, and scenarios in which they have to answer questions.

8.6 Towards a Normal Life

Three of the women who took part in this study had only just been diagnosed at the time of participating in this study. Within the three month study period, the transition from initial shock to learning to manage their disease and move towards an ordinary life could be seen. This transition has been described by Kralik (2002), who conducted a qualitative study of 81 women, aged between 30 and 50 years (mean age 44 years) living with a chronic disease. She found that the chronically ill women were somewhere along the journey between 'extraordinariness' and 'ordinariness', with extraordinariness conceptualising a phase of turmoil and distress, and ordinariness was the incorporation of the chronic disease into their lives. Although Kralik has previously reported the experience of life disruption in women living with chronic diseases, her research was generic and did not focus on working women living with COPD. This is the first time it has been reported in young and middle-age women with COPD.

The women in my study all found the onset of COPD caused considerable disruption to their everyday lives. The extent of this disruption varied between women and was dependent on contextual factors (environment, personal and social factors).

In this study, two participants in particular, Laura and Natalie, reported very different levels of disruption COPD had caused to their lives. Laura had been diagnosed with COPD shortly before participating in the study, and experienced great distress and

shock that she had developed COPD. However, through the baseline and follow-up interviews and diary-like interim messages, it was possible to follow her journey or transition from a state of distress, a term Kralik coined 'extraordinariness' towards successfully moving forward with her life whilst managing her, which Kralik termed 'ordinariness'. In order to make this transition, she had to actively find ways to accommodate COPD into her life. This involved making adjustments and re-prioritising her life, which enabled her to reconstruct her identity (as a woman) and move forward with her life. At the end of the study period, she described being surprised that she had managed to find ways of successfully managing her disease, while continuing to lead a fulfilling life. Laura had regained control of her life. This could have been because Laura was resilient, a personal quality previously found to be important in learning to adjust to life with a chronic disease (Kralik, van Loon, Visentin, 2006).

This participant had a good support network, which is thought to increase resilience (Kralik, van Loon, Visentin, 2006), and was in a financially stable position, both of which enabled her to make certain changes that would not be possible otherwise, for example, hiring a cleaner, which enables joining a gym and socialising with friends.

In contrast, Natalie, who had been diagnosed with COPD and lived with the disease several years prior to participating in the study, was had not made the transition into 'ordinariness'. She was stuck in the 'extraordinary' phase of distress, unable to make the necessary adjustments to accommodate her disease into her life. Instead, every aspect of her life had been negatively affected by COPD. Her functional limitations had resulted in her losing her job, her social life, her independence and had greatly reduced the possibility of her finding a partner. She was constantly aware of her breathlessness and described being embarrassed and ashamed when others witnessed her struggle for breath and difficulty performing basic day-to-day tasks. Natalie was the only participant who was unemployed, was not financially independent (as she had to rely on government benefits) and had no support network, factors which Kralik (2002) had found to be key in keeping chronically ill women in the extraordinariness phase. Natalie described herself as being stuck in life, unable to move forward from her current situation, and was the only participant who could not foresee a positive future with the disease. She had placed all her hopes on receiving surgery to remove the damaged part of her lungs, with the dream that this would enable her to regain her previous identity and former life.

Furthermore, in this study, the degree to which COPD disrupted these women's lives seemed to be independent of reported disease severity, level of physical limitations

and time since diagnosis. Rather, it appeared to be dependent on factors such as personality and level of support that enabled women with COPD to consciously move beyond their current situation. During the interviews it was clear that it was the first time all participants had voiced their experience of living with COPD, which they were grateful for. This suggests a need for someone to listen and possibly the requirement for counselling, either one-to-one or in a group, to be able to increase their ability to adapt their lives and make the transition to ordinariness.

8.7 Transferability of Findings

Although this study was conducted in one region, some of the key results were found to be transferable to women living with COPD worldwide. By comparing the findings from Phases one and two, this study found that the key issues the six participants described in Phase One around work and home life, such as difficulties performing work tasks and tasks related to being a mother and looking after children, also emerged in messages from online discussion forums. Though, forum users only briefly mentioned these themes and did not expand on these issues or describe their specific COPD-related challenges in their work and home life. Although a small amount of data was collected in the quantitative content analysis of one (COPD-specific) online discussion forum, the findings from this study suggest that the issues reported by the six participants in Phase One are typical in a broader range of women living with COPD worldwide.

Key themes and subthemes found in Phase One, that were 'not mentioned' in Phase Two include 'inability to meet expectations, and feeling judged, limitations at work and at home, family life, social life, dating and starting a family, and additional management techniques such as educating themselves about COPD, working from home, alternative ways to manage breathlessness and disclosing their disease.' There could be several reasons why such themes and subthemes did not appear in data collected (from an online forum) in Phase Two, including the limited amount of data that could be collected in a short time period and from one data source. Also, the study participants candidly described personal and highly sensitive issues in the two semi-structured interviews, some of which they had not told anyone else before. Issues such as their inability to meet expectations of others (and themselves), as well as the effect COPD had had on their social life, dating and starting a family. Such issues might not be comfortable to write about on an online health forum, visible to potentially hundreds of thousands, if not millions of people around the world (anyone with an internet connection). In addition, the data collected from the online forum

mainly sought advice or support from other users or gave advice to others and typing your thoughts into a message to be posted in a forum is distinctly different from talking about experiences and feelings in an interview setting, as there is more time to contemplate, reword and delete before posting a message, whereas when speaking this is not possible. In-depth qualitative research is needed in addition to this kind of internet search as it facilitates the collection of richer information from participants. Through semi-structured qualitative interviewing, the researcher is able to ask open questions regarding an area of interest for the study (Whiting, 2008), for example; 'in what way does COPD affect your everyday life?' As the interview is occurring in real time, the researcher is then able to ask further questions and possibly ask for clarity of go into further detail, depending on the answer from the research participant. In addition, as already mentioned, the rapport developed between the researcher and participant builds trust and the participant can feel comfortable enough to discuss very personal or sensitive information, that they would not disclose to a stranger. None of this is applicable to data collected from an online forum.

8.8 The Conceptual Model

The World Health Organisation created the International Classification of Functioning, Disability and Health (ICF) as a standard framework to describe the consequences of health and health-related limitations (or 'disability') on participation of daily activities, such as work (WHO, 2002). It can be used to explore health-related disability at work and help find solutions to keep chronically ill workers in the workforce (Varekamp, van Dijk and Kroll, 2013). In this bio-psycho-social model disability and issues related to participation in life activities, such as work, are perceived to be caused by a combination of medical, psychological and social factors (Varekamp, van Dijk and Kroll, 2013). The ICF model does not see disability as a personal characteristic, but as a consequence of the relationship between a person and their environment (Varekamp, van Dijk and Kroll, 2013). More specifically, disability is perceived as the gap between a person's capabilities and the demands placed on them from their external environment (Verbrugge and Jette, 1994). As a result, the level of disability can be altered by narrowing or removing this gap by increasing the individual's capability or altering the demands (Varekamp, van Dijk and Kroll, 2013). The ICF model also perceives personal, social and environment factors to be important contributors to the level of disability (Varekamp, van Dijk and Kroll, 2013). These three factors could hinder, as well as support participation (Varekamp, van Dijk and Kroll, 2013).

By applying the ICF model to work participation, the effect of personal, social and environmental factors on work participation can be shown, facilitating a better understanding of the effect contextual factors have on performing work tasks, as well as a greater awareness of work participation and social interaction among individuals with a health condition (Jelsma and Scott, 2011; Varekamp, van Dijk and Kroll, 2013). Examples of environmental factors involved in work participation, described previously include specialised equipment, and the ability to work from home, which can benefit work participation, while a heavy work load can have negative effects (Varekamp, van Dijk and Kroll, 2013). Social factors that reportedly positively affect work participation include supportive and understanding supervisors and work colleagues and the personal characteristics of being communicative and having an ability to problem-solve. Whereas negative illness perceptions can have a negative influence on work participation (Varekamp, van Dijk and Kroll, 2013). As environmental, social and personal factors are often modifiable, understanding the effect each of these factors have on work participation in women with COPD, can help increase knowledge in this area and in turn, lead to the introduction of suitable initiatives to help these women stay at work longer, despite their COPD. This is the first time that the ICF model has been used in the context of work, in COPD research. In the adapted model used in this study, the ICF model includes social factors as a separate, independent factor, unlike in the original model, in which it is combined with personal factors.

Findings from this study contributed to the ICF model and COPD research by finding specific personal/contextual factors that influence the level of difficulties working women with COPD who were under 65 years of age experienced, and in turn their ability to perform work tasks and stay at work. This is the first time this has been reported.

8.8.1   Contextual factors

Using the adapted ICF model, depicted in Figure 8 (p.209), contextual factors shown to have significantly influenced the participation of working age women with COPD in work and home activities were found to be the work and home environment, the type of activity, support, internal motivation and a positive, 'can do' attitude. This section discusses these factors, which are not mutually exclusive, and can and do overlap.

Work and home environment

This study found that the type of activity affected the level of disability. Physically demanding work and home tasks were very difficult for most participants to perform,

however, most women reported experiencing little or no functional limitations performing non-physically demanding tasks such as desk-based work roles. The ability to make adjustments to difficult tasks was an important aspect, enabling them to increase their capability and thus reducing the difficulty of the task, and facilitating continued performance of the task. Adjustments commonly reported in this study included asking colleagues for help and pacing themselves whilst performing the difficult task. Additional adjustments at work, such as the ability to work from home or park closer to the building, all helped in reducing functional limitations and made it easier for the women to stay at work with COPD. Adjustments at home were also important in managing the disease, with women in this study delegating difficult tasks or modifying how they performed the task, for example one woman adjusted the way she did her family's food shopping, instead of going to the supermarket and carrying the heavy bags, which was a great burden, she started to go to smaller supermarkets and order online, getting heavier items delivered to her kitchen. In this way, this participant was still able to perform what she considered to be a woman's role of food shopping, which made her feel like she had regained control of her life with COPD.

Social support

In this study, support and understanding from work colleagues and superiors was found to be very important in managing COPD at work and remaining productive, Support was associated with increased understanding of the work limitations experienced by these women and an increased flexibility in accommodating the disease and workers limited capacity within the work environment. Support was also important outside of work, with supportive family and friends not only helping with difficult tasks, but also buffering the negative effect of disability on the women's emotional wellbeing. The married women received both emotional and physical support from their spouses (and sometimes children), by taking over domestic chores and most women described having a supportive network of friends. While, the unemployed participant, did not have a family unit or a network of friends, and lacked support. This caused her to have a negative disease perception and affected her disease management.

Those women who received a lot of support from family and/or friends were more likely to believe they could manage life with the disease, more so than the woman who had little or no support. This was in accordance with previous research into chronic disease (Sandqvist, Scheja and Eklund, 2008; Munir, Yarker and Haslam, 2008; Wynne-Jones et al., 2011; Lofgren, Ekholm and Ohman, 2006). In addition, social factors such as stigma, assumptions and expectations which society placed on

these seemingly healthy-looking young and middle-age women, proved to be troublesome and could sometimes affect aspects of their work and home life. Feelings of embarrassment and shame that resulted from an inability to meet the expectations of others caused some participants to try and hide their disease, and in so doing they would avoid certain tasks or situations in which they perceived their COPD was obvious to others.

Personal characteristics

Personal characteristics were found to influence how the women in this study perceived and managed their life with COPD. Participants who employed problem-focused management strategies managed to successfully find ways to overcome their disease-related limitations, resulting in the perception of few functional limitations and a greater control of their condition. These participants described being positive thinkers, determined, motivated and assertive; recognising disease-related limitations and voicing their need for specific adjustments to be made, both in their work life and at home. However, the one participant who used emotionally-focused management strategies expressed distress and perceived severe functional limitations, which resulted in greater restriction in participation in life situations and events, perceiving COPD had a much greater impact on their life, compared to those who employed problem-focused management strategies. This could explain why the participant who employed emotionally-focused management strategies had to leave paid employment, while those who used problem-focused strategies successfully found ways of managing their disease, some participant doing so in a short period of time. This is in keeping with previous research into management strategies in chronic disease (Marcos et al., 2007; Boot, van Exel and Gulden, 2009; de Vries et al., 2011). However, this is the first time it has been found in working women with COPD.

Motivation to stay at work

Motivation was found to be an important factor to find ways to accommodate COPD and for these women to stay at work. In this study, the majority of employed participants expressed a motivation to stay at work. Two participants were both career-driven women, with work forming a large part of their identity, the onset of a chronic disease in the middle of their career had dramatically changed how they saw themselves as young women and made them reassess themselves and their future plans. Their work role still gave them an identity; 'a manager' or 'a business woman', providing them with self-confidence, social status and financial independence. However, after the onset of COPD, their work role gave them a platform to prove to

themselves and others (superiors and colleagues) that they were still capable of performing work tasks that they used to do (before the onset of COPD). One participant voiced her need to prove to herself, her colleagues and manager that she was *just as good as everyone else',* still able to accomplish tasks to a high standard, just like her colleagues, who did not have a chronic disease. Whereas for other participants, work provided their life with a routine, giving them a sense of being productive and provided them with a distraction from their concerns for their failing health. In addition, being in paid employment provided most women with financial stability, which, with their progressive limitations, enabled them to hire paid help to perform domestic tasks which they were no longer able to do themselves. This has been reported by de Vries and colleagues (2011) in their research into workers with nonspecific musculoskeletal pain, however this was the first time it has been found in research into COPD.
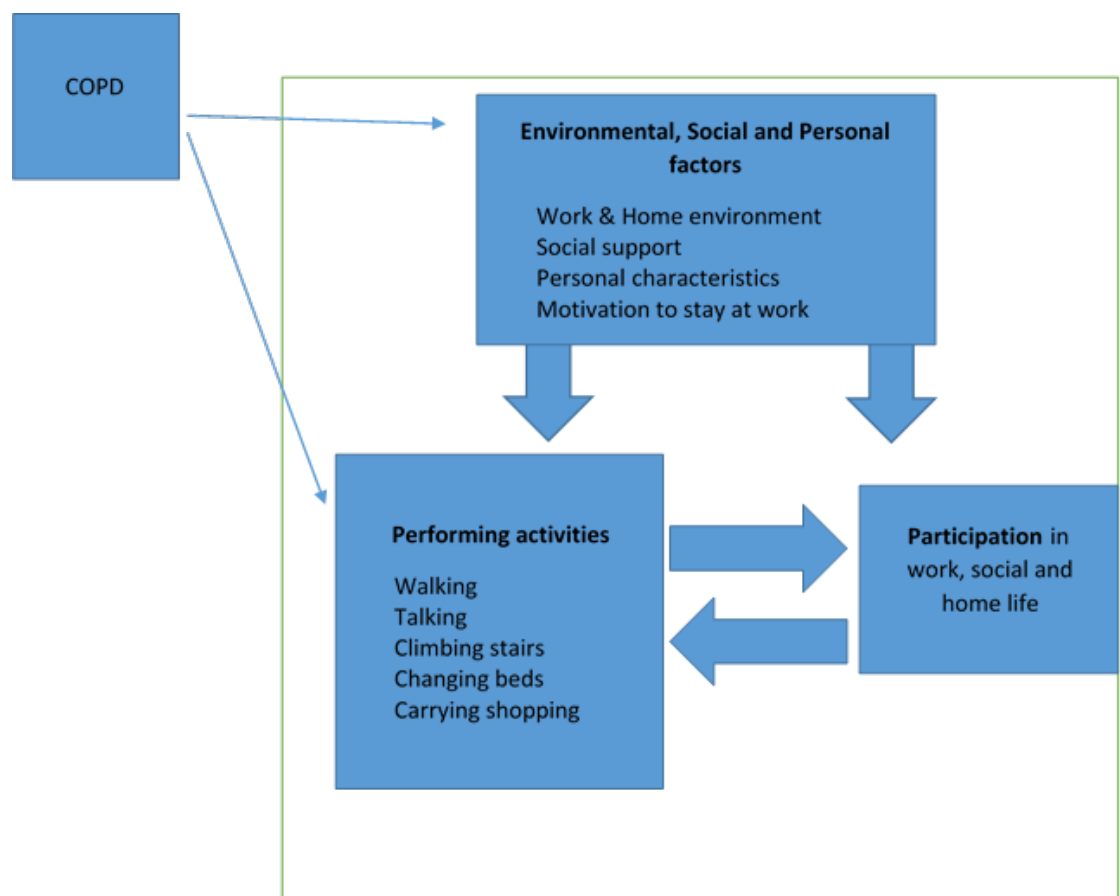

Figure 5: The findings from this study incorporated into the ICF model.

8.9 Strengths and Limitations

8.9.1 Recruitment and sampling

Locating this subpopulation of women of working age with COPD, in the East of England was more of a challenge than expected, as recruitment attempts in the obvious places, like the Respiratory departments of Hospitals in Essex and BreathEasy groups, failed to find women with COPD under 65 years. Therefore the six women that contacted me (five via Facebook recruitment posts and one by telephone, from a private COPD-specific exercise class) showing interest in the study, and that matched the research criteria were recruited. The main advantage of purposive sampling is that it is more straight forward and quicker to recruit a targeted sample, with specific characteristics.

8.9.2 Data collection methods

Strengths of the qualitative methods used in this study include; the collection of longitudinal data over a period of time, with diary-like interim messages potentially providing data as close in time to when it occurred as possible, and the second interview facilitating the collection of richer data. Also, the data collection methods were flexible and could be fitted in around the participants life, as and when was convenient for them.

Limitations associated with the data collection methods will now be discussed. The limitations related to telephone interviews include bad telephone signal and strong accents affecting collection and analysis of data. Other limitations with the qualitative methods in this study included a lack of compliance with the interim data. The researcher sent prompt messages to each participant every 2 weeks to ask them how they were or had been recently, some participants sent lengthy, detailed replies, while others either sent a short reply or did not reply. Also, there were conflicting responses as some of the women described experiencing severe symptoms however, they were adamant that they could function as normal. Although this may suggest adjustments were made to reduce the effect of COPD on their lives, it could also suggest the participant was understating the difficulties they experienced living with COPD.

There were a number of strengths of the quantitative phase. For instance, the quantitative contents analysis involved analysis of data already posted onto the forum, it was accessible (after gaining ethical approval) and a wide range of data could be collected from a diverse set of people living with COPD all over the world.

Limitations of the quantitative phase, Phase Two, have been mentioned previously and included the difficulty in obtaining permission to use pre-existing data on social media and online discussion forums. Despite the second phase of this study receiving ethical approval, administrators of the selected COPD-specific groups on the social media website Facebook or the COPD-specific online forum COPD Foundation were reluctant for the data on the sites be used for research purposes, thus the researcher was unable to collect data from these sites. This meant data collection was restricted to one online forum. Due to length of time it took to gain ethical approval and await a response from the individual sites, the data collection period was drastically reduced from the planned 12 month period, to a 3 month period. Both these factors could have affected the results as the amount of data was less, and possibly the users writing the posts could be less diverse, which could be reflected in the data being collected and analysed. This was the rationale for collecting data from a variety of online forums and social media sites, however, it proved to be ethically challenging. Also, the shorter time period meant that the small amount of data collected, despite the forum users living in various countries worldwide, could have affected the convergence of the data with data from Phase One and thus the transferability of the study's findings.

The majority of forum posts involved forum-user's describing their experience of symptoms and their perceived symptoms or symptom triggers, or asking for or providing support to other forum-users, few posts related to COPD in the context of work and/or home lives. Thus, data collected over a longer period of time and from a variety of sources could have resulted in a greater similarity between the findings of Phase Two with those of Phase One. Also, another limitations of Phase Two was that as only pre-existing data could be collected, the data had to be taken at face value, meaning there was no way I could clarify certain issues referred to in the data or obtain more detailed data. In addition, details about the author of the text were unavailable e.g. their gender, age, their location, marital status and work status. As mentioned earlier, all messages posted on the forum from male users, during this three month period, were excluded from the data collection process, by filtering the user pseudonyms by gender. Only messages from users with clearly female pseudonyms were collected and analysed. In addition, posts written by women that were about men with COPD e.g. 'my husband has COPD', were also excluded from Phase Two. This resulted in a loss of data if it was unclear whether a post was written by a man or a woman.

Some of the key themes and subthemes found in Phase One did not appear in the data collected from the online forum in Phase Two. This could have been because of the limited amount of data collected in a short time period and from one data source,

which limited the amount of data available for analysis. For example, the three month time period in which forum messages were collected was during Winter, this could have affected the content and volume of messages posted compared to other seasons. The particular online health forum from which data was collected in this study could have been used more by one gender and/or appeal to a certain group of people more than others, for example white people more than any other ethnic group. It could also be because of the different research methods used. Study participants candidly described personal and highly sensitive issues in the two semi-structured interviews, some of which they had not told anyone else before, however, they might not be comfortable to write about such issues on an online health forum, visible to anyone with internet access. This could suggest that semi-structured interviews are better research methods for collecting in depth, personal information, than using online health forums. However, it was possible to collect a broad range of data from a wide range of women living with COPD worldwide, which would not have been possible with interviews in a doctoral research project.

A limitation for both Phases One and Two was the short data collection period. Originally a 12 month data collection period for both phases was planned, however, due to numerous delays in obtaining ethical approval from the relevant ethical committees and the relevant health-related organisations, and as this was a three year doctorate research study, such delays resulted in the data collection period for each phase being just three months. This could have affected the research objectives of exploring how the participants managed their disease, especially those who had been recently diagnosed at the time of the study, as having a three month time period was a 'snap shot' in time, and although data collection overlapped different seasons of the year for some participants, a 12 month data collection period could have given a more complete and representative view of the participants lives with COPD. In addition, a longer data collection period could have shown change or evolution of coping strategies as the disease progressed and/or life situations changed. While the limited amount of data collected in Phase Two, as a result of using only one online forum as the source of data and the limited time period, could have affected the content of the data and in turn, the ability of the quantitative contents analysis (Phase Two) to confirm the findings of the thematic analysis (Phase One). This could have affected the data convergence and transferability of the overall findings on an international stage.

However, by using data posted on an online forum it was possible to gain an insight into issues experienced by a broader sample of individuals living with COPD. Despite difficulties in conducting Phase Two of this study, the results from this phase are still

meaningful, with novel findings for COPD research. This study has important implications for future research in this area which will be discussed in a following subsection.

8.10 Recommendations for Future Research

This study was the first to focus specifically on women under 65 years, with COPD, in the East of England. Further qualitative research is need to explore the challenges working women with COPD experience at work and in their home life, over a longer period of time, and whether the strategies used needed to be adjusted or new strategies employed, to continue managing work and home life as the disease progresses. Future research should be on a larger scale, with a larger sample of women from a greater geographical area. Such research could discover how the disease affects this cohort under different variables, for example, women living in different regions of the UK and internationally, women working in diverse job roles and women from different ethnic backgrounds. Increased understanding about the effects of COPD in this subpopulation is essential, as the prevalence of women under 65 years developing COPD continues to escalate and prove increasingly burdensome on individuals, employers and health care systems. Knowing more about the effects of the disease on this group of women would help to guide policy makers and medical professionals on how to keep these women productive both at work and at home, while successfully managing their disease and having a good quality of life.

Due to the ethical challenges I faced in obtaining ethical approval to conduct Phase Two of this study, I would suggest that future researchers who want to use the data collection methods used in Phase Two, allow more time to go through necessary ethical challenges and to be aware of barriers from the online groups.

8.11 Suggested Implications for Practice

Findings from this study show that increased awareness of COPD and its implications for young and middle-age working women are needed in the workforce and in the medical profession. Once diagnosed, support groups (e.g. telephone or face-to-face) and rehabilitation sessions (with an educational aspect), specifically aimed at young and middle-age women with COPD as soon as possible post diagnosis, and with follow-up sessions, could increase the self-efficacy of women successfully managing life with COPD. One-to-one counselling with a psychologist and genetic counselling for women with young family's or planning to have children, could also support women in successfully managing the emotional impact COPD has, at diagnosis, within their

daily lives and on their future prospects. Counselling could also be used to increase a woman's self-efficacy in positively managing their COPD. It is also recommended that further research is required to determine the models of pulmonary rehabilitation that might best suit people who work and have COPD. There may not be one model that suits all.

8.12 Recommendations for Policy

It is recommended that interventions are introduced to address the emotional impact associated with developing and living with COPD as a young and middle-age woman, especially for women who lacked a support network. This study found that participants who stayed at work with COPD perceived the disease to have less impact on their life (both physically and emotionally) and appeared to have a better quality of life than the participant who had left the workforce because of her COPD. This highlights the need for employers, medical professionals and the individual women with COPD themselves, to find ways of adjusting work and home lives to enable women of working age to lead a normal life, which includes staying at work, while successfully managing their disease.

Also, greater awareness and knowledge of COPD in the general public, and in the workplace is needed, as is developing ways to create a supportive and understanding environment and educating work colleagues and employers about COPD and its implications, could reduce the difficulties some working women with COPD reported in this study, and in turn, could enable these women to continue working for longer.

8.13 Conclusion

The overall aim of this mixed methods study was to explore how working women, aged under 65 years, with COPD and living in the East of England, managed their daily work and home lives. The original findings were:

- Stigma and expectations were a barrier to diagnosis, treatment and management of COPD in these women.
- In women (under 65 years) with COPD, support in the workplace and from family and friends was an important factor in managing the disease in their daily life.
- The impact COPD on the lives of women under 65 years, varied greatly;
- Influencing their ability to find a partner and maintain a relationship,

- Their ability to have children and perform the mothering role,
- Impacting their social life,
- Effecting their performance of work and home tasks. Various challenges at work were described, with the greatest difficulties performing tasks and staying in work, associated with more physical work. The ability to make suitable adjustments facilitated staying at work and managing home life with COPD.

Many of the participants experienced stigma and blame, from themselves but mainly from others, including medical professionals, as COPD has been strongly associated with cigarette smoking and in older people (over 65 years), however several of the participants had never smoked. This was found to be a barrier to diagnosis and treatment. The majority of these women had the genetic susceptibility to developing COPD (alpha1-antitrypsin deficiency), which could explain why they all developed COPD at a young age, however it had significant implications for their children, as they could potentially have passed the gene onto their children, who could develop COPD in the future.

Also, another key finding was that these women were confronted with the expectations of others. As COPD is invisible, they were seen as being well, and in turn, there were certain expectations that they were expected to fulfil. The high expectations placed on these women by others, to perform tasks that other women their age (without COPD) would have no difficulty preforming could cause emotional distress and influence disease management strategies.

In addition, support, both at work and at home, was found to be of great importance for these women to be able to balance their work and home responsibilities, as well as managing their COPD. In addition, this study found that COPD could have a significant effect on the ability of young and middle-age women to socialise, find a partner and maintain pre-established relationships. Having children and physical tasks involved in the mothering role were also found to be impacted by the onset of COPD in women under 65 years.

The women's role as a mother and as a wife/housekeeper had to be renegotiated, as did friendships, partnerships and work relationships. Determined to stay at work and successfully manage their COPD, several women chose to reprioritise their home life, trading time spent performing domestic responsibilities for socialising with friends and strategies for self-care, such as performing regular exercise and receiving a massage.

Support and understanding from employers, managers and work colleagues were important in managing COPD at work. All employed participants had disclosed their COPD to their employer and in return had received support. Supportive managers were mostly accommodating and implemented requested adjustments. However, if adjustments were not possible, there was no choice but to leave the job role. A lack of skills and retraining to move into a job role that was more suitable to their capabilities, resulted in a woman completely leaving the workforce significantly earlier than retirement age, with no prospect of returning to work.

This study also confirmed previous findings from previous research into chronic disease and work, however the current findings were novel in the context of COPD research. These findings were that the ability of these women with COPD to stay at work depended on a variety of factors, such as the nature of their work role, the level of perceived support and understanding from their supervisors and work colleagues, as well as family and friends, and their internal motivation to lead a normal life, which included staying at work. The participant's ability to continue working appeared to be more dependent on these factors and less dependent on their physiological disease severity. Also, the ways in which the women perceived their disease and the management strategies they implemented had significantly affected their perceived level of disability and the impact the disease had on their life, which in turn, influenced their quality of life.

The impact COPD had on the lives of all participants in this study varied greatly, with some experiencing few difficulties in performing work tasks while some had to make adjustments to stay in work, while one participant had to leave the workforce entirely. Almost all the women reported difficulties in performing certain tasks around the house. Using the ICF model, important contextual factors (environmental, social and personal factors) involved in work and home participation for these women with COPD were determined. Such findings underscored the areas involved in successfully staying at work and leading a normal life with COPD, while also highlighting areas that result in significant limitations performing tasks at work and at home and lead to the termination of employment, an unfulfilling social life and an unsatisfactory home life, impacting quality of life. This study found numerous issues influenced the ability of these women to stay productive at work while managing their disease. Further research is needed to explore these issues in more detail, as factors that lead to successful management of COPD in women of working age could not only improve the quality of life of these women, but also reduce the burden of COPD on the employer, the health service and society as a whole.

The convergence of findings from Phase One with the findings of Phase Two, showed that some of the key issues described by the participants (in Phase One) regarding COPD at work and at home, were not mentioned in the online forum messages. However, there were common findings that emerged in both phases, with a key commonality being working women with COPD experiencing disease-related fears for their and their family's future, their ability to work and the impact the disease will have on their young children.

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Appendices

Appendix 1. Participant Information Sheet

Participant Information Sheet

Section A: The Research Project

1. Title of project

Women 65 Years and Under, Living and Working with COPD

2. Invitation to participate

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 10 minutes.

Talk to others about the study if you wish. Please contact us, using the contact details below, if anything is not clear.

3. Purpose of the study

The purpose of this study is to find out how young women, diagnosed with Chronic Obstructive Pulmonary Disease (COPD) cope with the disease symptoms and getting on with their daily work and home lives. Many studies focus on elderly people with COPD, but there are many young women, with busy lives and responsibilities, that are being diagnosed with this condition. The difficulties faced by living with COPD, for an older, retired person, are completely different from those faced by young, working women.

This study wants to know, from the young woman's view, how she manages her life, the challenges she faces and the strategies she uses to overcome these challenges to lead her life.

4. Who is organising the research?

The chief investigator is Hanna Mal'ouf, who is a PhD candidate at Anglia Ruskin University, Chelmsford. She is supervised by Professor Sharon Andrew of Anglia Ruskin University.

5. What will happen to the results of the study

The findings of the study will be written up as a PhD thesis. They may also be presented at academic conferences and published in academic and professional journals.

6. Ethical Approval

This study has undergone independent ethical review by the NRES East of England-Hatfield Committee.

7. Contact for further information

Chief Researcher Hanna Mal'ouf   mobile: XXX

Email: XXX

Section B: Your Participation in the Research Project

1. Why you have been invited to take part?

You have been invited to take part because you are a woman, 65 years old or younger, who has been diagnosed with COPD. We hope to recruit a total of 15 women recruited through information leaflets and posters in Respiratory Departments of Hospitals throughout the UK and via social media.

2. Whether you can refuse to take part

It is entirely up to you to decide if you would like to join the study. We will describe the study and go through this information sheet, answering any questions you might have. You can then take some time to think about whether or not to take part. Your decision about whether to take part in the study will not affect, in any way, the treatment you receive from your COPD team.

3. Whether you can withdraw at any time, and how

You are free to withdraw at any time, without giving a reason. Even after the study has started you can change your mind and stop taking part in it. If you withdraw from the study, we will ask you whether we can use the information you have given us up until that point. If you decide you do not want the information to be used, we will destroy all your identifiable data and none will be used in the results of the study.

4. What will happen if you agree to take part

If you agree to take part in the study, which will last 9-12 months, you will be given a voice recorder and asked to record a diary every 2 weeks. We would also ask you to making a recoding after significant events like having to start a course of oral steroids, or being admitted to hospital. The diary entries should include how you are feeling and how you are finding life in general, any challenges at work or with your family or friends due to your disease.

Also, you will be asked to fill out a quick (5 minute) questionnaire at the beginning and end of the study, and every 2 weeks. We will ask you to include the score from this questionnaire at the beginning of your voice diary.

Your Respiratory Nurse or Doctor may measure your lung function every few months, and, if you are happy to do so, we will ask you to remember the results of the lung function test results and record them in the voice diary.

The researcher will interview you approximately every 3 months throughout the course of the study, at a convenient location or by telephone. Interviews should last no more than an hour and will be recorded for the purposes of the study only, and stored confidentially and securely. The researcher will also make quick calls between interviews, with your agreement, to make sure everything is going ok.

It must be made clear that your normal treatment will not be affected by this study, and you should continue your treatment regimen.

5. Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety.

There are no physical risks with this study, as it is just gathering your thoughts and feelings about how the disease affects your life.

It may happen that you feel somewhat upset by discussing a particular topic or event, related to your condition. If this should happen you are free to stop recording or

contributing to an interview. If you are very distressed the researcher will be able to suggest appropriate sources of help or advice.

Agreement to participate in this research should not compromise your legal rights should something go wrong.

6.   What happens if something goes wrong

In the unlikely event something goes wrong, and you would like to make a complaint, please send details of the concern or complaint to **[redacted]** or email **[redacted].** A response will be sent within 5 working days.

7.   What will happen to any information collected from you?

The information will be analysed and the findings written up as a PhD thesis, they may also be presented at academic conferences and published in academic and professional journals. These finding will be anonymised so that no-one reading the thesis or the papers will be able to identify you. We will take care to remove any identifying factors if we are using any quotations (for example we would not include the name of your employer or your hospital).

8.   Expenses

If you incur any travel expenses as a result of taking part in this study, such as travelling to meet the researcher, (in an agreed location), and you will be reimbursed. Please keep your receipts to make a claim. In addition, all participants can keep their voice recorders at the completion of the study.

9.   What are the possible benefits of taking part?

The study is unlikely to benefit you directly but the information we get from this study will help improve the treatment of young women with COPD.

10.   Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Information you have given us will be anonymised and kept securely.

Appendix 2: Participant Consent Form

Anglia Ruskin University
Cambridge Chelmsford Peterborough

Participant Consent Form

Name of participant:

Title of the project: Women 65 Years and Under, Living and Working with COPD

Main investigator and contact details: Hanna Mal'ouf

Members of the research team: Prof. Sharon Andrew, Dr. Susan Walker and Dr. Leica Claydon

1. I agree to take part in the above research. I have read the Participant Information Sheet (Version 7 26/03/2015) which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.

2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice, using the slip on the back of this consent form.

3. I have been informed that the confidentiality of the information I provide will be safeguarded.

4. I understand that I am free to ask any questions at any time before and during the study.

5. I have been provided with a copy of this form and the Participant Information Sheet.

6. I agree to my interviews and diary entries being audio-recorded.

7. I would like/would not like (circle as appropriate) to receive a copy of the findings of this study, once complete.

   Data Protection: I agree to the University[1] processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*.

Name of participant (print)…………………………
Signed………………..…… Date………………

Name of witness (print)…………………………..
Signed………………..………

Date………………..

You will be given a copy of this form to keep

<u>WITHDRAWAL NOTICE</u>

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: Women 65 Years and Under, Living and Working with COPD
'I WISH TO WITHDRAW FROM THIS STUDY'

Your name (print):

Signed: _____

Date: _____

Appendix 3: Ethical Approval Letter for Phase One

NRES Committee East of England – Hatfield

[Redacted from this version]

[Redacted from this version]

[Redacted from this version]

[Redacted from this version]

Appendix 4: Ethics Approval for Phase Two

From Anglia Ruskin University Faculty Research Ethics Panel:

17 November 2015

Dear Hanna,

Re: Application for Ethical Approval

Principal Investigator(s) Hanna Mal'ouf

Project Number:

Project Title: Exploring how working women live with COPD

Thank you for resubmitting your documentation in respect of your application for ethical approval. This has been reviewed by the Chair of the Faculty (of Health, Social Care and Education) Research Ethics Panel (FREP) in advance of the next scheduled meeting in November.

I am pleased to inform you that your ethics application has been approved by the Faculty Research Ethics Panel (FREP) under the terms of Anglia Ruskin University's Research Ethics Policy (Dated 23/6/14, Version 1).

Ethical approval is given for a period of 3 years from 17th November 2015.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Research Ethics Policy and the Code of Practice for Applying for Ethical Approval at Anglia Ruskin University, including the following:

- The procedure for submitting substantial amendments to the Panel, should there be any changes to your research. You cannot implement these amendments until you have received approval from FREP for them.

- The procedure for reporting adverse events and incidents.

- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.

- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP copies of this documentation if required, prior to starting your research.

- Any laws of the country where you are carrying the research and obtaining any other approvals or permissions that are required.

• Any professional codes of conduct relating to research or requirements from your funding body (please note that for externally funded research, a Project Risk Assessment must have been carried out prior to starting the research).

• Completing a Risk Assessment (Health and Safety) if required and updating this annually or if any aspects of your study change which affect this.

• Notifying the FREP Secretary when your study has ended.

Please also note that your research may be subject to random monitoring.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely

Dr Sarah Burch
For the Faculty (of Health, Social Care and Education) Research Ethics Panel

cc: Professor Jeffrey Grierson (Sponsor)   Professor   Sharon   Andrew (Supervisor)
        Beverley Pascoe (RESC Secretary)

Appendix 5: Correspondence with COPD-Specific Websites.

From Patient.Info

Hi Hanna,

As the forums are publicly viewable and if you are just reading the forums for information then you do not need to post in the forums themselves. If you are going to use direct quotes etc then you will need to ask us for permission and acknowledge the site.

Regards,
Patient Admin

From COPD Foundation.org

Dear Hanna,

I very much appreciate your reaching out to see if you would be able to observe our community for research purposes. As you can imagine, we at the Foundation have worked hard to create an environment where members feel secure and safe and where they may speak freely with other patients, caregivers and healthcare professionals. By introducing the component of research into the activity feed, I fear many individuals would feel their privacy would be invaded and might feel they were unwilling research participants. As this is not a research site and is promoted as a social site we will not be able to allow you to post anything regarding research on the site.

In the future, we may be adding a section that will include opportunities for research but that is not currently slated.

Thank you again for reaching out and I am sorry we will not be able to accommodate your request.

Sincerely,
[redacted]

Appendix 6: Interview Schedule for Phase One

Interview Schedule

General demographic information will be asked at the beginning of the study, during the first face-to-face interview. Information about the following will be gathered:

Age, occupation, how many hours they work and in what capacity (standing all day, sat at a desk, working outside etc.), their ethnic background, their highest level of education, who is the main breadwinner in their household, if they have children and if so, how many.

The following themes (1-3) are extracted from the research questions and will form the basis of the semi-structured interviews. A-c) are examples of the open-ended questions that participants will be asked during the interviews.

1. **Explore the experiences of young, working women with COPD**.

The participants will be asked questions such as

a) Can you tell me about when you first found out you had COPD?

To understand how their life has changed since developing this disease.

2. **Explore the experiences of these women managing their symptoms in combination with their family and working life?**

a)   Can you tell me in what way COPD affects your family life?
b)   And you're working life?
c)   And how you cope with both family and work life?

3. **Explore how and to what extent young women with COPD cope with periods of acute disease exacerbation, and the affect this has on their family life**

a)   Can you tell me about times when you have a 'flare-up' of your condition?
b)   What are the after effects of an exacerbation on you personally/ on your job and on your family life?

Appendix 7: A Sample of Thematic Coding

unwell knows signs.

basically I just managed to get an appointment at the doctors and they saw me 'cos of my condition they do see me straight away, I am quite lucky. And they told me I have another infection.

R: OK.

treatment.

P: so I have to take the antibiotics and steroids for another 7 days.

R: Could you tell me a bit about yourself, L.. please?

history/ background

P: Yeah, I am 44 years old, I am a full time, I am a mum and a wife, (wheezing), I was diagnosed with, erm, asthma, about 17 years ago, what else do you want to know?

$44 - 17 = 27$ yo

R: erm, whether you work?

before diagnosed

part time — coz of condition?

P: yeah, I work part time, I work 20 hours a week, I work as a customer services assistant for the local council. Obviously I am trying to work in between not being well as well, so it has been quite hard the past 6 months or so, and I am trying to juggle everything as much as I can.

hard to juggle – being unwell + financial.

R: so how do you cope when you're not so well, when you are at work?

m illness around work. — work hours etc to accommodate?

sick leave

P: well, basically, if I really not that well, then I don't go to work. I go off sick. But at the moment I have a chest infection, I will try and get into work because that is the type of person I am, I don't want to just sit down and let it take over me. So basically, like today, I haven't done anything at home. When I am not at work,

thorough.

just have to adapt.

sacrifice one thing for another.

'don't want to sit down + let it take over me.'