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An exploration of employment factors in working-age people with chronic obstructive pulmonary disease.

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An Exploration of Employment Factors in Working-age People with Chronic Obstructive Pulmonary Disease

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This thesis is submitted in partial fulfilment of the requirements of Robert Gordon University for the award of Doctor of Philosophy (PhD)

Declaration of Authorship

I, Pamela Georgina Kirkpatrick, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated and credited within the thesis.

Signature: Pamela Kirkpatrick

Date: 12.08.2022

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Dedication

This thesis is dedicated to my Dad who was the nicest man in the world

Robert Banks Ross

Abstract

Name: Pamela Kirkpatrick

Degree Award: Doctor of Philosophy (PhD)

Thesis Title: An Exploration of Employment Factors in Working-age People with Chronic Obstructive Pulmonary Disease

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a debilitating lung condition causing distressing symptoms. People with COPD experience variability of symptoms and have a greater number of comorbidities and lower quality of life than people with other long-term conditions. COPD is typically diagnosed from the age of 40, at a time where individuals are working to have a stable income and might be saving towards retirement. Employment is important for generating an income, social stimulation, a sense of purpose, use of skill and routine. Research suggests that people with COPD exit the workforce early and have a reduced income through having to work part-time or not work at all.

A narrative literature review was conducted and highlights that the research on the impact of COPD on employment is weak and conflicting making the role of COPD on absenteeism, presenteeism, early retirement, income and career difficult to determine. This lack of clarity is due to the deficiency in use of standardised and validated tools to measure these concepts in different organisations, contexts and countries. In addition, only grey literature considers the employment experiences of people with COPD indicating a dearth of publications to date. This body of work further addresses that gap to enhance our understanding of COPD and employment and to inform the development of recommendations to support people with COPD.

Aim

The aim was to explore employment in working-age people with COPD to investigate factors influencing employment and understand experiences of sustaining or leaving employment.

Methods

Through a pragmatic worldview, this research adopted a mixed-methods approach to address the thesis aims and objectives. Two studies were conducted: a mixed-methods study and a qualitative study:

Study 1 – The Psychosocial and Physical Factors Influencing Employment in People with COPD: A mixed-methods study.

This study comprised of two components: a quantitative cross-sectional survey and qualitative interviews. A health and well-being questionnaire consisting of a selection of validated and non-validated instruments was developed. The questionnaire incorporated the COPD Assessment Test (CAT), Quality of Life (EQ-5D-5L), Satisfaction with Life (SWLS), Warwick-Edinburgh Mental Well-being Scale (WEMWBS), The Hospital Anxiety Depression Scale (HADS), The Connor-Davidson resilience Scale (CD-RISC), The Work Productivity and Activity Impairment Questionnaire (WPAIG:GH), and The Stanford Presenteeism Scale (SPS-6), and a non-validated Workplace Control and Adaptation measure. The questionnaire was administered to 14 people with COPD who were either employed, or no longer employed because of their COPD. This questionnaire was administered in a private office and responses were captured in a paper-based format. Data were analysed descriptively. A sub-sample of four individuals completed face-to-face semi-structured interviews to explore their employment experiences. Interviews were conducted in a place of the participants choosing (office/home), digitally recorded and transcribed. The qualitative data were analysed using the Framework method.

Study 2 – The Employment Experiences of People with COPD: A qualitative study.

A qualitative study of 17 in-depth one-to-one semi-structured interviews exploring the barriers, facilitators, and support aspects of employment in people with COPD was conducted. Interviews took part in participants homes. An interview schedule with prompt questions developed from Study 1 interviews and responses was used to guide the interviews. Interviews were recorded and transcribed, and data analysed using the Framework method. The research methodology was guided by the principles of interpretive description and the theoretical perspective of resilience was considered throughout the study.

Results and Findings

Study 1 demonstrated that it was possible to recruit participants with COPD to collect both quantitative data on psychosocial and physical factors influencing employment and the impact of COPD on employment, and qualitative data on employment experiences. The procedures implemented and documentation designed for this study were appropriate and no modifications were required. A future study could be scaled up with some modification to the content of the questionnaire and the recruitment process dependent on the adopted study design and further resources.

The questionnaire used was effective in collecting the necessary data and the results illustrated broad trends. The CAT scores of people in employment were lower overall than those not employed. For employed participants, quality of life scores, perceptions of health, satisfaction with life, mental well-being, and mental health through HADS scores were higher than those not employed. Resilience was another construct where employed participants demonstrated greater resiliency than those not employed. The work productivity, presenteeism and workplace control and adaptation measures also provided data on the employed participants work activity and participants had low absenteeism and presenteeism and workplace flexibility.

Three higher order classifications of *health and COPD in the workplace, employment support for COPD and The bigger picture of COPD and employment* were developed. Participants experienced variability in their COPD symptoms and wellbeing at work and adopt personal and workplace strategies to manage the challenges were developed from the qualitative data. Participants were not always clear about their legal rights and what to expect from their employer or know where to access support. Further, people with COPD value their work for structure and routine and an early, unplanned exit from the workplace could be challenging for some. The findings indicated what was important for the participants in relation to their employment and related challenges in working with COPD. This realisation influenced the decision by the researcher to focus

solely on developing a deeper understanding of the employment experiences of people with COPD. Following discussion with the PhD supervisory team the decision to proceed with a qualitative study to provide a more robust foundation for the survey was agreed and implemented in the subsequent qualitative study.

Study 2 highlighted a willingness of people with COPD to engage in research exploring employment experiences. People with COPD want to continue working as long as possible and many are supported by their employers to do so; however, others might encounter pressure to leave their employment from their colleagues or employer. Personal finances can be a considerable concern. Managers and colleagues are more empathetic if they know about COPD or have experience of similar issues. Successfully implementing actions and strategies to self-manage COPD in the workplace requires resiliency skills and employer understanding and flexibility; physical and psychological job demands may cause workplace fatigue and exhaustion. Expressing workplace needs by informing management of health status can lead to improved employment experiences.

Conclusions

This research has contributed to the body of knowledge, illuminated some key findings and developed recommendations including: for healthcare professionals to provide more tailored support; for people with COPD to be more engaged in the communication of their needs; for employers to develop their understanding of their employees with COPD and how to make appropriate workplace adjustments; for research that investigates how people can make successful adaptation in the workplace; for policy and strategy to better integrate employment into healthcare planning.

Key Words

Chronic Obstructive Pulmonary Disease (COPD); Employment; Pragmatism; Mixed-methods; Questionnaire; Interviews; Interpretive description; Framework analysis.

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"An exploration of aspects of employment in people with Chronic Obstructive Pulmonary Disease (COPD)"

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Glossary of Abbreviations

BODE	BMI, Obstruction, Dyspnoea and Exercise Capacity
CAT	COPD Assessment Test
COPD	Chronic Obstructive Pulmonary Disease
DDA	Disability Discrimination Act (1995)
EA	Equality Act (2010)
EQ-5D-5L	European Quality of Life – 5 dimensions
FA	Framework Analysis
FEV_1	Forced Expiratory Volume in 1 second
FVC	Forced Vital Capacity
GOLD	Global Initiative for Chronic Obstructive Lung Disease
HRQoL	Health-Related Quality of Life
LTC	Long-term Condition
MCMQ	Medical Coping Modes Questionnaire
MSK	Musculo-skeletal
PF	Peak Flow
SF-12	Short Form Health Survey – 12-item
QoL	Quality of Life
WHO	World Health Organisation

1. Introduction

1.1. Introduction

This thesis is concerned with the employment experiences of people with Chronic Obstructive Pulmonary Disease (COPD). The thesis incorporates two studies (a mixed-methods pilot study and a qualitative study) whose combined aims were to explore the health and well-being of people with COPD who were either employed or had given up employment because of their COPD. The studies sought to provide a meaningful description, analysis and interpretation of psychosocial and physical factors, and the situations and contexts that people with COPD encounter related to their employment. The studies also inform future research and make recommendations for practice, people with COPD, employers, policy and strategy.

1.2. Chapter Structure

This chapter introduces both studies, justifying the importance of the topic within a public health context. The significance of the topic for people with COPD, their family and carers and how the findings might be useful to healthcare professionals and wider stakeholders including third sector agencies, voluntary and charity sectors is also discussed. This chapter also presents a critical reflection on my position as a nurse, academic and researcher and why the topic is meaningful to me. Reflection is important in illuminating my prior assumptions and experiences of working with people with COPD and considers my influence on the research and motivation for undertaking a Doctoral study. A reflective approach is employed for contextualisation in the qualitative research tradition and represents the *'Forestructuring'* which is characteristic of the interpretive descriptive approach, which is the qualitative methodology adopted in this thesis. Interpretive description will be explored in Section 3.6. Firstly, an overview of COPD is presented.

1.3. Chronic Obstructive Pulmonary Disease

The Global Initiative for Chronic Obstructive Lung Disease (GOLD 2021) defines COPD as follows:

> *"Chronic Obstructive Pulmonary Disease is a common, preventable and treatable disease that is characterized by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases and influenced by host factors including abnormal lung development" (GOLD 2021, p.4).*

GOLD (2021) indicates that COPD is a debilitating and progressive chronic lung condition that has breathlessness as its main symptom. COPD is a disease characterised by respiratory airflow limitation that is not fully reversible even with the use of bronchodilators (GOLD 2021). Evidence for risk of developing COPD comes from cross-sectional studies identifying associations rather than specific causal relationships (GOLD 2021). Cigarette smoking (tobacco) and occupational pollutants (vapours, gases, dusts, fumes (VGDF)) are reported as major contributors to the development of COPD for many, although genetics might play an important role (GOLD 2021; Lomas, Hurst and Gooptu 2016). Cigar and pipe smokers also have higher mortality and morbidity linked to COPD but it is lower than for cigarette smokers (Devereux 2017). In the European Community respiratory Health Survey, airway hyper-responsiveness was second only to cigarette smoking as the leading risk factor for COPD, responsible for 15% of the population attributable risk (smoking had a population attributable risk of 39%) (GOLD 2021).

However, in developed countries, it is estimated that around half of the people who smoke cigarettes indicate some obstruction in their airflow during their lifetime and around 10-20% develop COPD, and an increased risk of 20% is suggested for developing COPD with each 10 pack years of cigarette smoking (Devereux 2017). Although tobacco smoking is a dominant risk factor for developing COPD, it is not a prerequisite. It is now increasingly apparent that 5–12% of people with diagnosed COPD have never smoked and based on spirometry, 20–40% of individuals with COPD have either never smoked or have a minimal cumulative smoking history (Devereux 2017). Never smokers developing moderate and severe COPD is reported as high as 23% in older age groups, but the results varied dependent on the strictness of the FEV_1/FVC criteria used (Lamprecht et al. 2011). Asthma is also reported as a risk factor for developing COPD but those with asthma progressing to develop persistent airflow obstruction could be as low as 15% (GOLD 2021).

Exposure to biomass fuel smoke (burning wood, animal dung, coal and crop residue) caused by cooking indoors on open fires in poorly ventilated areas, particularly in the Asia-Pacific region, might also be a contributory factor (Lim et al. 2015; Pant et al. 2015); however, this is under researched (GOLD 2021; Lim et al. 2015). Although lung pollutants are likely to be the main contributors to developing COPD, socio-economic factors including deprivation and poverty might also play an important role and requires further investigation (GOLD 2021; WHO 2017; Fishwick, Barber and Darby 2010).

1.3.1. Symptoms and Diagnosis of COPD

COPD is an umbrella term describing the conditions of emphysema and chronic bronchitis, and in both conditions, the lung parenchyma (pulmonary alveoli and respiratory bronchioles) and the bronchial airways are damaged due to inflammation, causing a narrowing of the airways and airway obstruction (GOLD 2021; Gundry 2019a). Typical symptoms include dyspnoea (breathlessness), which often occurs during physical exertion or rest, a chronic disruptive cough and tenacious secretions (phlegm) (GOLD 2021). These symptoms, and a history of recurrent lower respiratory tract infections and exposure to COPD risk factors, points towards a diagnosis of COPD (GOLD 2021). Confirmation of persistent airflow obstruction is made through spirometry and a post bronchodilator ratio of forced expiratory volume (in 1 second) to forced vital capacity (FEV_1/FVC) of less than 0.7 (GOLD 2021; NICE 2019). A challenge in diagnosis is differentiating COPD from asthma, as both conditions can overlap (Linnell and Hurst 2020). GOLD classification is made in relation to severity levels (mild, moderate, severe, very severe), and people with more severe COPD experience the highest symptom burden affecting an individual's daily functioning and negatively impacting their quality of life (GOLD 2021; Yin et al. 2017). A shift towards considering symptomatic impairment assessment to determine the current impact of COPD on individuals has occurred, as airflow obstruction as measured by spirometry alone shows a weak correlation (GOLD 2021).

Other symptoms of COPD include chest tightness, pain, fatigue, low oxygenation (hypoxia), loss of concentration, physical and social dysfunction, and higher levels of psychological distress, including anxiety and depression, than individuals with other long-term conditions (GOLD 2021; NICE 2019; Gundry 2019a). The intensity and impact of COPD symptoms can fluctuate daily, making routines difficult and predicting exacerbations challenging (GOLD 2021; Gundry 2019b; Barnes et al. 2013). Embarrassment from symptoms and fear of subsequent stigmatising experiences are common in people with chronic illness (Munir, Leka and Griffiths 2005). Diagnosis of COPD is often determined during the first exacerbation when the disease has progressed to the moderate stage after years of undetected development (Gundry 2019a). Research indicates close links between people of lower socio-economic status and increased risk of developing COPD and that poverty and deprivation are closely associated with respiratory airflow obstruction (Townend et al. 2017).

Spirometry services have been curtailed throughout the UK as a result of the COVID-19 pandemic, which has potentially reduced the detection and diagnosis of chronic respiratory conditions including COPD, particularly in Primary Care locations (PCRS 2020). The provision of spirometry services, which were delivered pre-pandemic in primary, secondary and community care settings, and in respiratory physiology clinics, by a variety of healthcare professionals, greatly reduced or ceased entirely in most locations in the UK during the COVID-19 pandemic (PCRS 2022). Similar restrictions to halt pulmonary function tests were applied globally unless they were deemed clinically essential in people with pre-existing chronic respiratory diseases (Crimi et al. 2021).

Restoring spirometry services to maximum capacity to enable accurate diagnosis and implementation of therapeutic interventions is essential for the effective management of COPD and managing the backlog of people requiring the service (BTS 2022). The reimplementation of spirometry services provides an opportunity for service recovery and complete redesign, which makes best use of limited time and resources and ensures there is sufficient skilled staff to manage the service effectively. This is evidenced through the spoke approach linked to Community Diagnostic Hubs (CDHs) presently being established in England as a new model for service delivery (NHS England 2020).

COPD is rarely diagnosed before the age of 35; however, the recent government directive has emphasised the need for prompt detection, diagnosis and management to improve long-term health outcomes in younger age groups (Scottish Government 2021; NICE 2019). Although COPD is recognised as a systemic inflammatory condition, it can exist in the absence of inflammatory markers, so the role and impact of inflammation to the general impairment and poor function found in some individuals with COPD is unclear (Barnes 2010). Pan-continental studies reveal 10-20% of adults aged 40 years and over evidenced persistent airflow obstruction, although a formal diagnosis of COPD was confirmed in only 20-30% of that population (Diab et al. 2018; Labonté et al. 2016). With only a small proportion of that population diagnosed with COPD, it suggests up to 70% of people with respiratory symptoms could be underdiagnosed (Diab et al. 2018). Those underdiagnosed are therefore denied early lifestyle and therapeutic interventions and support to improve both health status and survival and known globally as the *'missing millions'* (Bakerly and Cardwell 2016; Labontě et al. 2016). Conversely, overdiagnosis of COPD is also common, with individuals previously diagnosed with COPD by physicians found later not to have the disease in 30-60% of cases (Diab et al. 2018; Miravitlles and Anzueto 2009). Even after interventions such as country-wide population spirometry and the use of COPD case-finding approaches, accurate diagnosis remains problematic in many countries including the UK (Lamprecht et al. 2015).

Whilst the traditional perspective of people who develop COPD is of an elderly male smoker, there is an emerging female face in whom we also find a high rate of underdiagnosis (Lamprecht et al. 2015). Although historically the prevalence of COPD has been higher in men than in women, more recent estimates indicate prevalence is now almost equal in both genders (NICE 2021). It is suggested that the increase in prevalence of COPD in women is possibly due to a greater use of tobacco smoking (NICE 2021) and a slower decline in smoking rates compared with men (Scottish Public Health Observatory 2021).

COPD is a particularly disabling condition due to its high symptom burden and shows considerable variability within and between individuals (Houben-Wilke et al. 2018; Hodson and Sherrington 2014). Additionally, people with COPD often have higher levels of morbidity than people with other long-term conditions and often avoid activity or occupation, experience more disability and have a poorer quality of life overall (Gundry 2019a; Scottish Government 2017a; Vestbo et al. 2013; Thornton-Snider et al. 2012). Patient reported outcomes including quality of life and work productivity are important measures in the proactive treatment and rehabilitation of persons with COPD, although few studies focus on those under the age of 65 years (Yin et al. 2017; Di Bonaventura et al. 2012). Up to 90% of individuals with COPD have comorbidities (GOLD 2021; Bakerly and Cardwell 2016; Soriano and Price 2015). Comorbidities influence poorer clinical outcomes and commonly include metabolic syndrome and osteoporosis, cardiovascular disease, musculoskeletal problems (muscle and weight loss) and psychiatric and neurological conditions (anxiety and depression) (GOLD 2021; Anzueto and Miravitlles 2017; Yin et al. 2017; Naylor et al. 2012). The presence of comorbidity adds complexity to the lives of people with COPD because of the interrelated health issues (Chetty et al. 2017). These health issues influence disease progression, exacerbation frequency and human suffering and includes drug interactions and polypharmacy, higher morbidity and more hospitalisations, inflating healthcare management and treatment costs (Yin et al. 2017).

Van Manen et al. (2002), found the risk for depression in patients with severe COPD to be 2.5 times higher than in control groups, but the increased risk for depression was not seen with mild to moderate disease. Studies indicate depression affects COPD symptoms by reducing physical functioning and social interaction, and increasing fatigue and hospital utilisation, and there is doubt about the efficacy of antidepressant medication inducing a sustained remission (Yohannes and Alexopolous 2014). People with respiratory illness and recently shielding due to the COVID-19 pandemic, could have compounded their risk of developing depression and a concomitant reduction in quality of life (Celli et al. 2017). Efforts must be made to control each comorbid condition to ensure the optimisation of health status (Burgel et al. 2013).

1.3.2. Prevalence of COPD

COPD is the third leading cause of death globally after ischaemic heart disease and stroke (WHO 2016a) followed by lower respiratory tract infections and is therefore a considerable public health issue (WHO 2016a). Whilst exact statistics for the UK prevalence of COPD are unclear, it is thought that more than

3 million people have COPD, but only 1.2 million have a confirmed diagnosis (ONS 2020). These 1.2 million people represent approximately 4.5% of people aged over 40 years, positioning COPD as the UK's second most common lung disease after asthma (ONS 2020; Devereux 2017). Prevalence of COPD in those aged over 40 years is around 10% and doubles with each subsequent decade of life (Keil et al. 2017; Buist et al. 2007). COPD prevalence is increasing globally due to ageing populations and relentless lung pollution (GOLD 2021; WHO 2016b). Prevalence in 2016 was around 251 million cases and approximately 3.17 million people had died from COPD in 2015 (constituting 5% of global deaths and around 8% of deaths in Europe) (ONS 2020; Organization for Economic Cooperation and Development OECD 2019; WHO 2016b). In Scotland, the Realistic Medicine report indicated that mortality rates for COPD in people under 75 years old had not reduced to the same extent as rates for cancer, coronary heart disease and stroke between 1994 and 2014, all of which had reduced by around 38% (Scottish Government 2017b). Globally, COPD is a growing problem warranting greater research attention to gain a clearer understanding of the challenges involved.

1.3.3. Exacerbation of COPD

Individuals with COPD sometimes experience acute worsening of their usual symptoms, (exacerbation), often caused by viral and bacterial infections or other triggers such as respiratory irritants (pollution), making these times unpredictable (Viniol and Vogelmeier 2018; Vestbo et al. 2013). During an exacerbation, individuals encounter reduced lung function, a worsening cough, increased sputum and dyspnoea and increased systemic and airway inflammation (Viniol and Vogelmeier 2018). Exacerbations can be debilitating, rendering the person with COPD bedbound, chairbound or hospitalised, whilst at other times those with COPD are able to manage their exacerbation without reporting it to their healthcare professionals and up to 50% can be unreported (Lim et al. 2015; Vestbo et al. 2013). Each exacerbation negatively impacts on health and well-being, signalling disease progression (Gundry 2019b), and it can take weeks to recover (Linnell and Hurst 2020). Frequent and severe exacerbations are traumatic experiences and herald a downward trajectory of declining health, potentially leading to respiratory failure and death (Morice et al. 2010; Gundry 2019b).

During the COVID-19 pandemic, people with COPD, considered extremely vulnerable, will have shielded to isolate themselves from unnecessary exposure to viruses and mitigate their risk of contracting the SARS-CoV-2 virus (Bostock 2020; WHO 2020). People with COPD are susceptible to virus-induced exacerbations, a compromised pulmonary function and often several comorbidities (Higham et al. 2020). In contracting COVID-19, individuals with COPD are more susceptible to the severe effects of the infection and greater morbidity and mortality (Simons et al. 2020; WHO 2019), particularly if their COPD is moderate or severe, poorly controlled, if they have comorbidities or their general health is poor (Gerayeli et al. 2021; Docherty et al. 2020). Whilst self-isolation can bring physical benefits in avoiding viral exposure, individuals are at greater risk of other negative unintended consequences including depression (Gerayeli et al. 2021).

1.3.4. Management and Treatment of COPD

Whilst there is no cure for COPD, NICE (2020) highlights significant progress in treatment and management in the last few decades and suggests greater focus is required to improve the outcomes and experiences of people with COPD (GOLD 2021, NICE 2019a). Many countries have dedicated policies, guidelines and strategies for tackling respiratory conditions, and Scotland recently launched a national Respiratory Care Action Plan 21-26 recognising the significant impact respiratory conditions have on individuals, families and societies (Scottish Government 2021). The COVID-19 pandemic has seen an unprecedented disruption to healthcare services and changes have been made to how respiratory care is delivered with substantially less face-to-face contact (Scottish Government 2021). However, the uptake of online video consultation through utilising systems such as the Near Me service, used widely in Scotland, has enhanced patient accessibility to clinicians and services for many (NHS Education for Scotland 2021).

Current treatments options for COPD include inhaled drug therapies and effective proactive self-management, which enable individuals to improve their well-being by controlling their symptoms and limiting disease progression (GOLD 2021; Gundry 2019b; Jones et al. 2016). NICE regularly update the national guidance for the prescription, dosing and combining of inhaled therapies depending on COPD severity, often determined using the GOLD guideline (GOLD 2021; NICE 2019a). Options include SABA's (short-acting Beta-2 agonists), which are used as a bronchodilator for stable COPD to relax the airway lining, dilate blood vessels and relieve breathlessness and LABA's (long-acting beta-2 agonists), which have the same action and last up to 12 hours and used in less stable COPD (BNF 2021; NICE 2019a; Gundry 2019b). Additionally, options include SAMA's (short acting muscarinic antagonist), which are used as bronchodilators by blocking the broncho-constricting effects of acetylcholine in stable COPD and LAMA's (long-acting muscarinic antagonist), which have the same action lasting up to 12 hours and used in less stable COPD (BNF 2021; NICE 2019a; Gundry 2019b). Inhaled corticosteroids are useful in reducing inflammation, swelling and congestion in those who have frequent exacerbations (more than two episodes in 12 months) or have exacerbations severe enough to cause hospitalisation (NICE 2019a; Gundry 2019b).

Pulmonary rehabilitation (PR), smoking cessation, use of personal protective equipment (e.g., masks/filters for VGDF management) and influenza and COVID-19 vaccination are also key factors in trying to reduce the likelihood of further lung damage and optimising an individual's health and well-being (GOLD 2021; Philip 2021). These measures are important when the disease is at the moderate and severe stages when the greatest lung damage often occurs (GOLD 2021; Csikesz and Gartman 2014). Pulmonary rehabilitation is a multi-component programme, emphasising the important role physical activity, education, self-awareness and behaviour change plays to enable and empower individuals to cope with their COPD (BTS 2021; Jones et al. 2016). The goal of PR is to ease and control COPD symptoms, reduce exacerbation frequency, lower severity and hospitalisations, improve health-related quality of life, increase daily engagement in society and reduce the costs to patients and healthcare services (Moore et al. 2016).

Participating in PR provides an important opportunity for people to learn the skills to effectively self-manage their COPD (GOLD 2021; NICE 2019a). Indeed, many PR sessions are now offered online, which has been useful for people shielding during COVID-19 restrictions as well as for people living remotely from expert support (BTS 2021). However, the benefits and drawbacks of online PR in comparison to face-to-face delivery are not yet clear. A recent, small-scale service evaluation of a population with chronic respiratory disease meeting the British Thoracic Society Guidance eligibility criteria for pulmonary rehabilitation (Bolton et al. 2013) was conducted (Lewis et al. 2021). This study evaluated the remodelled PR programme outcomes, the online delivery and staff normalisation elements and feasibility from the patient's perspective (Lewis et al. 2021). The researchers found within the remodelled PR programme, following patient preparation, that exercise was more successful online compared to face-to-face, although the healthcare staff involved acknowledged the online programme took greater time and effort for them to design and administer (Lewis et al. 2021). Ultimately, the patient participants perceived the educational component of the programme less successful than face-to-face as they felt they potentially missed out on individualised interactions with the healthcare staff delivering the programme (Lewis et al. 2021).

On a broader theme, taking a public health perspective in trying to optimise physical and mental health and well-being through health promotion and maintenance is key to achieving positive outcomes for people with COPD (GOLD 2021; Gundry 2019b). Although people with COPD have many unmet needs including disease management, daily living and emotional needs (Bragadottir et al. 2018; Clari et al. 2018; Gardener, Ewing and Farquhar 2019), patient empowerment and self-management seem key in the provision of support (Gundry 2019b; Cooney et al. 2013). Optimising effective self-management through learning breathing and bronchial clearing techniques, exercise, healthy nutrition, stress management and developing self-management and anticipatory care plans are essential for the effective ongoing management of COPD (BTS 2021; GOLD 2021; Csikesz and Gartman 2014). The importance of undertaking daily physical activity and engaging in meaningful social interactions has also been emphasised as contributing to the individual's physical and mental well-being and quality of life (Stridsman, Lindberg and Skar 2014). Well-managed COPD is likely to promote the maintenance of an individual's health and well-being and routine (Silvaggi et al. 2020; Hodson and Sherrington 2014). Further, effective COPD self-management could potentially prevent exacerbations, delay the progression of the disease and help many individuals maintain their employment status (GOLD 2021; Moore et al. 2016).

1.4. Work, Health and Well-being

In addition to earning a living, building savings for retirement in the face of higher living costs, higher taxes and possible shrinking returns on investments and pensions, the health benefits of employment are considerable (Palmer et al. 2015). Workplace health and well-being is a balance between the needs of employees and the needs of the organisation and is defined as:

> *"Creating an environment to promote a state of contentment which allows employees to flourish and achieve to their full potential for the benefit of themselves and their organisation" (CIPD 2020, p.3).*

Since the publication of the *Working for a Healthier Tomorrow* Report in 2008 (Black 2008), there has been a growing appreciation of the physical and psychological benefits of employment. Noted in the Black report was the key statement emphasising the importance of work:

> *"work is their key determinant of self-worth, family esteem, their identity and standing within the community, besides providing material benefits work is a means of social participation and fulfilment" (Black 2008, p.4).*

Working has several psychosocial benefits including offering a sense of purpose and achievement, normality, self-concept, social identity, status, job satisfaction, routine, time structure, autonomy, use of skill, sustained motivation, social engagement, and mental stimulation (Rai et al. 2017; De Wind et al. 2013; Palmer et al. 2015; Waddell and Burton 2006). There is also a protective benefit of employment on mental well-being (Van Der Noordt et al. 2014) and work contributes to an individual's quality of life (De Jong et al. 2015).

Evidence also suggests that unemployed individuals' use of healthcare services is higher than in employed individuals (Rai et al. 2017). Additional benefits of continuing employment also occur through maintaining mobility and muscle strength (Palmer et al. 2015), and physical activity has been shown to be a factor influencing better general health and quality of life in people with COPD

(Jones et al. 2016; Arne et al. 2011). Therefore, there are established connections between positive physical and psychological health and well-being in sustaining a workplace presence (CIPD 2020) and reinforced in the recent *Good Work* Report conducted in 2017, albeit with a greater emphasis placed on a *'quality job'* (Taylor 2017). 'Quality jobs' are those that increase workplace participation, job productivity and work performance compared to low quality work, which does not utilise workers' skills, reduces productivity, reduces workplace well-being and ultimately pushes people out of the workforce (Taylor 2017). However, there are demotivating factors influencing poorer work participation of individuals with long-term conditions including little autonomy and negative and uncomfortable working environments (Vooijs et al. 2018; De Jong et al. 2015; Verekamp and Dijk 2010). Despite these negative aspects, working is of more benefit than being unemployed.

1.4.1. Working with a Long-Term Condition and Ageing

Employment amongst those 50 years of age and above in the UK, like many industrialised countries, has increased over the last 20 years, which has shifted the age profile of the labour market (Taylor 2017). The ceiling on official retirement ages in many countries has also ended, so there is now no clear cut, age-defined *'cliff-edge'* of retirement for workers, opening-up the option to work well into later years (Silvaggi et al. 2020; Bevan et al. 2018; ONS 2018a). With a further projected increase of 15% of the population remaining in the European labour market after the age of 55 years of age by 2060, we are faced with an ageing workforce (Silvaggi et al. 2020; AgeUK 2015). Indeed, the UK economy may well have to increasingly rely on older workers from 2030 onwards, and many individuals already choose to work well into their 60's and 70's (ONS 2018b; Nicholson et al. 2016).

As a result of this ageing trend, there is an increase in the prevalence of people with long-term conditions in the workforce, which is increasing in line with a reduction in labour supply (declining birth rate in the UK), a shortage of skilled labour and a growing pressure on social systems and pensions (Silvaggi et al. 2020; WHO 2020). In younger workers, it has been noted that the incidence of new cases of the onset of long-term conditions has increased in the last decade (Office for National Statistics 2020). Bevan et al. (2018) note that general ill-health because of long-term conditions can cause a loss in work productivity, known as presenteeism, and have a negative impact on job efficacy leading to an early exit from the labour market. Presenteeism relates to work productivity i.e., when an employee is at work, but operating at a reduced level of performance due to their medical conditions or illness (Kirsch et al. 2019). Despite presenteeism being a relatively new concept, its impact is of concern to employers, as it causes a greater financial cost to employers than absenteeism; however, the data on absenteeism and presenteeism presented in the literature is inconsistent, limited and conflicting (Kirsch et al. 2019). Further, 'leaveism' may be problematic in that workers might use annual leave for sick time, take work home, or work whilst on holiday to complete work tasks (Hesketh and Cooper 2014).

Workers with long-term conditions also have lower employment rates than those without (especially those with comorbidities), prematurely exit the labour market through unemployment or early retirement, have higher sickness absence rates (absenteeism) affecting employer's productivity and might have reduced incomes (Bevan et al. 2018; Bajorek, Hind and Bevan 2016; Munir, Yarker and Haslam 2009). Older workers with health concerns might find it challenging to cope with the psychological and physical demands of work and be at higher risk of occupational injury when taking certain medications that affect their performance in the workplace (Palmer et al. 2015). Therefore, the importance of employers being creative in co-generating effective and sustainable workplace solutions with people who have long-term conditions to address the health and work issues they encounter is of pressing importance (CIPD 2020; Halpin 2019).

In the Review of the Scottish Government's Health and Work Strategy: Fair and Healthy Work for All report, contributors noted the perceived lack of employer understanding in offering flexibility to accommodate people with long-term conditions or disabilities through the adoption of reasonable adjustments (Scottish Government 2019). Reasonable adjustment is implicated from the Equality Act (2010), which stipulates the reasonable expectation of an employer to accommodate specific requirements in the workplace required so as not to disadvantage certain employees. The proposal for employers to adopt a *'life-stage'* approach responsive to their workforce's life course is gaining momentum with more employers taking a pro-active approach to supporting people with long-term conditions in the workplace (Scottish Government 2019). The suggestion is that, to maximise the contribution of workers, employers need to respond to changes in individual capability, capacity and circumstance through retraining, redeployment and focused specialist health and well-being policies and services including Occupational Health services (Scottish Government 2019). Such flexibility fits well with the Government's ambition for greater collaboration in tackling the workforce health concerns in preserving employment integrity and ensuring individuals can work effectively for as long as they wish in, *'good work'* (Taylor 2017; Black and Frost 2011). Work flexibility reflects an employee's *'adjustment latitude'* wherein their opportunity to adjust workload, working time or work tasks is high, which often leads to a reduced likelihood of sick leave (Gerich 2014). Adjustment latitude presents an opportunity for those with a long-term condition to be explicit about their needs in the workplace and gain maximum employer support. However, research has indicated that adjustment latitude and flexibility in role or tasks can lead to loss of productivity through presenteeism, so this approach is not beneficial to all employers of those requiring flexibility (Gerich 2014). Having sickness absence policies that heavily influence work attendance, might also however incur higher presenteeism and lower productivity as a consequence (Munir, Yarker and Haslam 2009).

1.4.2. Leaving Work and Retirement

Exiting paid employment can be a stressful event and could lead to a diminished social status, changes in role and daily patterns, financial hardship, reduced self-esteem, isolation and guilt for people with long-term conditions (De Boer et al. 2018; Hoving et al. 2013). Pathways for exiting employment can be due to early retirement, unemployment, disability pension or becoming economically inactive (Schuring et al. 2013). Leaving work and entering retirement is no longer a dichotomous decision, and transitioning is now considered important (Bevan et al. 2018). A longitudinal study of people with and without chronic disease has shown that it is possible to identify those who are likely to exit the workforce earlier than planned and that this can be determined years before the event (De Boer et al. 2018). A limitation of this study however is that it was conducted with a relatively young population with mean ages of 45 years (with chronic disease) and 41 years (no chronic disease). Despite this, it points to the potential usefulness of physicians, nurses, rehabilitation specialists, workplace supervisors and managers expanding their conversations with people with long-term conditions to enable them to support those who appear to be at greater risk of exiting employment early (Bosma et al. 2021; De Boer et al. 2018). Greater risk can be identified as employees with high sick-leave, more burnout, poorer health and well-being and people indicating their illness negatively impacts on their work or who have less or no support from co-workers (De Boer et al. 2018). Understanding patient motivations and drivers for effective self-management during consultations, which can include workplace concerns, would enable healthcare professionals to initiate preventative support and provide a more holistic approach to their interactions and interventions (Bosma et al. 2021).

1.4.3. COPD and Employment

According to Chaker et al. (2015), COPD is one of the main non-communicable diseases that has the largest impact on macro-economic productivity along with coronary heart disease, stroke, chronic kidney disease, type 2 diabetes and cancer. Around 50% of those with COPD are under age 65 years and at an age where meaningful and satisfying employment is anticipated and important from an economic and social perspective (Keil et al. 2017; British Lung Foundation 2016). Because of the variability of COPD symptoms, some of which are influenced by the environment, the season, level of physical activity, exertion, comorbidities and general health status, predicting how *'well'* or *'able'* individuals with COPD are for their workplace demands is often difficult (NICE 2019b; Keil et al. 2017; Fletcher et al. 2011). Condition variability creates uncertainty and inconsistency in work attendance patterns and a wider issue of the challenges of sustaining employment over time (Fletcher et al. 2011). As a result, Schofield et al. (2019) found adverse employment outcomes in late 50-year-olds and onwards associated with moderate and severe breathlessness and early retirement (Schofield et al. 2019).

As COPD deteriorates, employed people are faced with increasingly troublesome limitations in their functional capacity, which can negatively affect productivity (Fletcher et al. 2011). Rai et al. (2017), in a Birmingham based COPD cohort study, involving a questionnaire and clinical assessments with 1889 participants, found that only 41% of working-age people with COPD were in paid employment and those with severe COPD symptoms, comorbidities, poor prognostic scores, lower levels of education and who were female, were less likely to be employed. An additional finding was that self-employed individuals were more likely to be employed than those working for a wage (Rai et al. 2017).

Fletcher et al. (2011) had previously conducted a large cross-country, cross-sectional international survey with 2426 participants aged 45–67 with physician diagnosed COPD from Brazil, China, Germany, Turkey, United States and the United Kingdom. They found that 30% of the participants were in paid employment, some attributed retirement from work to their COPD (26%), and others had reduced their working hours or changed job to a less demanding role (12%) (Fletcher et al. 2011). For those retiring early due to COPD, average lifetime loss of earnings was estimated at around £200,000 (Fletcher et al. 2011).

In addition to concerns around employment and unemployment, there are issues around work attendance and productivity. Assessing the disease burden of those under age 65 years includes considering the indirect costs of absenteeism from work, the costs and effects of presenteeism and the impact of a reduction in quality of life (Fletcher et al. 2011). Costing 11 billion pounds per year in the United Kingdom, lung disease has a higher healthcare utilisation cost than other long-term conditions as well as more indirect costs associated with absenteeism and presenteeism (British Lung Foundation 2016). Sickness absence in individuals with COPD tends to occur if their illness threshold and quality of life is low, if they undertake manual work, if the work environment is cold, hot or dusty, and if the level of control they have over their workplace and workplace tasks is low (Kirsch et al. 2019; NICE 2019b; Rai et al. 2017; Fletcher et al. 2011). Additionally, other aspects including disease severity (and related comorbidities), an individual’s effectiveness in coping with their condition and symptoms (personal resilience), the support available within the employee’s workplace and their wider social network (social capital) were also implicated in employment success (Kirsch et al. 2019; Rai et al. 2017).

1.4.4. The Economic Burden of COPD on Individuals and Employers

In the last decade, there has been a concerted focus on examining the financial burden of COPD on employers, healthcare systems and on individuals (Ur Rehman et al. 2019; British Lung Foundation 2016). Direct costs of disease relate to healthcare and medicines and indirect costs relate to lost earnings and pensions, and the employer-borne costs of absenteeism, presenteeism and disability adjustments (Patel, Nagar and Dalal 2014). A wide variability of the costs of COPD across Asia and the USA are cited including annual out patient consultation costs from \$290 (Singapore) to \$1386 (USA) to \$1707 (South Korea), and in Europe, annual in-patient hospitalisation costs from \$613 (Serbia) to \$6929 (Norway) and annual productivity-related costs from €998 (Greece) to €5735 (Germany) (Ur Rehman et al. 2019).

Employers view productivity as a key component of the strength and sustainability of their business and many studies take this focus as 'the bottom line' because income is important for individual companies and global economies (Tillett et al. 2015; Hultin et al. 2013; Fletcher et al. 2011). However, highlighting financial burdens by estimating direct and indirect costs account for only a small proportion of the true costs of COPD and the research has not captured the extent of the economic burden on individuals of working-age particularly well to date (Wacker et al. 2016; Di Bonaventura et al. 2012). Individuals with COPD find being unable to work to earn a living, which causes them financial concerns, difficult to accept and more extreme when they must fund their own COPD treatment (Sigurgeirsdottir et al. 2019).

1.5. The Theoretical Perspective of this Thesis

As the purpose of the thesis is to describe the health and well-being and employment factors in people of working-age with COPD to direct analytical findings towards practice, and in the adoption of interpretive description to achieve this aim, there is no imperative for utilising a specific theoretical framework (Thorne 2016a). This is because the reason for employing a theoretical framework in non-applied research studies is to achieve *'meta-theoretical congruence',* assuming that the underpinning philosophy, methodology and methods are then systematically operationalised throughout the thesis (Durham et al. 2015, p.11). However, theories most associated with long-term conditions were considered, which could serve a wider purpose in this thesis than solely theorising. Therefore, several theoretical frameworks were considered to broadly frame and inform the research questions, influence the research methods selected and potentially guide the interpretation of the study findings and analysis (Lynch et al. 2020; Bordage, Lineberry and Yudkowsky 2016; Green 2014).

1.5.1. Theoretical Framework Considerations

Several theoretical frameworks relevant to the study of long-term conditions were located. These included Transition Theory, which helps to explain the experience of how individuals transition through various life stages and major events (Meleis et al. 2000), and Coping Theory, where individuals cope with health challenges through their emotional response to stress and where they make life changes by taking a positive, adaptive approach to stressors (Lazarus and Folkman 1984). Identity Theory is another relevant theoretical lens where the *'biographical self'* is disrupted because an individual's previously held ideas and conceptualisation of their 'self and self-identity', encompassing social roles and social identity, is altered due to changes in health and/or social status (Bury 1991). Identity Theory could have been appropriate in this thesis as biographical disruption is closely aligned with working-age individuals in health decline due to COPD and the subsequent threats of personal change related to 'losing their job or career' or 'potentially losing their income' (Bury 1991).

However, some of the broader psychological theories of self-determination and resilience were also considered. Self-determination theory, as a motivation-based theory could also have been an appropriate lens for thinking about an individual's motivation to remain in employment and how they cope with their ongoing health challenges (Deci and Ryan 2008). Self-determination theory is already widely used to support health behaviour change in the field of Occupational Health, and is focused on how an individual's autonomy, competence and relatedness contribute to the motivation to sustain positive actions e.g., successful smoking cessation, employee engagement and in satisfying needs (Ross and Barnes 2018; Wiedmann 2016).

Despite the attraction to some of these theories, it is the theory of resilience that was found to be most compelling as it considers that individuals not only bounce back from stressors they encounter, but that they can develop personal skills and learn to thrive following adaptation to life challenges (Seaman et al. 2014; Antonovsky 1987). In addition, the need for successful adaptation to change and challenge is increasing at societal and individual levels, highlighting the need for building capacity and capability for responding to unpredictable global crises (Seaman et al. 2014). A resiliency approach would appear relevant to people with COPD where acute exacerbation, physical decline and physical and psychological workplace challenges exist in an unpredictable world (Spruit et al. 2016).

1.5.2. Definition of Resilience

Resilience theory is firmly embedded in developmental psychology and historically from research on children and adolescents and is a dynamic process whereby individuals make positive adaptations within a context of considerable personal adversity (Windle, Bennett and Noyes 2011). Several diverse definitions, concepts and approaches to the study of resilience are recorded in the literature, although it is difficult to narrow down due to its multidimensional nature (Seaman et al. 2014; Masten 2001). The word 'resilience' stems from the Latin word resiliens which refers to the pliant or elastic quality of a substance and the term is also used interchangeably with the terms of adaptation, coping and persistence (Luthar and Ciccetti 2000). Resilience includes concepts such as invulnerability (Rutter 1987), rebounding (Seaman et al. 2014), and bouncing back (Luthar and Ciccetti 2000) and these are well recorded in the literature. The definition adopted in this thesis is that people can have *'good outcomes in spite of serious threats to adaptation or development'* (Masten 2001, p228).

1.5.3. Concepts of Resilience

Resilience is the individual variation in response to risk where the symptoms of COPD for example and workplace demands are considered as factors that risk the desire to live as 'normal' as possible everyday working lives (Windle, Bennett and Noyes 2011). Some individuals succumb to stress in times of adversity whilst others respond well; therefore, a positive response is influenced by individual and interpersonal competencies that are required to enable the process of resilience to occur (Keil et al. 2017; Aburn, Gott and Hoare 2015; Harrop et al. 2006). These competencies, or protective factors, consist of healthy skills and abilities that individuals access to mitigate perceived stress, enabling them to subsequently thrive and grow (Keil et al. 2017). The process of being resilient is also dependent on positive external factors such as a supportive social network and a favourable working situation (Lenfernik, Van der Palen and Effing 2018; Reich, Zautra and Hall 2010).

The 'status quo' resilience is where individuals return to normality after a crisis (Seaman et al. 2014) and is often called the 'predict and control' approach. An alternative perspective is transformational resilience where individuals 'bounce back', adapt and thrive when faced with new and challenging situations in their life (Seaman et al. 2014). The ability of individuals to transfer experience from one context to another is a useful skill in a world where individuals cannot always predict the next crisis but have developed resiliency skills to enable them to cope with the changes and make necessary personal adaptations (Antonovsky 1987). According to Reich, Zautra and Hall (2010 p.6) this is *'a forward lean toward engagement, purpose and perseverance'* approach. The lean forward perspective is useful for people with COPD, who often face challenging events and subsequently recover, manage to adapt and sustain successfully to make sense and cope with their unpredictable condition (Seaman et al. 2014). Resilience is therefore the interplay between multifactorial internal and external risk factors at individual, familial and societal levels. Resilience theory has traditionally been based on 'psychopathological' and 'deficit' models of illness cognition so understanding a strength-based model focused on healthy development, despite risk is important (Lin, Rong and Lee 2013; Windle, Bennett and Noyes 2011, Antonovsky 1987). The strength-based perspective is therefore useful as it views learned resiliency skills as protective (Seaman et al. 2014).

These learned behaviours of resilience could be at play in the concept of the '*disability paradox'* whereby people with similar biomedical markers of disease severity can report diverging symptom burdens and different degrees of impact on their daily lives (Albrecht and Devlieger 1999). According to Albrecht and Devlieger (1999) whose work was based on that of Levine et al. (1987; cited in

Albrecht and Devlieger 1999, p. 978), *"patients' perceptions of personal health, well-being and life satisfaction are often discordant with their objective health status".* The disability paradox suggests there is more to understand about how individuals can perform at near-normal levels in the workplace despite considerable physical and psychological challenge, in which they appear to achieve a high-quality of life through balancing body, mind and spirit (Cannon et al. 2018; Albrecht and Devlieger 1999). Indeed, it is unclear why some individuals with COPD perceive themselves as being less 'disabled' compared to others with long-term conditions (Keil et al. 2017), which suggests contextual factors are involved and that environmental and personal factors moderate individual resiliency perceptions (Fellinghauer et al. 2012). Individuals who can still achieve a high-quality of life, despite significant challenge, often associate the experience of having a long-term condition with an enriched meaning to their lives (Albrecht and Devlieger 1999).

1.5.4. Resilience in relation to COPD

The ability to 'bounce back' and adapt successfully to the challenges and changes in which people live is a concept relevant to many individuals with a long-term condition (Windle, Bennett and Noyes 2011). Coping with the dynamic circumstances of having a long-term condition, as in for example when people with COPD are having to re-normalise aspects of their life, or are required to reassess their role, identity, and sources of employment, can be a regular occurrence (Seaman et al. 2014). Individuals receiving a COPD diagnosis might consider coping with this lifelong condition as a major life event, in which being resilient could play an important role in optimising health and well-being outcomes (Keil et al. 2017). Identifying protective factors that could enhance employment capability and the experiences of people with COPD, through improving and maintaining physical and mental health, offers an alternative 'salutogenic' viewpoint where individuals can positively adapt and resolve their stressors (Luthar, Lyman and Crossman 2014; Becker, Glascoff and Felts 2010; Antonovsky 1987).

The aim of incorporating the theoretical lens of resilience in this thesis is to consider the presence of any resiliency factors (e.g., personal assets including internal-skills and attributes) and resources (external-support or conditions) which might positively affect employment. The identification of protective factors from the participants' experiences could be useful in determining factors that could contribute to positive employment outcomes.

1.6. My 'theoretical baggage'

My professional experience is as a nurse, lecturer and researcher. Having presented an in-depth introduction to the topic under investigation, it is important to now highlight my experience and interest in COPD. This section considers the 'theoretical baggage' required to *Foresturucture* my preconceived assumptions essential in undertaking studies through the qualitative methodological approach of interpretive description (Thorne 2016a). Interpretive description as a methodology will be explored further in Section 3.6. It is important to highlight that studies using interpretive description are those for which issues stem from the clinical or the professional practice situation and lead to research knowledge linking back and relating to practice where relevant. Throughout my PhD journey, I have ensured that the research is pragmatically driven through engagement with clinicians, national cross-party working groups on lung health in Scotland, meetings, conferences, and organisations such as Chest Heart Stroke Scotland (CHSS), British Lung Foundation (BLF), service users and study supervisors rather than only through the theoretical and academic world of *'Ivory Tower'* ideology.

1.6.1. Forestructure

Between 1997 and 2002, I worked in the community, most recently as a District Nurse. A substantial part of the client group required palliative care with others requiring support for various long-term conditions, many with comorbidities and complex needs. My role was to support individuals with long-term conditions to promote and maintain their optimum health and prevent exacerbations and deterioration. Working with patients, their families and carers required expert nursing skills and specialist knowledge and communication and psychological support skills to help individuals cope with their *'losses'* (loss of health, lifestyle, employment) and adapt to constant well-being changes requiring the development of resiliency skills. I visited housebound patients with COPD to provide a high standard of care and make a positive impact in their lives, which was often challenging. My interest in COPD has been sustained throughout my teaching career with undergraduate and postgraduate students and in my academic activity:

- 2012a - Support for older people with COPD in community settings: a systematic review of qualitative evidence (Kirkpatrick, Wilson and Wimpenny) Funded by Queens Nursing Institute Scotland and Joanna Briggs Institute, RGU £4000;
- 2012b - Research to support evidence-based practice in COPD in Community Nursing (Kirkpatrick, Wilson and Wimpenny);
- 2013 - Use of solution-focused brief therapy to enhance therapeutic communication in patients with COPD (Smith and Kirkpatrick);
- 2015 - The emerging health problem of non-communicable diseases (Nepal: book chapter) (Pant, Vijay, Simkhada, Kirkpatrick and Poobalan);
- 2016 - Sustaining people with dementia or mild cognitive impairment in employment: a systematic review of qualitative evidence (McCulloch, Robertson and Kirkpatrick).

My professional and academic background have influenced both the initial decision to study COPD at Doctoral level and further develop myself as an academic researcher. My motivation to contribute to improving the lives of people with COPD has led to the sustained effort reflected in the work of this thesis. The aim and objectives of the thesis are stated next.

1.7. Thesis Aim and Objectives

1.7.1. Aim

The aim of this thesis is to explore employment aspects in people with COPD to understand the factors affecting employment and people’s experiences of remaining in or leaving employment, to inform and influence the development of research, guidance and/or interventions to support people with COPD in relation to employment.

1.7.2. Objectives

1. To conduct a pilot study to test recruitment and study procedures to enhance the design of a later study;
2. To identify the psychosocial and physical factors that may influence paid employment in people with COPD;
3. To explore in-depth the perceptions and experiences of people with COPD who sustain or cease employment;
4. To understand, from the perspective of people with COPD, the facilitators and barriers to sustaining paid employment;
5. To understand the support required for people with COPD to sustain paid employment;
6. To use the evidence generated from objectives 2-5 to make recommendations for developing guidance and/or interventions to help support people with COPD in relation to employment.

The pilot study (Chapter 4) addresses objectives 1-3. As a pilot study, it was originally intended to pilot the processes for running a larger subsequent study leading to a larger cohort study exploring health and well-being. However, as will be discussed in the conclusion in Chapter 4, the findings from the pilot study informed a change of direction, as it became apparent that further in-depth qualitative research was needed to develop the knowledge foundation. The qualitative study (Chapter 5) addresses objectives 3-6 in full.

1.8. Chapter Conclusion

This chapter presented an overview of COPD and the challenges that people with the condition face in relation to their health, well-being and employment. It is evident that COPD is a pertinent subject of interest for an ageing workforce who will likely face working with one or more long-term conditions in their lifetime. This chapter has also explored the inextricable link between good health and well-being as an essential component for effective employment and having 'good work' as being a key requirement of subsequent good health. Gaining an understanding of individual circumstances relating to health and well-being experiences in the workplace and what it is like for individuals who work with COPD is important. Understanding more about what might help people with

COPD to maintain an employment presence and optimise productivity, is crucial for individuals and economies. This subject is also relevant following the SARS-CoV-2 pandemic where individuals, having recovered from the effects of the virus, have enduring lung damage and face similar symptoms and challenges to people with COPD.

This chapter has illustrated my personal and professional motivation for exploring this topic with enduring commitment. Contributing to the foundation for the studies and their trustworthiness, reflexivity is woven throughout the thesis and the application of interpretive description attributes and values adopted. The theoretical perspective of resilience provides a potential foundation for description and interpretation and interpretive description is explored in-depth in Chapter 2. The structure of the thesis is detailed next.

NOTE: Reference to 'employment' in this thesis relates to paid employment and either working for an employer or self-employed (Charmes 2019).

1.9. The Thesis Structure

The thesis comprises of seven further chapters:

Chapter 2 - Literature Review

This chapter presents a narrative review of contemporary literature exploring employment factors in people with COPD and illustrates the gaps in the research. The strategy taken to inform the literature search process and how the selected literature is critically appraised is also explained. The strengths and limitations of the findings from the literature are also explored. As the literature review was guided by interpretive description, the enabling of the 'scaffolding' of the literature for the qualitative components of the studies is also considered. Chapter 2 concludes by summarising the literature and highlighting the gap in the qualitative research.

Chapter 3 - Research Methodology

This chapter critically discusses the philosophical foundation and practical basis for the underpinning methodological approach taken and methods adopted in both studies. An exploration of the emergence and practice of mixed-methods research in healthcare is discussed and a rationale for adopting this approach is offered. Rigour in mixed-methods research and relevant ethical principles are also addressed in this chapter whilst specific ethical issues and processes are addressed and applied separately within each study.

Chapter 4 – The Psychosocial and Physical Factors Influencing Employment in People with COPD: A mixed-methods pilot study

This chapter presents the methods used in the pilot study, followed by the results and findings from the quantitative and qualitative components. The results and findings are analysed and discussed in full, contextualised to the wider body of literature, and summarised. Links between these results and findings and the subsequent direction of the thesis are explored.

Chapter 5 - The Employment Experiences of People with COPD: A qualitative study

This chapter presents the methods used to explore the experiences of people with COPD in relation to employment. The findings are presented, analysed and discussed in relation to the literature reviewed in Chapter 2 and the wider body of relevant literature on COPD and other long-term conditions. The key findings are brought together in a summary discussion and the original contribution to knowledge is highlighted.

Chapter 6 – Conclusion and Recommendations

In this chapter, key findings are stated, and conclusions are drawn. Strengths and limitations of the research are considered and the original contribution of the research to the body of knowledge reinforced. The main recommendations for healthcare professionals, people with COPD, employers, research, policy and strategy are also considered. The research dissemination plan is considered and, in keeping with the interpretive descriptive approach, reflexive thoughts conclude the thesis.

Chapter 7 – References

This chapter contains the reference sources used and cited throughout the thesis.

Chapter 8 - Appendices

This chapter contains the appendices to accompany and further expand the text in the thesis.

2. Literature Review

2.1. Introduction

Chapter 1 broadly explored aspects of COPD and health and well-being in relation to employment as a means of introducing the topic and setting out the focus of the thesis overall. This chapter reports the process and findings of a narrative review of the contemporary literature exploring employment factors in people with COPD to set the topic in the context of existing knowledge and identifies what this research will contribute to that understanding.

2.2. Chapter Structure

The chapter firstly considers the literature review purpose and process and then links with the methodological approach of interpretive description to further situate the important aspects of COPD and employment to be explored. This is followed by a detailed search strategy, description of studies and summaries of studies included in the literature review. The included studies, consisting of systematic reviews and quantitative research, are critically appraised and explored, and synthesised narratives of the relevant themes are presented. In addition, grey literature is also considered in the form of doctoral studies, which offers some qualitative perspectives on the topic. The strengths and limitations of adopting a narrative literature review are drawn, and conclusions are made about how the key themes from the literature review have informed the knowledge base and influenced the direction of this research.

2.3. The Literature Review Process

To establish a current perspective on a specific topic and to frame it within a wider theoretical understanding, the conduct of a literature review is required (Polit and Beck 2018). The literature review is important as it provides an indication of the gaps in the knowledge base as well as steering the researcher towards setting pertinent study aims and asking the most appropriate research questions (Poilt and Beck 2018). There is some debate as to whether a literature review should be conducted before or after data collection, particularly for qualitative research studies, as there is a concern it may influence the research and the researcher by limiting critical thinking and potentially biasing the study (Greenhalgh, Thorne and Malterud 2018). A literature review, however, is relevant in empirical studies where the research design must be determined and important when using a qualitative interpretive descriptive approach where attention must be given to *'scaffolding'* the research in advance (see Section 2.4) (Thorne 2016a). Reviewing the literature is also crucial in mixed-methods studies such as this because it provides the space and focus to enable contextualisation of the main concepts and themes and to determine the philosophical basis for the study before it is then conducted and reported (Parahoo 2014).

Rather than being considered as an academic exercise, the literature review is a means to add clarity to where the important unanswered questions lie, provide a broad foundation for the topic, and underpin a robust justification for the studies that follow (Parahoo 2014). A literature review also ensures that the subsequent research questions are grounded in a practical foundation that may contribute to the production of useable outcomes to inform future practice, policy and education (Greenhalgh, Thorne and Malterud 2018; Wolcott 2002). Ensuring the literature review is grounded in a practical foundation also fits well with the need to conduct practice driven research which explores employment issues of concern for people with COPD and their families and healthcare professionals.

A variety of literature review approaches were considered for this thesis including the scoping review, critical literature review, systematic review and the narrative review (or traditional literature review) (MacLure, Paudyal and Stewart 2016; Parahoo 2014). A narrative review was chosen for this literature review. Features of different types of literature review are recorded in Table 2.1.

Table 2.1 - Types of Literature Review and Their Main Features

Type of literature review	Description of literature review features
Scoping review	Identifies gaps in research literature by mapping and categorising existing literature to provide an accurate picture. Used to commission further reviews and/or primary research.
Critical literature review	Demonstrates extensive research and critical evaluation of quality. Goes beyond merely describing to include degree of analysis and conceptual innovation. Typically results in hypothesis or a model.
Systematic review	Addresses a specific research question and may use a protocol and a PICO question (population, intervention, context, and outcome) as a guide. Involves systematic appraisal and synthesis of the evidence and explicitly reports on the validity of studies included. Includes both experimental and non-experimental research for a more comprehensive understanding of a phenomenon. May statistically combine results from prior quantitative studies.
Narrative literature review (Traditional literature review)	Broadly examines and provides a summary of the current literature. Can cover a wide range of subjects and themes at various levels of completeness and comprehensiveness. May include research findings. Selection of evidence may not be systematic and may not report on quality. Largely descriptive and conclusions are usually subjective and not based on study quality alone.

Adapted from Booth, Sutton and Papaioannou (2016) p.26.

This thesis required a more in-depth analysis of the current literature than the scoping review offers, as this review reports on the specific nature and extent of the current literature. The main focus of a scoping review is to broadly map the literature into themes and types, illustrating areas where knowledge exists and where the gaps in the literature are and may involve critical evaluation or data analysis or synthesis, although this is not common (Peters et al. 2015).

A critical literature review was also considered, which is geared towards hypothesis building (Booth, Sutton and Papaioannou 2016). However, as the aim of this thesis is oriented towards establishing a clear and current account of the issues relevant to those with COPD in relation to employment, the critical literature approach was not the best option. Addressing a more focused question is best achieved through undertaking a systematic review which is methodologically explicit in using systematic techniques to select and critically review the relevant literature (Peters et al. 2015; Aromataris and Pearson 2014). Systematic reviews are based on an *a priori* protocol providing an audit trail of the systematic search for literature, critical appraisal of the included literature, data extraction methods and meta-analysis or synthesis of the results and or findings (Munn et al. 2018; Aveyard, Payne and Preston 2016). A systematic review will also adhere to the guidelines from the PRISMA statement (preferred reporting guidelines for systematic reviews and meta-analyses) for itemising the clear and consistent reporting of a review for clarity and transparency (Page et al. 2020; Munn et al. 2018).

Systematic reviews are regarded as the *'gold standard'* for summarising and producing the best available evidence relevant for practice; this is not to say that the narrative literature review is the *'poor cousin'*, as they are indeed complementary forms of scholarship (Greenhalgh, Thorne and Malterud 2018; Coughlan, Cronin and Ryan 2013; Pearson 2004). An interpretive overview in the form of a narrative literature review is considered appropriate here, as it takes a wide perspective incorporating themes and topics considered relevant to address the study aims (Greenhalgh, Thorne and Malterud 2018; Booth, Sutton and Papaioannou 2016).

The narrative literature review is less structured than a systematic review and does not require explicit transparency of the search strategy and critical appraisal processes (Coughlan, Cronin and Ryan 2013; Aromataris and Riitano 2014; Collins and Fauser 2005). However, it is useful to provide clarity on the basis of the literature review processes to enhance transparency and enable replication. This is especially pertinent for the key search terms, search strings, databases searched, findings from the search and the inclusion and exclusion criteria (Coughlan, Cronin and Ryan 2013; Booth, Sutton and Papaioannou 2012). Therefore, the literature review presented here details the search strategy and the criteria for inclusion. Due to the purpose of the literature review, to provide an overview of employment and COPD, the review is broad in nature, and it is acknowledged that I made the sole decisions on the inclusion and exclusion of items. The narrative literature review search strategy is documented after firstly setting the context of interpretive description, which is adopted as a methodology guiding the conduct of the qualitative studies in this thesis.

2.4. Interpretive Description - Scaffolding the Study

The primary motivation for undertaking the studies presented in this thesis was that the knowledge gained may in some way contribute to the holistic support of individuals through developing the knowledge base around COPD and employment. This relates in particular to having conversations about employment during clinical encounters between healthcare professionals and people with COPD. Setting the qualitative studies within a methodological framework warranted the adoption of an approach that would embrace my clinical expertise and further develop my knowledge of the topic, for which I could then use the outcomes to inform practice. To do this, I chose interpretive description as a framework to guide the methods of both qualitative studies (Thorne 2016a; Oliver 2012). Thorne (2016b) suggests that the importance of questioning the knowledge base in interpretive description is to ultimately make improvements in the quality of the lives of those that find themselves with difficult and complex health issues. Interpretive description will be discussed in greater depth in Chapter 3, although there are important aspects, pertinent to interpretive description, which must be detailed and explored before the literature review is presented. Thorne (2008) talks of the importance of *Scaffolding* the interpretive descriptive methodological framework at the study design stage. Scaffolding sets up the starting position from which the study design is built and consists of two elements (i) the literature review and (ii) clarifying the theoretical structure. In Chapter 1, I presented my personal and professional motivations for conducting COPD research and set the scene through declaring and explaining the knowledge and experience I bring to the study; the '*theoretical forestructure'*. Essentially this is about clarifying my preconceived assumptions on the topic.

Combining the process of '*theoretical forestructure'* from Chapter 1 with the narrative literature review in this chapter enables me to be located, as Thorne says, *"substantively, theoretically and within a disciplinary orientation"* enabling a broad and deep representation of the *"state of the science"* in relation to employment in people with COPD (Thorne 2008, p.54 and 55). This is an essential position from which to undertake a study of this nature and requires critical perspectives and reflection to be taken on what does and does not exist in the current body of research (Oliver 2012). Initially, a collation and theming of the literature is completed to provide a critical account (or interpretive description) of '*what is'* to assist in generating research questions and thereafter exploring the data to achieve the research objectives. Determining the general and particular insights derived from individual descriptions and explanations of experiences of the phenomenon through interpretive description enables progression beyond simple description. This approach allows provisional links to be made to important concepts and moves to actively influence a positive impact on people with COPD in respect of employment experiences and outcomes (Thorne 2015a; Oliver 2012). The literature review is carried out in a robust and systematic way in keeping with interpretive description, as the researcher is encouraged to ensure they are familiar with the literature through reading, re-reading and using logic, reasoning and interpretation to fully understand what is currently known about the topic's main themes (Thorne 2016a). In terms of the balance of discussion within the literature review, the focus of interpretive description is to provide equal weighting between the theoretical development of the studies selected and their practical and clinical application to the research themes thereafter (Thorne 2016a).

2.5. Search Strategy

In order to set the parameters for the literature search and address relevant topics, it is important to reiterate the purpose of a literature review. A literature review seeks to determine and contextualise the main concepts and themes relating to employment and COPD to inform the research questions and justify the study. With the ongoing support and guidance from a librarian, the key words and search terms for the search strategy were identified as: COPD and employment (see logic grid in Table 2.2). COPD was expanded to encompass the terms indicated in Table 2.3, and employment (including the term occupation), work (encompassing productivity), career and job were used to expand the scope of the search.

Study designs of interest included primary research of any type (quantitative, qualitative and mixed-methods) and systematic reviews. As pertinent literature sources were drawn from fields of health and social care literature, Medical Literature Analysis and Retrieval System Online (MEDLINE®) and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases were considered most appropriate to search initially. In addition, Web of Science, Mark Allen Group (MAG Online) and Science Direct databases were also searched for relevant studies. Although most relevant records should be found in MEDLINE and CINAHL databases, due to the potential for anomalies in indexing and to ensure a thorough search, publishers' databases were also searched.

The Cochrane Library and The Joanna Briggs (JBI) Database of Systematic Reviews and Implementation Reports were also searched for systematic reviews on the relevant topics; however, no further systematic reviews were identified. In MEDLINE® and CINAHL, the key words were combined to ensure the search remained focused. Boolean operators of 'AND' and 'OR', and truncation (*) were used to reduce the number of hits and maximise the relevant literature whilst making the process meaningful (able to fully explore the knowledge base of the topics) and manageable within the resource constraints (time and money), (Booth, Sutton and Papaioannou 2016).

Table 2.2 - Logic Grid with Key Words and Search Terms

COPD	**Employment**
COPD, chronic obstructive pulmonary disease, chronic obstructive airways disease, lung diseases, chronic obstructive lung disease	Employment, work/working, career, job

The literature review progressed during the study duration and was finalised in September 2021. The search was limited to the English language and date limits were not set to ensure it captured all relevant research. Although not a systematic review, this review was informed by systematic review methodology (Aromataris and Munn 2020). Anticipating a lack of literature specifically addressing employment factors in people with COPD from initial scoping searches, grey literature in the form of doctoral theses were also considered for inclusion. The search strings are detailed in Table 2.3.

Table 2.3 - Search Strings Used for MEDLINE and CINAHL

Databases and search strings	**Number of hits**
Search 1: MEDLINE®	
1. COPD OR chronic obstructive pulmonary disease OR chronic obstructive airways disease OR chronic obstructive lung disease [TI]	57,244
2. Employ*	675,963
3. Work*	1,803,094
4. Career	69,987
5. Job	131,222
6. 2 OR 3 OR 4 OR 5 [AB]	2,072,312
7. 1 AND 6	3,078
Search 2: CINAHL	
1. Pulmonary disease, chronic obstructive OR lung diseases, obstructive OR chronic obstructive pulmonary disease [TI]	16,247
2. Employ*	189,819
3. Work*	583,498
4. Career	59,946
5. Job	101,949
6. 2 OR 3 OR 4 OR 5 [AB]	775,455
7. 1 AND 6	955

A total of 3,078 records were located in MEDLINE® (Search 1) using MeSH headings where relevant, and 955 records located in CINAHL (Search 2). Three Doctoral theses were located in EThOS, the online e-thesis database giving a total of 4,033 records. (Similar additional searches were conducted in Internurse, Emerald Insight and Psychinfo, revealing no further records that met the inclusion criteria). Duplicate records (n=287) and those not in English (n=14) were removed leaving a total of 3,732 records.

Application of the inclusion criteria (COPD as main condition; sustaining or leaving employment; barriers and facilitators to employment; aspects of workplace well-being) provided the basis for sifting the titles and abstracts (Porritt, Gomersall and Lockwood 2014). Titles and abstracts were screened, and 3,717 records excluded leaving 15 reports for retrieval and critical appraisal. The reference lists and bibliographies of the 15 located reports were also hand searched, which uncovered no additional relevant literature.

Appropriate JBI Critical Appraisal Checklists were utilised to determine the methodological rigour of 15 reports (JBI critical appraisal checklist for systematic reviews and research syntheses; JBI critical appraisal checklist for analytical and cross-sectional studies) (JBI 2019). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 (PRISMA) diagram (see Figure 2.1), illustrates details of the selection and inclusion process (Page et al. 2020).

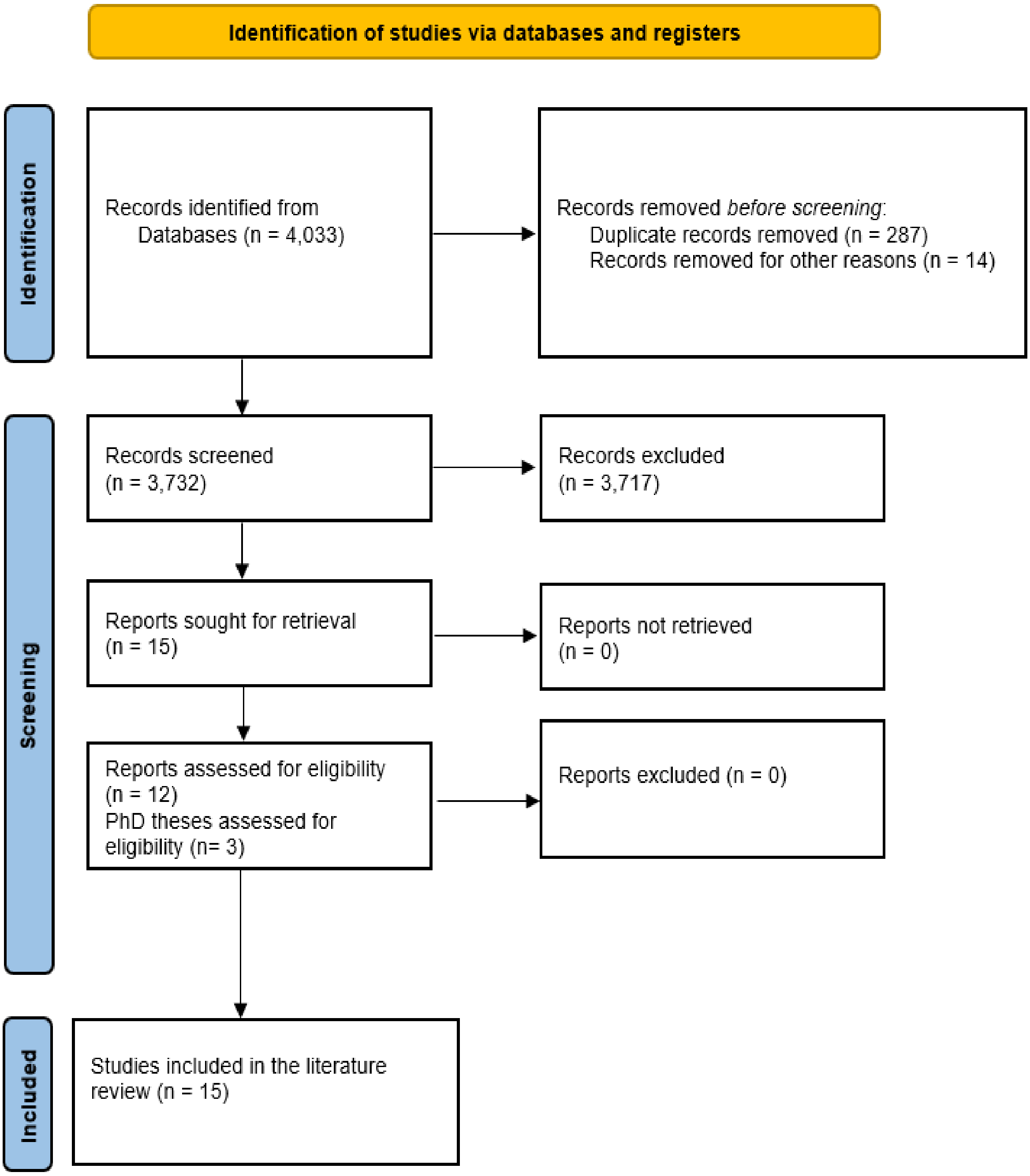


Figure 2.1 - The Preferred Reporting Items for Systematic Reviews and Meta-Analyses

2.6. Description of Included Studies

The search revealed several quantitative studies of interest. Two quantitative systematic reviews, one by Rai et al. (2018) and another by Zhu et al. (2018) are also included in this literature review, as they address employment aspects in people with COPD and represent the highest form of evidence with respect to validity and applicability (Murad et al. 2016) over other study designs including cohort and case control studies. In addition, there are a further ten quantitative studies (one cohort study and nine cross-sectional studies) that could offer further relevant perspectives on the topic were also included. The data collection approaches taken in the quantitative studies included written and face-to-face questionnaires, telephone questionnaires, company database reviews and hospital chart reviews. Confirmation of participants having COPD was mainly achieved in the studies through self-reports, physician or technician confirmed reports, database claims and through conducting spirometry. The studies focused on aspects of COPD and employment including demographic data, socioeconomic factors, lung health, physical health status, physical activity, respiratory symptoms, exacerbations, self-efficacy, quality of life, coping, psychological status, work characteristics, employment rates, sick leave, presenteeism, direct sickness absence costs, disability costs and costs to early retirement.

The literature search did not find any qualitative research on COPD and employment experiences, although wider searching of the grey literature located three doctoral studies which contained topic relevant content. However, there is a large body of qualitative research on COPD in relation to understanding peoples' experiences of: illness perceptions and health outcomes (Sawyer, Harris and Koenig 2019); chronic pain (Lee et al. 2018); declining pulmonary rehabilitation (Harrison et al. 2015); breathlessness (Kvangarsnes et al. 2013); psychosocial dimensions for patient and family (Gullick 2012); lived experience of COPD (Rubio 2019; Castelino et al. 2018; Steindal et al. 2017; Rzadkiewicz, Bratas and Espnes 2016; Sossai, Gray and Tanner 2011) and perceived COPD support needs (Gardener et al. 2018). In addition, there is an abundance of qualitative research on respiratory conditions including, for example, perceptions of asthma control (Menzies-Gow and Chiu 2017), physical activity in cystic fibrosis (Burnett, Barry and Mermis 2020) and quality of life in patients with lung cancer (Polanski et al. 2016; Pickard et al. 2008). The lack of qualitative research on employment experiences in people with COPD indicates a gap in the knowledge base for this subject and therefore the grey literature was included. In order to provide context for the thesis, and although this was not a systematic review, the inclusion of theses in the absence of published material is in keeping with methodological guidance (JBI 2017).

The grey literature utilised semi-structured interviews and employed thematic and framework analysis to analyse their data. The studies were broadly focused, with one solely focused on women, and were entitled: The experience of women under age 65 years working and living with COPD (Mal'ouf 2016), The working-age experience of living with COPD (Masters 2018), and Patient and professional perspectives on living with COPD (Watson 2015).

The next section of this literature review summarises and discusses the twelve quantitative studies included in this literature review.

2.7. Quantitative Systematic Reviews and Primary Research

Summaries of the quantitative systematic reviews and primary research are presented in Table 2.4 and Table 2.5

Table 2.4 - Summaries of the Included Quantitative Systematic Reviews

Quantitative Systematic Reviews			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
RAI, K et al., 2018 Systematic review: chronic obstructive pulmonary disease and work-related outcomes. ***Occupational Medicine*** UK	**Aim:** To summarise the findings of the studies and identify the key disease-related factors that are associated with poorer working outcomes among those with COPD.	**Methodology and Design:** Quantitative systematic review including cohort and cross-sectional studies. **Sample:** 44 studies met the inclusion criteria. **Data collection:** Search strategy on four databases (CINAHL, Embase, MEDLINE and the Cochrane Library) from 1937-Aug 2017 (1937 inception date of database). **Analysis:** Summary statistics and narrative due to a high study heterogeneity.	**Findings:** COPD patients have lower employment rates than those without COPD and of those in work. Patients with COPD took more time off and reported poorer work performance. Findings are broadly similar to other studies. **Limitations:** Impact of disease severity on the outcomes was unclear and generally there was a lack of adjustment for important confounders. No gold-standard tool available to determine the methodological quality of cross-sectional studies. One reviewer screened all the database citations. Not possible to compare, analyse or synthesise data.
ZHU, B. et al., 2018 Disease burden of COPD in China: a systematic review. ***International Journal of COPD*** CHINA	**Aim:** To quantify the disease burden of COPD in China.	**Methodology and Design:** Quantitative systematic review. **Sample:** 47 studies (published before October 2015) met the inclusion criteria. **Data collection:** Search strategy on six named databases (CNKI, Wanfang data, VIP, PubMed, Embase and Cochrane but there may be others). **Analysis:** Descriptive statistics. (Tools used SF-36, SF-12, EQ-5D, St George's respiratory questionnaire, MCMQ (Medical coping modes questionnaire).	**Findings:** The status of QoL was worse in patients with COPD than in non-COPD patients. Unclear what the impact of COPD is on productivity. Lifetime indirect costs reported between 678 – 7,256 USD. **Limitations:** Research studies included are varied in terms of study design and heterogeneity of sample characteristics which may bias findings.

Table 2.5 - Summaries of the Included Primary Quantitative Studies

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
ANDENAES, R et al., 2014 The relationships of self-efficacy, physical activity, paid work to health-related quality of life among patients with chronic obstructive pulmonary disease (COPD). ***Journal of Multidisciplinary Healthcare.*** NORWAY	**Aim:** To evaluate the relationships among physical activity, general self-efficacy, and the physical and mental components of HRQoL.	**Methodology & and Design:** Cross-sectional correlational analysis on HRQoL, physical activity, self-efficacy, and socio-economic factors. **Sample:** 97 COPD patients with physician-confirmed COPD recruited through people attending pulmonary rehabilitation programmes. **Data collection:** Quantitative – Self-report survey – written questionnaire detailing QoL (SF-36), self-efficacy, physical component summary (PCS) and a mental component survey (MCS) looking at physical and mental dimensions of HRQoL apperception and coping. **Analysis:** Cross-sectional correlational analysis.	**Findings/conclusions:** For people undertaking pulmonary rehabilitation, participation in paid work may be an important factor in improving the HRQoL in patients with COPD. **Limitations:** Lack of data on disease severity, performance-based activity and missing clinical variables – BMI, smoking and comorbidities – therefore, there were no clear strategies for dealing with these confounders. Cross-sectional design prevents interpretations of causality and self-reported data and the risk of participant response bias exaggerating or minimising effect of their disease.
BOOT, C et al., 2005 Sick leave in patients with obstructive lung disease is related to psychosocial and work variables rather than to FEV1. ***Respiratory Medicine*** NETHERLANDS	**Aim:** To investigate associations between sick leave in workers with asthma or COPD and variables related to disease severity, as well as psychosocial, and work characteristics.	**Methodology and Design:** Quantitative cross-sectional survey. **Sample:** 189 physician-diagnosed (self-reported sick leave) with asthma and COPD. (118 asthma; 71 COPD). Recruited through adverts in free local newspapers, posters in pharmacists, general practitioners and physical therapists and personal invitation by chest physicians, occupational physicians and medical advisors. **Data collection:** Face to face written questionnaires. Lung function was conducted by trained technicians. Dyspnoea measured by Physical Activity Rating Scale (PARS) QoL measured by 4 subscales of the Quality of Life for Respiratory Illness Questionnaire (QoL-RIQ) including social activities, relationships and sexuality, emotions, general activities in daily life. Fatigue measured through the Short Fatigue Questionnaire (4-item) (SFQ).	**Findings:** Number of episodes of sick leave in asthma and COPD is not associated with FEV^1. Psychosocial variables, work characteristics, functional limitations, and complaints play a more important role in sick leave in workers with asthma and COPD than FEV$_1$. Separated by GOLD criteria. **Limitations:** 1. Information about exacerbations during episodes of sick leave would have increased the validity about conclusions made about disease severity and sick leave. 2. Separated people using inhalers for COPD and asthma by GOLD criteria as valid. 3. Classified anyone with sick leave over 1 month as 'high sick leave' and others as high or low. 4. Self-report info on sick leave may have been biased (a combination of memory bias and social desirability responses might have biased the results). 5. Broad recruitment strategy through local adverts, posters and physician invitation to reduce selection bias. 6. Only people with light to moderate asthma and COPD participated.

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
		Work aspects measured by frequently used Dutch Questionnaires and measured physical and mental workload, pulmonary aggregating factors, utilisation of job control, capability of managing job and household, frequency and duration of sick leave, health complaints, functional limitations, work characteristics and the Beck Depression Inventory (BDI) was used to measure depression. **Analysis:** Data stratified by condition and allocated as high or low (3 or more episodes and 2 or less episodes sick leave in last 12 months). Multivariate analysis & logistic regression.	
ERDAL, M., et al., 2014 Productivity losses in chronic obstructive pulmonary disease: a population-based survey ***BMJ Open Respiratory Research*** NORWAY	**Aim:** To estimate annual, incremental societal productivity losses due to COPD and examine predictors of these.	**Methodology and Design:** Quantitative cross-sectional survey & control group. **Sample:** 102 hospital and 53 population people with physician-confirmed COPD (control with none = 107) age 40 – 67 recruited from hospital patient registers. **Data collection:** Face- to-face baseline interview for demographics (smoking habits, employment status, comorbidities (Charlson Comorbidity Index) and exacerbations of respiratory symptoms) and healthcare utilisation then four quarterly telephone or face to face interviews to discuss employment and productivity loss and sick leave. **Analysis:** t tests and ANOVA, x^2, Kruskall Wallis, trend test and Spearman's Correlation.	**Findings:** The societal burden of productivity losses in chronic obstructive pulmonary disease (COPD) is considerable and can, to a large degree, be explained by exacerbations and comorbid diseases. Studies on hospital recruited subjects may provide biased estimates of burdens of disease. Hospital recruited had more severe disease and more comorbidities and exacerbations. **Limitations:** Excluded never smoked. A low number of the population recruited with severe and very severe obstruction. Possible selection bias, although response rates high. Self-reported data may cause recall bias, but interviewers were trained and received comprehensive guidance notes and given a short recall period (3 months). Accept that through recall bias of sick leave and the potential presence of comorbidities there might be bias might be present that cannot be controlled. Human capital approach used to calculate productivity losses which doesn't allow for local absorption of actual losses (friction cost method). Occupation of participants was unknown and no data were collected on presenteeism.
IGARASHI, A et al., 2018 COPD uncovered: a cross-sectional study to assess the	**Aim:** To describe the socioeconomic burden of COPD in Japan and the impact it may have on	**Methodology and Design:** Quantitative retrospective cross-sectional chart review and patient reported outcomes.	**Findings:** High impact of work impairment and productivity loss observed frequently in the working-age population. Work activity impairment significantly higher in those with higher CAT scores.

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
socioeconomic burden of COPD in Japan. ***International Journal of COPD.*** JAPAN	the working-age population.	**Sample:** Physician confirmed airflow obstruction – 71 under age 65/151 over 65 recruited from patients attending a physician clinic. **Data collection:** 2-year retrospective chart review of socioeconomic details (age, gender, BMI, smoking history, employment status) clinical data (duration of COPD, severity, comorbidities, ongoing COPD treatment and exacerbation history), healthcare utilisation and a questionnaire. Outcome measurements of the questionnaire included BODE, CAT, Productivity) WPAI-GH, (Quality of Life) EQ-5D-5L and treatment, consultations, hospitalisations, emergency hospital visits and pulmonary rehabilitation. Measures correlate to CAT. **Analysis:** Descriptive statistics.	**Limitations:** Sample not powered for age group stratification. Confounders not specified as documentary and chart data missing and data were not accounted for in limiting this potential bias. Included questionnaires on current status e.g., productivity. Number of participants of working age small, as in Japan COPD diagnoses tends to be made later in life. Possible selection bias as low recruitment in younger age group. Most severely patients may have been motivated to participate to effect better care from physician.
KOURLABA, G et al., 2016 The disease burden of chronic obstructive pulmonary disease in Greece ***International Journal of COPD*** GREECE	**Aim:** To estimate the current self-reported prevalence of COPD in Greece, to quantify the burden of the disease on patients' daily living, work, and estimate patients' psychological distress.	**Methodology and Design:** Quantitative population based cross-sectional study. **Sample:** 351 people with physician diagnosed COPD selected through random dialling telephone numbers. **Data collection:** Survey – computer-assisted telephone interview (completed by the main caregiver for 62 participants)– from the global Confronting COPD questionnaire. Considered the impact of COPD on daily activities, work and psychological status. **Analysis:** Descriptive summary statistics and *t*-test, Mann-Whitney *U*-test, one way ANOVA.	**Findings:** Revealed a 28% employment rate, almost 20% of workers missed work in the last 12 months due to their respiratory condition and 40% limited in the type of work they could do. Only 6% were free of comorbidities with 77% having asthma, 52% having hypertension and 20% having diabetes. **Limitations:** Self-reporting COPD, so prevalence and severity may be underestimated. Limited to telephone survey and lower response rate. Telephone survey excludes those without telephones therefore biased towards those that do and cannot be controlled. GOLD categories estimated based on self-reported CAT scores and no spirometry or anthropometrical measurements was undertaken therefore COPD severity could not be ascertained.
LIM, S et al., 2015 Impact of chronic obstructive pulmonary disease (COPD) in	**Aim:** To gain further insight regarding the current prevalence and	**Methodology and Design:** Quantitative cross-sectional study. **Sample:** 1,841 people ≥40yrs with COPD Pan Asia (China, Hong Kong, Taiwan, Indonesia, Malaysia, Philippines, Singapore,	**Findings:** Collected data on prevalence and burden of COPD - used indicators of exacerbation (cough, sputum) to report on impact of exacerbation. Only 20% of sample over age 65. 56% female and 47% currently employed (30% sample from Singapore – 75% from Hong Kong). 23% reported

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
the Asia-Pacific region: the EPIC Asia population study. ***Asia Pacific Family Medicine*** 9 ASIA-PACIFIC TERRITORIES	burden of COPD in the Asia-Pacific Region.	Thailand, Vietnam) selected through random sampling. Participants recruited through screening geographically stratified samples of 201921 households and conducted through telephone and face-to-face interview. **Data collection:** A cross-sectional survey – using a structured questionnaire. Used a previously validated questionnaire e.g., EPIC study looking at prevalence, exacerbations and impact of COPD on employment and work loss to estimate the direct and indirect societal costs. **Analysis:** Descriptive statistics.	that COPD kept them from work (44% Indonesia/51% Philippines). 42% felt COPD limited kind/amount of work they can do. Estimated productivity 72% (okay day) to 45% on a day when condition at its worst. 39% limited normal activities (walking), 27-49% considered COPD to restrict sleep, household chores, sex life and recreation. Only 45% of sample had no ties with others having nasal allergy, rhinitis, arthritis, asthma, diabetes, hypertension and heart disease. 46% had an exacerbation within last 12 months. 26% visited hospital emergency rooms, 32% visited doctor/clinic and 19% had been hospitalised in last 12 months. **Limitations:** Considered bias and minimised through randomised sampling. Previous validation questionnaire used in larger studies with people with COPD. COPD not confirmed by physician or spirometry. Potential for recall bias and misperception of their symptoms and disease and could not be controlled. Potential therefore for underdiagnosis and inaccurate GOLD classification. Translation of English language questionnaire by local translator and reviewed by translator experienced in health & local medical experts. Data collected by trained 'fieldwork teams'. Country sample size small so question a meaningful conclusion.
PATEL, J et al., 2018 COPD affects worker productivity and health care costs ***International Journal of COPD*** USA	**Aim:** To provide incremental estimates of direct and indirect burden of COPD using data from nationally representative setting of working-age patients with COPD with employer-sponsored insurance. Explore the impact of frequency of exacerbations on both direct and indirect costs.	**Methodology and Design:** Quantitative, retrospective matched-cohort study (Observational). **Sample:** Included 5,701 people with physician-confirmed COPD (17,103 without) age 18-65. **Data collection:** Used insurance claims data from insurance claims company on absenteeism, presenteeism and indirect costs and Health and Productivity Management (HPM) databases. **Analysis:** Multivariate analysis with logistic regression.	**Findings:** Working-age patients incur significantly higher indirect costs due to their COPD compared to those who don't have the condition (66% male). Loss of productivity significantly greater in patients with COPD with an average of 5 more days off per year compared with this who do not have COPD. **Limitations:** Mean age of 53 (5.5), lowest age 18 and unlikely to have COPD. May underestimate costs due to considering only short-term disability and not absenteeism, presenteeism or long-term disability. Data not confounded by exacerbator classification, as no productivity metrics were used. Larger sample required to corroborate impact of exacerbator status on productivity and participation in workforce. Models were adjusted for comorbidities, although some conditions might not be accounted for. Only short-

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
			term disability was included meaning some absenteeism, presenteeism and long-term disability will be missed. Other confounders not accounted for include timing of diagnosis in the calendar year and inaccurate accounting for exacerbator effects could have led to underestimated costs.
UZASLAN, et al., 2012 The burden of chronic obstructive pulmonary disease in the Middle East and North Africa: results of the BREATHE study. **Respiratory Medicine.** MENA	**Aim:** To present data from the BREATHE study on the MENA region.	**Methodology and Design:** Cross-sectional epidemiological survey. **Sample:** 1,392 people with self-reported COPD recruited through a general population sample generated by using a random stratified sampling method. Participants from Algeria, Egypt, Jordan, Lebanon, Morocco, Pakistan, Saudi Arabia, Syria, Turkey, UAE. **Data collection:** Telephone screening questions then telephone interview - questionnaire with 77 items by trained interviewers using the Computer Assisted Personal Viewing (CAPI) method. Data on details of the disease, severity and cost of the disease were collected. Impact of COPD on work and activities of daily living. **Analysis:** Descriptive analysis.	**Findings:** Results indicate COPD has a substantial impact on work given that 28% report respiratory condition kept them from work. **Limitations:** Lower health expectations in this location skews the results and telephone survey and self-reports of COPD. Sampling and data collection methods pose limitations including exclusion of those without telephones, and older and more remote living individuals. Other areas of bias might have come from including people who smoked/had smoked and acknowledge other causative factors including exposure to smoke from biomass fuel common in the MENA region and may underestimate the real number of people with COPD. Clinical symptoms and diagnosis or treatments were not ascertained by interviewers so accuracy cannot be assured re diagnosis.
Van BOVEN, J et al., 2013 COPD in the working-age population: the economic impact on both patients and government ***Journal of chronic obstructive pulmonary disease*** NETHERLANDS	**Aim:** To explore the full economic impact on both patients and government, as a result of COPD in the working-age population.	**Methodology and Design:** Quantitative – cross-sectional cost analysis. **Sample:** Dutch population, age 45-64 based on COPD verification. **Data collection:** Database - data from 2 secondary sources – National (UK) and COPD Uncovered data (Fletcher et al. 2011). Direct medical costs and costs due to early retirement and impaired productivity. **Analysis:** Cost model calculation.	**Findings:** Early retirement financial loss is high for people with COPD of working age (twice the direct medical costs). 52% of those with COPD retired between the age of 45-64 and of those, 37% retired before the age of 65 because of the severity of their COPD. **Limitations:** May have underestimated costs due to underdiagnoses or misdiagnosis and COPD considered as both a primary diagnosis and as a comorbidity. Used some UK data as a baseline for productivity calculation, as no Dutch data were available. Family member loss of productivity due to caregiving not included so costs might be underestimated.

Quantitative Studies			
Author, Date, Title, Journal, Country	**Aim/s**	**Methodology and Design**	**Key Findings**
YELIN E et al., 2006 Work life of persons with asthma, rhinitis, and COPD: a study using a national, population based sample. ***Journal of Occupational Medicine and Toxicology*** USA	**Aim:** To estimate the duration of work life among persons reporting a physician's diagnosis of COPD, asthma or rhinitis compared to those with select non respiratory conditions or none. To delineate the factors associated with continuance of employment.	**Methodology and Design:** Quantitative cross sectional, structured telephone survey. **Sample:** Physician-diagnosed people with COPD, asthma or rhinitis age 55- 75. Recruited through random-digit dialling techniques in 'hot spots' of the areas with the highest COPD mortality rates from the National Institute of Occupational Safety and Health Atlas of Respiratory Disease Mortality in the US 1982-1993. Also included top-quartile localities with elevated age-adjusted mortality rates and did random sampling. Excluded those not reporting a physician diagnosis of COPD. **Data collection:** Structured telephone interview and SF-12 and health, employment history, and employment status questionnaire. **Analysis:** Statistical analyses: xtabs, F-tests, Wilcoxon, Cox regression analysis and demographics.	**Findings:** COPD (and to a lesser extent asthma and rhinitis) are associated with a substantially shortened working life, an effect not due to demographics or work characteristics. At age 55, only 62% of people with COPD were working, which is lower than those with asthma or rhinitis. People with COPD left work significantly earlier than those with asthma, rhinitis and other chronic conditions. **Limitations:** Diagnoses based on self-reports of physician diagnosis. Recall bias could also limit the study findings. Some data related to asthma and rhinitis. Missed a population within institutions who might have severe COPD. Advanced age weakly but significantly associated with decreased risk of leaving work, but because those who had died just prior to data collection were not included they might have left work early and have been missed. However, this might offset other biases.

2.7.1. Critical Appraisal

Critical appraisal of the systematic reviews and quantitative studies was conducted to determine their quality and methodological rigour. The critical appraisal table for the included systematic reviews is shown in Table 2.6. The review by Rai et al. (2018) met all the relevant criteria in the JBI critical appraisal checklist for Systematic Reviews and Research Syntheses demonstrating high methodological quality (Aromataris et al. 2015). The Zhu et al. (2018) review is of a satisfactory quality but was judged to be unclear on questions considering whether the inclusion criteria were appropriate for the review question and on whether the likelihood of publication bias was addressed.

Table 2.6 - Critical Appraisal Table of the Included Systematic Reviews

JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses	**Rai et al 2018**	**Zhu et al 2018**
Appraisal Questions		
1. Is the review question clearly and explicitly stated?	Y	Y
2. Were the inclusion criteria appropriate for the review question?	Y	U
3. Was the search strategy appropriate?	Y	Y
4. Were the sources and resources used to search for studies adequate?	Y	Y
5. Were the criteria for appraising studies appropriate?	Y	Y
6. Was critical appraisal conducted by two or more reviewers independently?	Y	Y
7. Were there methods to minimise errors in data extraction?	Y	Y
8. Were the methods used to combine studies appropriate?	NA	NA
9. Was the likelihood of publication bias assessed?	Y	U
10. Were recommendations for policy and/or practice supported by the reported data?	Y	Y
11. Were the specific directives for new research appropriate?	Y	Y

Y = Yes; N = No; NA = Not appropriate; U = Unclear

The recent systematic review by Rai et al. (2018) is discussed first as it takes an international perspective. It is therefore useful as a foundation for the remainder of the literature review in outlining and explaining pertinent topic related themes and concepts.

2.7.2. Systematic Review by Rai et al. (2018)

The aims of the systematic review conducted by Rai et al. (2018) entitled '*Systematic review: chronic obstructive pulmonary disease and work-related outcomes'* were to identify the main disease-related factors associated with poorer working outcomes in people with COPD and to consider the effect of COPD on employment, absenteeism and presenteeism. Ten of the studies included in the systematic review were considered *'high quality'* with the review authors stating that the researchers *'verified the degree of airflow obstruction through spirometry'* for all participants (rather than unreliable self-reports without physician diagnoses). This implied an accurate diagnosis of COPD and therefore convinced the researchers it was a high-quality study (Rai et al. 2018). The high-quality studies included in the review also accounted for confounders addressing issues of potential bias on several variables including, for example, comorbidities, gender and smoking, which is important for studies of this type often limited by confounding factors. A clear systematic review process audit trail was evident and additional data tables available for scrutiny, confirming a rigorous approach was taken and appropriate critical decisions made about study inclusion in the review.

There are also some limitations of the systematic review. One reviewer (the first author) screened the initial citations which may be considered a bias (Porritt, Gomersall and Lockwood 2014), although a second reviewer was tasked with reviewing the included studies and assured methodological quality in a random sample of 45% (Rai et al. 2018). However, no justification was given for the percentage of studies selected for the second review or indeed which studies were checked by the second reviewer. Also, no mention was made to account for variation in data extraction methods, although a sample of these were also verified by a second reviewer. There was overall agreement with the reviewer/s that, in the main, confounding variables had been controlled for or analytical adjustments made in the relevant studies, but some issues were noted, for example, around lack of accounting for time in a longitudinal study and how this was subsequently analysed (Rai et al. 2018). Due to a lack of standardised tools for measuring the robustness of the methodological strength, bias was not determined in the cross-sectional studies. Indeed, Rai et al. (2018) were unable to perform further analyses on the results, as most of the studies were cross-sectional so they present a selection of descriptive outcomes and a narrative discussion. Therefore, subjectivity coupled with issues around diagnostic methodology and measurement instruments used highlights important caveats in trying to develop conclusions from this data. Additionally, the review was restricted to the English language publications only and may have missed other important studies.

2.7.3. Systematic Review Findings of Rai et al. (2018)

The systematic review generated the following three themes: (I) Employment and retirement; (II) Absenteeism (Sickness absence), (III) Presenteeism (Productivity), which are now presented in the same order in this discussion.

2.7.3.1. Employment and Retirement

Rai et al. (2018) in their systematic review, found evidence indicating people with COPD had significantly lower employment rates in comparison to individuals without COPD. This was applicable across study types (cohort and cross-sectional) and various settings (general population and primary and secondary care) reporting rates of employment between 13% - 69% (Lin et al. 2016; NHANES 1988-1994 in Sin et al. 2002). Significantly lower rates of employment were also found in people with COPD than those with no long-term condition and when compared to those who have asthma or other chronic respiratory conditions (Montes DeOca et al. 2011). One study included in the Rai et al. (2018) review, a US population survey with age group adjusted analyses, demonstrated consistently lower employment rate of 50% in people with COPD compared to 60% employment in those without COPD (Mannino et al. 2002).

In the Rai et al. (2018) review, one study conducted by Ward et al. (2002), found that when respiratory conditions were analysed independently of COPD, higher unemployment rates were found in those with self-reported emphysema (63%) when compared to those with asthma (25%) or chronic bronchitis (18%). This may indicate that specific symptom burdens such as dyspnoea, which is a key feature of and often worse in emphysema (a common pathology in obstructive airways disease), may play more of a role in employment rates than a diagnosis of COPD. There was also weaker evidence that as disease severity increased (as indicated by symptom severity scores) the person was less likely to be in paid employment (Rai et al. 2017), which appears to be a reliable outcome as confounders were adjusted for. Another study within the review also found that once individuals were out of work, re-joining employment was less common for those with COPD when compared to those without a chronic condition (Eisner et al. 2002).

Early retirement rates were also found to be higher in people with COPD than those without COPD or those with asthma in several studies included in the Rai et al. (2018) review (Wacker et al. 2016; Fletcher et al. 2011; Julin and Wilhelmsen 1967). However, in the study by Julin and Wilhelmsen (1967), employment and retirement conditions and welfare benefits at that time differ significantly to those today, so the findings should be considered with caution. Premature retirement before the age of 65 years of age varied between 35 – 72% in people with COPD, which was significantly higher than the control group at 15% (Julin and Wilhelmsen 1967). Increasing severity of airflow obstruction also implicated a greater likelihood of early retirement from employment although the evidence was weak (Wacker et al. 2016). Evidence from these studies synthesised by Rai et al. (2018) demonstrate a wide variation in employment rates in the literature ranging from 13% to 69%, and that when individuals were out of work, having COPD may be a hindrance to returning to employment. Overall, the early retirement rates were within a wide range indicating possible financial and health factors accounting for the variation.

2.7.3.2. Absenteeism

Absenteeism was determined by Rai et al. (2018) in the systematic review as the mean number of days/hours sick (disability days) from work and the proportion of people reporting time off work. Studies included by Rai et al. (2018) assessed rates of absenteeism and compared rates for people with COPD to those without COPD or other respiratory conditions. Samples were drawn from all populations (general population, primary care, combination of both) and produced mixed and inconclusive evidence. Classed as disability-related work loss, people with COPD were twice as likely to encounter short-term work loss and four times more likely to encounter long-term work loss compared to those without COPD in the study by Darkow (2007). However, there were questions on the clarity of the definition of *'disability days'* in some of the included studies as data were drawn from company databases.

Whilst a Canadian study included in the review, that did not adjust for important confounders, found no difference between those with COPD and those without in relation to absenteeism (Stein et al. 2006), another with self-reported absenteeism found higher absenteeism in people with COPD than those without the condition (Jedrychowski 1976). Rai et al. (2018) noted the potential for unreliability of recall over time and that participants may incur recall bias as a limitation of this study. Additionally, the Jedrychowsky study was published in 1976 (data collected from 1968-1972 in Poland), producing data unlikely to be comparable or relevant to both long-term condition management practices and workplace and employment compensation benefits available today. Furthermore, the participants in the Jedrychowski (1976) study were workers in a fertiliser factory and may have been susceptible to workplace pollutants including VGDF, which may have directly affected sickness absence outcomes. As a result, this study must be considered with caution. The role of confounders here is important and poses challenges for accurately determining absenteeism because of the many variables present in the populations included, data generation methods utilised, individual person and job variables, systems of working and welfare benefits available.

Wacker et al. (2016) found that sick days over a period of 12 months were increased by a factor of 3.7 – 5.6 in people with COPD when compared to a control group, whilst other studies included in Rai et al's (2018) systematic review found higher absenteeism in people with asthma than COPD. Most notably, these studies did not adjust for confounding (Darkow 2007; Eisner et al. 2002). Nair et al. (2012) in a matched cohort study included in the Rai et al. (2018) review, found that, once sick, people with COPD were also more likely to have prolonged disengagement with the workplace as those with COPD took an average of 12 days off per year as opposed to 7 days in those without COPD.

Time off work was also assessed in the systematic review by Rai et al. (2018) which compared those with COPD with those without the condition revealing there was strong evidence of higher mean number of days off work per month at

1.0 for those with COPD and 0.6 for those without COPD (Nair et al. 2012). Nair et al. (2012) also found there was conflicting evidence on the effect of disease severity (e.g., breathlessness) on actual work performance, or indeed the relationship with airflow obstruction, but a significant association was apparent with disease severity and work performance when confounders were well controlled. Further, the Nair et al. study (2012), another self-report of COPD diagnosis, indicated that there was a risk that some of those captured in their study may not have had a formal diagnosis of COPD due to classification and categorisation issues inherent in the system (COPD ICD-9). The possibility of including participants without COPD erroneously further reinforces that collecting large amounts of COPD specific data on employment through databases is challenging and poses limitations to research (Nair et al. 2012).

Overall, there seems a lack of clarity regarding the label of *'disability days'* from databases used to harvest data, and some of the studies over 10 years since publication show little difference in sickness absence rates between those with COPD and those without the condition. Recall issues and other confounders make the results inconclusive.

2.7.3.3. Presenteeism

Presenteeism was determined in the review by Rai et al. (2018) by a mean score estimating the number of hours that were affected by presenteeism and the proportions of individuals reporting presenteeism. Presenteeism was assessed by a variety of measurement tools in the included studies (Work Productivity and Activity Impairment (WPAI), Stanford Presenteeism Scale (SPS-6), World Health Organisation Health and Work Performance Questionnaire (WHO-HPQ), Work Limitation Questionnaire (WLQ) and the Health and Work Productivity-One Survey (HWP-1)). Rai et al. (2018) suggested that in the Allen, Rogers and Bunn (2012) study, various challenges were involved in determining presenteeism such as inconsistent use of measurement tools and the use of different measures. Subsequently, there was weak evidence to suggest that people with COPD have a poorer performance at work when compared to people without COPD. Poor work performance was recorded (but not statistically significant) as more common in individuals whose jobs usually or always entailed walking or standing and manual or physical work but was not associated with the number of hours worked (Allen, Rogers and Bunn 2012).

Other variables associated with higher presenteeism were a higher COPD Assessment Test (CAT) score, increasing breathlessness and number of exacerbations per year, which were found in several of the studies incorporated within the Rai et al. (2018) review (Solem et al. 2013; Onoue, Omori and Katoh 2016; Rodriguez et al. 2009). Presenteeism was greater in people with a higher recorded number of exacerbations within the last three years (Solem et al. 2013), suggesting the importance of preventing exacerbations in order to maintain optimal productivity. In many cases, however, effect sizes were not reported as the variability prevented statistical analysis. However, two further studies found no significant association between presenteeism and COPD (Holden et al. 2011; Wang et al. 2003) indicating these findings are inconsistent and therefore unreliable indicators of productivity.

Within the Rai et al. (2018) review, evidence that disease severity negatively impacted on presenteeism in people with COPD as measured through airflow obstruction was also conflicting and inconclusive (Ding et al. 2017; Solem et al. 2013). However, emphysema (44%) was reported as causing a greater negative impact on the quality of work output compared to asthma (19%) and chronic bronchitis (3%) (Ward et al. 2002). When stratified by severity, using adjusted mean % presenteeism, a significant positive association was found when comparing mild COPD (23%), moderate COPD (27%) and severe COPD (35%) (Ward et al. 2002). The evidence was weakly suggestive that presenteeism may be higher in people with COPD than those without (Onoue, Omori and Katoh 2016; Fletcher et al. 2011). This again indicates the important role that COPD symptoms, especially emphysema, play in affecting productivity rather than just the biophysical markers of the condition.

2.7.3.4. Workplace Adjustments

A cross-sectional study by Kremer, Pal and Van Keimpema (2006) included in the Rai et al. (2018) review found that 25% of 617 Dutch participants in the age range of 45-60 had workplace adjustments due to their COPD. The most common workplace adjustments were to reduce workload (15% of respondents) and reduce hours worked (13% of respondents). Additionally, 32% of respondents who left work after a COPD diagnosis stated they could have remained in employment if their employer had facilitated the implementation of reasonable adjustments in the workplace, but no details of what adjustments would have been beneficial were recorded (Kremer, Pal and Van Keimpema 2006). It is important to remember that reduction in workforce participation may be overlooked at the expense of absenteeism, which can occupy an employer's focus hence missing the real impact of COPD and other long-term conditions on productivity. Overall, the mechanisms of productivity loss in people with COPD are poorly understood.

2.7.4. Summary of the Systematic Review by Rai et al. (2018)

Overall, Rai et al. (2018) highlights that there is weak, conflicting and inconclusive evidence by which to understand the effects of COPD in the workplace. Rai et al. (2018) also highlighted that people with COPD have lower employment rates and take more time off work than those who do not have the condition. The findings on absenteeism and presenteeism are mixed, but COPD appears to have a greater impact on employment than asthma, other respiratory conditions and other long-term conditions. The review authors concluded that well controlled, further longitudinal research is needed to accurately determine the impact of COPD on employment, absenteeism and presenteeism using validated instruments and more reliable reporting methods. In addition, Rai et al. (2018) suggest that understanding the modifiable factors related to lower employment and higher presenteeism is required so that appropriate workplace interventions can be developed.

2.7.5. Systematic Review by Zhu et al. (2018)

The aims of the systematic review conducted by Zhu et al. (2018) entitled *'Disease burden of COPD in China: a systematic review'* were to quantify disease burdens, determine risk factors of the disease and report on prevalence, mortality, direct and indirect costs and quality of life. Their intention was to inform and improve public awareness of COPD. Zhu et al. (2018) searched six databases including local Chinese databases, PubMed, Embase and the Cochrane Library. Following removal of duplicates and application of the inclusion criteria, 47 studies were included in their systematic review based on their higher quality critical assessment scores and six studies of low quality, were excluded.

The reviewers presented descriptive statistics, as meta-analyses were not possible due to population heterogeneity and the variety of research designs utilised within the included studies. They also found varied reporting in loss of working time with some studies noting individuals with COPD losing between 15-17 days working time per annum, similar to those found by Rai et al. (2018), and others rendered incapable of working for as many as 150 days (Zhu et al. 2018). This result indicates a considerable burden of productivity loss attributable to COPD. The lifetime indirect economic losses for working people with COPD appeared low from a global perspective, estimated around 678 USD per annum, in part possibly due to the low working wage experienced in many areas of rural Asia. However, reports of the financial impact were as high as 7,256 USD per annum in some studies. Overall, the Rai et al. (2018) and Zhu et al. (2018) reviews have similar absenteeism averages for people with COPD of between 12 and 16 days respectively, both acknowledging a multitude of measurement approaches and lack of standardisation.

There are some limitations of the review. The inclusion criteria were unclear, although studies were limited to and focused on the Chinese population. There was no commentary on the potential for publication bias of the studies included in the review. The review authors acknowledge the limitations with regards to lack of meta-analysis as a result of study variability and call for urgent, well-designed research on the Chinese population to better understand the COPD burden (Zhu et al. 2018). Methodological quality was assessed through critical appraisal by two reviewers independently, which is good practice (Porritt, Gommersall and Lockwood 2014). Appraisal was achieved using a self-established scale based on the ARHQ assessment (Rostom et al. 2004) and the Drummond criteria (Drummond et al. 2008). However, no recorded detail was made as to which aspects of the scale were *'self-established'*. Utilising a standardised data extraction form, data was collated from the studies which focussed on prevalence (15 studies), quality of life (14 studies), disability adjusted living years (DALY's – 9 studies) and economic burden (18 studies) all specific to the Chinese population. There was no detail to suggest two reviewers were involved in this review; therefore, there is the potential for there to be considerable bias (Gerrish and Lathlean 2015). Most studies (n=33) were published in Chinese with the remainder in English. Study types were not specified; however, six were based on institutional data, six from official statistical records and 35 generated through survey studies (Zhu et al. 2018).

2.7.6. Summary of the Systematic Review by Zhu et al. (2018)

The results from this systematic review are highly variable mainly due to heterogeneity of sample characteristics and populations and in the research designs employed in each of the included studies. Mirroring the Rai et al. (2018) review, the varied methods and tools utilised by the studies in the Zhu et al. (2018) review, attempts to measure employment and productivity and presents a varied picture preventing statistical analysis. The review authors conclude that because of these variations it is difficult to establish a clear perspective of the burden of COPD in China (Zhu et al. 2018). Although the results from both reviews have similarities and report on the challenges of accurately measuring employment factors, the relevance of the results of the Zhu et al. (2018) review may be more applicable to Chinese employment practices and customs and less relevant to other societies with differing social and employment structures.

2.8. Quantitative Research Studies

Ten quantitative studies are also included in this literature review and consist of one cohort study and nine cross-sectional studies. The methods, design, findings and limitations for these studies are detailed previously in Table 2.5 and critical appraisal tables for the included studies are included in Table 2.7 and Table 2.8.

Patel et al. (2018), conducted a retrospective observational matched cohort study of data taken from health insurance and productivity management databases to provide estimates of the direct and indirect burden of COPD on an employer. Critical appraisal highlighted the study was of moderate quality, meeting six out of the eight relevant criteria, with strategies for confounders being unclear and participants not free of the outcome at the start of the study.

The further nine cross-sectional studies were also critically appraised and were of varying quality. Andenaes et al. (2014), Boot et al. (2005), Erdal et al. (2014), Kourlaba et al. (2016) and Lim et al. (2015) met six or seven out of the seven relevant criteria and can be considered higher quality. Kourlaba et al. (2016) and Lim et al. (2015), scored either no or unclear in relation to whether there were objective, standard criteria used for the measurement of the condition. In question 3, as to whether the exposure was measured in a valid and reliable way, was not relevant to any of the studies, so each study was judged out of a maximum of seven. The studies by Igarashi et al. (2018), Uzaslan et al. (2012), Van Boven et al. (2013) and Yelin et al. (2006) met five of the seven relevant criteria indicating the studies were of moderate quality. Igarashi et al. 2018, Uzaslan et al. 2012, Van Boven et al. 2013 and Yelin et al. 2006 were all unclear on confounders and all but Igarashi et al. 2018 were considered unclear or no, for question 4, which asked: were objective, standard criteria used for measurement of the condition. Relevant findings from these studies are synthesised and presented next in the order of the themes identified from the systematic reviews.

Table 2.7 - Critical Appraisal Table of the Included Cohort Study

JBI Critical Appraisal Checklist for Cohort studies	**Patel et al 2018**
Appraisal Questions	
1. Were the two groups similar and recruited from the same population?	Y
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	NA
3. Was the exposure measured in a valid and reliable way?	Y
4. Were confounding factors identified?	Y
5. Were strategies to deal with confounding factors stated?	U
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	N
7. Were the outcomes measured in a valid and reliable way?	Y
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	NA
9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	Y
10. Were strategies to address incomplete follow up utilised?	NA
11. Was appropriate statistical analysis used?	Y

Y = Yes; N = No; NA = Not appropriate; U = Unclear

Table 2.8 - Critical Appraisal Table of the Included Cross-sectional Studies

JBI Critical Appraisal Checklist for Analytical Cross-sectional studies	**Andenaes et al 014**	**Boot et al 2005**	**Erdal et al 2014**	**Uzaslan et al 2012**	**Igarashi et al 2018**	**Kourlaba et al 2016**	**Lim et al 2015**	**Van Boven et al 2013**	**Yelin et al 2006**
Appraisal Questions									
1. Were the criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Were the study subjects and the setting described in detail?	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the exposure measured in a valid and reliable way?	NA	NA	NA	NA	NA	NA	NA	NA	NA
4. Were objective, standard criteria used for measurement of the condition?	Y	Y	Y	N	Y	N	U	U	U
5. Were confounding factors identified?	Y	Y	Y	U	U	Y	Y	Y	Y
6. Were strategies to deal with confounding factors stated?	Y	U	Y	Y	U	U	Y	U	U
7. Were outcomes measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. Was appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y = Yes; N = No; NA = Not appropriate; U = Unclear

2.8.1. Quantitative Research - Employment and Retirement

Like the findings from the Rai et al. (2018) systematic review, employment rates were also lower than those with other long-term conditions or with no other conditions in the quantitative studies. Yelin et al. (2006), in a cross-sectional telephone survey, found that at age 45, 85% of their participants with COPD were employed, at age 55, 62% were employed and by age 64 this had fallen to 31%. By age 64, 40% of those with asthma were employed and 45% of those with rhinitis were employed, indicting the greater burden for those with COPD and the increasing impact on employment with age (Yelin et al. 2006).

Erdal et al. (2014), undertook a population-based survey in which they carried out structured telephone and/or face-to-face interviews with people with COPD aged from 40-67, and examined employment and sickness rates. They found paid employment rates in a hospital clinic recruited group at 31%, the population recruited group 55% and the controls 87%. Both COPD groups had slightly older participants with mean ages of 59 (hospital), and 58 (population) compared to a mean of 53 for the control. The hospital recruited (through the hospital database) and the population recruited groups were of similar age, although the hospital recruited had more severe COPD cases and participants with higher exacerbation rates. This indicated the hospital sample had people with more severe disease hence the lower employment rates and higher exacerbation costs compared to the population recruited group (Erdal et al. 2014). This illustrated the time taken out of the workplace due to exacerbations and the burden of costs for poorly controlled COPD.

A study carried out by Kourlaba et al. (2016), looking at the impact of COPD on daily activities, work and psychological status, found a 28% current employment rate (98/351). This was captured through a telephone survey on a total population study of Greek people aged 40 years of age and above with COPD; however, COPD severity is not described so direct comparisons cannot be made to other studies. In contrast, employment rates in the Lim et al. (2015) study showed a much wider variation of 66-75% in North Asia and 30-40% in South Asia but this was difficult to account for within and between the study populations. Igarashi et al. (2018) found that, of those under age 65, 58% were in paid employment, which is like the population recruited group in the Erdal et al. (2014) study compared to 18% in the over 65-year-old age group. However, comparisons are difficult because of population variability in terms of country, age ranges, COPD severity and workplace factors. It appears that the Rai et al. (2018) review, which broadly illustrates a wide employment rate between 13-69% across different age groups, provides an accurate but varied picture.

Similar to the lower early retirement ranges found in the Rai et al. (2018) systematic review, i.e., before the age of 65 and due to COPD, rates were found to be 39% for men and 37% for women in a cross-sectional cost analysis study carried out by Van Boven et al. (2013). Productivity loss due to early retirement was also costed at €223M across all age ranges. Approximate indirect costs across all age ranges for productivity losses in those working with COPD were estimated at €63M (M - €55M: F – €8M), with each person with COPD (men/women), costing an average of €1,397 per year (men – €2,004; women - €479) (Van Boven et al. 2013). These costs illustrate the potential for COPD to have a considerable negative impact on the economic status of employers.

2.8.2. Quantitative Research - Absenteeism

Absenteeism as determined in the quantitative studies was highly variable. Erdal et al. (2014), revealed inconclusive results on absenteeism. Mean number of days off sick per-annum in the hospital recruited group was low and reported as 12.6, the population recruited group reported 19.3, and a total of 15.7 in the non-COPD control group. This reveals a higher sickness rate for those in the population recruited group and, as no population specific data is provided in relation to employment for those participating in the study, these results do not provide clarity on the impact of COPD on absenteeism. Also, the standard deviations were wide (55.4), indicating a large variability, and the numbers within the groups varied considerably making a direct comparison difficult. Another study (Boot et al. 2005a) found that higher sick leave also led to an openness with others regarding their respiratory disease as participants did not hide dyspnoea because it helped them explain and justify their sick leave. Higher sickness rates were found by Patel et al. (2018), who included patients with and without COPD (average age 53yrs) where a higher likelihood (60%) of taking sick days in those with COPD and more absenteeism hours with an average of 56 hours more per year was evident. This represents a statistically significant difference of around five days more compared to those who do not have COPD (Patel et al. 2018). Kourlaba et al. (2016), found that 25% of respondents reported missing working days due to their COPD and the highest percentage at 41.2% was found in those with severe COPD according to the GOLD classification. The mean number of sick days reported was 10, but the variability was high at ± 23 days (Kourlaba et al. 2016). Similarly, Uzaslan et al. (2012) noted that 28% of participants were prevented from working due to their COPD in the last year and rose to 48% with those that perceived their disease as severe. Overall, however, the mean number of sick days was broadly similar with those found in both the Rai et al. (2018) and Zhu et al. (2018) reviews at 12-16 days indicating the important burden of COPD on employment engagement.

2.8.3. Quantitative Research - Presenteeism

Erdal et al. (2014), found productivity loses of 56% over the last year for the hospital recruited COPD group, 25% losses for the population recruited COPD group and 5% losses for the population recruited controls. Productivity losses were also higher in those having completed less education and also in females; however, the findings were based on descriptive data and self-reports. These self-report, descriptive and lack of consistency aspects potentially weaken the credibility of the outcomes. The authors also noted that only 8% of hospital recruited COPD cases had no productivity losses over the year, whilst population recruited COPD cases and controls had 38% and 41% loss of productivity respectively. This indicated the potential for workplace factors having an impact e.g., amount of manual work, tasks involved and element of control over workplace environment. Similar levels of presenteeism were noted by Lim et al. (2015) where participants recorded productivity around 72% on a typical day and 45% on days when their COPD was at its worst.

Igarashi et al. (2018) conducted a retrospective cross-sectional chart review and used a previously validated measurement instrument similar to the WPAI, to determine productivity. Considering disease severity as a variable, the under 65's productivity was higher in those with CAT scores over 10 indicating symptom severity is more highly associated, although not statistically significant, with workplace productivity impairment than those with scores under 10 (Igarashi et al. 2018). Similar results were found by Uzaslan et al. (2012) where disease severity was associated with increased levels of presenteeism at 4% in those with mild COPD and 25% with severe COPD as measured on the GOLD scale (GOLD 2021).

As part of the Van Boven et al. (2013) study, the economic impact of COPD on the workforce in The Netherlands considered productivity, which was measured and presented as national financial costs and losses. Van Boven et al. (2013) found self-reported impaired productivity rates for men at 6% and women at 3% with an overall average at 5% lost productivity amounting to around 11 impaired working days per year. Two aspects were considered from the medical insurance claims database: that of tax revenue lost estimated as €77M, and disability pensions paid as €180M across all age ranges and genders. Overall, the lost productivity found in these studies is broadly similar to those found by Rai et al. (2018); however, they are mainly descriptive figures as rates of presenteeism are difficult to determine or measure accurately.

2.8.4. Quantitative Research - The Impact of COPD on Income and Career

Having established the high but variable financial costs of lost work in the Zhu et al. (2018) systematic review, it is also notable that several studies broadly address the impact of COPD on financial income and implication on career. The study by Igarashi et al. (2018) found that 6% of participants had retired before the age of 65 because of their COPD, and Lim et al. (2015) noted that 23% reported their COPD restricted the type and amount of work they are able to undertake. However, there may have been other motivations or incentives for retiring early that are not captured within the study such as spouse/partner position, financial security, early retirement packages, other sources and other methods of personal income. This aspect is further explored in the qualitative studies in Chapter 4 and Chapter 5.

Kourlaba et al. (2016) and Lim et al. (2015) found similar percentages of participants were restricted to the type or amount of work they could do because of their COPD at 40% and 42% respectively, but details of the physical or financial impact of COPD on employment was not considered. None of the studies considered participants careers specifically, although Yelin et al. (2006) acknowledged that an early withdrawal from employment endangers financial security, as pension contributions tend to accumulate the most during later working years. Exiting employment early due to COPD increases the likelihood of individuals having to spend down on their savings or pension assets faster than other members of the population, who may draw down similar money from their pensions but over fewer years (Yelin et al. 2006).

Another notable feature was the consideration of quality of life in relation to employment, and Yelin et al. (2006) reported lower quality of life in those with respiratory conditions compared to those without. The findings by Igarashi et al. (2018) concurred with work activities most affected in those with reduced quality of life and correlated with increased CAT scores. Igarashi et al. (2018), however, do caution that demographic differences in populations and study variations prevent direct comparisons in their study. Andenaes et al. (2014), in a study of people undertaking a pulmonary rehabilitation programme, found that physical health was associated with paid work, whereas mental health was not. This suggests there may be benefits to the physical activity and actions that work offers individuals with COPD, or that those who were more physically fit continued with a workplace presence (Andenaes et al. 2014). These studies further highlight the burden of COPD on employment and broaden our understanding of the impact of COPD on individuals and economies; however, they do not add specific data on income and career progression directly associated with having COPD.

2.9. Summary of Quantitative Research

The challenges illustrated in the research reviewed in this chapter reflects the difficulty in accurately and consistently assessing employment aspects in COPD populations. This is due to factors including variability in the way productivity is measured in different organisations and countries and variations in the management of and payment for sickness absence. It appears there is weak, conflicting and inconclusive evidence by which to understand the effects of COPD in the workplace due to a multitude of variables, which is further confirmed in the wider research.

There is a likelihood that people with COPD have lower employment rates and take more time off work than those who do not have the condition. The findings on absenteeism and presenteeism are mixed, but again COPD appears to have a greater negative impact on employment outcomes than asthma, other respiratory conditions and other long-term conditions. Motivations for exiting the workplace earlier than would normally have been planned is also unclear, and there may be an interplay of complex physical health and financial push and pull factors involved where individuals trade off health and wealth. Many researchers concluded that well controlled, further longitudinal research is needed to accurately determine the impact of COPD on employment, absenteeism and presenteeism using validated instruments and more reliable reporting methods.

2.10. Grey Literature

Three pieces of qualitative grey literature are included, and summaries of the studies are detailed in Table 2.9. Critical appraisal was conducted using the Joanna Briggs Critical Appraisal Checklist for Qualitative Research (JBI 2017) and the results are included in Table 2.10.

Table 2.9 - Summaries of the Included Grey Literature

Author, Date, Title, Journal, Country	Aims	Methodology and Design	Key Findings
MAL'OUF, H., 2016 The experience of women aged under 65 years working and living with chronic obstructive pulmonary disease (COPD). ***EThOS*** UK	**Aim:** To explore how working women with COPD managed their daily lives, which included work. What are the strategies these women implement to manage work and other daily responsibilities with the disease symptoms?	**Methodology and Design:** Sequential Mixed-Methods study. **Population:** Six working-aged women (age 36-58). **Data collection:** Semi-structured qualitative interviews and online health forum analysis. **Analysis:** Thematic and content analysis.	***Findings:*** Study highlighted 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 manage COPD were able to stay at work and had a good quality of life. ***Limitations:*** Location of a population, telephone interviews, use of social media, permissions and small data set.
MASTERS, L.R., 2018 The working-age experience of living with chronic obstructive pulmonary disease (COPD). ***EThOS*** UK	**Aim:** To understand age differences in quality of life for people with COPD and learn more about the working-age experience.	**Methodology and Design:** Meta-analysis of literature and qualitative study. **Population:** Eleven working-age people with COPD (age 53-62). **Data collection:** Literature search and semi-structured interviews. **Analysis:** Framework analysis.	***Findings:*** The majority of participants did not report concerns about loss of employment or no sense of distress arising from participants having to leave work. ***Limitations:*** Lack of population diversity and methods adopted.
WATSON, J.A., 2015 Patient and professional perspectives on living with chronic obstructive pulmonary disease. ***EThOS*** UK	**Aim:** To explore the lived experience of people with COPD. To establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry out their day-to-day activities.	**Methodology and Design:** Qualitative **Population:** Nine people with COPD and ten healthcare professionals (age of those with COPD 60-80 and data for those working was identifiable). **Data collection:** Semi-structured interviews. **Analysis:** Thematic network analysis.	***Findings:*** COPD patients happy with their experience of healthcare although valued prompt, accessible care in emergencies highly than routine review appointments. No indication that psychosocial needs were met in routine consultations although reported some needs met during pulmonary rehabilitation. HCPs perceived that they provided good care but were barriers to introducing psychosocial issues into routine appointments ***Limitations:*** Participants all active in self-care, socially active and not representative of COPD population. Snapshot of situation and may have been influenced knowing healthcare professionals also included in study.

Table 2.10 - Critical Appraisal Table of the Grey Literature

JBI Critical Appraisal Checklist for Qualitative Research	**Malouf 2016**	**Masters 2018**	**Watson 2015**
Appraisal Questions			
1. Is there congruity between the stated philosophical perspective and the research methodology?	Y	Y	Y
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y
4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	Y	Y	Y
7. Is the influence of the researcher on the research, and vice- versa, addressed?	Y	Y	Y
8. Are participants, and their voices, adequately represented?	U	U	U
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y

Y = Yes; N = No; NA = Not appropriate; U = Unclear

Within the three qualitative studies located, there was limited specific content on the employment aspects. Although these studies are yet to be published, they contain relevant detail worthy of including in this study. The study by Mal’ouf (2016) produced the most substantive findings relevant to this literature review.

As part of a mixed-methods study, Mal'ouf (2016) conducted interviews with the aim of exploring how working-age women with COPD managed their daily lives. Six women, with an age range of 36-58 years, were interviewed twice over a three-month period. Five of the women were in paid employment and one had recently left work because of the severity of her COPD. The study objectives included exploring how the women viewed the impact that COPD had on their lives and what strategies they implemented to manage work and other daily responsibilities.

Four themes were presented in the study, although only one is relevant to this review. The theme working with COPD had three subthemes: renegotiating work, just as well as anyone else and finding ways to adjust. The main findings were that common strategies were adopted by participants, which involved disclosing their COPD to their employer, work colleagues, family and friends. In disclosing their COPD to their employer, they were able to request and receive workplace adjustments and re-prioritise their lives. The nature of the work role (whether manual or sedentary) and the individual's ability to make adjustments at work (adjustment latitude) were two important factors that appeared to influence the ability of the women to remain in employment.

The aim of the study conducted by Watson (2015), was to explore the lived experiences of patients with COPD and also the views of healthcare professionals involved in the care of these patients. Nine semi-structured interviews were conducted with participants between the age of 60–80 years. Although the participants in this study were mainly outside the age range for inclusion in this review, it was evident that some data could be extrapolated from the younger participants who were still employed or had left employment because of the severity of their COPD, which was considered useful to understanding aspects of the employment experience.

The relevant theme in this study was 'Loss of employment, role or identity'. Loss of employment came through work roles which required communication with the public and caused issues with breathlessness for people with COPD. In addition, some participants lost their capability of contributing to the workforce which caused them some concern. Other participants reduced their working hours or retired early because of their COPD. Lower paid workers, although initially might have had financial worries, were better off financially long term once they received their disability living allowance.

The study by Masters (2018), considered the experiences of the quality of life of working-age (53-62 years of age) men and women with COPD. Eleven unemployed participants (five males and six females) took part in semi-structured interviews. Some valued their contribution to society in working, but for others in low-paid and manual roles, work did not offer them satisfaction. Those not employed did not consider getting back to work as a priority.

2.11. Summary of Qualitative Research

From these three studies, it appeared that there were various factors influencing participants decision making in whether to remain in or leave employment including financial reasons, lack of job satisfaction, the nature of the work role, adjustment flexibility and their COPD severity and impact. There was also variation in the level of disease disclosure by the employees. The studies demonstrated some willingness by employers to accommodate employee requests for adjustments including closer parking, additional heating for the workplace and changing working patterns to make the experience of their employees in the workplace more comfortable. The findings from these three studies with small samples provide limited insight into the important subject of employment aspects in those with COPD. This indicates a lack of qualitative research focus on COPD and employment.

2.12. Chapter Conclusion

This literature review has offered a current perspective on the main concepts and themes relating to employment and COPD. The chapter has highlighted the dearth of high-quality research specifically focusing on people with COPD and aspects of employment and highlighted difficulties in accurately determining employment outcomes. In addition, there is very little qualitative research focusing on the experiences of people with COPD and the context and situations that they encounter in the workplace, thus there is a need to explore this in further detail to begin to address the gap in research. The two studies that follow address the knowledge gap by fulfilling the thesis aims and objectives set out in Chapter 1.

3. Research Methodology

3.1. Introduction

Having illustrated the impact of COPD on employment for individuals, families and societies in the Introduction and Literature Review, this chapter now considers the theoretical basis for the methodological approach taken and the methods selected for the conduct of both studies included in this thesis. The chapter draws on a long and vibrant methodological debate in the nursing and social science literature. This has mainly been in relation to the nature, quality, and applicability of quantitative, qualitative and mixed-methods research in the respective fields. A pragmatic epistemological position using mixed-methods research is adopted. Two studies are presented in this thesis, using a mixed-methods approach in the pilot study (Chapter 4), and a qualitative approach to explore employment experiences (Chapter 5). Interpretive description is adopted as a qualitative methodology.

3.2. Chapter Structure

Section 3.3 considers current debates on research philosophies and the nature and application of research. It provides a general overview of the main philosophical concepts then describes and justifies those related to and applied to both studies in this thesis. The discussion then provides a rationale for the choice of methodology adopted for the two studies and the philosophical choices that underpin the decisions made in this thesis. The emphasis in this thesis is about practice driven research rather than research driven practice. Thus, the studies in this thesis seek to address the questions that need to be answered from a practice perspective rather than creating questions that fit neatly with specific research philosophies or academic research agendas.

The discussion proceeds to explore and clarify relevant concepts and to develop a robust understanding of the relationship between the selected research designs and their ontological, epistemological and methodological foundations to provide methodological rigour. Ethical principles are also broadly laid out here and discussed in greater detail when applied to each study within their respective chapters (Chapter 4 and Chapter 5). Researcher reflexivity is further developed as an important aspect of transparency. Firstly, the discussion will explore paradigms, methodology and methods.

3.3. Paradigms, Methodology and Methods

A variety of paradigms, strategies of inquiry (methodology) and well-developed research methods exist and are available to researchers (Creswell 2015). The planning stage of a study helps the researcher lay a firm foundation for the subsequent research design selected to best address the research questions (Welford, Murphy and Casey 2011). Creswell (2009) advises that researchers need to carefully plan their research studies to incorporate an *"intersection between philosophy, strategies of inquiry and specific methods"* and that they must also clearly communicate these philosophical assumptions and perspectives within their studies to establish clarity and rigour (p.5). However, the literature is replete with confusing variations of terminology, used interchangeably, describing research philosophies, paradigms and methodologies representing distinct hierarchical levels of decision-making, which make their conceptualisation and clarification challenging (Creswell 2013; Crotty 1998).

An early definition of paradigms proposed by Kuhn around 1970, referred to them as ways that researchers summarise their beliefs on the creation of knowledge (Morgan 2014). A more applied definition of a paradigm proposed by Morgan (2007) signifies the influence researchers have on their study in the choices they make is outlined in the key terms defined in Table 3.1, and is adopted in this thesis. Definitions of Strategies of inquiry; for example, the methodology (the broad theoretical lens through which the research is examined) and the research methods (tools to collect the data), aid transparency, and are also made explicit in Table 3.1 (Harding 1987; Creswell 2009). If the methods are considered the tools for collecting data, then the strategies of inquiry (methodology) help to determine the way the selected tools can be best utilised to obtain relevant data within a given paradigm (Kelly, Dowling and Millar 2018; Durham et al. 2015; Watkins and Gioia 2015).

Table 3.1 - Key Terms and Definitions

Paradigm	Systems of beliefs and practices that influence how researchers select both the questions they study and methods that they use to study them (Morgan 2007, p.9).
Strategies of Inquiry (Methodology)	Types of qualitative, quantitative and mixed-methods designs or models that provide specific direction for procedures in a research design (Creswell 2009, p.11).
Methods	Techniques for gathering evidence (Harding 1987, p.2).

A research paradigm is a conceptual framework useful for viewing and interpreting the world (Babbie 2015) and is described as the entire "*package of beliefs about knowledge that influences how a researcher makes sense of and studies the world*" (Crotty, 2003 p.35). Sometimes called "*worldviews*" (Creswell 2009, p.6), paradigms are the *"net that contains the researcher's epistemological, ontological and methodological premises*" (Denzin and Lincoln 2008, p.26) and is discussed in the following section. The researcher's beliefs guide the choices, decisions, actions and interactions within a study, shaping the research question, literature review, methods, data collection, data analysis, interpretation and discussion (Durham et al. 2015).

The researcher's beliefs are drawn from and characterised by the specific and individual differences in philosophical assumptions of their knowledge on a topic (Creswell and Plano Clark 2017). Based on our individual assumptions of reality, Kuhn (1970) noted that "*what we see depends on what we look at and what previous visual-conceptual experiences have taught us to see*" (Bowling 2002 p.119). In other words, it is not possible to separate ourselves from what we know (Guba and Lincoln 1994). These influences come from the researcher's past experiences, education and tacit knowledge of the topics under study. Thus, the paradigm enables the researcher to share important information about their beliefs and values, illuminating where their methodological ideas and decisions come from and where possible researcher influences may be apparent throughout all aspects of a research study (Watkins and Gioia 2015).

3.3.1. Ontology, Epistemology and Axiology

Despite paradigms being defined in conflicting ways in the literature (Carter and Little 2007), stating ontological, epistemological, axiological and methodological views can help the researcher map out and frame the specific territory being investigated and those areas which are not (Miles and Huberman 1994). Further consideration of the philosophical assumptions influencing this study will be explored as the section develops.

Ontology relates to the objects of interest within a topic area. It is "*the study of the nature of knowledge and justification*" (Schwandt 2001, p.71). The prefix '*Ontos*' means '*reality*' and the suffix '*logos*' means to '*study*', so ontology is the '*study of reality*', how I as a researcher view reality and how I come to understand that reality (O'Gorman and MacIntosh 2015). It also considers the beliefs I have on the nature of the world being studied (e.g., COPD, nursing) and an ontological question asks, "*what the nature of the world is*" and "*what is known about and what is 'real' about a topic*" (O'Gorman and MacIntosh 2015).

Epistemology is the philosophy of knowledge and is determined by ontological beliefs (Bryman 2015). The prefix *'episteme'* means knowledge and the suffix *'ontos'* means *'reality'*, or the study of knowledge (O'Gorman and MacIntosh 2015). Its focus is about the nature of the relationship between the knower (the inquirer) and the known (or knowable) and may have subjective and objective points of view (Creswell 2013). In other words, it details the relationships between all the objects of interest in a study (study constructs) and helps question *'How do I know what I know?'*

The axiological aspects of philosophy are those which inform the notion of the values which a researcher brings to the research and may cause bias (O'Gorman and MacIntosh 2015). Closely aligned to personal ethics, axiology requires the researcher to acknowledge and act on all the aspects they bring to a study. This includes the researcher's ego, personal motivations and desires for undertaking a research study and, through development of reflexivity, make transparent any value laden inherent biases (O'Gorman and MacIntosh 2015). My values and interests as a researcher investigating COPD were described in Chapter 1 when discussing reflexivity and providing *forestructure* to the study.

Further explanation of these philosophical views are presented in Table 3.2 and positioned in relation to the most common paradigms, and further discussed and applied in this thesis in Section 3.4.

Table 3.2 - Common Elements of Worldviews and Implications for Practice

	Worldviews			
Worldview element	***Post-positivism (Quantitative)***	***Social Constructivism (Qualitative)***	***Advocacy and Participatory***	***Pragmatism (Mixed-methods)***
Ontology (What is the nature of reality?)	Singular reality (e.g., researchers reject or fail to reject hypotheses)	Multiple realities (e.g., researchers provide quotes to illustrate different perspectives)	Political reality (e.g., findings are negotiated with participants)	Singular and multiple realities (e.g., researchers test hypotheses and provide multiple perspectives)
Epistemology (What is the relationship between the researcher and that being researched?)	Distance and impartiality (e.g., researchers objectively collect data on instruments)	Closeness (e.g., researchers visit participants on their sites to collect data)	Collaboration (e.g., researchers actively involve participants as collaborators)	Practicality (e.g., researchers collect data by "what works" to address research question/s)
Axiology (What is the role of values?)	Unbiased (e.g., researchers use checks to eliminate bias)	Biased (e.g., researchers actively talk about their biases and interpretations)	Biased and negotiated (e.g., researchers negotiate with participants about interpretations)	Multiple stances (e.g., researchers include both biased and unbiased perspectives)
Methodology (What is the process of research?)	Deductive (e.g., researchers test an a priori theory)	Inductive (e.g., researchers start with participants views and build "up" to patterns, theories and generalisations)	Participatory (e.g., researchers involve participants in all stages of the research and engage in cyclical reviews of results)	Combining (e.g., researchers collect both quantitative and qualitative data and mix them)

Adapted from Creswell and Plano Clark (2017, p.38) and Carter and Little (2007).

3.3.2. Research Paradigms

In order to justify the paradigm selected for this thesis, a brief overview of common paradigms is provided here. Throughout history, the traditional paradigms used in conducting research in the health and social science fields of inquiry have fallen into the two well-established but opposing camps of positivism - using *'quantitative'* approaches (which have numbers as data), and constructivism - using *'qualitative'* approaches (which have text as data) (Creswell 2013; Guba 1990). Fortunately, the term *'paradigm'* is not one that is cast in stone, a situation that Guba (1990) refers to as *"intellectually useful"* (p.17), as it enables our understanding of paradigms to be reshaped and revised. Guba (1990) records details of Thomas Kuhn, the philosopher who developed the term and who himself referred to paradigms in 21 different ways. Indeed, as evidence accumulates over time, paradigms shift, as challenges on the dominant paradigm forces a growing realisation of how inadequate it is and it is then, in turn, replaced with a more contemporary view (Bowling 2002).

Denzin and Lincoln (2017) favour six paradigms including constructivism, interpretivism, feminism, positivism, post-positivism and critical theory. Weaver and Olson (2006) consider four paradigms including positivist, post-positivist, critical social theory and interpretivism (Welford, Murphy and Casey 2011). Creswell (2009) also proposes four research paradigms including Post-positivist, Social Constructivism, Advocacy or participatory and Pragmatism. Creswell (2013; 2009), refers to paradigms or *'worldviews'* as providing a general orientation to the world and his preferred perspective and language are selected to clarify concepts and guide this discussion further. Whilst no single paradigm can be thought of as being superior to another, as each can inform practice in different ways, determining a clear consensus and standpoint on paradigms is difficult because of the long-standing theoretical tensions between some of the perspectives (Creswell and Plano Clark 2017; Parahoo 2014).

3.3.3. The Post-positivist Paradigm

The post-positivist worldview, previously called the positivist tradition, which tries to identify causal relationships and, generalise a study's findings to the wider population, is normally based on statistical relationships, and is hypothesis testing and is purely deductive in nature (Creswell 2013). That is, it is an objective and value free approach in scientific research where the outcomes are presented as numerical information (Scotland 2012; Teddlie and Tashakkori 2009). The researcher is considered independent and objective in taking an etic approach to the research process (Doyle, Brady and Byrne 2016). Thus, the *'truth'* is quite separate from the researcher and waits to be discovered by them. Post-positivism reflects the thinking following a long period of positivism where *'truth'* was thought to be absolute, to a view that absolute *'truth'* cannot be guaranteed and that, because of the limitations of positivism, now look to reject hypotheses rather than claim proof of results (Parahoo 2014). As a result of a paradigm shift, as noted above, it moves post-positivist thinking towards a refining and revising approach based on new thinking around the important questions of the usefulness or otherwise of research outcomes (Creswell 2009).

3.3.4. The Social Constructivist Paradigm

The social constructivist worldview is also referred to as the naturalist or interpretive approach; and is relevant to qualitative research, which aims to gain a deeper understanding of a phenomenon of interest (Creswell 2009). Reality is socially constructed through a collegiate interaction with participants on the objects of interest to the study (Crotty 1998). The main characteristics in using qualitative methods are induction, discovery, exploration and theory and the researcher recognises they are an integral and active part of the research process covering design, adoption of strategies, data collection, data analysis and data interpretation (Johnson, Onwuegbuzie and Turner 2007). The researcher considers there to be *'multiple realities'* or *'multiple truths,* and varying interpretations of these truths are possible making them inappropriate to generalise to wider populations. Thus, the *'truth'* is created through people's experiences which are dynamic and continuously evolving. Interpretation of data is developed through the philosophical beliefs based on the researcher's personal background and experiences and are co-constructed through the entirety of the research (Babbie 2015; Crotty 1998). For those reasons, constructivists assert that experience holds subjective meaning for individuals and that meaning is constructed socially within a given context (Scotland 2012; Creswell 2009; Appleton and King 2002). Whilst there are elements of the social constructivist approach relevant to the qualitative components of this study, it would not be sufficient to use as a foundation for the quantitative component.

3.3.5. The Advocacy and Participatory Paradigm

The advocacy and participatory worldview is closely linked with the qualitative approach but has developed further to address shortcomings in advocacy in particular for marginalised or disenfranchised groups (Creswell 2009). Paying particular attention to politics and the political agenda, the advocacy and participatory worldview considers a road to reform through actively pursuing an action agenda. Dealing with social issues such as inequality, oppression, suppression and alienation, it takes a collaborative approach involving participants throughout the research process helping to build a strong united voice to further the cause for reform and the development of implementation ideas (Creswell 2013). Whilst the study of COPD has many social aspects to it, as the focus of this thesis is in exploring the experiences and health and well-being of individuals in a workplace context, it is not driven by political ideologies and agendas and thus the advocacy and participatory paradigm does not fit well.

3.3.6. The Pragmatic Paradigm

In pragmatism, the worldview considers multiple viewpoints, perspectives, and positions (Johnson, Onwuegbuzie and Turner 2007). It is a pluralistic philosophy which rejects the choice between positivist or constructivist approaches. Pragmatism is derived from the Greek word *'pragma'* from which practice and practical are derived and is focussed on the *'doing'* part or *prasso* (I do) (Johnson, Onwuegbuzie and Turner 2007, 2007 p.7). The philosophical foundation for pragmatism is represented through the methodological dichotomy of selecting between the post-positivist or constructivist approaches, where it is often the case that neither one approach provides the researcher with a best fit for addressing the questions posed. This is because the issues that arise in real world healthcare settings are not necessarily amenable to being addressed by only one approach (Teddlie and Tashakkori 2009).

Peirce, the founder of pragmatism, held that pragmatism was relevant, as there was a need to place greater focus on concepts and theories that make a real difference to human endeavour and to remove some of the power from what he considered meaningless philosophy and science (Allmark and Machaczek 2018). For Peirce, the positioning of pragmatism was important in order to make a practical impression and enable purposeful research activity (Allmark and Machaczek 2018). Pragmatism assumes the middle ground between post-positivism and constructivism and as a result is not committed to one philosophical stance in understanding reality. This provides a sound basis for the development of knowledge, addressing several research questions types such as those in this thesis (Creswell and Plano Clark 2017; Dures et al. 2011).

Doyle, Brady and Byrne (2016) describe mixed-methods as the *'third or middle way'* between the opposing positivist and interpretivist views. Durant-Laws (2005) records the philosophical trinity as the researcher's belief system in which the researcher's philosophical alignment is illustrated by an overlap of the researcher's ontological, epistemological and axiological positioning. Durant-Laws (2005) also highlights how identification of the philosophical alignment is a precursor to choosing an appropriate methodology and describes another trinity - the alignment between the researcher's philosophical alignment, the research paradigm and the research methodology. Therefore, pragmatism is positioned and associated with mixed-methods research approaches that liberate researchers to select the methodology and methods most appropriate for addressing a topic to optimise the overall understanding of the research issues of concern (Creswell 2013; Johnson, Onwuegbuzie and Turner 2007; Onwuegbuzie and Leech 2005). For these reasons, pragmatism is the paradigm used as a foundation in this thesis to guide the research studies addressing the matters of importance relating to employment for people with COPD.

3.3.7. A Critique of Pragmatism

Critics of pragmatism assert that it does not do justice to either approach (quantitative/qualitative) (Creswell 2013) and postulate the *'incompatability thesis'* judging it inappropriate to combine methods where the underlying premises of their paradigms (i.e., their philosophical assumptions) are in direct opposition with each other (Teddlie and Tashakkori 2009, p.15). As a result, researchers made decisions about which end of the continuum they were most vested in i.e., being more of a positivist or constructivist (Guba 1990). Counter arguments to this perspective consider the *'compatibility thesis'* suggesting there had been a polarisation of paradigms through a misunderstanding of science where differences were exaggerated, and similarities minimised (Teddlie and Tashakkori 2009). Howe (1988, in Teddlie and Tashakkori 2009), provides some commentary to justify the less constraining alternative viewpoint:

> *"The compatibility thesis supports the view, beginning to dominate practice, that combining quantitative and qualitative methods is a good thing and denies that such a wedding is epistemologically incoherent" (P.10)*

Greene and Cachelli (1997), note on philosophy and paradigms, that methodological decisions regarding research and its methods for carrying it out should be driven by both, the inquiries problems, and the practical demands of the real world. They clarify, that:

> *"Paradigm differences do not really matter very much to the practice of social enquiry, because paradigms are best viewed as descriptions of, not prescriptions for, research practice" and that "enquirers, should be able to choose what will work best for a given problem" (Greene and Cachelli 1997, p.4).*

The current volume of mixed-methods studies in the field of healthcare adds weight to the compatibility thesis as popularity in the mixing of paradigms increases (Loft et al. 2018; O'Reilly et al. 2018; Ferguson and Cosby 2017; Cabilan et al. 2016). In addition, both paradigms have been utilised by researchers for decades and influenced healthcare policy and practice and have been supported by funding agencies (Tashakkori and Teddlie 2008). Sandelowski (1998) also emphasises that as positivist and constructivist paradigms have their inherent strategies for minimising bias and increasing validity, using the philosophical framework of pragmatism as a guide to the research process strengthens the coherence of a study thus adding to its rigour. This helps researchers unravel complex phenomena, as it capitalises on the established strengths of data collection and analysis techniques of quantitative and qualitative methods to address broad and complex healthcare issues (Denzin and Lincoln 2017; Johnson, Onwuegbuzie and Turner 2007).

An important caveat when considering the pragmatic approach, however, is the possibility of a methods-experience gap for researchers (Hesse-Biber 2010). Researchers must learn to be proficient in the skills of both quantitative and qualitative research approaches and the methods adopted. This adds to the potential for increased workload, learning demands and indeed costs where funded projects are concerned (Ross 2012). In terms of time, effort and costs, adopting a pragmatic approach may not be the most efficient way of conducting a research study because it might take longer than a single method study, as there are added processes involved in double the data collection and analysis

(Bryman 2012). However, this thesis wanted to consider employment factors in those with COPD from different perspectives to provide a broad understanding of current issues. Therefore, pragmatism offered the flexibility to design studies to address both the psychosocial and physical influences on employment as well as considering individual experiences in maintaining or ceasing employment within different employment contexts. Overall, there appears to be a strong body of support for the use of pragmatism within healthcare literature and despite the criticisms levelled at pragmatism within this section, epistemologically, pragmatism offers researchers a logical justification for combining rather than compartmentalising the approaches.

3.4. Selecting a Research Methodology

According to Braun and Clarke (2013), methodology is the specific framework within which research is conducted. They describe methodology as:

> *"A theory of how to research needs to proceed, to produce valid knowledge about the psychological and social world. It is what makes our research make sense, both in the terms of design, and in terms of process" (p. 31).*

In order to provide sufficient justification for the choice of methodology in this thesis, consideration is given to the practical foundations of quantitative, qualitative and mixed-methods approaches (Lipscomb 2008). Qualitative research involves an exploration of social phenomena by studying the content or process of participant interactions using ethnography, phenomenology, grounded theory, narrative or case study research (Parahoo 2014). In comparison, quantitative researchers believe the best way of investigating phenomena is to apply research methods adopted by the natural sciences through using survey instruments or through experimental strategies (e.g., randomised control trials or cohort studies) (Robson and McCartan 2015; Creswell 2009). The qualitative perspective contends there are no real *'social facts'* and that *'reality'* is socially co-constructed by researchers and participants during the research process (e.g., through language in focus groups, interviews, diaries); thus, a qualitative research perspective can take on multiple forms of reality using data from relatively small sample sizes (Creswell and Plano Clark 2017; Hesse-Biber

2009). Conversely, positivists view the existence of *'social facts'* that can and do occur independently of any researcher's actions (Creswell and Plano Clark 2017). Further, in quantitative approaches such as cross-sectional studies and clinical trials, sample sizes are large and sampling strategies, such as probability or non-probability methods are used to reduce the sources and influence of bias on the outcomes (Robson and MCartan 2015; Teddlie and Tashakkori 2009).

These polarised perspectives of how knowledge is discovered are significant in that they have direct implications for methodological decisions that researchers must make at the outset of a research study as previously discussed in Section 3.3. Although quantitative and qualitative research approaches have differing ontological and epistemological positions, some authors contend that these are simply general viewpoints rather than guidelines that must be followed (Doyle, Brady and Byrne 2016; Hesse-Biber 2010). In any case, it is likely that a researcher's epistemological perspectives will change over time so might not be permanent perspectives.

The popularity of mixed-methods research (sometimes called mixed strategy designs) has grown in the fields of social science, health sciences, nursing and healthcare over the last decade (O'Reilly et al. 2018; Doyle, Brady and Byrne 2016). However, these have not always been transparently reported in publications (Tatano Beck and Harrison 2016). As a large body of researchers have established robust grounds for a multi-method approach to nursing research, there is an increased awareness and recognition of its value (Loft et al. 2018; Ferguson and Cosby 2017; Creswell and Plano Clark 2017). The middle-ground, mixed-methods research is a pragmatic approach in which the researcher collects, analyses, and interprets both quantitative and qualitative data, integrates the two approaches within a single research study and frames that study within a specific design (Halcomb 2018; Creswell 2013; Sandelowski 1998). In essence, it bridges the gap between purely quantitative or qualitative approaches to research. Johnson, Onwuegbuzie and Turner (2007) refer to mixed-methods methodology as:

> *"Research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative*

> *and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (p.123).*

Mixed-methods studies benefit from the advantages of quantitative and qualitative approaches and thus it is a realistic and practical approach to address the complexities of health and well-being issues (Creswell and Plano Clark 2017; Shannon-Baker 2016). Mixed-methods research therefore, seems to be well justified for offering flexible techniques, options to address a range of practice focussed questions, and holistic and innovative approaches as the diversity of quantitative and qualitative research methods are positively embraced (Loft et al. 2018; Ferguson and Cosby 2017; Robson and McCartan 2015). A mixed-methods approach in this thesis enables the design of studies to provide a detailed exploration of well-being factors as well as perceptions and experiences of people with COPD in relation to employment.

Most of the mixed-methods research to date, however, has somewhat neglected the qualitative strands and leaned towards a more positivist approach with the main study supplemented with additional qualitative data (Bryman 2006). This somewhat 'handmaiden' relationship has not been perceived to be helpful in the early development of mixed-methods research. Additional issues also report a lack of integration of methods in studies, time implications, implicit or unclear rationale that fails to show the benefit of combining methods, and researcher skills and training gaps (Robson and McCartan 2015). Despite the many constraints and challenges, current perspectives justify robust mixed-methods research for incorporating data that has complementary purposes in answering specific and different research questions that have an equal value in addressing practice issues, such as those in this thesis (Creswell 2013; Bryman 2006). Hesse-Biber (2010) reviewed several mixed-methods studies on healthcare topics to determine the researcher's justification for selecting a mixed-methods approach. The justifications for the method adopted and research process conducted are included in Table 3.3. Reasons given include accessing the intended population through a large quantitative study, looking for any links between studies and to generate and develop relevant research questions. Although all the justifications listed are the important reasons for considering a mixed-methods study, those most pertinent are highlighted, reflecting the main reasons for adopting the approach in this thesis. They are further discussed in the sections that follow.

Table 3.3 - Justification for Adopting Mixed-Methods Studies in this Thesis

	Justifications for adopting a mixed-methods approach	**Process and outcomes**
1	To increase the representativity and generalisability of research	*Using a quantitative study to obtain a representative sample, with the goal of enhancing the generalisability of qualitative findings*
2	To locate a target population or defining a population of interest to study in depth	*Using a quantitative study for purposive sampling* *Using a quantitative study to define a population of interest that was not anticipated*
3	To enhance the validity and reliability of research findings	*Linking qualitative and quantitative methods*
4	To address inconsistent results	*Using a qualitative study to explore contradictions found in quantitative data*
5	To test the validity of qualitative results	*Using a quantitative study to test the validity of qualitative findings in a wider population*
6	To enhance the understanding of the research problem and research findings	*Using quantitative results to generate new qualitative research questions*
7	To provide convergence in findings: Triangulation	*Providing a more robust understanding of results by triangulating results (seeing what research findings of two studies on similar topics are in agreement)*
8	To advocate for social transformation	*Promoting social change, social transformation and social justice*

Adapted from Hesse-Biber (2010, p.465-467).

Selecting a research method most appropriate to meet real-life challenges is also an essential part of the foundation of the interpretive descriptive approach. This is discussed in Section 3.6, in addition to the approach taken to situate, structure and manage the qualitative elements of both studies (Thorne 2016a).

3.5. Adopting a Mixed-Methods Study

I read and critically reflected on the literature detailing research methodology and carefully considered what was suited to addressing the thesis research objectives (Creswell 2013; Dures et al. 2010; Andrew and Halcomb 2009). I considered that incorporating quantitative and qualitative elements in a mixed-methods design was appropriate. A pragmatic epistemological approach was taken which supports a mixed-methods methodology and research method to gather relevant evidence to address the holistic study aims and objectives identified within Table 3.4. The objectives developed for this thesis would not be achievable if a mono constructivist or post-positivist approach was adopted. Further, the advocacy and participatory paradigms were not directly relevant because the objectives of this research are not related to the political agenda nor do they contain actions calling for policy reform (Creswell 2009).

Objective 1 of the pilot study was designed as the descriptive reporting of the feasibility of the study processes in terms of whether the data collection system worked and whether the questionnaire and other processes were logical, feasible and manageable within the expected timeframe (NIHR 2016; Van Teijlingen et al. 2001). In objective 2, I wanted to explore psychosocial and physical factors of well-being and productivity in relation to employment using validated tools which required a quantitative cross-sectional study utilising a deductive logic method (Creswell 2015). Objective 3, exploring the contextual and experiential aspects of individuals with COPD in relation to their employment required a qualitative inductive-logic method which could be achieved by interviewing a sub-sample of the participants who had already completed the cross-sectional study (Tashakkori and Teddlie 2008).

In the main qualitative study (Chapter 5), all objectives could be achieved through taking a pragmatic qualitative approach through interviewing people with COPD.

Table 3.4 - Aims and Objectives of the Thesis

Study	**Study Aims**	**Research Design**	**Participants**
Pilot **Chapter 4**	***Aims***: The aims of this study were to test the feasibility of conducting a scientifically robust study and identify the factors and experiences that influence employment in people with COPD: 1. <u>The Pilot Process</u> - To test recruitment and study procedures to enhance the design of a later study including sample size estimation. Specifically, that organisational processes have the required steps in place; that resources/time are adequately planned, that the researcher is appropriately prepared; that management of data collection and processing is smooth and that transparent and important data is not missing. 2. <u>Quantitative Study</u> - To identify the psychosocial and physical factors that may influence employment in people with COPD. 3. <u>Qualitative Study</u> - To provide a detailed exploration of a sub-sample of participants' employment contexts and related experiences.	**Mixed-methods study** **Quantitative Cross-sectional study** (Objectives 1&2) **Qualitative Interviews** (Objectives 1&3)	**14 people with COPD** **4 people with COPD**
Qualitative **Chapter 5**	***Aim***: The aim of this study was to explore the employment experiences of working-age people with COPD who sustain or have left paid employment: 1. The context in which employment is enabled or constrained for people with COPD. 2. The facilitators and barriers for people working with COPD in trying to maintain/sustain employment (physical and psychological). 3. The specific support available in various workplaces for people with COPD to enable them to sustain or leave paid employment, and 4. The perceived support needs of people with COPD in	**Qualitative study** **Qualitative Semi-structured Interviews**	**17 people with COPD**

	enabling them to sustain or leave paid employment. 5. And to use the knowledge generated by 1-5 to make recommendations for further primary research or supportive interventions that may enable people with COPD in employment to work effectively or more satisfactorily for a longer period of time or cease employment in a positive way.		

3.5.1. The Explanatory Sequential Mixed-Methods Design

Several variants of mixed-methods design are described in the literature and summarised in Table 3.5. These include the exploratory sequential where qualitative data is collected to explore the phenomenon, develop an intervention, and then collect quantitative data to explain it (Harvey and Land 2017). Another option was the explanatory sequential approach which collects quantitative data followed by qualitative data, which may or may not be linked together to explain the results (Harvey and Land 2017). Additionally, the use of a triangulation design, where different and complimentary data on a topic are collected and analysed, could have been utilised (Creswell 2015). The explanatory sequential approach was considered most suitable for the pilot study in terms of collecting data addressing divergent objectives in the same population (Plano Clark and Creswell 2018; Harvey and Land 2017).

Table 3.5 - Features of Mixed-Methods Study Designs

Design	**Key features**
Exploratory sequential	Qualitative strand completed and followed by quantitative strand
Explanatory sequential	Quantitative strand completed and followed by qualitative strand
Convergent parallel	Data from qualitative and quantitative collected at a similar point in time
Embedded (Sequential/concurrent)	One strand is embedded within the opposing strand e.g., qualitative within a larger quantitative study
Transformative	Quantitative and qualitative strands are informed by theoretical framework e.g., feminism
Multiphase	Multiple quantitative and qualitative strands are used in research concerned with evaluation and intervention

(Adapted from Plano Clark and Creswell 2018).

In constructing this new knowledge, I take a neutral stance and value both objective and subjective ontological perspectives making the assumption that both singular and multiple realities are possible (e.g., I conduct a cross-sectional study to measure well-being and provide experiential accounts through taking multiple participant perspectives). Therefore, the measures from the quantitative study produce objective data derived from a realist version of ontology believing the facts are there to be discovered (Ryan 2018; Porter 2007). The qualitative elements subsequently gather subjective data from a relativist version of ontology, dependent on how individuals view and experience the world in their context (Ryan 2018).

From an epistemological perspective, I took a pragmatic stance by collecting data through adopting a *'what works best'* approach (Creswell and Plano Clark 2017). The influences on this are my exposure to and experience of nursing theory and practice, nurse education, healthcare research, and COPD practice as well as my specific *a priori* knowledge about COPD. My interest in COPD and experience of supporting people with COPD were explored in the '*forestructure'* in Chapter 1, with my justification for choosing COPD as a focus for development. Thus, knowledge generated in this thesis comes through quantitative survey outcomes and from my interactions with participants and the relationship we co-created in achieving the mutually negotiated goals of each interaction in addressing the research objectives (Teddlie and Tashakkori 2009). This, I consider knowledge to be both constructed and based on the reality of experience of the world, and I acknowledge my expertise in these real-world contexts and in the psychosocial support I have provided for people with COPD.

3.6. Interpretive Description

Several qualitative methodologies are available to researchers to select from when beginning a research study. These include narrative research, case study research and the three most found in healthcare studies: ethnography, phenomenology and grounded theory (Creswell 2015). As written text was not relevant, as I was not examining narratives in this thesis and case studies would provide too few opportunities to gain a wider understanding of experiences of people with COPD, neither of these options were considered appropriate. In thoroughly exploring ethnography, phenomenology and grounded theory, and considering their theoretical bases, my preference was drawn towards an applied method that more closely linked theory and practice knowledge. This section details interpretive description as a method and then explores aspects of ethnography, phenomenology and grounded theory accounting for those techniques which are borrowed.

Interpretive description is further explored in this section to provide context and detail on its relevance in guiding the conduct of both qualitative studies in this thesis. According to Thorne, Stephens and Truant (2016), interpretive description enables the application of qualitative inquiry to the field of healthcare in order to develop new knowledge and insights, as its focus is pragmatic in attending to pressing nursing and healthcare related problems rather than addressing formal theoretical interests. Consequently, interpretive description is contentiously described as a *'non categorical'* approach drawing upon, but not closely fitting with, any of the established qualitative methodologies such as phenomenology, ethnography or grounded theory that are well embedded in the sociological and anthropological traditions (Thorne, Stephens and Truant 2016, p.453). Interpretive description, therefore, is considered less of a discrete qualitative research methodology and more of a conceptual label by which to represent the attributes of high-quality research (Thorne 2016a).

Interpretive description emerged through a growing need to foster a research methodology that could explore the types of clinical issues and questions relevant to nursing to produce knowledge directly useful for practice and which were more challenging to address through the adoption of other methodologies (Thorne, Kirkham and O'Flynn-Magee 2004). This occurred because of a perception that conventional methods of qualitative inquiry were not able to realistically advance clinical knowledge in the practical way that was required in healthcare, prompting variations of those in existence to gain a better fit for practice needs (Thorne 2016a). This was because of the perception that traditions in qualitative health research methods were derived through the historical development and context of *'social sciences'* with an intention that new knowledge was mainly enacted through careful theorising - a concept known as *'theoretical baggage'* (Thorne, 2016a p.26). Indeed, moving away from the methodological orthodoxy of conventional methods (discussed later in this section) created tension and attracted accusations of being intellectually sloppy and that *'methodological slurring'* may be occurring because there appeared, at that time, little to support credibility and rigour in interpretive description (Thorne, 2016a p.35). Despite these concerns, it was evident there was a large volume of authentic, high-quality, qualitative research being conducted that was unnamed in methodological approach as researchers did not want to pursue their research through these recognised labels (Morse 1989 in Thorne 2016a). Many researchers identify interpretive description as their chosen methodology or method to indicate an applied research approach which is true to practice requirements, rather than be labelled as a simple qualitative description approach which may lack rigour (Doyle et al. 2020; Neergaard et al. 2009), or as a *'no method'* approach (Rasmussen et al. 2018; Thorne 2008).

The purpose of interpretive description is to produce descriptions of phenomena that are logical and closely related to the issues under investigation (Thorne 2008). These descriptions are known as *'tentative truth claims'* oriented towards addressing the research questions and subsequently providing useful information and knowledge to influence practice (Thorne 2016a). In other words, an interpretive description approach not only offers insight that takes understanding beyond a superficial appreciation of the human experience (Rasmussen et al. 2018) but also produces co-constructed truths rather than simply facts (Thorne 2016b). However, there are no detailed procedures suggested for the conduct of interpretive description and it may be considered as no more than an amalgamation of borrowed techniques from other established methods (Berterö 2015).

Another important aspect of adopting the interpretive descriptive method is to provide clear and credible, in-depth descriptions and explanations during the research process and that all decisions made throughout the development of, and duration of a study should be recorded. Interpretive description requires integrity of purpose from both a) a practice goal, and b) a broad and deep appreciation of what is already known and not known about a topic, both clinically and theoretically, with the evidence coming from all credible sources (Thorne 2016b; Thorne, Stephens and Truant 2016). Interpretive description therefore aligns closely with interpretivist orientations as it is inductive, acknowledging the contextual aspect of human experience and the need for researchers and participants to co-create and construct reality (Thorne 2016b).

3.6.1. Reflexivity in Interpretive Description

Further consideration of reflexivity here is important. Interpretive descriptive research needs to be reflexive to be authentic and honest in illuminating how and in what ways a researcher's views and experiences impact on the research process and outcomes, to ensure complex and multiple co-constructed realities are interpreted appropriately (Thorne 2016a). As Levy (2003 p. 94) puts it, the role of the researcher in being reflexive is not *"to suspend subjectivity, but to use the researcher's personal interpretive framework as the basis for developing new understandings".*

To enhance authenticity in this thesis, I highlight my viewpoints at the macro-level, during data organisation and management, and at the micro-level, during abstraction, interpretation, and presentation. Interpretive description is identified as fitting with a pragmatic epistemological position informed by practice and heralding my decision to depart from following a conventional qualitative research tradition for the conduct of the qualitative studies in this thesis (Thorne 2016b). This clarifies an auditable logic in aligning pragmatism with interpretive description and borrowing the best techniques from ethnography, phenomenology and grounded theory, having thoroughly considered the alternative, traditional methods as discussed next.

3.6.2. Ethnography

Ethnography focuses on describing and interpreting the activities of a cultural, social or group system in their natural environment and uncovers the patterns and behaviours that the group display (Creswell 2009). In taking an ethnographic approach, the focus is on group interactions and behaviours as a whole rather than on individuals, and the researcher spends significant time immersed in the culture of interest to enable an understanding and analysis of it (Creswell and Plano Clark 2017; Parahoo 2014). Both qualitative studies in this thesis aimed to gain an understanding of the individual's experiences relevant to each unique situation and context to partly address the literature gap on the topic as well as go on to develop meaningful knowledge that could be helpful for healthcare practitioners. Therefore, immersing in a specific cultural situation was considered less relevant. One element from the ethnographic tradition that is utilised in this thesis is reflexivity, which will be discussed in greater depth in the section on reflexivity to follow. Reflexivity is an inherent part of trying to imagine being in the participant’s position and is similar to staying close to the data and making subjectivities transparent and recorded throughout the decision-making process as required in an interpretive descriptive study (Thorne 2016b; Berger 2015).

3.6.3. Phenomenology

Phenomenology was also considered as a method for conducting this research. Phenomenology enables researchers to focus on the perception of an individual’s lived experiences and how they are expressed and is based on the work of philosophers including Husserl, Merleau-Ponty and Gadamer (Parahoo 2014; Creswell 2009). There is a considerable body of philosophical and theoretical underpinning related to phenomenology and it is considered difficult to do without a comprehensive understanding of the associated theories (Robson and McCartan 2015). Husserl mooted that the researcher was required to cast-off their culturally induced preconceptions through a process he called *“phenomenological reduction”* (Converse, 2012 p.30). In this, he felt, researchers are able to access the *‘essence’* of an individual’s experience which involves endless description uncontaminated by researcher biases (Converse 2012). Many claim that taking a simple, stripped back approach in a phenomenological study, in some cases, is sufficient (Harvey and Land 2017; Porter 2007; Annells 1996). However, and as with the theorising around paradigms, the literature is conflicting and contradictory (Harvey and Land 2017; Parahoo 2014).

Phenomenology is founded on the assumption that only those experiencing a context-based phenomenon can truly understand and express their experiences which are witnessed and communicated with and through others (Harvey and Land 2017). Interpretation of experiences are possible (Reiners 2012). Heidegger claimed that interpretation could not be gained through looking at data without understanding the participant’s perspective (Creswell and Plano Clark 2017). The Heideggerian conceptualisation of phenomenology offers researchers options to access deeper analysis which consider the *‘being’* of a phenomenon (the meaning of our understanding of a phenomenon), not just the *'essence'* (Converse 2012). Accessing the *'being'* of a phenomenon occurs through a never-ending circular (or hermeneutic) process (Converse 2012). Gadamer developed perspectives suggesting hermeneutic phenomenological approaches could not be managed without understanding the participant's background, putting importance on the influence of an individual's psychological make-up, personal history, education, social class, culture, past events, and experiences (Parahoo 2014). Heidegger and Gadamer's views of the rejection of the researcher *'bracketing off'* their preconceptions and prejudices (encouraged in the Husserlean phenomenological approach) is more closely aligned to the interpretive descriptive approach as discussed earlier (Reiners 2012).

The interpretive descriptive approach in this thesis embraces researcher subjectivity, which is made transparent and considered in all stages of the research process (Creswell 2017). The notion of *'being'* is also relevant here, as in order to link data to the clinical field, interpretation and an understanding of what that means to people with COPD is also relevant to the outcomes and is a feature of interpretive description. Additionally, the collaborative property of phenomenology is relevant to the co-constructed nature of interpretive description and an important aspect of this research and again is a good fit (Thorne 2016a).

3.6.4. Grounded Theory

Grounded theory was also considered as viable for conducting the qualitative studies and is a commonly used qualitative method sharing its epistemological foundations with interpretive description (Thompson Burdine, Thorne and Sandhu 2020; Corbin and Strauss 2008; Creswell 2017). A key feature of grounded theory is its inductive approach whereby theory or hypotheses are generated through the data which can then be tested deductively as a research study proceeds (Parahoo 2014). Similar to interpretive description, grounded theory helps to explain social processes and increase our understanding of human behaviour in drawing from the constant comparative analysis where the focus is to look for patterns and commonalities within the data. It is this comparing and questioning technique that is carried through to the interpretive descriptive approach where data collection and interpretation occur simultaneously (Thorne 2016a). Indeed, as all qualitative methods essentially seek to uncover and interpret the experiences of individuals or groups, the similarity in technique often leads to *'methods slurring' (*Johnson, Onwuegbuzie and Turner 2007; Morse 2000). This comes as no surprise because all the qualitative methods discussed here have more commonalities than differences, further justifying the borrowing from other qualitative method techniques advocated in the adoption of interpretive description (Thorne 2016a; Sandelowski 2000).

3.6.5. Interpretive Description in this Thesis

Thorne (2016a) considers interpretive description as fitting well with the pragmatic positioning of mixed-methods research, as its foundation is in doing what is required to address pragmatic questions and it is not shackled by the *'theoretical baggage'* associated with conventional methods. However, a clear and credible explanation of the research processes and decisions that I make within these studies is key to closely following the interpretive description method and values. Another significant advantage of adopting interpretive description is the flexibility around the way the research is carried out as there are no fixed limitations or constraints for sampling or analytical processes for example (Thorne, Kirkham and O'Flynn-Magee 2004). Interpretive description borrows from other techniques to achieve the highest quality outcomes (Thorne 2016a). This is further clarified, where appropriate, in the methods and concluding sections of both studies.

Although the qualitative studies in this thesis are not wholly *'clinical'* in nature (a proviso for the use interpretive description), as their focus doesn't appear immediately relevant to a direct healthcare context, the outcomes are related to the provision of person-centred care (Thorne 2016a). Healthcare professionals may find the study recommendations could contribute towards developing truly holistic psychosocial client assessments and self-management plans, which are daily activities for those supporting people with COPD. This may subsequently help in the development of workplace management support plans that recognise the significance of employment to working-aged people with COPD.

3.7. Ensuring Research Rigour

Validity in mixed-methods studies can be considered as any steps taken in checking the validity (or precision) of the generated quantitative data and results and the accuracy of the qualitative phenomena under investigation (Ritchie et al. 2014; Creswell 2009). Validity measures must be in place to assure the quality of both aspects (Onwuegbuzie, Johnson and Collins 2008). An important factor to ensure cohesion and credibility in mixed-methods research is not to use conflicting research questions between or within quantitative and qualitative studies (Creswell 2009), which I believe is achieved in this thesis. Issues of research quality have been described in relation to quantitative research (O'Leary 2010). There are numerous stages during the conduct of a study for actions and events to threaten a study's internal validity (the way the research is generated and how data is handled) and the external validity (whether findings are particular to the population studied or can be applied to a wider population, over time/setting) (O'Leary 2010; Creswell 2009). In the pilot study, considerations are made around validity, which questions whether outcomes are of value with regards to the sample size, the participant selection process, bias in data collection, adequacy of procedures and the use of appropriate measurement tools and databases to process quantitative data (SPSS for example) (O'Leary 2010; Creswell 2009).

3.7.1. Credibility

Fundamental to ensuring trustworthiness in qualitative studies is the establishment of credibility. Credibility in qualitative research may be defined as the extent to which research findings accurately represent the phenomena being investigated (Robson and McCartan 2015; Ritchie et al. 2014). In this thesis, credibility is dependent on focusing on the COPD population to harness their employment experiences to address the study objectives. I also needed to be confident and transparent about my choices and decisions to ensure credibility in the research process, particularly around analysis and that the study generated outcomes that would be relevant (valid) for practice contexts. Alongside this was the need for research objectives to be consistent with my epistemological view of pragmatism and that the data interpretation and the interpretive approaches employed were emanating from the research questions and the real world (Thorne 2016a). Taking account of the indicators of quality in quantitative studies (validity, reliability, generalisability and reproducibility) and the qualitative indicators of *credibility, auditability, transferability, authenticity, dependability* and *confirmability,* the detail to demonstrate rigour and examples of how these are handled in the studies are highlighted and are woven throughout both studies (Parahoo 2014; Creswell 2009; Nicholls 2009; Thorne, Kirkham and O’Flynn-Magee 2004).

3.8. Researcher Reflexivity

As discussed in Chapter 1 and throughout this chapter, it is impossible to separate ourselves from what we know, and my background as an experienced nurse, lecturer and researcher with an active and subjective involvement in the social world of people with COPD can influence the research findings (Guba and Lincoln 1994). Being knowledgeable and passionate about the topic and striving to improve the outcomes for people with COPD is what drove me to develop the body of knowledge on health and well-being and employment experiences. Whilst these are significant assets for a researcher, and must be valued, certain biases are inherent from my motivation and engagement with the subject. Nonetheless, through being reflexive and adopting the values of interpretive description, my subjective involvement is not cast off, but is illuminated and embraced in this pragmatic approach (Thorne 2016a).

Reflexive excerpts are woven throughout this thesis, which enable the reader to make judgements on the objectivity of the study in terms of how I dealt with the processes and the data to gain meaning (Green and Thorogood 2018). Stating my position at the outset of the research process was important to examine and understand how and in what ways my assumptions on the social world of people with COPD could have an impact on the outcomes/findings (Thorne 2016a). As participants were taking part in research with someone wearing three hats, as a nurse, an academic and a researcher which could have a considerable influence on the research outcomes, it was also important to try to limit any bias. Closely linked to the ethical power relationships, I made efforts to downplay as much of this as possible whilst remaining truthful to the situation as discussed within each study. I was transparent in the participant information sheet and again reinforced that I was a researcher interested in building our understanding of the knowledge base as part of a PhD study. It was challenging to remain neutral at times when participants gave their accounts of harsh and poor treatment in the workplace, or I witnessed their emotions in providing in-depth accounts of their efforts to maintain their employment. I was also cognisant of the physical effort and time participants willingly gave to explore their personal experiences and the efforts I made to resist becoming a problem solver.

The diversity of accounts provided by the participants, both positive and negative, convinced me that the data collected is true to their experience. In addition, several participants indicated that they were appreciative of my interest in COPD and that as they had lacked so much support, were delighted someone had it on their agenda. However, participants may have been reticent in providing a full and honest account of their status or experiences to someone they met for the first time, so at times my enthusiasm may have been important in cementing the rapport. Although there are always limitations in research of this nature, there can be confidence in asserting that data were valid and particularly relevant for practice and that I was authentic and credible as an ethical researcher.

3.9. Ethical Considerations

Ethical issues and the need for robust governance in healthcare research are well recorded in the literature (Green and Thorogood, 2018; Offredy and Vickers 2010; Beauchamp and Childress 2001; Holloway and Wheeler 1995). Research must be ethical to protect both participants and the researcher, as both undertaking research and taking part in it can, in some circumstances, cause harm to those involved. In order to reduce risks to both parties the researcher must uphold specific ethical principles (Parahoo 2014; RCN 2011). According to Beauchamp and Childress (2001), consideration of ethics in relation to research is structured around the four principles of *beneficence* (the balance of benefit or good to come from the research), *autonomy* (an individual's right to freely choose to take part in research without coercion), *non-maleficence* (an individual's right to be protected from harm at any point in the research process) and *justice* (an individual's right to be treated equitably and fairly).

As a registered nurse, I had professional obligations to consider the Nursing and Midwifery Council's (NMC) *'The Code: professional standards of practice and behaviour for nurses, midwives and nursing associates'*, which makes explicit the principles that nurses must uphold in their everyday practice (NMC 2018). The NMC (2018) state that the values and principles written in *'The Code'* are not negotiable or discretionary. These standards hold nurses accountable for their actions and must be upheld regardless of their role in practice, education, or research.

Where participants are patients and service users, ethical approval through a review of planned research, is sought from the Research Ethics Committee (REC) (Integrated Research Application System (IRAS) 2022). Through an ethics review process, designed to *"safeguard the rights, safety, dignity and well-being of people participating in research in the NHS",* approval to proceed may be given (IRAS 2022). Ethical review takes the form of one of two processes; *proportionate review*, which is an accelerated ethical review process where no material ethical issues are identified, or a *full REC review* where the proposed studies are more complex and risks to participants are less clear (IRAS 2022). In addition to this, registration and approval with a local NHS Research Governance Team is also required to ensure the interests of patients and the public participating in health and social care research are protected locally (NHS Grampian 2022). Even though ethical approval might not be required through the IRAS process for some PhD studies, institutional (non-NHS) ethics is usually required prior to the commencement of a research study. In this PhD, ethical approval was also sought from two academic Schools (to which the PhD study student was aligned at that time), the School of Nursing and Midwifery and the School of Health Sciences Ethical Review Panels. In designing and planning these studies, ethical aspects were carefully considered, and the ethical approvals processes are detailed in the methods sections of both studies.

3.10. Chapter Conclusion

To demonstrate intellectual and methodological rigour for these studies, this chapter has presented a robust and transparent account of my underpinning philosophical thoughts and beliefs (Durham et al. 2015). Through the exploration of research paradigms, research methodologies and study design options, I have presented and justified the decisions made to guide the research studies. In doing so, my epistemological beliefs have been illuminated and the adoption of a pragmatic position has led to the development of a mixed-methods methodology comprising two studies – one mixed-methods, and one qualitative. Furthermore, the use of reflexivity throughout the thesis shapes the design decisions and analytic manoeuvres so the reader can clearly establish who I am, what I represent and what I am trying to accomplish (Thorne 2016a).

This chapter has illustrated an overall strategy for the two research studies presented in Table 3.6 and how they were planned to produce research to contribute to the knowledge base of COPD and employment. The next chapter now presents a mixed-methods study on the psychosocial and physical factors influencing employment in people with COPD.

Table 3.6 - A Philosophical, Methodological and Methods Map of the Thesis

Paradigm	**Strategies for Inquiry** **Mixed-methods Methodology**	**Methods, processes & analytical approach**	**Strategies for Inquiry** **Qualitative Methodology**	**Methods, processes & analytical approach**
Pragmatism	**Quantitative**	**Cross-sectional, Explanatory – sequential** Questionnaire (Measures) Data Data Analysis Interpretation Narrative	**Qualitative**	***Interpretive Description*** Interviews Data Transcripts Data Analysis *(Framework analysis)* Interpretation Synthesis
	Qualitative	***Interpretive Description*** Interviews Data Transcripts Data Analysis *(Framework analysis)* Interpretation Synthesis		

4. The Psychosocial and Physical Factors Influencing Employment in People with COPD: A Mixed-Methods Pilot Study

4.1. Introduction

Chapter 3 presented the philosophical, methodological and ethical perspectives which contributed to and underpinned this mixed-methods pilot study. That chapter also presented the aims and objectives for both this study and the qualitative study (Chapter 5). Crucial to a robust study utilising a mixed-methods approach is the researcher's detailed consideration of the reporting of the study methods, design and conduct. Conducting a pilot study on a small scale was important to test the feasibility of methods to assist in preparing for the potential subsequent conduct of a larger, more robust, cohort investigation of well-being and employment in working-age people with COPD. This pilot study is characterised by testing whether something can be done or not, whether and how it should or could proceed, and if it is workable in practice (Eldridge et al. 2016) and could identify potential problem areas and guide the direction of a future study (Fraser et al. 2018).

4.2. Chapter Structure

This chapter explains the need for a pilot study, specifies the study designs used, describes the research processes adopted in collecting the data and details the challenges involved. It firstly outlines the study methods and then discusses the feasibility of the study processes. Following this, the discussion details and reports on the trends in the cross-sectional study results and presents the qualitative study findings, analysis and discussion. The chapter concludes by considering the important points of learning from the pilot study and how they informed the future direction of the subsequent qualitative study of this PhD research (Chapter 5).

4.3. Study Aims and Objectives

4.3.1. Study Aims

The aims of this study were to test the feasibility of conducting a scientifically robust study and identify the factors and experiences that influence employment in people with COPD.

4.3.2. Study Objectives

As the study objectives comprised specific questions requiring both quantitative and qualitative assessment, a mixed-methods design was adopted. The three study objectives were:

1. The Pilot Process - To test recruitment and study procedures to enhance the design of a later study including sample size estimation. Specifically, that organisational processes have the required steps in place, that resources and time are adequately planned, that the researcher is appropriately prepared, that management of data collection and processing is smooth and transparent and important data is not missing.
2. Quantitative Study - To identify the psychosocial and physical factors that may influence employment in people with COPD.
3. Qualitative Study - To provide a detailed exploration of a sub-sample of participants' employment contexts and related experiences.

An explanatory sequential mixed-methods approach was adopted to address the above objectives as previously discussed in Chapter 3. The study was conducted over a seven-month period in 2014. A cross-sectional study comprising of a battery of questionnaires addressing health and well-being and workplace control and adaptation were administered to address objective 2. Following completion of the questionnaires, individual one-to-one semi-structured interviews exploring employment contexts and related experiences in a sub-sample of participants were conducted to address objective 3. The methods for both study components are considered next.

4.4. Methods

This section presents the methods for the quantitative and qualitative studies. The broad outlines of the studies are presented first.

4.4.1. Quantitative Cross-Sectional Study

A questionnaire, comprised of mostly validated health and well-being tools, was considered the best way to gather data to address objective 2, as it enabled questions in relation to attributes, characteristics and opinions of given phenomena to be answered (Harvey and Land 2017). One additional section was included to determine recent workplace control and adaptation, and, as no equivalent validated tool could be located, I designed this myself. The questionnaire has several advantages, as it could reach large numbers of participants at one time, particularly if a postal or online approach is taken, and can therefore represent a wide population, generating standardised quantifiable empirical data (Green and Thorogood 2018). If required, a questionnaire could also include some short open qualitative questions if additional individual detail and information is required (Harvey and Land 2017). Using a questionnaire is cost efficient, cost effective and can address several relevant facets at one point in time (Green and Thorogood 2018; Plano Clark and Creswell 2018).

A cross-sectional approach is a commonly used, non-experimental research design for healthcare research (Harvey and Land 2017). It is sometimes called the *'one-shot design'*, and its purpose is to collect data from a sample (or cross-section) of participants on one occasion in order to represent the target population (O'Leary 2010). In a sufficiently large and well-controlled study, this would enable the results from the survey to be generalised to the wider population (Creswell 2009). A cross-sectional design is advantageous, as it is also time efficient, low in cost and, large samples can be achieved in a short time (Creswell and Plano Clark 2017).

Using a questionnaire does have some weaknesses, however, and consideration must be given to possible low response rates (Harvey and Land 2017). Other limitations include risks that extreme views or results can be obscured because the results are often reduced to averages, the fact that it provides only a snapshot of the here and now, and also that the data can occasionally be superficial (Harvey and Land 2017). As the focus of this study was to pilot test the running of a larger subsequent study and not the outcomes or relationships per se, the target sample size was set at 30 participants (Fraser et al. 2018). Thus, as the data being collected were scaled and scored according to validated protocols, there was less concern that it would be superficial and unsuitable for analysis (Richards 2014; Teddlie and Tashakkori 2009).

This cross-sectional study was designed as a self-assessment instrument with accompanying explanatory information included in each section. The questionnaires were reasonably quick to administer (20 minutes) and inexpensive to carry out (Harvey and Land 2017; Babbie, 2015). Participants could request my assistance in completing the questionnaires to help address or explain any queries they had on any of the instruments, ensuring all items were completed. This was believed to be an approach that would enhance response rates and reduce the burden on participants and ensure that missing data would not become a later issue (Newell and Burnard 2011).

4.4.2. Qualitative Interviews

Within the explanatory sequential mixed-methods approach adopted, the philosophical perspective of the use of a cross-sectional study using these validated questionnaires is part of the positivist philosophy which seeks to explain the *'what is'* (Doyle, Brady and Byrne 2016; Creswell 2015). There is an assumption that the study outcomes can discover a certain 'truth' about participants' psychosocial and physical well-being through the questionnaires utilised i.e., quality of life, satisfaction with life, resilience and health and well-being in relation to employment (Green and Thorogood 2018). As was apparent from the literature review, little was known in relation to well-being and the factors that influence employment in those working-age people with COPD. Explanatory surveys are widely used to assess health and well-being in other chronic conditions including rheumatoid arthritis, (Graham, Stephenson and Williams 2017) cardio-metabolic conditions (Boehm et al. 2016) and mental health conditions (Vaingankar et al. 2017). The explanatory element of this study provides a foundation to understand well-being before identifying the employment experiences of those with COPD and develop an understanding of different workplace contexts. The addition of open-ended questions, found in 'Section J' of the questionnaire, asks participants about Workplace Control and Adaptation which enables a broader understanding of the impact of COPD on employment (Harland and Holey 2011).

It was important to also gather data on people's experiences of working with COPD (or leaving employment due to their COPD) to gain a more complete perspective on the challenges and opportunities involved. This type of data could cast light on the impact of COPD in relation to the participants' employment situations (and vice versa) and how much workplace adaptation was implemented. This helps build up an in-depth understanding of, and the interrelationships between, the qualitative findings and quantitative results enabling an integration of ideas emanating from the data (Plano Clark and Creswell 2018; Thorne, Stephens and Truant 2016).

4.4.3. Population

The population of interest were people aged between 40-70 years with a diagnosis of COPD as their main presenting condition and confirmed by a Consultant Respiratory Physician and their medical team. This age range was selected, as most COPD diagnoses are made after the age of 40 and, currently, many people with COPD have retired from their employment by age 70 (NICE 2018). A high percentage of people with COPD (90%) have comorbid conditions (such as diabetes, hypertension, coronary heart disease, malnutrition, anxiety, depression and osteoporosis) and it would be challenging, if not impossible, to find a sizeable population with only COPD as a single condition (Dal Negro, Bonadiman and Turco, 2017; Maclay and MacNee 2013). Therefore, it was important that COPD was the participants' main presenting condition and identified as having or having had the greatest impact on them in relation to their employment (Franssen and Rochester, 2014; Cavaillies et al. 2013). Confirmation that COPD was the main presenting long-term condition was made entirely subjectively, as it could not be easily determined or measured clinically and was therefore a decision made by the medical team (during their initial sifting of prospective clinic lists of patients well known to the team). Participants confirmed that COPD was their main presenting condition during the informed consent process.

4.4.4. Ethical Approval

This study was designed to comply with UK Research Governance Framework requirements (2005) (now UK Policy Framework for Health and Social Care Research, 2018) and the Robert Gordon University School of Nursing and Midwifery, School Ethics Research Panel (RGU: SERP) and the local research ethics committee (REC), North of Scotland Research Ethics Service (NOSRES) provided approval. In addition, Robert Gordon University research governance and research ethics policies were also adhered to (RGU 2021a; RGU 2021b). Documentation for the SERP process was prepared and submitted, and following feedback and some minor amendments, approval was obtained for the study in September 2013. Subsequently, an online Integrated Research Application System (IRAS) application for permission and approval was also developed and submitted. This involved a site-specific form prepared for local research and development governance process purposes. As no material ethical issues were identified in the study design and proposed method of conduct, ethical approval for a proportionate review was appropriate. Approval was provided by the NHS Research and Development committee (2013RG001 October 2013, Appendix I), as participants were recruited as patients of the National Health Service, and later approved through NOSRES in December 2013 (North of Scotland Research Ethics Committee No. 13/NS/0139).

4.4.4.1. Ethical Issues

In the planning of the study and preparation of the IRAS application, the consideration of several ethical principles was paramount. These included consent, confidentiality, anonymity and duty of care. Being able to predict and prevent unethical research practice is necessary as some of the issues that can evolve, particularly in qualitative studies where there are sensitivities, are subtle e.g., power imbalances, participant distress, fear of being identified (Creswell 2013; Orb, Eisenhauer and Wynaden 2001). Actions were taken throughout the study to maximise the benefits to participants whilst minimizing the potential for harm to occur (Gerrish and Lathlean 2015; Newell and Burnard 2011) by ensuring privacy during the survey administration, protecting anonymity throughout, by carrying out interviews in a location of the participant’s choice (to reduce the power balance) and by underplaying researcher expertise unless specifically asked.

Following informed consent, obtained and countersigned by me, the process of administering the questionnaire involved participants providing demographic details, perceptions and experiences of their health condition and employment factors in relation to health and well-being. Data were collected in paper-based questionnaire booklets, coded, anonymised by the use of pseudonyms and entered onto SPSS. The booklets were securely stored in a locked filing cabinet in my office (Harvey and Land 2017; RGU 2021a) and will be retained for 10 years in accordance with the Data Protection Act (1998) and local NOSRES and RGU research governance regulations (RGU 2021a; GDPR 2017). Participant identities were protected by using pseudonyms from the data management stage onwards (Green and Thorogood 2018).

Informed consent was gained for the subsequent interviews, each participant having again read the PIS and signed the consent form discussed further in the following section. Participant confidentiality was always ensured, and it was made explicit during the informed consent process that future representation of the 'participant voices' would be in anonymised direct quotations (HRA 2017a; Holloway and Galvin 2017). All subsequent publications and presentations would ensure individuals cannot be identified, as only general findings and trends would be made available for dissemination purposes thus assuring participant anonymity.

As a registrant of the Nursing and Midwifery Council, I have a duty of care to protect patient confidentiality and their health and well-being (NMC 2018). A plan for managing potential participant distress was considered and, should a participant have become distressed during or after the survey or interview, contact numbers for their respiratory consultant and their GP and national COPD focused websites for information, guidance and support (e.g., Chest Heart and Stroke Scotland (CHSS) could be made available.

Clearly articulated in the participant information sheet (PIS) was the need for me to refer on to the participants' GP's should they score above the threshold level on the HADS assessment (Hospital and Anxiety Depression Scale - threshold score of 11 and above). Participants would have previously understood and discussed this referral requirement as part of the informed consent process. Should the GP deem it necessary to refer the individual to a mental health specialist, this would be undertaken in accordance with routine clinical procedures outside the study and unknown to the researcher.

4.4.5. Sampling Strategy

The purpose of a sampling strategy is to maximise efficiency and validity in the sampling process whilst being consistent with the research approach, aims and assumptions (Ritchie et al. 2014; Morse and Niehaus 2009). As a clearly defined sampling strategy for mixed-methods research does not exist, probability and non-probability sampling options were considered (Creswell 2015). Probability sampling, including simple random sampling (e.g., random number generator) or cluster random sampling (e.g., everyone attending a clinic on a given day) aims to select participants in a way that means they are representative of the population as a whole and have an equal chance of being selected for a study (Parahoo 2014; Neale 2009). A strength of this approach is that participant selection is non-biased, making the data generated suitable for hypothesis testing and statistical analysis (Ritchie et al. 2014). In terms of non-probability sampling, the two most often used are purposive sampling, where the researcher makes judgements on the suitability of potential participants, and convenience sampling based on potential participants who are available to take part (Ritchie et al. 2014).

As this was a pilot study to determine the feasibility of methods for conducting a later study, meet the study objectives and understand more about the experiences of those with COPD, the results were not intended to be generalizable (Cooper et al. 2020). However, the results could inform a subsequent sample size calculation (Harvey and Land 2017; Van Teijlingen and Hundley 2001). Purposive sampling was chosen in order to select those participants with characteristics (e.g., COPD) who, by virtue of their knowledge or experience, could provide the information required to address the study objectives (Etikan, Musa and Alkassim 2016). Using this approach made the best use of available study resources to identify and select relevant, information-rich sources (people of working age with COPD) and likely those most well-informed and knowledgeable about the study topics (Etikan, Musa and Alkassim 2016; Ritchie et al. 2014).

Sampling was determined by taking account of the availability of resources (people, facilities, clinics, offices) and time to conduct the study, whilst taking a pragmatic approach to obtain the best possible dataset to address the study objectives (Andrew and Halcomb 2009). Although conflicting views exist, some of the literature suggests 10% of the intended population size should be utilised as a pilot assessment and it is about obtaining enough to balance information needs with resources, including time and cost (Fraser et al. 2018). The pilot sample was set at 30 participants for the cross-sectional study and six for the interview. However, due to unforeseen workforce circumstances, the primary care practice was unable to operationalise the recruitment process within the agreed time and were withdrawn. A potential larger study would require around 300 participants, albeit in larger funded projects the pilot study normally informs the sample size (Polit and Beck 2018).

4.4.5.1. Inclusion Criteria

People with COPD as their main presenting condition were included in the study. Initial decisions were made on the appropriateness of inclusion by the respiratory consultant and the medical team, as they were fully aware of the coexistence of their patient's conditions and could scrutinise their clinical notes and local disease registers. Potential participants were excluded if they were living outside the study area, or if they were unable to complete the questionnaires due to cognitive limitations which could prevent full participation. As there was no budget available for translation services, only English speakers could be included. The inclusion requirements were confirmed as part of the informed consent process. Inclusion and exclusion criteria are illustrated in Table 4.1.

Table 4.1 - Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
COPD as the main presenting condition	Evidence of cognitive limitations
Age between 40 - 70 years	Resident outside North East Scotland
Attending the designated hospital clinic as outpatient or GP practice	
Fluent in the English language	

4.4.6. Participant Recruitment

Initially, a target sample of 30 people with COPD meeting the inclusion criteria from the two clinical sites were sought to take part in the study: (i) The respiratory clinic with a COPD Register and eight respiratory physicians in an acute hospital in one Scottish Health Board, and (ii) a primary care General Practice from one Scottish Health Board's COPD Managed Clinical Network. However, the hospital chest clinic became the single study site due to unforeseen resource circumstances and time constraints.

Eligible patients were screened and identified as suitable for inclusion by the lead respiratory consultant and their team of respiratory nurses. A letter of invitation was sent to those patients due to attend the chest clinic in the following six-weeks along with their clinic appointment letter (Appendix II). The letter of invitation outlined the purpose of the study and included the invitation to participate. Enclosed with the letter of invitation was the participant information sheet (PIS) explaining the purpose and process of the study, what to expect if taking part and the governance aspects of the study (Appendix III).

In addition, the inclusion of an intention to participate form with an accompanying stamped envelope addressed for my attention was sent to enable individuals to indicate their willingness to take-part. As patients were sent these forms in advance of their clinic appointment, this ensured they had a minimum of 14 days to read the PIS and consider taking part. This timeframe also provided participants with the opportunity to follow up with any questions or queries. Recruitment was therefore considered as an opt-in approach and no material or financial incentives were offered for participation. Prospective participants were asked to return the participant response sheet to me indicating their intention to take part in the study following their next scheduled hospital appointment at the chest clinic. This was my first point of contact with any prospective participant. On indicating their intention to participate in this pilot study, I met with the prospective participants following their clinic appointment. The quantitative and qualitative data were collected sequentially with the interview being carried out within a short period of time after the cross-sectional survey (within two-weeks).

4.4.7. Informed Consent, Confidentiality and Anonymity

Based on the ethical principles of autonomy and justice, informed consent, as discussed in Chapter 3, refers to providing prospective participants with sufficient and relevant detail about the nature of the study, its purpose, aims and the expectations of them (Green and Thorogood 2018). Full information enables participants to make informed decisions about whether to participate or not (beneficence) (Green and Thorogood 2018; Neale 2009). The PIS addressed ethical principles ensuring transparency of all aspects of the study. On returning the participant response sheet indicating their wish to participate, a mutually convenient time was agreed following clinic appointment time for the administration of the questionnaire. Prospective participants then had the opportunity to discuss any element of the study face-to-face to with me and consider the statements included in the consent form to enable a full understanding (NRES 2009).

In obtaining informed consent, the dignity and the rights of people are protected to ensure they are not coerced, understand the expectations of participation and research conduct thereafter, and participate in the study on a *'voluntary'* basis (Silverman 2017). It was reinforced to participants that they had the right to withdraw from the study at any point without an adverse effect on their healthcare, treatment or relationships (autonomy) (Silverman 2017; Priest and Roberts 2010). Once individuals agreed to take part (by completing the Participant Response Sheet (Appendix IV)), they read and initialled each statement in the consent form indicating their understanding of what was involved in participation and how the data would be subsequently handled (non-maleficence) (Appendix V). The consent form was then counter signed by me.

Gaining written consent provided a formal record of the participants’ willingness to participate (Green and Thorogood 2018).

4.4.8. Research Rigour

The results of the questionnaire in this study can be considered as valid, as the questionnaires used were mainly standardised tools, and decision-making around their selection and detail on how the study was conducted has been explored. Other aspects of quality are *reliability* (internal consistency of collection and measurement of data), g*eneralisability* (findings are relatable to larger population), and *reproducibility* (whether similar results could be obtained were the same methodology used in a different study and context) and are dealt with in the section for objective 2 (O’Leary 2010; Creswell 2009). Aspects of credibility and transferability, crucial to the trustworthiness of high-quality qualitative research, are discussed in the section for objective 3 and illustrated next in Table 4.2.

Table 4.2 - Strategies for Assuring Quality in the Qualitative Studies

Strategy	**Criterion**	**Example of how the strategies are integrated and managed in the study**
Credibility (Internal validity)	Prolonged engagement in the topic	• Purposive sampling. • Building trust during interviews. • Keeping field notes. • Data analysis (Framework clearly detailed). • Inter-rater reliability (PhD supervisor member checking a sample of transcriptions).
Auditability (Record keeping)	Strategy for reporting participants' ideas	• Audit trail of analytic logic. • Transparency of processes. • Data traceability (Examples of data stages in appendices).
Transferability (External validity)	Provides thick description	• Thick description of methodology and results. • Captured detail to make reasonable conclusions from interviews and transfer findings to other settings. • Direct quotes from participants.
Authenticity	Pragmatism and Interpretive description	• Describing the 'truth' from the people having the experience. • Staying close to the data.
Dependability (Reliability)	Audit trail	• Audit trail of analysis available for external scrutiny. • Methods account for subjectivities – reflexivity. • Data extraction checks with supervisor. • Analytical checks (PhD supervisor checking samples of coding, indexing, data summaries, elements, dimensions and categories). • Detail about how data is collected and kept and accuracy assured.
Confirmability (Objectivity)	All the above strategies and reflexivity	• Reflexive journal (about self and method) recording methodological decisions. • Reflexivity. • Transparent decision trail regarding processes and decisions taken from study to study.

Adapted from O'Leary (2010) and Nicholls (2009).

4.5. Study Objective 1 – Evaluating the Pilot Process

To test recruitment and study procedures to enhance the design of a larger cohort study including sample size estimation.

4.5.1. Introduction to Study Objective 1

Pilot studies are important to conduct prior to running larger studies to enhance the likelihood of success (Teddlie and Tashakkori 2009). Lancaster, Dodd and Williamson (2004) note that a 'dummy run' to test the study protocol and data collection documents, as well as a questionnaire to understand how they are likely to perform in similar situations, is vital in the conduct of high-quality research (Harvey and Land 2017; Van Teijlingen et al. 2001). Pilot runs can highlight areas where problems can occur in a study and that could be compounded in larger projects (NIHR 2019; Harvey and Land 2017; Van Teijlingen et al. 2001).

Aspects that required careful consideration in this pilot study were fourfold: firstly, to test that the study organisational processes have the required steps in place; secondly, that the management of data collection and associated processes are practical, seamless and achievable; thirdly, that resources and time are adequately planned and finally, that the researcher is adequately prepared with sufficient knowledge and skills to take on a larger study (Bowling and Ebrahim 2005). This discussion now addresses these four aspects in turn.

4.5.2. The Organisational Processes Have the Required Steps in Place

The testing of the study protocol methods and the organisation and conduct of the recruitment procedure worked effectively. Those aspects included issuing participant study recruitment letters, participant information sheets, intention to participate response sheets, consent forms, completion of the questionnaire and carrying out the follow-on interviews. There were some challenges, however. The timing of sending letters of invitation and administration of the questionnaire based on when participants volunteered was unpredictable. Sometimes these aspects occurred in bunched timeframes and at other times occurred weeks apart. This made time management and planning difficult, as I had only some control of these aspects. In a larger study, there would be a need to utilise time more effectively by making attendance at the recruitment sites for data collection more streamlined and manageable. The planning and conduct of the follow-on interviews posed no concerns.

4.5.3. The Management of Data Collection and Processing are Practical, Seamless and Achievable

The original intention of the study was to recruit participants from two sites: a hospital based respiratory clinic and a primary care practice, although the primary care practice was withdrawn. The respiratory clinic then became the single recruitment site for the study. Future study would require factoring this type of risk into the planning.

Lancaster, Dodd and Williamson (2004) clarify the need to ensure that the data collection tools reliably measure the intended primary outcome measures and that they are achievable within the study design method. The questionnaire was successful in eliciting the information required to address objective 1 and could enable a sample size calculation for a larger subsequent study to be made. The protocol for the conduct for administering the questionnaires was straightforward and carried out as planned. A concurrent audit trail of the data collection process was maintained, and data were entered onto the SPSS database as it was collected. I assisted with the questionnaire completion at the participants request in all but three cases, and I double checked the self-administering questionnaires for missing data before finalisation. This was done to prevent missing data, which was a concern as the sample size would be around half of the intended number due to the loss of a recruitment site and tight timeframe. Providing assistance for completion does leave questions on whether participants self-administering the questionnaire in a future study could complete them independently with a similar accuracy level (Parahoo 2014). Most of the questionnaires are validated for self-completion in similar populations and should be achievable. The internal and external validity of the tools are discussed in the methods section. The battery of questionnaires, therefore, appears to be an effective tool to elicit the psychosocial and physical factors of interest in this study. The questionnaire can be further refined and adapted as required to meet the focus of a future study following discussion with a research team (Cooper et al. 2020).

Four of the six planned semi-structured interviews were also carried out according to the research protocol and posed no practical issues. Interviews were short and lasted up to 33 minutes. As the sample size was reduced, there were fewer opportunities to secure volunteers for the interviews though sufficient rich data was collected to both address research objective 3 and inform the future direction of the study. No changes or amendments to the process were required, but the interview findings and researcher experience influenced both the interview schedule and the conduct of the qualitative study (Chapter 5) (DeJonckheere and Vaughn 2019).

4.5.4. Resources and Time are Adequately Planned

All resources developed for the study were adequate. The order in which the individual tools were presented in the questionnaire brought up no issues or concerns, and the questionnaire could be completed within 20 minutes. However, given that I worked full-time, and colleagues provided cover during recruitment and data collection, the time resource was high. I encountered occasional time delays during data collection, as some patients would attend at the clinic having indicated their intention to participate in the study but then changed their minds or ran out of time. This meant time was spent on the journey to the clinic and waiting in attendance. In addition, the questionnaire sometimes took longer than the anticipated 20 minutes, as participants were often keen to talk about their wider circumstances relating to the questions asked about their COPD. This meant the questionnaire could take 30 to 40 minutes to complete. This timeframe precludes the face-to-face approach for one person conducting this study using these processes and timeframes and, therefore, is impractical. These challenges reduce the feasibility of a similar large-scale study being successful without the addition of adequate additional resources. This would apply, particularly if there was one researcher conducting the study irrespective of the number of data collection sites and an alternative approach of using a postal or online questionnaire to recruit the numbers required would be appropriate (Holloway and Galvin 2017). The benefits and drawbacks of online and postal surveys have been discussed previously and lack of authenticity is a concern. In addition, running a national campaign to recruit interest from 'people' with COPD could be considered to remove the need for clinicians' time to locate 'patients' at the outset.

The interviews posed no unexpected challenges in the time allocated and resources required. Individuals were keen to participate and provide accounts of their employment experiences relating to COPD. The interview approach could work well in future studies on working-age people with COPD.

4.5.5. The Researcher is Adequately Prepared with Sufficient Knowledge and Skills to Conduct a Larger Study

The study organisation, questionnaire administration and the semi-structured interviews were conducted efficiently and professionally. I was a novice in carrying out in-depth semi-structured interviews, although I was experienced in conducting focus group interviews. Researcher learning continued in tandem with the conduct of the studies through reflexivity, research methods training, good clinical practice research updates and discussion, and ongoing support from the PhD supervisory team. Indeed, the findings from the pilot interviews provided some illuminating findings and heavily influenced the subsequent study, which is further discussed at the end of this chapter. The experience I gained in carrying out the pilot interviews also enabled the development of interviewing skills to enhance the conduct of the qualitative study (Chapter 5).

4.5.6. Summary Discussion of Study Objective 1

The procedures, questionnaires and documentation used in this pilot appeared appropriate for their intended purpose. The questionnaires were effective in eliciting the required data and the data was completed as a result of researcher assistance and questionnaire checking during administration. Although the questionnaire's results were not intended to be generalizable, given a larger future sample, the use of the selected questionnaires could assure validity. The interviews were conducted as planned and the interview schedules facilitated the interviews effectively. In addition, my interviewing skills were developed.
Time was managed as efficiently as possible given the piggy-backed approach with the clinic appointment times and the reliance on clinicians completing the initial sifting and sending letters of invite to patients. The non-participation of

the primary care practice was a risk not considered from the outset, and risk management and contingency for recruitment sources should be prioritised in a future study. The main challenge in conducting this study on a larger scale is that it would not be practical to run in the same way as the pilot with the involvement of only one researcher and one recruitment site and would require redesign. The use of an alternative online or postal survey is a potential solution and that the use of a multi-site approach is also required. Other options include removing the focus from healthcare ‘patients’ and running a national campaign to attract members of the public to participate. Finally, ensuring there are robust additional resources in place (for example, the support of a research assistant) would also enhance the success in a scaled-up future study.

4.6. Study Objective 2 – Quantitative Cross-Sectional Study

To identify the psychosocial and physical factors that may influence employment in people with COPD.

4.6.1. Introduction to Study Objective 2

Chapter 2 highlighted a need to better understand the factors that can contribute to successful employment in people of working age with COPD. This included aspects of the physical and psychosocial well-being of individuals and warranted a cross-sectional investigation. This section presents the process, administration, data analysis and description of results from a questionnaire.

4.6.2. Cross-Sectional Study Considerations

In order to select the most appropriate health and well-being questionnaires to use in the cross-sectional study, a review of frequently used tools to measure psychosocial and physical factors was considered (Creswell 2009). Measurement tools from the Review of Scales of Positive Mental Health Validated for use with Adults in the UK: technical report and others were consulted, (Scottish Government 2007) and a list of suitable measures complied. The validated questionnaires considered for inclusion are listed in Table 4.3, and those selected are highlighted in bold text. Some tools were rejected, as they were either burdensome on the participant (usually having a high number of items), prohibitively costly, not widely used in respiratory research, or were less familiar to me and the supervisory team. It was also important to include health and well-being questionnaires that had a high level of participant usability and interpretability, were suitable for self-completion, and those which were most utilised in published studies focused on people with COPD (Curtis and Patrick 2003; Jones 2001). The questionnaires included were selected based on a number of practical reasons including being freely available or inexpensive to purchase and shorter for participants to complete in terms of item number and complexity (Parahoo 2014; Ross 2012). For example, the CD-RISC tool measuring resilience incurred the highest cost of the purchased questionnaires, but inclusion was made possible due to funding received for the pilot study from Chest Heart and Stroke Scotland. Also, the study utilised the 10-item version of

CD-RISC rather than the 25-item one, which was considered lengthy for a pilot study and contained some redundant items (e.g., spiritual influences) (Campbell-Sills and Stein 2007).

In addition, the principal PhD study supervisor at the time was experienced in the use of the CD-RISC having utilised it in a previous study (Falconer, Alexander and Klein 2013). It was also important to consider the length of the questionnaires, whether paper-based or online, as there can be respondent fatigue if too lengthy (Bryman 2015; Mathers, Fox and Hunn 2009). The final battery of validated questionnaires was considered psychometrically sound (other than the final tool on workplace practices designed by me) using mainly closed ended questions and pre-set scoring components, selected because of their prior use in healthcare and validated in populations with long-term conditions (Andrew and Halcomb 2009). The questionnaires are included in Appendix VI.

Table 4.3 - Validated Questionnaires Considered for Inclusion

Domain	**Tools**
Quality of Life	CCQ (Clinical COPD questionnaire) **EQ-5D-5L;** EQ-5D-3L (EuroQol – 5 dimensions; 5 levels) SF-36; SF-6D (Satisfaction with life 36 item; 6 dimensions) SGRQ (ST Georges Respiratory Questionnaire) WHO-5 index for QoL (World Health Organisation) HUI1 (Health utility index) QWB-SA (Quality of Well-Being self-administered) (ZAMZAM et al. 2016; LINTON, DIEPPE and MEDINA-LARA 2015; NOLAN et al. 2016; LIN et al. 2014; YORDANOVAA, et al. 2014; WELDAM, SCHUURMANS, and LAMMERS, 2013; SIEBER et al. 2008; EuroQoL 1990; FEENY et al. 1995)
Satisfaction with life	QOLS (Questions on life satisfaction) **SWLS** (Satisfaction with Life Scale) Delighted-Terrible Scale GQOL (Global Quality of Life Scale) WQOL (World Health Organization Quality of Life – BRIEF) (LINTON, DIEPPE and MEDINA-LARA 2015; SCOTTISH GOVERNMENT 2007; DIENER et al. 1985)
Well-being & mental health	**WEMBS** (Warwick Edinburgh mental well-being scale) HADS (Hospital anxiety depression scale) BDI-2 (Beck Depression index-2) ABS (Affect balance scale) AHI (Authentic happiness index) CASP-19 (control, autonomy, self-realisation and pleasure) CESD-R (Centre for epidemiological studies depression scale-revised) EQOL (EUROHIS-QOL) HWB (Health and well-being assessment) WHO-5 (WHO5)

	(LINTON, DIEPPE and MEDINA-LARA 2015; STEWART-BROWN, et al. 2011; TENNANT et al. 2007; ZIGMOND and SNAITH 1983)
Anxiety and depression	Beck Depression Inventory (BDI) GDS-15 (15-item Geriatric Depression Scale) CES-D (Centre for Epidemiological Studies Scale on Depression) **HADS** (Hospital and Anxiety Depression Scale) (BOCK et al. 2017; LACASSE, ROUSSEAU and MALTAIS 2001; DE VOOGD et al. 2002; JULIAN, GREGORICH and EARNEST et al. 2009; Van MANEN et al. 2002; ZIGMOND and SNAITH 1983)
Resilience	**CD-RISC-10** (Connor-Davidson Resilience Scale) RS14 (Resilience Scale 14 items) Attributional Style Questionnaire Brief COPE Scale Coping Styles Questionnaire Functional Dimensions of Coping Scale General Self-Efficacy Scale Ways of Coping SHIS (Salutogenic health indicator scale) (LINTON, DIEPPE and MEDINA-LARA 2015; CONNOR AND DAVIDSON 2003)
Work productivity & activity impairment	**WPAI:GH** (Work productivity and activity impairment-general health) HPQ WHO (Health and performance questionnaire) (SOLEM et al. 2013; REILLY, ZBROZEK and DUKES 1993)
Presenteeism	**SPS – 6** SPS – 13 (Stanford presenteeism scale 6/13 item) SF-HLQ (Short form health labour questionnaire) Health and work performance questionnaire Endicott work-productivity scale Valuation of lost productivity WPAI (Work productivity and activity impairment) (OSPINA et al. 2015; KOOPMAN et al. 2002)

There has been a growth in the conduct of online questionnaires, and they are a good alternative to paper-based, as they are usually designed with clear visual presentations and some have built-in filters (Bryman 2015). Completeness and accuracy of data in online questionnaires can be higher than paper-based, as data is entered in live-time and online checks are performed before submission (Bryman 2015). Online questionnaire costs tend to be lower than paper-based, but a paper-based approach also enables a postal option which can achieve higher response rates than electronic surveys (Ebert et al. 2018). However, a disadvantage of the paper-based approach is that the cost of paper, printing, and distribution must be considered when budgeting as well as possible additional costs if distributing by post (Bryman 2015). A postal survey was also considered as an alternative to face-to-face administration of paper-based questionnaires, but response rates can be lower and are prone to missing data (Newell and Burnard 2011). Conducting a self-administered postal questionnaire can however minimise the social desirability effect bias where participants respond according to how they think the researcher expects them to (Green and Thorogood 2018; Bowling and Ebrahim 2005). However, postal surveys often incur additional researcher time for preparation, distribution follow up and collation and do not enable further explanation of the items. The face-to-face approach selected here offered me some control of the administration process and participants were able to ask questions and have guidance and clarification on any unclear aspects (Gerrish and Lathlean 2015; Newell and Burnard 2011). In addition, it was thought to be convenient at a local level for the pilot as the sample size was small and the costs minimal. Additionally, the paper-based approach did not require the use of technology and authenticity of respondents could be assured (Harvey and Land 2017; Bryman 2015). Finally, the face-to-face approach to administration can be more acceptable to participants, as the topic of COPD could be perceived as less intimate than other health issues (Parahoo 2014).

A common problem where the researcher is present during data collection is the interviewer effect that might bias responses based on ethnicity, age, gender and social background as well as creating a social desirability bias (Bryman 2015). This could cause participants to report or record what they think the researcher wishes to hear or know (Bryman 2015). However, as the questionnaire had several tools included, it was felt engaging in a social encounter where participants could contribute to the completion of all items and could be considered as an assisted self-administered questionnaire (Green and Thorogood 2018; Bowling and Ebrahim 2005). Assistance was offered to all participants, and all but three requested this support. This assisted approach could possibly foster relationship-building, build trust and encourage participants to take part in the follow-on interview.

4.6.3. Cross-sectional Study Questionnaires

Participants were invited to complete the paper-based battery of questionnaires comprising demographic details, seven validated psychosocial health and well-being tools and one focused on work productivity and activity impairment (Bryman 2015). Additional questionnaires relating to those in employment were also included to determine the working practices and health (presenteeism) and for workplace control and adaptation (researcher developed). Table 4.4 illustrates aspects of the reliability, validity and general use of each instrument included in the questionnaire. Reliability pertained to the degree to which the tool was free from error in measurement and validity as well as the degree to which the tool measures the intended constructs (Mokkink et al. 2010). This ensured that the tools contained in the questionnaire achieved a high level of scientific credibility combined with practicality and efficiency (Bryman 2015). In addition to the health and well-being tools outlined above, demographic, psychosocial and physical factors associated with employment capability and aspects of workplace control and adaptation consisting of open-ended questions were also included in the questionnaire.

The first part of the questionnaire was designed to obtain details on health status e.g., medication, smoking status, exacerbations, hospitalisations and antibiotic use in the last year. The question determining ethnicity was based on the Office for National Statistics harmonised ethnicity measure for Scotland recommended for use in social surveys (Office for National Statistics 2013). It was important to also capture an understanding of the participant’s current COPD severity through the COPD Assessment Test (CAT) score thought to be useful for potential cross-tabulation during the analysis (Jones et al. 2009).

Table 4.4 - The Reliability, Validity and General Use of the Included Questionnaires

COPD Assessment Test
COPD Assessment Test (CAT) The COPD assessment test is a validated instrument for assessing and monitoring the impact of COPD on individuals and provides a reliable measure of overall COPD severity. Eight items are scored on a scale of 0 – 5 and calculated as the sum of the responses present (Jones et al. 2009 p. 652). The CAT was chosen over the St Georges questionnaire as it is the preferred test in the North East of Scotland.
Quality of Life
The EQ-5D-5L quality of life questionnaire is a standardised instrument for use in measuring generic health status. Designed by the EuroQol Group in the late 1980's, it takes only a few minutes to self-complete. The tool contains five dimensions enquiring about health and a related visual analogue scale (VAS) yielding a health utility score to estimate of the impact of the condition. Participants indicate their current health status at the time of completing the questionnaire by ticking a box against the most appropriate statement in the five dimensions. Statements are: none, slight, moderate, severe and extreme/unable and the dimensions are: mobility (walking around), self-care (washing and dressing), usual activities (work, study, housework, family or leisure activities), pain/discomfort, and anxiety/depression. The visual analogue scale has endpoints labelled 'Best imaginable health state' and 'Worst imaginable health state'. Participants rate their perceived health status with a line from a box to whichever point on the scale indicates how good or bad their current health state is. It is validated for use with a variety of health conditions including diabetes and chronic pain (Torrance et al. 2014; Solli, Staven and Kristiansen 2010) and has been used previously in COPD populations (Pickard et al. 2008 p. 5).
Satisfaction with Life
Satisfaction with Life Scale (SWLS) The SWLS assesses various perspectives on life satisfaction with good psychometric properties and normative data. It is a short 5 item instrument designed to measure global cognitive judgements of satisfaction with life. Because of its size it does not pose a large burden on respondents. The scale demonstrates good internal consistency ($\alpha = .87$) and moderate test-retest reliability

(r = .82). Respondents rate the extent to which they agree with the five items (e.g., “I am satisfied with my life.”) on a seven-point Likert scale (1 = strongly disagree, 7 = strongly agree). The SWLS was developed from a positive psychology tradition. It seemed prudent to include an outcome measure associated with positive well-being in addition to the later HADS measure, which focuses on symptoms of negative affect (Diener et al. 1985 p. 74).

Well-being and Mental Health

Warwick-Edinburgh Mental Well-being Scale (WEMWBS) The WEMWBS was *c*ommissioned by NHS Health Scotland and developed as part of the Mental Health Indicators Programme, the primary aim of which was to establish a core set of national, sustainable mental health and well-being indicators for adults in Scotland (Health Scotland 2007). As a measure of mental well-being, the WEMWBS focuses solely on positive features of mental health rather than its determinants. Its development derived in part from the Affectometer 2 and, in part, from the findings of qualitative focus group research conducted in Scotland. Comprising 14 items, the WEMWBS is a brief but psychometrically robust scale with no ceiling effects in a population sample evidenced by its validation in two Scottish population surveys in 2006 (WEMWBS User Guide, Version 1; June 2008; WEMWBS). It is validated for use for monitoring well-being in diverse populations over 16 years including those with long-term conditions. There are many tools from which to select and WEMWBS was chosen as it is used widely in the NHS in Scotland and relevant to all populations (Tennant et al. 2007 p. 9).

Anxiety and Depression

The Hospital and Anxiety Depression Scale (HADS) is a valid and reliable self-rating scale that is widely used to assess psychological distress in the non-psychiatric population in both primary care and the general population. It has commendable psychometric properties and comprises two subscales: one for anxiety (HADS-A) and one for depression (HADS-D) to give a total score (Crawford et al. 2001). It is a 14-item measure for each subscale of seven items (each of which is scored from 0 to 3), a total score ranging from 0 to 21 can be obtained to signify the likelihood of psychological distress. A score of 0–7 for either subscale is regarded as being in the “normal” range; a score of 8–10 is suggestive of the presence of “moderate” levels of anxiety or depression, and a score of 11 or more indicates “caseness” (i.e., were the individual to be examined by an experienced mental health professional, it is highly likely that he/she would be diagnosed to be suffering from an identifiable psychiatric disorder) (HADS; Zigmond and Snaith 1983 p. 236). It was considered suitable for use, as it is easy to complete and has a small item burden for participants. As part of the consent process, participants were made aware that their GP would be informed if scores on either the subscales of the HADS suggested potentially clinically significant levels of anxiety or depression in keeping with good governance processes. A letter template used for this purpose is included in Appendix VII.

Resilience

The Connor-Davidson Resilience Scale-10 (CD-RISC) is a brief, 10-item scale that was developed from the original 25-item self-report scale that measures the ability to cope with adversity. The CD-RISC-10 has demonstrated good test-retest reliability, internal consistency and construct validity and overall displays excellent psychometric properties to allow for the efficient measurement of resilience as a dynamic process that is quantifiable and influenced by health status. The 10-item scale was developed from the CD-RISC25 but made leaner by reducing item redundancy making it less onerous to complete. Retained items reflect an ability to bounce back from challenges such as personal problems, change, illness, failure and painful feelings. The 10 items focus on hardiness, persistence, faith and purpose. Participants are required to select each item on a scale of ‘not true at all’, ‘rarely true’, ‘sometimes true’, ‘often true’ and ‘true nearly all of the time’. The CD-RISK-10 is also validated for use with many long-term conditions with population means of 29 recorded in adults (Antunez, Navarro and Adan 2015; Connor and Davidson 2003 p. 81; Wald et al. 2006; Campbell-Sills and Stein 2007).

Work Productivity and Activity Impairment: General Health

Work Productivity and Activity Impairment Questionnaire: General Health (WPAIG:GH-V2.0) Comprised of eight open questions on flexible working, adaptations and hours worked, and is used to assess work productivity and level of work activity impairment (WPAI:GH; Reilly, Zbrozek and Dukes 1993). It can be used in people with various diseases and occupations and was found to be the most frequently used and well documented tool among many other health-related

productivity measures (Prasad et al. 2004). This instrument explores four items and yields four types of scores: Absence (work time missed), Presence (impairment at work / reduced on-the-job effectiveness), work productivity loss (overall work impairment / absenteeism plus presenteeism) and Activity impairment.
Presenteeism
Stanford Presenteeism Scale (SPS-6) is a brief 6-item version of the original SPS-34, which has been shown to have excellent psychometric properties to measure health status and employment productivity based on work experiences in the past 4 weeks. Whilst absenteeism affects productivity, it is increasingly recognised that, when employees are physically present at their jobs, they may experience decreased productivity and below-normal work quality, a concept known as "presenteeism". The scale provides a high level of internal consistency, with a Cronbach Alpha co-efficient of .80. The SPS-6 is a self-administered 6-item questionnaire using a 5-point Likert type response (Koopman et al. 2002 p. 17).
Workplace Control and Adaptation
The Workplace Control and Adaptation measure considers adaptations in the workplace and provides open-ended questions with an opportunity to capture free text responses. Devised by me, this is a non-validated tool to broadly elicit the individual and direct impact of the participant's COPD on work and any adaptations required in the workplace in the last 4 weeks.

4.6.4. Cross-sectional Study Data Collection and Data Management

Participants completed the battery of questionnaires within the planned timeframe. The questionnaires were administered face-to-face in a private office in the hospital clinic. Occasional time delays were encountered, as some patients turned up having indicated their intention to take part but subsequently changed their minds. I attended the clinic to see if volunteers came forward on that day, whether they had previously volunteered or not. This was important, as some participants who had not returned their intention to participate form chose to participate on their clinic day bringing their intention to participate form with them. The questionnaire took between 20-30 minutes to complete and, although designed for self-completion, I was in attendance to help and address participant questions. All but three participants requested my support, which involved prompts, clarifying some of the questions, providing further explanation on the measurement scales and reading some of the questionnaires out loud to participants. Sometimes completing the questionnaire took longer than anticipated, as participants were keen to chat and provide some detail around the items raised from the questionnaires. The outcomes from the first three completed questionnaires were discussed with the PhD supervisory team. This was completed to detect any early issues that might inhibit a larger scale study being possible. Although this was not technically a piloting of the pilot questionnaire, it was helpful to 'try out' the question format, wording, and order to ensure that the instrument was appropriate to efficiently capture the required data (Van Teijlingen and Hundley 2014). Whilst no immediate issues were apparent from the first administered questionnaires, it was evident that not all demographic data were required at this stage (e.g., BMI), and that this data could be easily collected in the subsequent study through a researcher recording weight and height measurements if required.

The participant's personal and demographic details and item responses were recorded in writing on each questionnaire, and a few participants wanted to discuss their wider COPD experiences including hospitalisations and smoking history. It appeared that most participants found the questionnaires easy to understand and all were uninhibited in openly discussing the stresses and challenges of their condition and lives. On completion of the questionnaire, participants were asked if they would be willing to participate in a follow-on interview if required.

Each item in the questionnaire was assigned a numerical code which was previously mapped onto a blank questionnaire used as a coding template (Green and Thorogood 2018). This helped classify data and label each score to facilitate ease of data entry into the Statistical Package for the Social Sciences (SPSS V20) software used for data management and analysis. The data were examined, cleaned (detecting any missing values, unclear, inaccurate or inconsistent records), and analysed (Bowling 2002). There was no missing data and, on careful checking, only three data entry errors were noted and corrected.

4.6.5. Cross-sectional Study Results and Analysis

As an opt-in approach to the study was adopted, and letters of invitation were sent to eligible participants by the clinical respiratory team. The exact number of people with COPD who could have participated in the study was unknown; therefore, an accurate response rate cannot be estimated. An approximate population of people with COPD was 7,387 in Grampian and Aberdeenshire (total population of 500,000 with mean of 1.38% with COPD across Aberdeen City, Aberdeenshire and Moray (NHS Grampian 2010). Approximately 63 letters of invitation were sent out to eligible patients and 14 participants volunteered, producing an estimated response rate of 22%.

It is acknowledged that those who have taken part in this study could have very different characteristics from those who chose not to (Parahoo 2014). The results are described and presented for the sample as a whole and then by people who are employed (n=3) and those not employed (n=11). This is to enable a full description and to identify possible trends, but not to draw inferences because, with smaller sample sizes, parametric calculations are not appropriate and generalisations to the wider population cannot be inferred (Green and Thorogood 2018). The participant-reported outcomes using descriptive statistics enables the trends and variations in this population to be highlighted (Loeb et al. 2017). These trends offer some insight and enable an exploration of health and well-being dimensions related to COPD and employment (Okley et al. 2017). This section now provides a descriptive analysis of the results from the questionnaires.

The ranges, means, medians, standard deviations, percentages and scores where applicable from the questionnaires are presented in the following sections and are presented in graphs and tables and organised to depict the trends. Ten men and four women completed the questionnaire. The age of the participants ranged between 42 and 69 years with a mean age of 57. All participants were Caucasian; therefore, there was no ethnic variation within the sample. Three were employed and 11 were no longer employed due to poor health. Table 4.5 presents the participant characteristics.

Table 4.5 - Characteristics of Participants who Completed the Questionnaire

(The three employed participants are highlighted in bold text)

Participant Identifier	Gender Age	Employment status/ hours worked	CAT Score
1	M 63	Not employed because of poor health	Very High Impact
2	M 51	**Employed part-time flexible hours** **Self-employed**	High Impact
3	F 42	Retired early due to poor health	Medium Impact
4	M 51	Retired early due to poor health	Very High Impact
5	M 52	Not employed because of poor health	Very High Impact
6	M 50	Not employed because of poor health	Upper Limit of Normal
7	M 65	Not employed because of poor health	High Impact
8	F 52	Not employed because of poor health	High Impact
9	M 62	Not employed because of poor health	Very High Impact
10	F 60	Not employed because of poor health	Very High Impact
11	M 65	Not employed because of poor health	Very High Impact
12	M 60	Not employed because of poor health	Very High Impact
13	F 69	**Employed part-time flexible hours**	Medium Impact
14	M 55	**Employed Full-time**	High Impact

KEY: M=Male; F=Female, CAT=COPD Assessment Test.

Table 4.6 presents the Results for the Total Population and Table 4.7 presents the Results by Employment Status and can be referred to in conjunction with the following sections reporting on the individual measures.

Table 4.6 - Results for the Total Population

Results - Total Population	
	Frequency (%)
Age range (Years, mean (SD))	42 - 69 years (57 (7.3))
Gender	
Male	n = 10
Female	n = 4
Employment Status	
Employed	n = 3
Retired	n = 2
Unemployed	n = 9
CAT Total Score	
Very high impact level	n = 8 (57.1)
High impact level	n = 3 (21.4)
Medium impact level	n = 2 (14.2)
Low impact level	n = 0
Upper limit of normal	n = 1 (7.1)
Mean CAT score (SD)	26.3 (8.6)
Quality of Life (EQ-5D-5L)	
MOBILITY	
Level 1	n = 1 (7)
Level 2	n = 0
Level 3	n = 6 (43)
Level 4	n = 6 (43)
Level 5	n = 1 (7)
SELF-CARE	
Level 1	n = 3 (21)
Level 2	n = 3 (21)
Level 3	n = 4 (29)
Level 4	n = 3 (21)
Level 5	n = 1 (7)
USUAL ACTIVITIES	
Level 1	n = 1 (7)
Level 2	n = 2 (14)
Level 3	n = 4 (29)
Level 4	n = 7 (50)
Level 5	n = 0
PAIN/DISCOMFORT	

Level 1	n = 4 (29)
Level 2	n = 3 (21)
Level 3	n = 5 (36)
Level 4	n = 2 (14)
Level 5	n = 0
ANXIETY/DEPRESSION	
Level 1	n = 3 (21)
Level 2	n = 4 (29)
Level 3	n = 4 (29)
Level 4	n = 3 (21)
Level 5	n = 0
HEALTH TODAY – EQ VAS Score	
Mean (SD)	57.5 (21)
Satisfaction with Life Scale (SWLS)	
Mean/Median Score	17.6/16.5
Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)	
Mean (SD)	44 (11)
Hospital Anxiety Depression Scale (HADS Anxiety)	
Normal (non-case) 0-7	n = 6
Borderline case 8-10	n = 2
Probable Caseness 11-15	n = 6
Median Score (min, max)	9 (0, 15)
Hospital Anxiety Depression Scale (HADS Depression)	
Normal (non-case) 0-7	n = 7
Borderline case 8-10	n = 4
Probable Caseness 11-15	n = 3
Median Score (min, max)	7 (0, 12)
Connor Davidson Resilience Scale (CD-RISC)	
Quartiles	
Q1 – Lowest 25%	n = 6
Q2 – 2nd 25%	n = 3
Q3 – 3rd 25%	n = 1
Q4 – Highest 25%	n = 4
Mean (SD)	28 (9)

Table 4.7 - Results by Employment Status

Results – Employed and Not employed		
	Employed **Frequency (%)**	**Not Employed** **Frequency (%)**
Age range (Years, mean (SD))	51 – 69 years (58, (9.45))	42 – 65 years (57, (7.51))
Gender	n = 3 (21)	n = 11 (79)
Male	n=2	n=8
Female	n=1	n=3
CAT Total Score		
Very high impact level		n= 8 (73)
High impact level	n = 2 (67)	n = 1 (9)
Medium impact level	n = 1 (33)	n = 1 (9)
Low impact level		
Upper limit of normal		n = 1 (9)
Mean CAT score (SD)	20.6 (4.9)	27.9 (8.9)
Quality of Life (EQ-5D-5L)		
MOBILITY		
Level 1	n = 0	n = 1 (7)
Level 2	n = 0	n = 0
Level 3	n = 3 (21)	n = 3 (21)
Level 4	n = 0	n = 6 (43)
Level 5	n = 0	n = 1 (7)
SELF-CARE		
Level 1	n = 1 (7)	n = 2 (14)
Level 2	n = 1 (7)	n = 2 (14)
Level 3	n = 1 (7)	n = 3 (21)
Level 4	n = 0	n = 3 (21)
Level 5	n = 0	n = 1 (7)
USUAL ACTIVITIES		
Level 1	n = 0	n = 1 (7)
Level 2	n = 1 (7)	n = 2 (14)
Level 3	n = 2 (14)	n = 4 (29)
Level 4	n = 0	n = 7 (50)
Level 5	n = 0	n = 0
PAIN/DISCOMFORT		
Level 1	n = 0	n = 4 (29)
Level 2	n = 1 (7)	n = 2 (14)
Level 3	n = 2 (14)	n = 3 (21)
Level 4	n = 0	n = 2 (14)
Level 5	n = 0	n = 0
ANXIETY/DEPRESSION		
Level 1	n = 2 (14)	n = 1 (7)

Level 2	n = 0	n = 4 (29)
Level 3	n = 1 (7)	n = 3 (21)
Level 4	n = 0	n = 3 (21)
Level 5	n = 0	n = 0
HEALTH TODAY		
Range	65, 80	30, 90
Mean (SD)	71.6 (7.6)	53.6 (22.1)
Satisfaction with Life (SWLS)		
Mean/median Score	20.3/21	16.9/16
Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)		
Range	44, 61	26, 59
Mean (SD)	51 (8.8)	40 (11.7)
HADS (Hospital Anxiety Depression Score) Anxiety		
Normal (non-case) 0-7	n = 2	n = 4
Borderline case 8-10	n = 0	n = 2
Probable Caseness 11-15	n = 1	n = 5
Median Score (min, max)	5 (0, 15)	10 (0, 15)
HADS (Hospital Anxiety Depression Score) Depression		
Normal (non-case) 0-7	n = 2	n = 5
Borderline case 8-10	n = 1	n = 3
Probable Caseness 11-15	n = 0	n = 3
Median Score (min, max)	3 (3, 10)	9 (0, 12)
Connor Davidson Resilience Scale (CD-RISC)		
Quartiles		
Lowest 25%	n = 1 (29)	n = 5 (13, 14, 14, 19, 29)
2nd 25%	---------------------------	n = 3 (27, 30, 32)
3rd 25%	n = 1 (35)	------------------------
Highest 25%	n = 1 (39)	n = 3 (37, 38, 40)
Mean (SD)	34 (5)	26.6 (10.1)
WPAI:GH (Work productivity and activity impairment)		
Missed time from work-last 7 days	n=1 (30 hours)	
	No effect Score 0 n=1	

Limited in amount or kind of work they could do	Moderate Score 3 n=1 Considerable Score 7 n=1	
Daily activities	No effect Score 0 n = 1 Moderate Score 3 n = 2	
Stanford Presenteeism Scale – SPS-6		
Scale		
High Presenteeism		
26-30	n = 2	
21-25	n = 0	
16-20	n = 1	
11-15	n = 0	
6-10	n = 0	
Low Presenteeism		

4.6.5.1. COPD Assessment Test - CAT

The CAT test provided an objective, reliable and current lung and COPD severity level for each participant on the day they completed the questionnaire. As illustrated in Table 4.8, participants scored mostly in the medium, high and very high impact levels. Those who were employed scored only within the high impact (n=1) and very high impact levels (n=2) and still were able to undertake their work despite COPD having a considerable impact on them. All but one participant indicated an impaired health status with that participant scoring four, indicating a normal limit on that day.

The mean score of the sample was 26.3, those not employed had a mean score of 27.9 and those employed had a mean score of 20.6 indicating the potential impact their COPD had on them that day. Those people with COPD who were not employed had a wider range of impact than those employed. Although the mean for those people still in employment was lower than the mean of those not employed, COPD still had a considerable impact on them on the employed participants on that day.

Table 4.8 - CAT Score Representing COPD Severity Level

CAT score Range 0 - 40	**All** n (%)	**Employed** n (%)	**Not employed** n (%)
Very high impact level >30	10 (72)	0	8 (73)
High impact level >20	2 (14)	2 (67)	1 (9)
Medium impact level 10-20	1 (7)	1 (33)	1 (9)
Low impact level <10	0	0	0
Upper limit of normal <5	1 (7)	0	1 (9)

4.6.5.2. Quality of Life - EQ-5D-5L

Quality of life was assessed through the five attributes of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Scores are ordered in the same way for all attributes; no problems are highlighted in Table 4.9 as Level 1, and the remainder of the results indicated - slight problems (Level 2), moderate problems (Level 3), severe problems (Level 4), and extreme problems/unable to do (Level 5).

Table 4.9 - EQ-5D-5L Attributes by Level of Impact and Dimension

EQ-5D-5L Levels	**MOBILITY** n (%) Total pop **Employed** Not employed	**SELF-CARE** n (%) Total pop **Employed** Not employed	**USUAL ACTIVITIES** n (%) Total pop **Employed** Not employed	**PAIN/ DISCOMFORT** n (%) Total pop **Employed** Not employed	**ANXIETY/ DEPRESSION** n (%) Total pop **Employed** Not employed
Level 1 No problems	1 (7) **0** 1	3 (21) **1 (7)** 2 (14)	1 (7) **0** 1 (7)	4 (29) **0** 4 (29)	3 (21) **2 (14)** 1 (7)
Level 2 Slight problems	0 **0** 0	3 (21) **1 (7)** 2 (14)	2 (14) **1 (7)** 1 (7)	3 (21) **1 (7)** 2 (14)	4 (29) **0** 4 (29)
Level 3 Moderate problems	6 (43) **3 (21)** 3 (21)	4 (29) **1 (7)** 3 (21)	4 (29) **2 (14)** 2 (14)	5 (36) **2 (14)** 3 (21)	4 (29) **1 (7)** 3 (21)
Level 4 Severe problems	6 (43) **0** 6 (43)	3 (21) **0** 3 (21)	7 (50) **0** 7 (50)	2 (14) **0** 2 (14)	3 (21) **0** 3 (21)
Level 5 Extreme problems/ unable to do	1 (7) **0** 1 (7)	1 (7) **0** 1 (7)	0 **0** 0	0 **0** 0	0 **0** 0

Scores for mobility in those employed indicated that all three participants had moderate problems, whereas in those not employed, mobility scores revealed a wider range from no problems to extreme problems. This indicated that those people who were not employed had the equivalent or worse mobility issues than those people who were employed.

For self-care in those employed, scores indicated they either had no problems, slight problems, or moderate problems. Those participants no longer in employment had problems on every level of self-care with one participant having extreme problems and the others mainly having moderate or severe problems indicating why they might no longer be in employment. It can also be seen that two of those not employed had no problems with self-care whilst another two had slight problems.

In those employed, usual activities were affected causing participants slight and moderate problems, whilst those not employed scored in all but the extreme level of problems. This indicates that undertaking daily activities is more of a challenge for those no longer employed.

In considering pain/discomfort, those employed participants indicated they had slight or moderate problems, and those not employed scored in all but the extreme pain level. It can be seen that four of the participants who were not employed had no problems with pain related to their COPD. This could also suggest pain might be associated with comorbidities in other participants. Those not in employment had lower pain scores overall than those who were employed.

The three employed participants indicated they had moderate problems and no problems range for anxiety/depression, and those not employed scored in all but the extreme problems level.

Across all domains, it is evident that none of those employed participants have severe or extreme problems suggesting their quality of life overall is better than those participants no longer in employment.

The ***'health today'*** scale within the EQ-5D-5L is measured by rating health today as worst health you can imagine (0) to best health you can imagine (100) and presented as an actual value illustrated in Figure 4.1. The mean (SD) EQ VAS score for the sample was reported as 57.5 (21), (employed 71.6 (7.6); not employed 53.6 (22.1)), both which are below a general population mean of 77.9 (Encheva et al. 2020). The mean score for employed participants was closer to the population mean for best health possible than the mean score for those not employed. Scores were highest in those in the employed group (80, 80, 70:80). Those employed generally felt healthier despite their COPD having a considerable impact on their life compared to those not employed who felt less healthy overall (The EQ-5D-5L quality of life measure (EuroQol Group 1990).

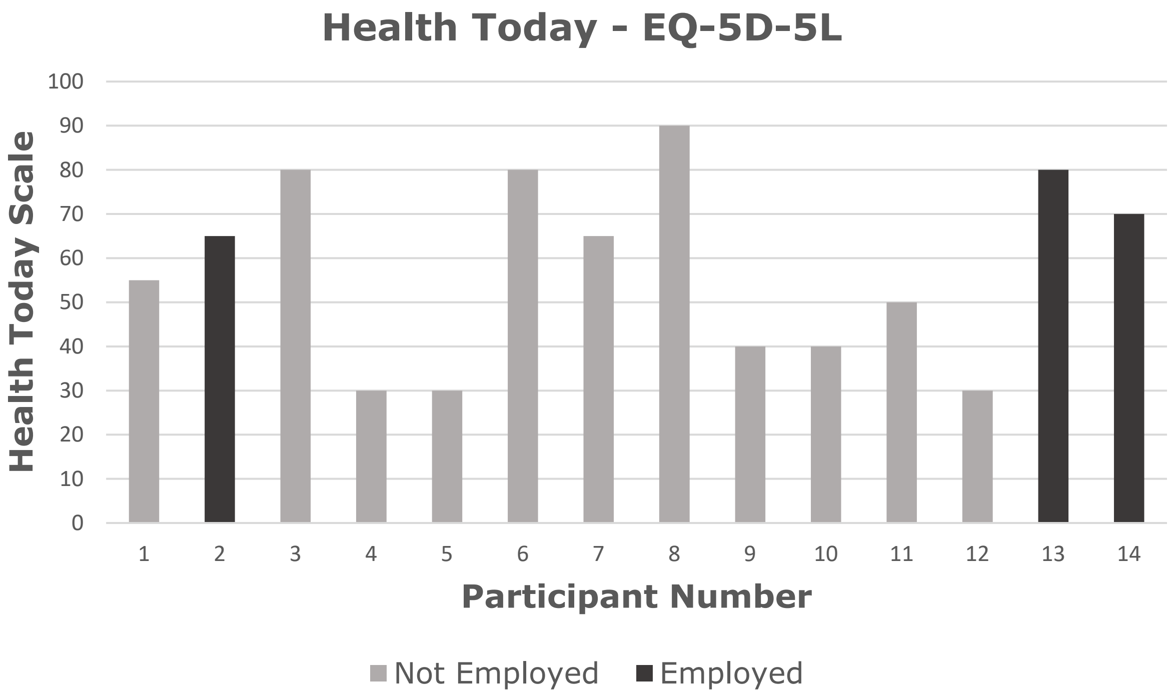


Figure 4.1 - Health Today Scale (EQ-5D-5L)

4.6.5.3. Satisfaction with Life Scale - SWLS

The range of scores were from 5 to 30, although there was no clear pattern as illustrated in Figure 4.2. Those in employment were either slightly satisfied with their life (scores from 21-25) or slightly dissatisfied with their life (scores from 15-19). Those not in employment gave a wider range of responses indicating a lower mean score than those people who were employed. This suggested that those employed participants were more satisfied with their lives than those people who were not employed. The sample mean (SD) was 17.6 (7.3), (employed 20.3 (5); not employed 16.9 (7.8)), which is higher than single individuals with spinal cord injury (16.1) and lower than people with diabetes (24.9) (Pavot and Diener 2008).

Figure 4.2 - The Satisfaction with Life Scale (SWLS)

4.6.5.4. Warwick Edinburgh Mental Well-being Scale - WEMWBS

The possible range for scores for the WEMWBS is between 14 and 70, and the construct has an average population mean of 51 (Stewart-Brown and Janmohamed 2008). The sample mean in this study was 44, which is below the average population mean, whilst the employed participants had higher mean of 51, (the same as the population mean). Those not employed had a mean score of 40, which was lower than the population mean indicating a poorer mental well-being status than those employed participants and the general population. It may be that being in employment is good for a person’s mental health or that good mental health enables the continuation of employment in people with compromised physical health. The means are illustrated in Table 4.10.

Table 4.10 - Warwick Edinburgh Mental Well-being Scale

WEMWBS Range 13-65	**All participants** Range Mean (SD)	**Employed** Range Mean (SD)	**Not employed** Range Mean (SD)
WEMWBS range	26-61 44 (11)	44-61 51 (8.8)	26-59 40 (11.7)

4.6.5.5. Hospital Anxiety Depression Scale - HADS

As highlighted in the description of the HADS measure ‘caseness’ (to the likely presence of the mood disorder Anxiety and/or Depression) in the HADS assessment tool identified through a score of 11 or above (Zigmond and Snaith 1983 p.366. ‘Caseness’ therefore can be considered as a contributory factor in the overall distress of having COPD. Seven participants indicated caseness on either or both the depression and anxiety scores. Six participants indicated the presence of anxiety and three indicated the presence of depression [six not employed (participants 1, 4, 5, 7, 9, 11) and one employed (participant 2)]. One of those employed, scored 11 for anxiety. Two participants had high scores on both anxiety and depression (A= score of 12 and D= score of 12; and A= score of 14 and D= score of 11).

The sample mean for anxiety was 8 (with a median score of 9), which was higher than the recognised population mean of 6.1, and the sample mean was 6 for depression (with a median score of 7), which was higher than the population mean of 3.68 (Crawford et al. 2001). Those participants not in employment demonstrate higher mean scores for anxiety (9) than the population mean (8) and for those people in employment (5). For depression, the mean score for those not employed (7) is higher than the population mean (6) and of those in employment (5). Overall, the results indicate that the employed participants have better mental health than those not in employment. The ranges, means and standard deviations are illustrated in Table 4.11.

Table 4.11 - The Hospital Anxiety Depression Scale

HADS Anxiety **HADS Depression** Scoring Range 0-21 Mean (SD)	**Employed**	**Not employed**
Anxiety Sample Range - Score 0-15	5 (5)	9 (6)
Depression Sample Range - Score 3-12	5 (4)	7 (4)

4.6.5.6. Connor-Davidson Resilience Scale - CD-RISC-10

The possible scoring range was 0 – 40, and participants in this sample scored from 13 – 40. The sample mean in this study is 28, indicating lower resiliency than in a recorded adult population mean of 29 (Antunez et al. 2015). However, those in employment scored a higher mean of 34, indicating they had greater resiliency than those people not employed who had a mean of 26.6. Both employed and not employed participants scored in the most and least resilient quartiles as illustrated in Table 4.12. This illustrates that six of the fourteen participants scored in the lowest quartile indicating they were less resilient than the general population.

Table 4.12 - Connor-Davidson Resilience Scale

CD-RISC-10 Range of scores 0-40 0=less resilient 40=most resilient Mean (SD)	**All participants**	**Employed**	**Not employed**
	28 (9)	34 (5)	26.6 (10.1)
QUARTILES (n)			
Most resilient Q4 Highest 25% (score 37-40)	4	1	3
Q3 3rd quartile (score 33-36)	1	1	0
Q2 2nd quartile (score 30-32)	3	0	3
Least resilient Q1 Lowest 25% (score 0-29)	6	1	5

4.6.5.7. Work Productivity and Impairment - WPAI: GH

This questionnaire addressed absenteeism, presenteeism and daily activity impairment and was completed by the three employed participants. Two participants had not missed any time from work (21 hours and 37 hours), whilst one had lost 30 hours of work (a self-employed participant working only 20 hours of his usual 50). Participants were also asked about their productivity in the past seven days where they were limited in the amount or kind of work they could do or where they accomplished less than they would have liked to because of their COPD. Scores were indicated on a 10-point linear scale with zero being ‘health problems had no effect on my work’ to 10 representing ‘health problems completely prevented me from working’. One participant felt their COPD had no effect on their productivity (scoring zero), one considered COPD to have had a moderate effect on their productivity (scoring three). The self-employed participant scored seven noting COPD to have had a considerable effect on productivity and prevented him from fully functioning at work in the past seven days. The results are summarised in Table 4.13.

Table 4.13 - Work Productivity and Activity Impairment Scores in Those Employed

Work productivity and activity impairment questions (WPAI:GH)	**Employed**
Absenteeism Missed time from work in past 7 days due to health problems	30 hours (60% of hours lost) n=1
Presenteeism Limited in amount or kind of work they could do, days they accomplished less than they would like or days they could not work as carefully as usual due to health problems	No effect n=1 Moderate effect n=1 Considerable effect n=1
Activity Impairment Health problems affect daily activities over pas seven days	Zero effect (=0) n = 1 Moderate effect (=3) n = 2

The final question asked participants whether their COPD affected their ability to undertake daily activities outside of the workplace such as shopping, housework, exercising and childcare, in the past seven days. Scores were indicated on a 10-point linear scale with zero being ‘health problems had no effect on my daily activities’ to 10 representing ‘health problems completely prevented me from doing my daily activities’ other than work at a job. One participant felt work was easier to manage than day-to-day activities and one noted a moderate effect on daily activities due to their COPD. The participant scoring a seven on the previous question scored three in this question indicating that COPD affected their work (physically heavy industry) more than it did their activities in daily life during the past seven days.

4.6.5.8. Stanford Presenteeism Scale - SPS-6

This questionnaire considered presenteeism and the six-item scale asked for detail of the participant’s type of work and how their COPD affected their work over the past four weeks. The three employed participants completed this item. A high SPS-6 score indicates increased presenteeism, meaning that despite the health and social challenges of COPD, participants could still concentrate on work and accomplish activities in the workplace. A low SPS-6 presenteeism score indicates decreased presenteeism indicating those workers who were present at work but experience below normal work-quality or productivity (Koopman et al. 2002). Two participants scored 30, indicating high presenteeism, and they remained effective in the workplace (Table 4.14). The third participant scored 18, which is below the mean score of 22 found in population studies (Koopman et al. 2002).

Table 4.14 - The Stanford Presenteeism Scale

(Three participants - lower scoring participant represented in bold text)

Item	**Strongly Disagree**	**Somewhat Disagree**	**Uncertain**	**Somewhat Agree**	**Strongly Agree**
1. Because of my (COPD), the stresses of my job were much harder to handle.	5 √√	4	3	2 **√**	1
2. Despite having my (COPD), I was able to finish hard tasks in my work.	1	2	3	4	5 √√**√**
3. My (COPD), distracted me from taking pleasure in my work.	5 √√	4	3	2 **√**	1
4. I felt hopeless about finishing certain work tasks due to my (COPD).	5 √√	4	3	2 **√**	1
5. At work I was able to focus on achieving my goals despite my (COPD).	1	2	3 **√**	4	5 √√
6. Despite having my (COPD), I felt energetic enough to complete all my work.	1	2	3	4 **√**	5 √√

4.6.5.9. Workplace Control and Adaptation

The measure related to any workplace adaptations made by the participants in the past 4 weeks because of their COPD. Participants were asked to circle YES or NO in the first seven questions and then provide additional information for the remaining three questions if applicable. All three employed participants responded to this item. When asked whether their employer knew they had COPD, one indicated yes, one said no, and the other was self-employed. Participants were also asked whether they had taken time off work for any COPD related treatment or appointments - one had not taken any time off work and felt COPD had not affected their productivity, and two participants had taken time off work to attend hospital appointments with one taking almost four hours.

Another question asked whether participants had made any adjustment to their working hours because of their COPD. Only one had worked flexibly but no specific reason was given for this. Neither of the participants who worked for an employer claimed to have taken a reduction in pay, although the self-employed participant acknowledged they had not earned as much money from their work as usual, as they had reduced the hours worked.

When asked if they had been able to be flexible in how they worked and, if so, what changed, one indicated they had been able to start work later in the day or work later in the day depending on how well they were feeling, and another was able to vary days worked that week due to their COPD. Two participants indicated they had not needed to change their job role, responsibilities or duties. The participant who was self-employed was able to lighten their physical pressures by not undertaking the heavier jobs and by delegating them to others. This participant also indicated they were able to use equipment and machinery for lifting to ease the lifting load weight as required. Strategies were adopted by participants to improve their situation when COPD affected them most at work; these included: to slow down their movement, walk slowly, relax and take their inhalers and medication as required. Another participant found lying down or bending over and taking their inhalers or nebuliser helped most. When asked when COPD most affected them at work and what made things worse, responses included dust fumes, rushing around and heavy lifting.

The final question asked participants if there was anything else that was important to consider about having COPD and being in the workplace. Two thought it helpful for colleagues to know about their physical limitations e.g., to then be able to take time out and observe their condition and that employers should be aware of their disability without it prejudicing their job. One participant acknowledged they normally coped well with their COPD symptoms at work, but excess or fast physical activity negatively affected them by inducing breathlessness, which meant they usually had to slow down at that point.

4.6.6. Summary Discussion of Study Objective 2

The aim of this quantitative research objective was to better understand the physical and psychological well-being factors that might influence and contribute to successful employment in people of working age with COPD. The results of this cross-sectional study are based on a sample which recruited 14 participants. A descriptive analysis of the data has been conducted and general trends are reported in relation to those participants who were employed or not employed. The means, standard deviations and medians from the questionnaire have been presented and related to population norms where appropriate, although it is possible that the scores were due to chance findings in this small sample. Statistical comparison between people with COPD who are employed and not employed was not possible and therefore no inferences can be made to the wider population.

Participants scored in all levels other than the low impact level in the COPD Assessment Test (CAT). The scores of people in employment were lower overall than those not employed, indicating that COPD was having a lesser impact on them on the day they completed the questionnaire. This indicated that it was still possible to maintain a workplace presence despite COPD having a considerable impact on an individual’s well-being.

The quality-of-life attributes found in the EQ-5D-5L measure revealed varying results. Employed participants had issues on all the attributes but did not score in the severe or very severe areas. The scores indicated they had a higher quality of life than those not employed. Participants who were not employed had a wider range of levels of severity than those employed across the attributes but did not have extreme problems in their usual activities, pain/discomfort or anxiety and depression. The VAS score indicated that generally those employed felt healthier than those not employed but were less healthy overall than the general population indicating the impact of COPD on their well-being. Employed participants also appeared to be more satisfied with their lives than those no longer employed, although they scored less than people with diabetes.

In regard to self-perceived mental well-being, those not employed had a poorer mental health than those people still employed and also the general population. A similar picture was found with the HADS score for anxiety and depression, indicating better mental health in those employed than not employed. Resilience was another construct where those participants who were in employment demonstrated a greater level of resiliency than those not employed.

The measures on productivity in the workplace, presenteeism and workplace control and adaptation also provided some data on employed participants work activity and opportunity. However, as there were only three participants in this group the data was limited. It was evident participants had some level of flexibility but had low absenteeism and presenteeism in the short measurement timeframe.

The questionnaire appears to have been an effective tool in eliciting the information required to understand the psychosocial and physical factors that might influence employment in people with COPD. This objective also demonstrated that working-aged people with COPD are willing to participate in a questionnaire-based study of this type. The study has enabled a test-run of the questionnaire and provided important information on the practical aspects of the recruitment process, time taken for completion, and how to develop ideas on how a future study could be conducted successfully (e.g., online or postal and multi-site).

4.7. Study Objective 3 – Qualitative Interviews

To provide a detailed exploration of a sub-sample of participants' employment contexts and related experiences.

4.7.1. Introduction to Study Objective 3

Obtaining a further in-depth exploration of qualitative data in the follow-on interviews, with a subset of participants having already completed the questionnaire, was required to address study objective 3. This objective aimed to complement the data obtained from the questionnaire and gain a more detailed understanding of the participants' employment contexts and related experiences (Procter, Allen and Lacey 2010; Creswell 2009).

4.7.2. Population and Sample

No specific inclusion criteria were required for the follow-on interview, as those in employment and those having previously been in employment but left due to COPD could contribute to the study by providing insight into their experiences, constituting purposive sampling. Each participant who had completed the questionnaire had an opportunity to consider taking part in the interview and complete the *'willingness to participate in a follow-up interview'* section at the end of the survey questionnaire, constituting convenience sampling (Richie et al. 2014).

Thorne (2016a) suggests that interpretive description is best suited to smaller-scale qualitative studies such as this, and perspectives of the participants are considered valuable, enabling identification of the nature and context of participant experiences. Six interviews were originally planned. However, as only four participants volunteered for interview, and there appeared to be a richness in the data being collected, this number was considered sufficient to enable the identification of initial themes and inform the future direction of the PhD research.

4.7.3. Qualitative Recruitment and Informed Consent

Four of the 14 participants completing the questionnaire indicated their willingness to take part in the follow-on interview and provided their contact details. A meeting was planned with each participant thereafter, approximately one week later at their convenience. This timeframe allowed those volunteering to further consider their participation and change their minds and have no further involvement in the study if they wished. Those interviewed were then considered as a sub-sample of the main sample and the sequential component following on from the quantitative study. Participants were recruited to this part of the study following reiteration of the study purpose and further exploration of the PIS. Participants were advised the interview would take around 30 minutes to complete. Informed written consent was obtained on a consent form specifically designed for the interview (Appendix VIII).

4.7.4. Interviews

Interview formats include structured, semi-structured and unstructured approaches (Green 2015; Priest and Roberts 2010). In-depth, semi-structured interviews were utilised for data collection in this study (Ritchie et al. 2014). In-depth interviews, or 'conversations with purpose' (Webb and Webb 1932, p.130) combine structure with flexibility. In-depth interviews can provide detailed contextual information for the researcher to enable a detailed and thorough exploration of the topic under examination allowing for a critical reflection of participant experiences, beliefs and emotions (Green and Thorogood 2018; Kvale 2009). The structured approach is useful for studies that follow a strict interview schedule where it is important to ask questions in a pre-set order to all participants (Doody and Noonan 2013) but can appear to be a rigid approach that lacks flexibility (Ritchie et al. 2014). The semi-structured interview method was preferred over an unstructured approach, which allowed for a pre-prepared list of questions addressing the research topic to be used. It allowed for some flexibility in what was subsequently discussed with each participant but provided an overall *aide memoir* to ensure items were not missed (Holloway and Galvin 2017; Richards 2014; Priest and Roberts 2010).

Focus group interviews were also considered as an alternative means for data collection. Focus group interviews include a number of participants in one discussion and are used mainly to collect opinions on a broad range of healthcare issues. Individual interviews, in contrast, focus on the experiences of individuals at a personal and individual level and can deal with more sensitive and emotive issues (Parahoo 2014; Newell and Burnard 2011). Although it is more challenging to control the interview process and manage the debate within focus groups (especially with dominant individuals), focus groups can also obtain equal and opposing opinions on one topic which can be helpful (Parahoo 2014). However, confidentiality is more difficult to protect due to the participatory group process (Holloway and Galvin 2017).

Individual semi-structured interviews were selected as the most useful approach, as individual interviews enhance the validity of the findings because of the flexible nature of the questioning, probing and clarifying it enables (Creswell

2015). Individual interviews can also allow the researcher to maintain the discussion in context and with focus, as participants are encouraged to talk about their experiences (Ritchie et al. 2014). Individual interviews also facilitate the prioritisation of the participant's perspectives and reflects their direct expertise on the subject, and, because of the inductive nature of the discussion, data can be uncovered on a topic with a limited knowledge base as evident in this study (Creswell 2015; Neale 2009). In relation to interpretive description, interviews are recognised as a *'useful core for the development of knowledge in relation to clinical issues encountered'* and fits well with the approach (Thorne 2016a, p.87).

4.7.4.1. Interview Procedure

As individuals with COPD usually have breathlessness as their most significant symptom, interviews can be challenging and even more so if participants use oxygen or nebuliser therapy (Devereux 2017). Although Thorne (2016a) notes that appropriate interview durations for an interpretive descriptive interview are from 45 minutes to 2 hours long, a cautious approach was taken with these suggested timeframes as participants in this study experienced breathlessness, coughing and fatigue as typical COPD symptoms. Therefore, a balance was made between obtaining sufficient high-quality data suitable for addressing the research objective of the pilot study, with participant comfort, well-being and safety. Adequate time to enable the interview to be carried out effectively, without rushing and possibly distressing participants, was incorporated into the interview planning process and schedule. Participants were offered a repeat interview date if the time was considered too lengthy for one sitting or if they experienced any distress; this was, however, not required. As a researcher and nurse with experience of supporting people with COPD in clinical situations, in conducting the interviews I used my knowledge, skills, empathy and understanding to take a flexible approach in the data collection process and maintained the participants' physical and mental well-being as my primary concern.

The interviews were conducted face-to-face at the participants' preferred location at a mutually agreed time. Two interviews were carried out in participants' homes, one in a private workplace office and one in a private office in a public building. This approach ensured participants were afforded flexibility and choice in scheduling both the timing and location to begin to build up trust and help them feel valued in the organisation and conduct of the research process (DeJonckheere and Vaughn 2019). Participant control and engagement is highlighted as an area that is vital to developing a good researcher-participant rapport when conducting individual interviews (Denzin and Lincoln 2017; Creswell 2015). At the commencement of each interview, it was ensured the participant was fully aware of what to expect during the interviews. A semi-formal approach to asking questions, prompting and exploring ideas from the interview schedule was taken (Thorne 2016a; Priest and Roberts 2010). Privacy and confidentially were maintained and the environment was kept relaxed helping to build rapport with participants, which is important when discussing personal and healthcare issues (Holloway and Galvin 2017; Neale 2009).

The interview schedules (Appendices IX and X) lists the broad questions used to guide the interview, which was designed by considering study objective three, and informed by the literature review, breaking it down into sub-components and rewording it to aid clarity (Creswell 2013). The interview schedules were used to guide the interview, which was kept short and enabled time and space for further exploration of issues important to each participant (Holloway and Galvin 2017). The sequencing of the questions asked varied for every participant depending on individual responses during the interview. However, it is important that similar data is collected from all participants; therefore, the interview schedules were crucial to provide a broad guide for the interviews (Green 2015; Creswell 2013).

Gentle interview openers were used to begin the interviews, and, at the end, participants were thanked for taking part. Brief written notes were taken during the interviews as an *aide memoire* to enable me to return to certain topics for later exploration and clarification and to add to the transcriptions of the interviews (Holloway and Galvin 2017). Note taking was kept to a minimum to maintain the flow of the discussion, as it was important to be fully engaged in listening to participants and for me not to appear distracted in writing the notes (Priest and Roberts 2010).

Thorne (2016a p.125), notes that the researcher should, where possible, also refrain from using language such as ‘I agree’ or ‘that’s good’ as these ‘value laden’ prompts would direct the participant interaction and is not an approach that serves a purpose within an interpretive descriptive methodology (Thorne 2016a). Adopting a non-value laden approach was thought to enhance the validity of the interviews. Participants were open and willing to talk about ‘their COPD story’ often volunteering wider detail about their personal lives, emotions and finances than requested or required. Holloway and Galvin (2017) note the interaction between researcher and participant can be beneficial to those taking part, as it enables them to discuss and explore events in their chronic illness history, which sets their experiences in a narrative context where their opinions and voices can be aired and acknowledged. Participants often wandered off topic and prompts to revisit items for further detail and explanation were sometimes required.

4.7.4.2. Digital Recording

Digitally recording interviews and accurately transcribing them are good markers of credibility and dependability in qualitative research, as it enables the researcher to help generate a description and understanding from interviews that are accurate and reflect the ‘truth’ of each participant (Green and Thorogood 2018; Creswell 2013; Guba and Lincoln 1994). There is a risk in not recording interviews that we fail to capture significant issues that could later be retrieved and realised from a digital recording (Holloway and Galvin 2017). Recordings therefore allow for an authentic revisiting of the interview detail and overall experience. Frequent re-listening to recordings is a key feature of both data familiarisation and the analytical process and is important for further verification and clarification of specific points of interest as the analysis proceeds (Spencer et al. 2014). Interviews were digitally recorded using a password protected digital voice recorder and then transferred and stored as MP3 audio files on a password protected computer. The recorded files were then deleted from the digital voice recorder once transcribed and anonymised on Microsoft Word documents. Information on this process was provided in writing for the participants in the PIS and in the interview consent form and discussed during the process of informed consent.

4.7.4.3. Lone Working

As the data collection method required undertaking individual interviews in a private and comfortable environment, agreement with the participants as to a suitable venue was an important consideration (Ritchie et al. 2014). Two of the four participants requested the interview take place in their own homes which ensured participants were afforded choices with the aim of making them feel valued in the planning and organising process. These considerations are particularly important in helping build rapport and trust with participants (Denzin and Lincoln 2017). Undertaking interviews in the participants' homes can also be conducive to their comfort, particularly if they can be managed in a quiet area where they are free from distractions and interruptions (Creswell 2013). This meant participants did not have to travel any distance to participate in the study saving them time and effort, which is important where this could have an impact on their health and energy or fatigue levels. As a result, I had to travel to two different locations on two separate days.

Undertaking interviews in unfamiliar venues, whilst not necessarily considered dangerous, carries risks including travel risks (especially when travelling during winter) and personal safety risks in terms of entering unfamiliar environments. The Robert Gordon University Lone Working and Out of Hours Access Policy (2015) was followed to minimise all considered risks; specifically, the issues relating to managing need, carrying out the activities only if necessary, and that there were no alternatives available to the activity. As it was difficult to carry out an accurate risk assessment until entering the home or office environment and there was a lack of immediate on-hand support should concerns be apparent, this required a dynamic risk assessment approach. I managed this via careful assessment and reassessment of the situation and by leaving personal contact details of the approximate location and timings of the planned meeting with a 'buddy' (principal supervisor). There was also an arrangement to contact the 'buddy' in the event of an emergency or travel complications. Making a 'check-in-call' with my buddy before and on immediate completion of the interview was also carried out to complete the risk process.

4.7.4.4. Transcription

Transcription refers to the written recording and documenting of audio data (Silverman 2017). Data can be transcribed in several ways with varying levels of detail retained in the document. The literature suggests that researchers must be clear about how transcripts can fit with their differing research requirements for their analysis and how this influences the decisions on what and how the transcription is managed, produced and presented (Davidson 2009). Transcription support from a research assistant was available and carried out for all four interviews. At this point, data were anonymised, and participants allocated pseudonyms, which were kept with biographical data but not personal identifiers or consent forms, which were all stored securely in a different location. These are important actions to ensure participant anonymity in keeping with good ethical practice (Holloway and Galvin 2017). Data were transcribed onto Microsoft Word documents and line numbered for ease of reference.

Professional transcription companies promote their services as three types of transcription. Verbatim Transcription (where each utterance of paralanguage is included such as the 'ums' and 'erms'), Intelligent Verbatim Transcription (where the paralanguage is removed) and Edited Transcription (where the transcriber edits for grammar and streamlines the entire response) (Corden and Sainsbury 2006). Poland (1995, p 292) defines the term *"verbatim"* as *"word-for-word reproduction of verbal data, where the written words are an exact replication of the audio recorded words".* However, the notion of accurate transcription is difficult due to its subjective nature and the inter subjectivity of human communication in general and also that it is part of the interpretive process (Creswell 2013; Poland 1995). Holloway and Galvin (2017) note that gaining the fullest and richest data comes from verbatim transcribing.

Verbatim transcription was selected for this study and, therefore, there was a high level of detail contained in the transcripts, which enabled a rich and full understanding of each interview. Pauses, exact words and any interruptions were recorded to remain accurate to the events. This was important at the analytical stage where key decisions have to be made on the data available. Transcription was carried out independently by a research assistant to help meet the timeframe for the study completion. In reading and re-reading the transcripts it was evident that the constant engagement was a fundamental part of the analytical process (Richards 2014; Davidson 2009).

4.7.5. Decisions on Qualitative Data Analysis

Framework analysis was selected for the purpose of qualitative data analysis, as it is an applied approach used in nursing research often for informing policy and practice (Ward et al. 2013). Developed by social researchers, its pragmatic structure is applicable for real-world investigations and its use in healthcare research is increasing (Matlock et al. 2017, Parkinson et al. 2016; Pickup, Ford-Holloway and Samsi 2015; Ritchie et al. 2014; Gale et al. 2013; Cooper et al. 2009). The influence for adopting this approach was based on both study objective 3 and the type of data being collected (interview transcripts) (Parkinson et al. 2016). Whilst the approach is best placed to address questions relating to *'strategic', 'evaluative'* and *'diagnostic'* questions, it is the *'contextual'* elements of Framework analysis that most closely matched with the aims of this study. That is those relating to identifying the form and nature of the topic under scrutiny and in what way and how it exists i.e., what employment challenges exist for people with COPD and in what contexts are these challenges evident (Parkinson et al. 2016). Framework analysis is an interpretive approach to data analysis with an eclectic mix of principles taken from several epistemological traditions in the social sciences and, because it is independent of theory, it can be applied across various theoretical approaches such as interpretivist (Ritchie et al. 2014). Overall, Framework analysis is a highly pragmatic method of analysis for analysing data rather than a research approach such as phenomenology, grounded theory or ethnography (Ritchie et al. 2014; Ward et al. 2013, Dixon-Woods 2011) and is well suited to the analysis of data produced through semi-structured interviews (Green 2015; Gale et al. 2013).

Framework analysis is a form of thematic analysis where the main organising structure is to develop themes (categories) that are then logically organised and presented (Ritchie et al. 2014). The Framework approach enables research data to be managed through established and rigorous processes and offers a transparent and auditable matrix-based structure that allows the flexibility required in a qualitative enquiry (Ward et al. 2013; Cooper et al. 2009). The interconnections of the matrix approach itself enables the researcher to move from description to guide the analysis in a systematic way to develop explanatory accounts (Ritchie et al. 2014). It is more highly structured than some of its cousins such as the analytical techniques proposed by Madison (2005) and Huberman and Miles (1994), which often require substantial choreographing by the researcher. Because of its straightforward approach, using basic analytical steps, it helps to maintain a focus on the prominent themes, as effort can be put into considering findings, linkages and concepts rather than be concentrated on processes (Hackett and Strickland 2018; Ward et al. 2013). This simplicity in many ways adds to the rigour, as the process is made transparent. More specifically, the Framework approach enables the researcher to move backwards and forwards through different levels of data abstraction for cross checking. Here, the researcher looks for similarities and differences and refines and confirms themes and patterns without losing sight of the raw data (Spencer et al. 2014). This allows for thorough analytical processing enabling the researcher to delve deep into and across the data set without restriction to theory.

Ontologically, Framework analysis is closely aligned with subtle realism. This view holds that the social world, which is independent of subjective understanding by individuals, is accessible only through participant interpretations and subsequently through the researcher's analysis, understanding and interpretation (Ward et al. 2013). The focus, therefore, is on using existing qualitative ideas to structure the Framework approach with less of a focus on producing new theory per se, which can stand alone without a theoretical allegiance (Ritchie et al. 2014; Ward et al. 2013). Thus, the Framework approach is generic in its nature and '*a theoretical*', which attracts some criticism around methodological congruence (Smith, Bekker and Cheater 2011; Smith and Frith 2011; Braun and Clarke 2006). However, Framework analysis also aligns well to interpretive description, which encourages the researcher to stay closer to the data rather than the research process (Thorne 2016a).

The drawbacks of using a Framework approach are that the process driven method can sometimes supress the researcher's interpretive creativity, which is vital for generating the qualitative research of the highest quality (Dixon-Woods 2011). The terminology used contributes to the existing repertoire in the qualitative field having the potential to pose additional challenges for the researcher (Hackett and Strickland 2018). Furthermore, the steps involved, where there is ambiguity in the data, lead to further complexity e.g., starting interpretation too soon (Hackett and Strickland 2018). Additionally, there is a need for well-developed skills in information technology and software use in charting and crafting the spreadsheets at each stage of the analysis (Hackett and Strickland 2018), elements that may add considerable time demands to a research project. Although no approach to qualitative data analysis is completely free of assumptions and biases, which come through the individual and subjective conceptual processes and critical thoughts of the researcher, other thematic approaches to analysis can be less transparent than Framework (Dixon-Woods 2011; Furber 2010; Braun and Clarke 2006). Lack of transparency is a concern for qualitative research and is a key requirement for demonstrating rigorous qualitative analysis in a study (Green and Thorogood 2018).

Other approaches to qualitative data analysis were considered for the study including grounded theory, which, in contrast, aims to inductively generate theory during the analytical stage, which is tested out during the research process (Green and Thorogood 2018; Furber 2010; Corbin and Strauss 2008). Grounded theory begins deductively and ends with inductively generated knowledge seeking to theorise relationships in transcripts that reflects participant accounts of the experiences and observations (Creswell 2013). Grounded theory, as a method of analysis, requires re-engagement with rounds of data through constant comparative analysis to enable the refinement of the emerging theory (Newell and Burnard 2011). Eventually, categories are developed like Framework and other qualitative approaches (Holloway and Galvin 2017). However, the aim of this study is not to generate theory but to describe the context and experiences of people with COPD in relation to employment and analyse the findings to begin to move towards action in practice. Therefore, grounded theory was not suitable as a form of analysis, although it shares some methodological commonalities with interpretive description as explored in Chapter 3 (Thorne 2016a).

Other types of thematic analysis were also considered for use in this study including that proposed by Braun and Clarke (2006), which is not methodologically tied to any specific epistemological or theoretical perspective. Thematic analysis is a clear and researcher friendly approach to identifying patterns and clusters from the data that appear interesting and important in addressing the research objectives (Clarke and Braun 2013). Thematic analysis is an established generic method for thematic coding; however, it does not offer the matrix approach which Framework affords to enable ease of looking across and between case searches to detect patterns and links (Spencer et al. 2014; Braun and Clarke 2014).

4.7.6. Qualitative Data Analysis

As discussed above, the Framework analysis approach is a rigorous and methodical way of analysing interview data helpful for the novice analyst due to its clear structure (Spencer et al. 2014). When utilising Framework analysis, a two-stage approach is taken to data analysis, and the authors suggest a fluid relationship between the *data management processes* and the *data abstraction and Interpretation processes* (which include constructing categories, identifying linkage and accounting for patterns) (Spencer et al. 2014). During these analytical paths, some interpretation occurs, and further refinement and reorganisation of the data is required. This means there is a constant backwards and forwards through different levels of abstraction as new themes and questions are discovered like the technique employed by Miles and Huberman enabling cross-case and within-case analyses (Miles, Huberman and Saldana 2020; Spencer et al. 2014). Thorne (2016a) also agrees that in taking the interpretive descriptive perspective, data collection and analysis occur concurrently with the researcher thinking carefully about *"why is this here? Why not something else? What does this mean?"* (p.174). The steps involved in the Framework approach enable transparency of the data management process and provide an audit trail to ensure the analytical process is clear for scrutiny (Cooper et al. 2009). The analytical process itself was supported using NVivo, Microsoft Excel and Microsoft Word software throughout both the data management and abstraction and interpretation stages. Computer software has been used extensively for quantitative data analysis for some time and today there are numerous options for utilising software for supporting the management and analysis of qualitative research studies (Jackson and Bazeley 2019). The use of software is commonly referred to by the acronym CAQDAS (Computer Assisted Qualitative Data Analysis) (Cabrera 2018). Rather than CAQDAS acting as a function of the analytical process, which is a common misperception, it serves to support the analytical process by helping researchers to simplify and organise data making it more transparent and accessible (Jackson and Bazeley 2019). The use of information technology (IT) equipment and software during the various stages of data collection, management and interpretation of the data in this study is illustrated in Table 4.15.

Table 4.15 - Information Technology Equipment and Software used During Data Collection, Management and Interpretation.

Stages of data management and analysis	**IT and software used**
Data collection	*Audacity®* software used on password protected laptop to record the interviews.
Data transcription	Data recorded using the *Audacity®* software programme which was initially used to transcribe. Discovered and trialled transcription software *Transcribe Wreally*. Transcribed recording onto Microsoft Word documents.
Data familiarisation	*Audacity®* used to re-listen to recordings. NVivo 11 used to code the data into the initial thematic framework.
Coding data and developing the analytical framework	Microsoft Word used for developing the initial coding framework.
Applying the analytical framework	The analytical framework was applied back to the transcripts using NVivo then changing and amending the framework on the Microsoft Word document.
Charting data in a matrix	Excel spreadsheets.
Data interpretation and analysis	Microsoft Word documents. Refining the dimensions, categories and the higher order classifications – moving them around to find the best fit.

The advantages of using CAQDAS such as NUD*IST, ATLAS.ti, MAXqda, N6 and indeed NVivo includes making the process of coding and retrieving faster and allows for the retrieval of rich text within themes to compare and contrast (Cabrera 2018). It also helps with the exploration of patterns and relationships in the data, particularly with larger data sets involving several transcripts, and is useful when sharing data sets (Jackson and Bazeley 2019). However, there are drawbacks with CAQDAS, as software takes time for the novice to learn, and its use is usually not beneficial in small studies. Also, some claim that data could be fragmented in a way that can lose some of the important narrative and valuable contextual information for the researcher (Hesse-Bieber 2010).

Thorne advises against using computer assisted technology when adopting the interpretive descriptive approach, as it may push the researcher more towards the process than the data (Thorne 2016a). As a result, there can be a tendency to prematurely code the data, potentially overshadowing *"reason, intelligence and inductive thinking"* (Thorne 2016a p.161). Thus, although it is important to provide some detail about the relationship between the broader interpretive descriptive approach and the analytical technique of Framework analysis in this study, it is important to emphasise it is the principles of both approaches that are being used and that neither shall detract from the centrality of the participants voices (Thorne 2016a). Having identified challenges in using fragmenting approaches to data analysis such as Framework, when working with large data sets it is helpful to use CAQDAS. In doing so, the researcher is cognisant of not allowing the analytical process take centre-stage at the expense of creative and interpretative processes (Thorne 2016a).

4.7.7. Data Management Using the Framework Approach

The Framework approach has two main processes to follow: data management (explored in this section), and abstraction and interpretation (which will be explored in the following section). Data management activity is a conceptual and intellectual process carried out through the following five steps:

1. Data familiarisation
2. Constructing an initial thematic framework
3. Indexing and sorting (charting and mapping)
4. Reviewing data extracts
5. Data summary and display

(Spencer et al. 2014, p. 281)

Data management is an active process of finding and developing themes (Spencer et al. 2014; Braun and Clarke (2006). Through the process of reading and detailed re-reading of the transcripts and repeated listening to the audio recordings, I further immersed myself in the data, a process known as *'Data Familiarisation'* (Step 1) (Ritchie et al. 2014, p.297). This was completed immediately, as I had conducted the four interviews and had developed initial thoughts of the relevant issues during that time. The PhD study supervisors checked the first recording and transcript for accuracy and to detect any areas for immediate interview technique improvement and assure credibility in the process (Thorne 2016a; Guba 1990). No changes were required to the process or interview technique. Throughout the process of reviewing the transcripts, I made additional notes about other interesting points relevant to the research objective in the document margins (Hackett and Strickland 2018). These notes and ideas formed the long list of topics (or labels), which would inform the thematic framework, which I then applied back to the raw data as described next (Spencer et al. 2014). The PhD study supervisors were also in agreement with this list of topics. See Table 4.16.

Table 4.16 - Initial Topics from Notes and Data Familiarisation (Step 1)

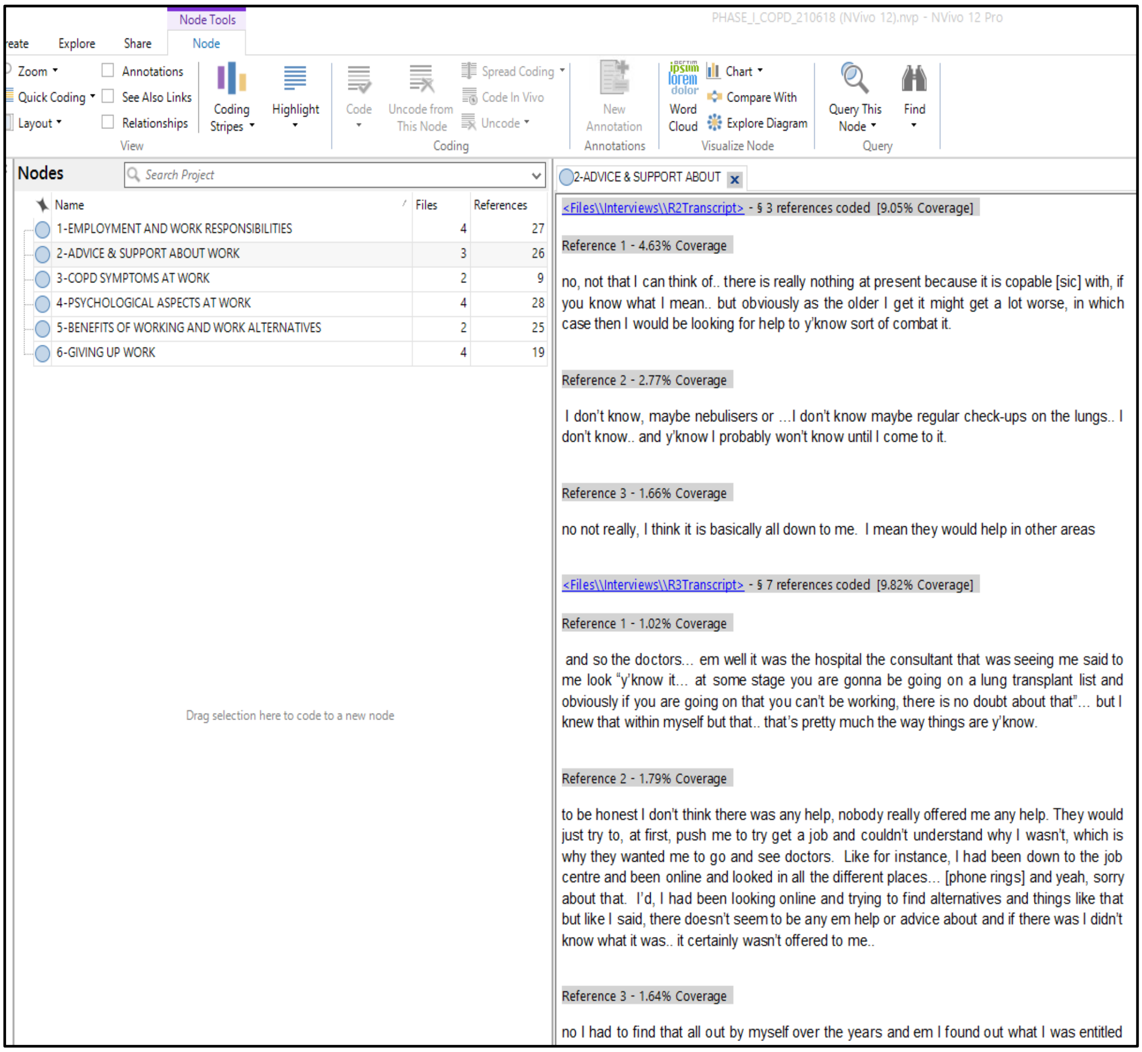
- **Psychological**
    - Anger
    - Assertiveness
    - Attitude
    - Boredom
    - Defeated
    - Denial and loss
    - Depression
    - Fear
    - Frustration
    - Regret
    - Self-esteem
- **Social factors**
    - isolation
- **COPD/symptoms**
    - Effect on personality
    - Environmental influences
    - Individual nature
    - Self-management/coping strategies
    - Unpredictability
    - Variability
- **Employment**
    - Alternatives to employment
    - Benefits of work
    - Ceasing employment
    - Employers' attitudes
    - Employers' responsibilities
    - Impact on others
    - Type of employment
    - Work environment & adaptations
- **Other people's understanding**
    - Colleagues
    - Jobcentre staff attitudes
    - Others
- **Work adaptations**
    - Demeaning/degrading/defeatist
    - Stair lift
    - Finance
    - Flexible working
- **Advice/support**
    - Colleagues/managers
    - Community/family
    - Health professional

The construction of an *'initial thematic framework'* (or coding index) was identified and developed by considering relevant *a priori* themes, using the additional notes I had collected, and then collating groups of recurring themes (ideas and concepts) from data that I had already organized into a draft index 'thematic framework' (Step 2) (Ritchie et al. 2014). At this point, I kept an open mind about other themes that may be relevant within the data. Remaining cognisant of the research objectives, the index of items, shown in Table 4.17, was applied back to the transcripts. This enabled me to explore and determine the 'best fit' with the data and ensure that a workable structure containing the important themes and sub-themes could be developed from the data (Ritchie et al. 2014). The same process was replicated independently by the PhD study supervisors with high agreement on the relevance and allocation of most of the initial themes.

Table 4.17 - The Thematic Framework (Step 2)

Theme	Subtheme
Health & Well-being	Current/past symptoms/daily symptoms/limitations/actions to improve
	Diagnosis
	Lung pollution history
	Smoking history
	Fatigue
	Exercise
	Autonomy
	Sickness absence/disability/disclosure
	Health checks & health support
Working	Context – job/role & duties
	Benefits of work (social/financial/expertise/satisfaction)
	Getting to work
	Challenges of job demands (limitations/productivity/events)
	Challenges with symptoms (variability of condition)
	Control over duties/environment/hours worked
	Coping strategies (Actions/covering/hiding/deceiving (double life)
	Workplace adjustments (other role/duties/flexible diary/PT/redeployment)
	Giving up work/retirement
Advice & Support	Employer/boss/HR conversations/attitudes
	HCP conversations/attitudes
	Family/friends conversations/attitudes
	Colleague conversations/attitudes
	Community & practical
	Others (CAB)
	Financial (benefits (ESA/PIP) & pension) blue badge & practical advice
Psychological	Feelings & Emotions (self-esteem/embarrassment/stigma/upset/shame/pride/sadness /humiliation/embarrassment/demoralising/fear/guilt/denial/self-blame)
	Discrimination
	Stress/depression/anxiety/worry/down
	Boredom/activity
	Perceptions (self/others/employer)
	Loss of lifestyle
Other aspects	Spouse & family
	Past/future life (loss)/what should/could be happening/ reflecting
	OH lies/collusion
	Loss of expertise
	Info for employers

'Indexing and sorting' the data into themes was undertaken next (Step 3). This process was time consuming, as each line and paragraph was read and re-read to interpret the meaning so I could apply the relevant thematic labels to each set of data that related to the same thing (Hackett and Strickland 2018). Sometimes known as *'charting and mapping',* I completed this step through reviewing, refining and restructuring the themes in NVivo, which required less movement between nodes as I progressed through the themes towards completion. An NVivo chart for the theme of advice and support is included as Figure 4.3.



Name	Files	References
1-EMPLOYMENT AND WORK RESPONSIBILITIES	4	27
2-ADVICE & SUPPORT ABOUT WORK	3	26
3-COPD SYMPTOMS AT WORK	2	9
4-PSYCHOLOGICAL ASPECTS AT WORK	4	28
5-BENEFITS OF WORKING AND WORK ALTERNATIVES	2	25
6-GIVING UP WORK	4	19

<Files\\Interviews\\R2Transcript> - § 3 references coded [9.05% Coverage]

Reference 1 - 4.63% Coverage

no, not that I can think of.. there is really nothing at present because it is copable [sic] with, if you know what I mean.. but obviously as the older I get it might get a lot worse, in which case then I would be looking for help to y'know sort of combat it.

Reference 2 - 2.77% Coverage

I don't know, maybe nebulisers or ...I don't know maybe regular check-ups on the lungs.. I don't know.. and y'know I probably won't know until I come to it.

Reference 3 - 1.66% Coverage

no not really, I think it is basically all down to me. I mean they would help in other areas

<Files\\Interviews\\R3Transcript> - § 7 references coded [9.82% Coverage]

Reference 1 - 1.02% Coverage

and so the doctors... em well it was the hospital the consultant that was seeing me said to me look "y'know it... at some stage you are gonna be going on a lung transplant list and obviously if you are going on that you can't be working, there is no doubt about that"... but I knew that within myself but that.. that's pretty much the way things are y'know.

Reference 2 - 1.79% Coverage

to be honest I don't think there was any help, nobody really offered me any help. They would just try to, at first, push me to try get a job and couldn't understand why I wasn't, which is why they wanted me to go and see doctors. Like for instance, I had been down to the job centre and been online and looked in all the different places... [phone rings] and yeah, sorry about that. I'd, I had been looking online and trying to find alternatives and things like that but like I said, there doesn't seem to be any em help or advice about and if there was I didn't know what it was.. it certainly wasn't offered to me..

Reference 3 - 1.64% Coverage

no I had to find that all out by myself over the years and em I found out what I was entitled

Figure 4.3 – Nvivo Extract from the Advice and Support Node (Once data was indexed and sorted into themes – Step 3)

To enhance the study dependability, the themes were also audited by the PhD supervisors who agreed with my indexing and sorting and subsequent charting and mapping process into NVivo (Coughlan, Cronin and Ryan 2013).

In concluding step three, data were summarised into thematic charts in a Microsoft Excel spreadsheet providing a row for each participant with individual themes running across the columns. *'Reviewing data extracts'* (Step 4), involved looking at the whole picture of the data and checking if there were other ways of organising and theming the data to ensure it was coherent. During data summary and display, the development of matrices is a fundamental part of the Framework approach, allowing analysis to be managed by both case and theme working back and forth through various levels of abstraction to find links (Spencer et al. 2014). Finalisation of the *'data summary and display'* (Step 5) concludes the data management stage of the Framework approach (Ritchie et al. 2014). Re-reading transcripts to ensure accuracy or review the original context of the extracts was required to make further adjustments as necessary. Writing concise data summaries of participants' contributions to each theme, although time consuming, helped to keep the volume of material manageable and reduced the need to revisit the transcripts to check authenticity.

4.7.8. Data Abstraction and Interpretation Using the Framework Approach

The process of further mapping and interpretation was carried out to *'construct categories, identify linkages and account for patterns'* (Spencer et al. 2014, p. 310). Throughout the analytical process, I continued to look for similarities and contradictions, clues, patterns and associations that would help to explore and explain the data. In carrying out the Framework processes as described above, data were managed efficiently. The constructed charts were able to guide my interpretation and analysis as they were easily accessible and clear to follow. The abstraction and interpretation stage of the Framework process involved the construction of categories from the various dimensions detected and then synthesising the findings where this was feasible (Spencer et al. 2014) and were further verified by the PhD principal supervisor. From this point, broader higher order classifications were determined. However, it was not possible to develop the analysis further and consider single typologies along a continuum on the data, but this may be possible with 'cases' in a much larger study (Ritchie et al. 2014). The process detail illustrates the systematic and transparent approach taken in this study to document the researcher's decision trail and establish the trustworthiness of the findings (Guba and Lincoln 1994).

4.7.9. Qualitative: Description, Findings and Discussion

4.7.9.1. Description of the Participants

Four participants participated in an interview. Two were employed (one self-employed) and two had retired early due to ill-health at a relatively young age. Interviews lasted between 7 and 33 minutes; the shortest one was a woman who did not have in-depth responses about her employment experiences, as her COPD was mild and not troublesome for her. The age range of the participants was 42-69 years, and their characteristics are illustrated in Table 4.18.

Table 4.18 - Characteristics of Participants Who Completed the Interview

Participant Characteristics				
Pseudonyms	**Susan**	**Oliver**	**Arnold**	**Alice**
Gender	Female	Male	Male	Female
Age	42 years	51 years	51 years	69 years
Employment status	Was employed Retired due to ill-health aged 39	Was self-employed Retired due to ill-health aged 39	Self-employed	Employed
Job Type	Skilled Manual	Skilled Manual	Skilled Manual	Sedentary
Employment Contract – hours worked	None	None	Part-time flexible hours	Part-time flexible hours
Type of employment	Animal healthcare	Restaurant owner & chef	Plant & maintenance owner	Office administrator
CAT Test	Medium Impact	Very High Impact	High Impact	Medium Impact

Three higher order classifications were developed from the analysis: COPD in the Workplace, Employment Support for COPD, and The Bigger Picture of COPD and Employment. The dimensions, categories and higher order classifications are illustrated in Table 4.19, and examples of the elements within each dimension are included in Appendix XI.

Table 4.19 - The Dimensions, Categories and Higher Order Classifications Representing the Final Analysis

Dimensions	**Categories**	**Higher Order Classifications**
• Daily variability of health and COPD • Dealing with COPD symptoms at work	Health and COPD Symptoms at Work	1. Health and COPD in the Workplace
• Work duties and role demands • Workplace adjustments • The impact of work adjustments on others	Workplace Challenges and Solutions	
• Information, advice and support about employment	Employment Support	2. Employment Support for COPD
• Purposeful employment • Exiting employment • Searching for alternative employment	Benefits of Work and Exiting Employment	3. The Bigger Picture of COPD and Employment

The following sections present the description, findings and discussion of the relevant employment contexts and experiences of the four participants. As discussed in Chapter 2, there is a lack of specific research on working-age people in relation to the employment aspects of those with COPD or respiratory conditions. It was therefore necessary to incorporate relevant research conducted on those with other long-term conditions encountering symptoms and employment challenges and the wider body of research on employment.

Direct quotations are incorporated within the discussion text when under 40 words in length and indented separate from the text in italics when greater than 40 words (Goldberg and Allen 2015). The use of ellipses (…) indicates where words have been removed. Square brackets ([ ]) are used to incorporate additional text has been added for clarification. The following abbreviations are used: Name = Pseudonym; E = Employed; SE = Self-employed; RE = Retired Early; Age.

4.7.10. Higher Order Classification 1 - COPD in the Workplace

This higher order classification consists of two categories: health and COPD symptoms at work, and workplace challenges and solutions.

4.7.10.1. Health and COPD Symptoms at Work

This category included the two dimensions of daily variability of health and COPD and dealing with COPD symptoms at work.

Daily variability of health and COPD

Concerns around daily variability of lung health and general health and well-being were raised by all participants. The influence of weather (wet or cold), activities they had undertaken the day before (e.g., working long hours, consuming alcohol), how fatigued they felt (general fatigue or poor sleep patterns due to symptoms) could impact on how well participants felt at work. Some noted they could not predict how they would be able to perform at work on any given day, for example Arnold, who struggled to maintain consistent productivity in running his heavy plant business. His condition could change dramatically as the following excerpt illustrates:

> *"There is not an actual pattern to it … I may have been out working from 8-3 and then 4 o'clock comes and you are 'whacked out'… and the next day*

> *you could be tragic in the morning and then still going strong at half past 6 at night" (Arnold SE 51yrs).*

Diurnal variation in COPD symptoms and general well-being was also recognised as challenging by participants. Morning, daytime and night-time variability further added to the unpredictability of COPD and inconsistent patterns in their contribution to productivity as illustrated by Arnold above. This concurs with findings from Miravitlles and Ribera (2017), who concluded from a narrative review that COPD symptoms even compromise an individual's ability to function in their usual day-to-day activities. Daily variability of COPD symptoms was also recorded in a large international study conducted by Fletcher et al. (2011), which was shown to cause individuals difficulty with consistent attendance and performance at work. In addition, Miravitlles et al. (2017) also noted that variability is also likely to occur in those with stable COPD potentially accounting for some of the unpredictability in those with mild or moderate COPD.

COPD was also considered a *'hidden'* condition, which could be problematic in the workplace as colleagues might not appreciate the considerable effort made by those with COPD to function effectively in their job. In the following quote, Susan described her efforts:

> *"It is a very hidden thing, you have not got an obvious limb missing or a speech impediment or anything … that is the biggest issue, it is a hidden disability and because I used to get up and get on with my work there was no consideration for how much of a struggle it was for me … because I did not make a fuss" (Susan RE 42yrs).*

Susan felt the endeavours she made to try to function effectively in the workplace were not acknowledged by others, although she knew her employer was aware of the severity of her COPD. She discreetly dealt with increasingly disabling symptoms, including breathlessness and fatigue and felt her hard work to remain productive and retain her employment status was not appreciated by her employer or work colleagues. This perspective was like the working women in the interviews conducted by Mal'ouf (2016) who found that work colleagues did not understand what it was like for those with COPD to be breathless. In other studies, participants felt colleagues did not appreciate how much chest problems affected their lives and onlookers were baffled how those with COPD could look so well and yet hear them claim they were not (Varekamp and Van Dijk 2010; Clancy, Hallet and Caress 2009). Unpredictability in health and well-being for people with COPD appears to influence individuals' productivity and how others perceive them in the workplace.

Dealing with COPD symptoms at work

Experiencing symptoms of COPD at work including breathlessness, chest tightness, coughing and fatigue were common to all four participants. Getting up and ready for work in the morning could pose significant challenges for some participants:

> *"Because there are many times … even to be self-employed, when I have gone to do something … got up to do something in the morning and have found out it is too difficult … trouble to get up… got to get breathing and that ... so I am 4 hours late" (Arnold E 51yrs).*

The impact of the participants' COPD symptoms on their work and productivity varied depending on individual circumstances, including the degree of autonomy they had in their workplace and the extent to which their work was sedentary or manual. Alice, who worked in a flexible part-time sedentary role at the age of 69, did not find her COPD to be *"too bad"* other than feeling a *"bit tight chested at times"* (Alice E 69yrs). This was similar to individuals in the Mal'ouf (2016) study where the sedentary workers also felt their COPD had no impact on their work roles.

Arnold felt that what kept him working on a daily basis was *"down to my physical and mental attitude to the condition of my lungs …." (Arnold E 51yrs),* and that his resolve to continue running his own business, even when his COPD was graded as "very severe", was instrumental to the effort he made and how he approached his work:

> *"You just gotta keep telling yourself, well push really, to just go further forward and then you go as hard as you can, then you just gotta stop, take a bit of a break and just keep pushing but, if you do not push, I feel you just would not be able to do anything" (Arnold E 51yrs).*

He also referred to when he was eventually *"running out of puff"* which limited what he could achieve at work and made him feel *"useless"*.

When Alice felt her chest was tight at work, she said *"just a few puffs into the salt-pipe* [inhaler] *and I am fine*". Others had more of a challenge managing their COPD symptoms at work and Susan reported that she frequently sat in her car during her tea break to use her portable oxygen, before returning to work and carrying on with the remainder of her shift. She considered it obvious to others how oxygen depleted she was by her colour and breathlessness and the physical effort she put in to doing her job:

> *"You could tell by how red my eyes used to get with the lack of oxygen … and I used to get eh ... quite a big carbon dioxide sort of build-up and erm … you could tell come 4 o'clock that I was really trying" (Susan RE 42yrs).*

One participant reached a point that he could not keep up with the pace required at work and knew that *"was not acceptable"* from a personal health perspective and in running a business. His workplace demands were high, and his health had declined significantly over a period of 2 years, such that in continuing to try to keep his work-rate up, he *"was close to collapsing in the kitchen a couple of times" (Oliver RE 51yrs).* Susan (RE 42yrs) similarly felt she had reached a point where *"she could hardly hold a conversation in the consulting room without being really, really breathless".* At times, her work was physically demanding, for example - when she would have to carry a post-treatment animal from the kennels to the consulting room to be reunited with its owners. When this happened, she would have to carry the animal so far then stop and wait outside the consulting room until she caught her breath before entering. Susan felt that in a less strenuous role holding conversations would have been easier. These types of experiences are reported in interviews conducted by Watson (2015) and Mal'ouf (2016), where participants with COPD reported that communicating with the public was difficult in the workplace due to their breathlessness. These accounts suggest that those with COPD working in strenuous jobs, or where significant communication was required in the workplace, find work challenging and, at times, their productivity is compromised.

4.7.10.2. Workplace Challenges and Solutions

This category was made up of three dimensions: work duties and role demands, workplace adjustments, and the impact of work adjustments on others.

Work duties and role demands

A key feature of work duties and role demands involved others taking on tasks in the workplace as a means of supporting those with COPD. One participant recalled colleagues completing tasks for her, which she found difficult to accept, including cleaning jobs requiring bending, mopping floors and reaching deep into animal pens. Susan noted that as her condition deteriorated, doing these tasks *"used to kill her"*. Some of the cleaning products used in the workplace caused her breathing issues and a fellow colleague also reported they *"caught her throat"* too, which subsequently made her breathless. Initially, Susan felt her employer was not too concerned with this situation, but they later reluctantly changed their cleaning products to accommodate the workers concerns. Certain tasks were easier than others, although one of the most challenging parts of her physical role was lifting and restraining heavier animals, dogs in particular. Susan illustrates the degree of challenge involved in varying tasks: *"I could do my job in theatre because I was standing still … but I was finding it difficult to lift animals; to restrain animals was definitely really difficult" (Susan RE 42yrs).*

Susan felt she had little control over her work tasks and the daily job responsibilities like those illustrated by the cleaning tasks and chemicals and in large animal restraint. Hultin et al. (2013), in a study of illness or disease, found workers who had low adjustment latitude (to be able to temporarily adjust their work demands due to altered physical or psychological health), led to increased sickness absence levels. Lack of or low adjustment latitude typified workers toiling in the workplace with little scope for flexibility, like Susan.

Oliver on the other hand, as head chef and manager in his own restaurant had high access to adjustment latitude. However, this proved difficult to realise as the work still had to be done. The exceptionally high standards required in the food industry to sustain a competitive business meant Oliver promoted some staff into more senior roles (e.g., to head chef) with the aim of relieving some of the pressure on him. The demands of his job were evident in this example:

> *"In the kitchen … there's a lot of heat … and it is fast paced … and I was managing the kitchen as well, so I could not do both, so I stopped doing the cooking side so much and then started managing … but there is not enough to just be a manager in the kitchen, you need to be part of the workforce and active" (Oliver RE 51yrs).*

Both Susan and Oliver experienced some difficulty accepting they were unable to continue in their job, signalling an early exit from the workplace, loss of an enjoyable career, a dramatic change in their personal lifestyle and a loss of expertise to the workplace. Given alternative jobs, they may have coped with work better and for a longer time.

In terms of others helping, there was no compromise for Oliver, and he realised his career and business were unsustainable because of the physical demands it put on him. Feeling there was no workable compromise in terms of commitment and effort, Oliver adopted the attitude of *"I would not take second best anyway and if I could not do the job, then I could not do the job..." (Oliver RE 51yrs).* Taking more of a health focus, Arnold recognised that if he put himself forward for a lung transplant that his career (and business) was finished as he would not be able to continue in the heavy plant business:

> *"Basically, if I had a lung transplant, I would not be able to go back to what I am doing now. I would have to change my whole working career or job that I was considering … because it would not be … I need something physical and something to tease my mind" (Arnold E 51 yrs).*

Here, Arnold's strategy was to balance continuing to keep working as long as he could without jeopardising his opportunity to have a lung transplant [by making himself ill in continuing to exert himself at work. Arnold realised that either way, his business and ways of working would have to change in the near future. Resuming paid work for kidney transplant patients was noted to be a complex dynamic between an individual's personal and work-related factors. Returning to the same role would require consideration of personal values, perceptions of their own abilities, skills required for the job, job-specifics and employer characteristics (Nour, Heck and Ross 2015). This would pose challenges for Arnold due to his physically heavy business and being self-employed.

Workplace adjustments

Participants who were self-employed had different perspectives on workplace adjustments than those who were employees. Various approaches to adjusting the workplace or tasks were discussed including taking on lighter duties, flexible working (including changing the hours worked and working from home), colleague support and the use of equipment. Arnold acknowledged that no adjustment could make his job any easier although did discuss lighter duties but would *"feel degraded by taking on light duties".* Acknowledging that whilst some people would be happy to do so and still feel they were serving a purpose, he felt he *"would not be achieving his goals"* [personal fulfilment and financial gain]. He further explored the practicalities of workplace adjustments and captured the essence of maximising the contribution of individuals by enabling a flexible approach to work depending on an individual's health condition and workplace opportunities:

> *"Because everybody needs help, but it is all in a different way… well the way I see it is, to help everybody there would be some sort of financial incentive … to put people into a working condition… like er, a floating thing of 20 hours a week but ... they could, have them do 6 hours today, 4 hours tomorrow ... then 6 hours the next day … then 4 depending on how they are breathing and to be took [sic] into consideration …" (Arnold E 51yrs).*

Oliver, also self-employed running a small company, initially adjusted his workload and started to put more work onto others by *"moving people up the chain a little bit …. sort of promoted them if you like and let them further their* *career a little bit" (Oliver RE 51yrs),* but soon felt that he was not giving enough of himself in the workplace. The pressures of running the restaurant and working with declining health eventually meant Oliver was working more hours with fewer returns. He found reducing his responsibilities less satisfying and, despite trying to just do the management element and less in the kitchen, it was not enough to make the business work efficiently or maintain its viability. Implementing workplace adjustments were not helpful, as he needed to be part of the active workforce and be a manager (which was like Arnold, who felt he would not be able to achieve his personal goals). Being self-employed appeared to bring specific challenges including questions of business viability for small business owners and reduced satisfaction in their accomplishments.

Other participants who were employees had different challenges and opportunities to implement workplace adjustments. Susan worked with a larger employer and reported that she found implementing reasonable adjustments challenging because of the negative and unhelpful employer attitude, which also made undertaking alternative roles, such as a receptionist's job, almost impossible. Alice, who was employed in a sedentary role, could essentially *"set her own pace in how she tackled work"* and noted that she worked at a certain pace in the office in order to keep busy:

> *"I prefer to be in a rush if you know what I mean. I gotta get this done, it has gotta be done by tomorrow. I work under pressure a lot better than I do with nothing to do or very little to do, then I get bored" (Alice E 69yrs).*

Alice considered herself fortunate to work for an employer that encouraged flexitime around core business hours of 10-2pm where she could work to suit her needs. Overall, her company did their best to ensure her immediate work environment was suitable although adjustments to her role at this time were not required. The high adjustment latitude that Alice had might have contributed to her satisfaction in her employment situation.

Reducing working hours was another strategy used, and initially Susan went from full-time hours to part-time hours working 5 mornings each week. She felt *"the company got the best out of her"* as mornings were when she was at her best physically. She later converted to 2.5 days a week on the advice of her physiotherapist, as she was completely exhausted:

> *"I was never getting the down time to recuperate, so it was on the advice of the physiotherapist who said to go to the 2 and half days and it meant I got actual days that I did not have to do anything but try and recuperate" (Susan RE 42yrs).*

Changes in shift patterns were also implemented by her employer, which caused further challenges and required her to work until 8pm: *"There was no way I could work until 8 o'clock ... the late shift started at 11 and there was no way I could work until 8 o'clock at night" (Susan RE 42yrs).*

Susan retained her usual shift pattern due to the support given by her colleagues, as they worked flexibly. Installing a stair lift to enable access the top floor of the building was also a major adaptation enabling Susan to function with dignity in the workplace. She recalled how implementing reasonable adjustments was a requirement under the Equality Act (2010), but her employer was initially not supportive, and she had to initiate the grievance process and sought and obtained the financial support to be able to implement it. Here, she reflects on the experience:

> *"They had to by law* [implement reasonable adjustments] *… I had to take it to a grievance meeting to get it there, so HR were worse than useless, so there is nobody else other than your HR but my line manager, a new girl that came in, she was better and she was more supportive and was more of kinda a go getter" (Susan RE 42yrs).*

She recalled the struggle in trying to promote her rights as a worker disabled by a long-term condition and the energy involved in the pursuit of optimising her workplace experience and productivity. Susan also tells of her experience attending hospital appointments at a time when she was still working full-time. Hospital appointments were to be taken as annual leave days and she recounts that the only allowance given to her was for attending the physiotherapist for weekly pulmonary rehabilitation (PR) some 6 miles away. She explains the planning and execution of this process in detail:

> *"I went to physiotherapy when I was working full-time, which I went to in my lunch hour, so I got two hours a week, because I left at half 12 to go to the hospital and my lunch hour was between 1 and 2pm, so I got between 1230 and 1pm to change and get up to the hospital" (Susan RE 42yrs).*

The compromise she made to attend PR and return to work in a short timeframe, she felt was unappreciated by her employer and there was pressure on her to be back in attendance at work quickly. On return to work, Susan hurriedly changed into her uniform and had to *"throw something down her throat"* for lunch before returning to the 'floor'. Time away from work for healthcare appointments was documented by the employer and she was concerned it could be later used against her. Whilst acknowledging the employer put the minimum adjustments in place (as illustrated in examples of the cleaning materials and stair lift) she knew that the small things would have protected her dignity and made her feel more valued as an employee.

The impact of work adjustments on others

The effect that workplace adjustments made on colleagues, where they take on additional or difficult work in supporting those with COPD was also acknowledged and discussed. Adjustments were perceived negatively by participants, for a variety of reasons. For Susan, colleagues supported her with manual cleaning duties including bending and mopping deep into the lower kennels and pens, and colleagues covered a broader range of hours and worked late into the evening which she could not do. Susan felt that because it was not handled particularly well by management there was a *"lot of back biting and bitchiness"*, which caused issues for her with some colleagues in terms of negative comments with the occasional sideswipe of *"she's nae doing her work"*. The lack of formality and transparency for the employer, the employee and colleagues were potential barriers to conducive outcomes. Susan felt a more structured and transparent approach to managing her reasonable adjustments with her employer would have served them all better and enhanced the working environment and her overall experience. Greater employer and employee collaboration is an approach encouraged by Scottish Government (2019) and noted by Bosma et al (2020b) to be part of developing an understanding culture which breeds trust and employees might be able to exert greater self-control in these types of situations.

In Oliver's case, his adjustments put additional pressure on his team to compensate for what he could not do, and he felt uncomfortable seeing the negative effects on both them (in their fatigue) and the standard of their work (drop in food production quality). He also felt his staff noticed the changes in him and his work rate and began to behave differently towards him as they were noticing his decline and began to *"mollycoddle him"*. Although supportive colleagues might be helpful, there are potential issues in having a negative impact on an individuals' self-esteem and judgement about capability.

Such flexibility and adaptation illustrated in Oliver's (and Susan's) situation fits well with the UK Government's ambition for adjustment latitude, which is thought to reduce the likelihood of sick leave; however, the downside is it can be demoralising to have others carry out tasks to help, which could increase presenteeism in the long term (Taylor 2017). His restaurant staff worked harder and longer to keep the business going, but he grew concerned for the wider knock-on effect of his diminishing input in the business:

> *"Staff were trying to do extra for me, extra hours ... some of the staff were coming in a bit early and going home a bit later and that was not fair on them, their partner or families, and stuff like that you know, so it would have got worse …" (Oliver RE 51yrs).*

As Oliver subsequently acknowledged the impact of his condition on others in this quote, he appreciated what the eventual outcome would be, which led him into making tough decisions about his future. These examples illustrate the negative impact COPD can have on an individual's productivity resulting in degrees of presenteeism. Support provided by colleagues and an employer may be helpful to those with COPD but is not always perceived positively.

4.7.11. Higher Order Classification 2 – Employment Support for COPD

4.7.11.1. Employment Support

This higher order classification is made up of one category: employment support, which has one dimension: information, advice and support about employment.

Information, advice and support about employment

Participants who had implemented workplace adjustments to accommodate their COPD felt a lack of support in the workplace and thought that employers and Jobcentres were unfamiliar with COPD as a condition. Alice felt *"they* [employer] *don't really have any strategy as to what to do" with* regards to making reasonable adjustments or providing employment advice that she was aware of. However, she was confident that she was currently in control of her condition and the demands of her job and that, although it was difficult to predict the support she might need in the future, she was confident she could seek specific support and negotiate these from her employer.

Oliver also felt there was no real help available to him with regards to his workplace, his career alternatives or finances:

> *"Nobody really offered me any help … there does not seem to be any erm help or advice about and if there was, I did not know what it was … it certainly was not offered to me ..." (Oliver RE 51yrs).*

Susan felt there was a lack of support in the workplace meaning she *"had to fight for everything"* from her employer. When she had a period of sickness absence or asked for a reduction to her working hours, her employer sent her for an Occupational Health Medical, which she perceived as punitive and unhelpful. She felt that attending Occupational Health was no better in helping to develop relationships to support her in her employment. She recorded one experience where an Occupational Health Physician approached her with *"you sure you need* *oxygen*"? prior to their introduction, which she thought demonstrated a lack of understanding of the impact of her symptoms on her life and her work.

Susan considered the hospital medical team (respiratory consultant, nurses and physiotherapists) as *'brilliant'* in writing letters of support for her in requesting reasonable adjustments through her employer. Similarly, Oliver found his respiratory consultant supportive in helping him appreciate his declining health in the context in which he was living and trying to maintain his employment status and help his business survive:

> *"The respiratory consultant helped me understand how sick I was, whereas you do not sort of face up to it to be honest ... at first you do not wanna accept what's going on so* [hesitant] *I found it a bit difficult" (Oliver RE 51yrs).*

Susan explained that she continuously faced an uphill struggle with her employer who, she felt, provided no support for her, and her line manager had *"absolutely no concept whatsoever of what my condition was, and they did not even ask, you know ... it was, it was terrible".* During periods of sickness absence, she explained that she was never followed up as part of their policy commitment to supporting employees with long-term conditions, indicating the employer did not understand how debilitating her COPD was:

> *"They were supposed to have a health erm like chat every month or something, just by phone just to see how things were going. That never came about, there was no follow up, no strategy put in place erm … so I think* [the employer] *understanding the condition is important because not at all conditions are the same" (Susan RE 42yrs).*

As a result of her experiences, Susan felt she was treated unfairly in the workplace. Lack of employer understanding of the impact that a long-term condition has on an individual was acknowledged as a contributor to prejudices and discrimination in the workplace by Silvaggi et al. (2020) and could have been a factor in this example. Susan also felt her employer did not want to implement strategies to support her, as she was already costing her employer money through lost time and sickness absence. She heard of 'phased-return' to work through a colleague who returned to work after a short period of sickness part-time. Despite Susan being off sick with exacerbation of her COPD several times per year over the last few years, she did not recall ever being informed by her employer that phased return was an available option:

> *"I never had a phased return to work, I did not know it was possible … and I have seen me before been in hospital for 2 weeks, been at home for a week and back to full-time duties* [despondent]*" (Susan RE 42yrs).*

Susan had also asked her employer about pension options and early retirement on health grounds, as her health deteriorated, she felt the support was not there and reported they *"were not forthcoming"* and she felt that they were trying to end her tenure. Nararov et al. (2019) considered the key for effective return to work as being able to influence own behaviour through self-management which Susan appeared to do at all times, although this might not have been evident in the communication process with her employer. Drawing on the wider literature on long-term conditions, it is evident that a more sustainable employment strategy through positive employer and employee engagement could have created an improved experience for Susan and her employer (Silvaggi et al. 2020). Developing a supportive and communicative relationship is key to this process. Beatty (2012), in 23 interviews with people with chronic illness, also notes that others' reactions to illness, misperceptions about individual capability, pity, and a belief that they will soon leave their jobs, were factors leading to shortened careers.

Fact finding was an important theme for people who had retired early. Oliver explained that he sought out options for himself for the future through trying to change the way he worked by adjusting his role, looking for alternative work, and exploring the benefits system. As the company owner, he had to manage any workplace changes himself and found this required additional time and effort so *"I had to find that all out by myself over the years and erm I found out what I was entitled to and was not entitled to myself you know" (Oliver RE 51yrs).* Susan also acknowledged that she was not aware of her employment rights or entitlements or how to ask about them or check on various government websites. Susan indicated that she felt there was a real need for support in terms of who to ask for help and what specific help could be provided by the employer: *"Helpful things would be easy to understand information of what you can ask for in relation to aids, like the chair lift, then who to ask for things" (Susan RE 42yrs).*

Looking back at this time when she was clinically unwell and fatigued with work, her advice to others would be to *"not rely on your work to provide you with the answers, it has to be somebody independent because they* [employer] *are not always going to work on your best interests" (Susan RE 42 yrs).* Overall, Susan reported that she felt a lack of support and understanding from her employer, which caused her to feel anxious and fear for her career and her financial future. Her feeling was that people should be able to seek advice and information from an external independent person to come to the workplace on your behalf to make communication and negotiation between colleagues and employers easier.

Susan also felt more effective communication would help to clarify the expectations on both sides and facilitate the formalisation of any agreed workplace arrangements. A systematic review conducted by Nazarov et al. (2019) on individuals with chronic illness, incorporating respiratory disease, illustrated that work-related interventions achieved positive changes in workability, return to work and sick leave rates. These work-related interventions can only be achieved through collaborative processes involving planning and partnership approaches (Silvaggi et al. 2020) and that additional expert sources of vocational advice and support relevant to COPD could have been suggested to improve employment outcomes (NICE 2019).

4.7.12. Higher Order Classification 3 - The Bigger Picture of Employment and COPD

This higher order classification is made up of one category: benefits of work and exiting employment.

4.7.12.1. Benefits of Work and Exiting Employment

This category was made up of three dimensions: purposeful employment, exiting employment, and searching for alternative employment.

Purposeful employment

Being employed was important in the daily lives of the participants. All were celebratory with regards to talking about their careers and professions and acknowledged the positive aspects of engaging in productive employment. Aspects including enjoying the physical elements of the job, the mental demands of their roles, giving them something to do, the social interaction in mixing with people, pride in their accomplishments, the financial benefit of work and the routine and purpose work offered were discussed. Two participants who had left employment reflected on and spoke positively about their enjoyment of working as having *"absolutely loved it", and that work was "something to get up for" (Oliver RE 51yrs)* and that work was *"good for the soul"* and that it was more than work, as it was about her *"self-esteem" (Susan RE 42yrs).* Employment was also seen as important aspect of providing a structure to the day and boosting morale.

In a study by Silvaggi et al. (2020), work appeared to contribute to participants' overall sense of well-being and purpose in life, reflecting many of the beneficial aspects of employment. In their study, a collation of evidence on various chronic illness related workplace factors, they found that work improved the quality of life, minimised social exclusion and poverty, and positively contributed to employee mental health and well-being (Silvaggi et al. 2020). Similar perspectives are found in guidelines for healthy workplaces (European Network for Workplace Health Promotion 2013).

The more expert participants were in their jobs, combined with the suddenness of the termination of their employment, appeared to create a greater 'loss' for them and was particularly difficult for two participants to cope with. One noted that it was *"traumatic"* to have built up two decades of experience to be cut short in one day, which caused feelings of deep sadness. As an expert in her field with more than 20 years' experience, Susan was frustrated because she was not mentally ready to stop working when she did, but her declining physical health and sickness-absence took its toll and was the final decider. The daily routine of work had acted as a distraction to her ongoing daily physical challenges and what she had to do to cope with COPD: *"The days when you are not having a great day, you just get up ... and work and you know ... you forget about your own problems, and get on with it, yeah" (Susan RE 42yrs).*

Work as an effective distraction from health worries was a feature of work participation found by Boot et al. (2016) in a study of working people with depression, cardiovascular disease and osteoarthritis. Oliver recounted the *"sudden disconnect"* from the workplace with no warning or time for physical or psychological adjustment. Bevan et al. (2018), noted that retirement, or early retirement in current times, is a transition process rather than a one-off day where work ends, and retirement commences. Similarly, Arnold was concerned in looking to the future with severe COPD and declining health that the daily motivation he gets from working, what he called his *"mental drive",* would be taken away. He feared he would not be able to continue working if he had a lung transplant. In addition, Susan also reflected on the structure that the working day gave her and how she now *"missed using her brain" (Susan RE 42yrs).*

Working until they could no longer continue, due to their health decline, illustrates individual aspects of resiliency in both Susan and Oliver who scored in the highest resiliency quartiles in the CD-RISC measure (Q^1 with scores of 40 and 37 respectively (potential scoring range 6-40)). Beliefs about self-efficacy and coping capacity are borne out in several of their extracts and illustrate their determination and self-belief around their ability to adjust, adapt and keep going. This concurs with Reich, Zautra and Hall (2010) as indicating resilience. Both participants also had strong social networks (which could have strengthened their resiliency) and positive and practical approaches to their work, although their determination could also have pushed them beyond a reasonable expectation that it was time to cease working (Wu et al. 2013). Likewise, Arnold, with very severe COPD, demonstrated his willingness to 'push-on' where others might have already stopped working. His excerpts highlight an ability to positively reappraise his situation (know when he has greater limitations because of COPD) and subsequently self-regulate his activities (factoring in adjustments to his work and number of hours worked). These are important components of self-management and are also indicative of high resiliency (Keil et al. 2017).

A clear message from the participants who were no longer working was that people should stay in work if they can physically manage the challenges and gain support to do so. Oliver still felt that being able to do some part time work would have given him something look forward to and keep him occupied. He was feeling *"ignored and forgotten about"* in society, despite his expertise as a cook: *"I just wish … there was somebody out there who could make use of me ... I cannot see that changing that much but that's the way it is for now" (Oliver RE 51yrs).* Oliver feels he has become less and less important as a person as the years not working pass believing he would be *"much happier if he was still working".* Participation in work added meaning, structure, and increased physical health, and was an important distraction from illness in the lives of people with various conditions including heart disease, arthritis, cancer, diabetes and COPD (Vooijs et al. 2018).

Exiting employment

For two of the participants, leaving employment was premature and difficult. Both had major financial concerns, were leaving professions as experts, and felt they were largely unsupported in the workplace, by the Jobcentres and the benefits system. Oliver spoke with great sadness about giving up work at the age 39 and reported on the impact it had on him and his business:

> *"I was having breathing attacks all the time. I was more of a hindrance and so I gave up* [sad] *it was my own business at the time, so I had to get rid of it all together and went into bankruptcy because of it" (Oliver RE 51yrs).*

Oliver accepted his overall deterioration in health and the need to prioritise his health over a career or business to survive and concluded: *"I had to concentrate* *on my own health and illness, and just look after myself" (Oliver RE 51yrs).* He realised he could no longer worry about the other employees, their jobs or their development and subsequently put himself first. This decision was difficult, as he had been relatively healthy, cycling to work and going to the gym trying to remain fit. The sudden decline in his health meant he found it challenging even to walk up a flight of stairs as the following quote highlights:

> *"… and like suddenly I cannot climb stairs and things like this, and I was just deteriorating all the time … so I expected it to happen at some point you know but I did not expect it to happen as quick as what it did you know" (Oliver RE 51yrs).*

After battling declining health and making several adjustments at work, Oliver was told by his doctor *"you are not going to be able to do this job anymore"* and his career and business ended abruptly. This was akin to making a trade-off between his health and wealth. De Wind et al. (2013), found in a study on individuals with chronic illness that poor health is a recognised predictor of retiring early. Retiring early was seen when individuals considered the finiteness of their lives in tandem with physical decline often adopting the view that they are better stopping gruelling work whilst they can still enjoy life but potentially at great financial cost (De Wind et al. 2013).

Oliver found his sudden exit from the workplace difficult as his decline happened within a year. *"It is hard, right, because you are taken out of a lifestyle altogether and all of a sudden there is nothing at all and there is no backup plan" (Oliver RE 51yrs).* Susan was also frustrated thinking about the way she exited the workplace at age 38 and the animosity she had recently endured in the workplace. Eventually, Susan's symptoms became more severe, and work so unrelenting that she took sick leave as she *"was not physically capable of doing it anymore"* [the job]. Having no backup plan for their employment coming to a sudden end left both Oliver and Susan without job options.

They considered it highly likely that they would have been able to sustain their careers longer and enable a more phased exit from their jobs had they been in more sedentary roles or more senior positions. The notion of phased retirement being of benefit to individuals has had some attention in the literature on long-term conditions. De Vaus et al. (2007), found mixed evidence in their review of gradual retirement with positive associations with health after 12 months of retirement. However, they also found people who had retired abruptly were more satisfied with their retirement than those who had had a gradual phased retirement (De Vaus et al. 2007).

Oliver missed working and his interactions with employees. He noted the importance of the social aspects of working and communicating with others and felt more isolated once he lost his employment status: *"It does not take very long before you become separated from everyone else you know; you cannot interact with people" (Oliver RE 51yrs).*

He still feels he could contribute to his industry in a teaching and education role. He felt it was a shame that his expertise could not be harnessed to combat boredom and help others but accepted he was a long time out of the workplace (12 years). His longing for meaningful work in providing him with occupation was evident:

> *"Being able to work would take the monotony out of the day the biggest thing now is boredom; living here 7 days a week in a flat, is not any fun for anybody you know" (Oliver RE 51yrs).*

Susan also missed working and the structure and routine of the working day. She felt she needed something to occupy her time, as she was now sitting most of the day with nothing to do. Susan considers the impact that not working has on her and how it affects her motivation:

> *"The days where I wake up and you are not really having a good day, when you had your work to go to you just bloody got up and got on with it ... whereas now I do not have to and that is bad* [laughs] *you know it is too easy to give up I think and give in to it" (Susan RE 42yrs).*

The excerpt illustrates that having to get up out of bed in the morning and travel to work was motivating for Susan, giving her purpose and occupation in doing a professional job that she loved. Bevan et al. (2018), note that people with long-term conditions, exiting the workforce early can have negative health and well-being impacts for those in lower socio-economic groups.

Having exited from established careers during rapid physical decline gave both Oliver and Susan time to reflect and consider what could have been done differently. Looking back, Oliver feels he should have resisted giving up the business and looked further into options available to him and thinks *"I should've been a lot more forceful and not just given up and taken no" (Oliver RE 51yrs).* Susan concurs and she would:

> *"Bloody well stand up and get it done,* [stand up for her rights as a person becoming increasingly disabled in the workplace] *you know and do not accept it* [her perceived harsh treatment and lack of support from her employer]*" (Susan RE 42yrs).*

> *"I think in realising how poorly I had been treated, whereas when you are in the midst of it you do not. I was going through all the papers and came across a letter that I had written … about the grievance meeting and think ... why the hell did I put up with that" (Susan RE 42yrs).*

Needing to be *"more assertive"* was a feature of Susan's experience but, at that time, she was so clinically unwell and fatigued she felt she could not go on with the battle to maintain her job. These examples illustrate difficult employment journeys and the ending of successful careers where individuals had high levels of expertise and a great deal to offer employers.

Searching for alternative employment

Oliver provides a valuable insight into searching for alternative employment. He describes feeling useless and frustrated that alternative employment could not be found despite his extensive skill set and experience as a chef [with the Jobcentre's support]:

> *"Nobody would take me on .... as soon as I mentioned the fact that I was ill, I was a liability … I found that quite harsh because I was only 39 … I would like to have carried on and done a lot more but there was not anything out there for me" (Oliver RE 51yrs).*

Oliver felt that his valuable skills and experience should have been captured and used to help others. Adapting his skills in a more sedentary situation such as online education could have been possible given some support. He believed that continuing to work would have helped him feel stronger for longer and helping others would have given him some happiness as well as enabling him to continue to earn a wage. He feels this could have helped prevent his bankruptcy and having to enter homeless accommodation. His overall experience is that they [the Jobcentre], give up on people too easily:

> *"I just needed somebody to say to me you know … this bloke's useful, what can he do, rather than you know, when I go down to the Jobcentre, they say no, we ain't got nothing for you" (Oliver RE 51yrs).*

Here, Oliver emphasised his notion of having some important skills useful for society but, as he was physically limited, it was difficult to fit him into similar roles with the same types of physical demands. He still wishes he could find a job and earn a living today, but appreciates issues of reliability in turning up to the job and the risk of declining health:

> *"It is not that I do not want to work, I would love to do something from home maybe you know … there is always going to be the case that I can have an attack* [exacerbation]*, so I see why people would not trust me because I am not trustworthy you know" (Oliver RE 51yrs).*

Oliver considered his physical limitations in the workplace, which gives him some resolution to the situation having himself been an employer and manager, but, like Susan, he thinks about lost opportunities, as there was the potential for him to undertake meaningful work from home. Although there is some research in the field of mental health conditions that is focused on individuals returning to existing employment, there appears to be little in relation to help in gaining work that is more suitable to an individual's requirements and capabilities (Fadyl et al. 2020). Wider support through organisations such as Remploy (the employment disability specialists) is available nationally (Remploy 2021) and can help people with disabilities and long-term conditions find and sustain work through creating inclusive workplaces and building partnerships of support.

4.7.13. Summary Discussion of Study Objective 3

The aim of the qualitative objective was to provide a detailed exploration of a sub-sample of participants' employment contexts and related experiences. The interviews illuminated important themes on the employment contexts and experiences of people with COPD and enhanced the understanding of the types of challenges they have. Three higher order classifications were developed from the findings: health and COPD in the workplace, employment support for COPD, and the bigger picture of COPD and employment. The key issues raised by participants in relation to the higher order classifications were as follows:

Health and COPD in the workplace

- People with COPD experience daily variability of symptoms and therefore unpredictability of wellness
- Effort is required by people with COPD to attempt to function normally in the workplace despite COPD
- Mind-set of people with COPD is important in trying to maintain productivity
- People with COPD developed personal and workplace strategies to overcome symptoms and challenges at work
- Workplace tasks can have a positive or negative impact on the health and well-being of people with COPD

Employment support for COPD

- People with COPD can find support difficult to access
- People with COPD are not clear about their legal rights and what support to expect from employers
- Strategies for supporting people with chronic illness in the workplace were not identified or operationalised

- People with COPD adopted strategies to counter the impact of challenging tasks e.g., cleaning and heavy lifting
- People with COPD made various adjustments depending on their role, but these were not always helpful.

The bigger picture of COPD

- People with COPD value work for structure, routine and purpose
- Early unplanned exit from the workplace was challenging for some
- People with COPD must be self-sufficient in seeking employment support around their condition
- The impact of workplace adjustments made by people with COPD on others can be considerable
- People with COPD find it challenging to secure alternative employment when they can no longer continue in their current role
- Harnessing expertise and applying it to the workplace in different ways could be useful for others e.g., online or working from home

Overall, the interviews demonstrated a willingness and enthusiasm of working-age people with COPD to volunteer to participate in important qualitative studies such as this. It is likely that research in this area could consolidate and further explore these initial themes to better understand the experiences of people with COPD in relation to maintaining or leaving employment, so that the appropriate person-centred recommendations for healthcare professionals, people with COPD, employers, research, and policy and strategy can be made.

4.8. Chapter Conclusion

The pilot study provided valuable information about the study recruitment processes and procedures that might be required for a similar future study to be scaled-up and conducted. It has tested whether the questionnaire is feasible to run and how it could be designed and adapted in the future. The pilot has also determined how workable the entire study is in practice and the potential pitfalls to overcome.

The questionnaire contained appropriate tools that could be used to identify psychosocial and physical factors influencing employment in people with COPD. However, time management and practical scalability are issues to consider, and the use of an online or postal survey and a multi-site approach with additional resources might be required. COPD had a considerable impact on participants' general well-being on the day the questionnaire was administered and, although this impact was less for employed participants than those not employed, it indicated they could still maintain their employment status despite health compromise. Employed participants were generally healthier overall according to their VAS score on health today compared to those not employed, and, overall, they had a better quality-of-life, which might be because of them continuing to access the benefits of a workplace presence and maintaining their income. However, the scores for both the employed and not employed participants were below expected population scores indicating the loss of health because of their COPD (Encheva et al. 2020).

All participants offered some notion of being satisfied with their life, but those not employed had similar satisfaction levels of people with spinal cord injuries and those employed to people with diabetes, confirming the perceived incapacitation of those severely compromised by their COPD (Pavot and Diener 2008). This construct is closely linked to symptoms of negative affect (Diener et al. 1985) and is also reflected in the higher anxiety and depression scores of those not in employment on the HADS scale indicating better mental health in those employed than not employed. Self-perceived mental well-being in those not employed was also poorer than those people still employed and the general population (Stewart-Brown and Janmohamed 2008).

Resilience was another construct where those participants who were in employment demonstrated a greater level of resiliency overall than those not employed; however, both employed and not employed scored across all quartiles demonstrating a broad range of resiliency. The employed participants mean score (although an exceptionally small sample) indicated they were more resilient than the general population according to the study by Antunez et al. (2015). As indicated in the thesis introduction, resilience appears to be a construct worthy of further in-depth investigation in relation to COPD (Cannon et al. 2015).

Productivity measures in the workplace, presenteeism and workplace control and adaptation also provided varied data in this exceptionally small sample. It appeared participants had some flexibility in their role and absenteeism and presenteeism appeared minimal.

The interviews successfully recruited people with COPD who were keen to discuss their experiences, and the findings will contribute some useful themes to the existing limited body of knowledge. Three higher order classifications were evident. The categories were: Health and COPD symptoms at work (people with COPD experience variability in their symptoms and wellbeing at work and adopt personal and workplace strategies to manage challenges); Employment support for COPD (people with COPD find accessing support difficult and they might not be clear about their legal rights and what support to expect from their employer); and The bigger picture of COPD and employment (people with COPD value work for structure and routine and an early, unplanned exit from the workplace could be challenging for some people).

At the inception of the pilot study, the intention for the follow-on study was to inform a larger-scale, mixed-methods cohort study. However, the findings from the qualitative component made me critically reflect on, and rethink, what was most important to the participants in relation to optimising their employment opportunities. Rather than generating more knowledge on the relationship between health and well-being constructs and employment in people with COPD, it appeared to be the human side of their perceptions and experiences that were key in order to address the main issues around sustaining employment and inform practice and the workplace. I considered it appropriate, therefore, to refocus the study and prioritise an in-depth qualitative exploration of the employment experiences of people with COPD. In discussion with and agreement from my PhD supervisors, I planned the conduct of a qualitative study to establish a robust foundation on this topic, which lacked published empirical evidence. Exploring the experiences of people with COPD in relation to employment in greater depth would also ensure that a future cohort study is suitably contextualised to explore the most important constructs and ask the most pertinent questions. The in-depth qualitative study is detailed in the next chapter.

5. The Employment Experiences of People with COPD: A Qualitative Study

5.1. Introduction

In the pilot study, the qualitative objective explored the employment contexts and related experiences of four individuals with COPD. The study also demonstrated that people with COPD would be willing to take part in a larger qualitative study of this type and valued discussing their employment experiences.

The categories established in the pilot study: health and COPD symptoms at work, workplace challenges and solutions, employment support and the benefits of work and exiting employment provided a foundation for understanding the employment factors that are important for people with COPD. These categories informed the interview questions and subsequent dimensions in this study. It was also evident that given the considerable lack of qualitative research conducted to date on working-age people with COPD (Chapter 2), it was appropriate to develop a more in-depth understanding of their employment experiences. It was decided to focus on participants experiences and not to measure their symptoms therefore no additional demographic data were collected.

5.2. Chapter Structure

The chapter explores the study methods adopted, study findings, interpretation and discussion of the employment experiences of working-age people with COPD. This study was conducted by broadly following the same study methods as the qualitative component of the pilot study, and the methods section in this chapter details only those aspects which differ from the pilot study or require further explanation. The chapter concludes by summarising the key findings from the study.

5.3. Study Aim and Objectives

5.3.1. Study Aim

The aim of this study was to explore the employment experiences of working-age people with COPD who sustain or have left paid employment.

5.3.2. Study Objectives

The study objectives were to explore:

1. The context in which employment is enabled or constrained for people with COPD.
2. The facilitators and barriers for people working with COPD in trying to maintain or sustain employment.
3. The perceived support needs of people with COPD to enable them to sustain or leave paid employment.
4. The specific support available in various workplaces for people with COPD to enable them to sustain or leave paid employment; and
5. Make recommendations for further research or interventions that may enable people with COPD in employment to work effectively or more satisfactorily for a longer or end employment in a positive way.

5.4. Methods

5.4.1. Semi-structured Interviews

Semi structured individual interviews were selected as the most appropriate method for data collection to gain a deeper understanding of the participants' employment experiences (Ritchie et al. 2014). Interviews allow for specific detail to be explored in private, and with confidentiality being maintained, participants might feel more comfortable revealing personal and health information (Harvey and Land 2017). Further, as individual experiences rather than collective experiences were being sought, individual interviews were a better option than focus groups, which were also considered. Focus groups are an efficient way to collect information on a broad topic from a variety of perspectives (Parahoo 2014). Focus groups enable an exploration of important issues through a shared group discussion where participants address the researcher's questions and issues raised by others, which is not possible in a one-to-one situation (Parahoo 2014). Although everyone in a focus group must congregate at the same time, once conducted, they can save time and effort for the researcher (Harvey and Land 2017). However, people with COPD often have challenging symptoms and may have needed to use their inhalers and oxygen, which they may have found uncomfortable being in the company of strangers.

5.4.2. Population and Sample

As in the pilot study, purposeful sampling was employed to locate working-age people with COPD who would likely have employment experiences to share. There are no firm and fast rules for the ideal number of interviews required in an interpretive descriptive study; therefore, there is no objective justification for the most suitable sample size (Thorne 2016a). Creswell (2013) suggests the average number of interviews in an in-depth qualitative study could be between 20-30 participants; however, there is no consensus on this in the literature (Ritchie et al. 2014). Data saturation, according to Huberman and Miles (1994), is about sampling until no new substantive information is found. Strauss and Corbin (1998 p.136) argue that category saturation is a *'matter of degree'* and there is a point where more data becomes counter-productive and might not add anything of value. Whilst the notion of data saturation at the conceptual level is helpful to the researcher, there is little guidance for determining sample size estimation before data collection (Fusch and Ness 2015; Mason 2010). As Morse (2000) also indicates, the researcher may be convinced that data saturation has been achieved but can do little to make this transparent. As this study was building on from the qualitative findings from the pilot study, to develop a *'meaningful clinically related descriptive account and pose and reflect on the kinds of issues and concerns'* for people with COPD in relation to employment; a smaller qualitative study would be sufficient (Thorne 2016a, p.105). Between 16 and 20 interviews were considered as a possible cut-off point to provide a sufficient amount of data as beyond this volume of data, within the limited timeframe available, would be considered challenging for one researcher to manage.

To participate in the study, individuals would be under 65 years of age and in paid employment or have ceased paid employment because of their COPD. As in the pilot study, the main presenting condition was considered as COPD having or having had the greatest impact on the participant's employment, or that employment ended because of their COPD. Individuals required to have had a physician confirmed diagnosis of COPD, be fluent in English and able to provide informed consent. I verified these inclusion requirements with participants during the recruitment and informed consent processes.

5.4.3. Ethical Approval

The study was designed to meet the requirements of the UK Research Governance Framework (2005) (now UK Policy Framework for Health and Social Care Research 2018) and the Robert Gordon University Research Governance and Research Ethics policies (RGU 2021a; RGU 2021b). Ethical approval was granted from Robert Gordon University School of Health Sciences Ethics Review Panel in June 2017 (SHS/16/38). A proportionate review was considered appropriate, as no material ethical issues were identified in the proposed study design and method and an Integrated Research Application System (IRAS) (no. 216306) application was made (NHS HRA 2017a). Ethical approval was obtained following the Health Research Authority review panel's request for minor changes and clarifications in August 2017 (no. 17/SW/0168 Appendix XII), and local NHS Research and Development department approval (no. 2017RG003) awarded in October 2017 (Appendix XIII).

5.4.3.1. Ethical Considerations

Consent, confidentiality and the power balance between the researcher and participant were the main ethical issues of concern. Consent and confidentiality are explored further in Section 5.4.5 on the interview procedure and data management. The potential power imbalance between participants and researchers is recognised in the literature (Raheim et al. 2016). As a white female researcher, nurse and academic undertaking a PhD, I might have been perceived as being in a privileged position, and I therefore had a responsibility to *"minimise the distance and separateness of the researcher-participant relationship"* (Karnieli-Miller, Strier and Pessach 2009, p. 279). At the same time, the researcher must appear credible, knowledgeable and professional in order to build the trust and respect of participants. Raheim et al. (2016) argues that the power relationship between the researcher and participant is dynamic, and the researcher's status is constantly renegotiated during the research process. Additionally, the researcher is not necessarily the sole controller of the interview discussion as the participant also has their own agendas for the research and decides what to bring to the discussion (Raheim et al. 2016). I endeavoured to counter any perceived imbalance by visiting participants in their own homes. Although participants were aware of my professional background from the letter of invitation and participant information sheet, I did not discuss any of these roles unless participants enquired.

5.4.4. Participant Recruitment

As the study recruitment area was Scotland-wide, both face to face and telephone approaches for conducting the interviews were considered appropriate. A dual approach was taken to the recruitment process. The first approach was through established contacts in a hospital chest clinic in a Scottish Health Board (as in the pilot study), and the second through national and local newspaper press releases. This broader approach was adopted to enable a wider selection of people beyond the local hospital population and with the aim of recruiting a sufficient sample within a short, but manageable timeframe.

The process of recruitment through the hospital clinic was identical to that adopted in the pilot study and participant information sheets (Appendix XIV) were sent to patients with communication from the clinic team (Appendix XV), incurring no cost. Once the selected patients had considered the detail within the participant information sheet, potential participants contacted me directly to discuss their interest in the study. Potential participants either emailed or called to discuss their eligibility for participation. As a result, there was no requirement for me to attend the clinic setting, and all interviews with clinic recruited individuals were conducted independently of the hospital setting. Interviews were subsequently conducted in a private venue of the participants choice.

A press release containing an outline of the study and my contact details was launched in five local and national newspapers (Appendix XVI). A press release, considered as a form of social media, has been shown to be a successful source of study recruitment that can generate numerous enquiries in healthcare research (Ruban et al. 2019). Once the press release was issued, over 20 enquiries were received directly to me in the first few weeks through email or telephone call, and I sent them the participant information sheet and consent form by return email. Once prospective participants had time to consider the study more fully and ask any questions, and after a period of at least three days had passed, a mutual date and time for the interview was arranged with those who wished to participate.

5.4.5. Interview Procedure

Interviews were conducted from November 2017 to March 2018. At the beginning of each interview, I discussed the purpose of the study with participants ensuring they understood the detail in the participant information sheet and what to expect during the interview. I addressed participant questions and informed written consent was subsequently obtained (Appendix XVII). Participants were informed both in writing (within the consent form) and verbally by me that the interview would be digitally recorded on a laptop and that the recordings would be transcribed and then stored in an electronic Microsoft Word format on a password protected computer. The interview schedule and prompt questions (Appendices XVIII and XIX) were further developed both from the questions used in the pilot study, and from a review of similar questions in current literature that explored the experiences of people with other chronic conditions (Chaplin and Davidson 2016; Engström et al. 2016). Interviews were conducted either face to face or by telephone. Creswell (2013) notes that in telephone interviews informal communication is missing; however, from a practical perspective, substantial travel requirements could have slowed down the recruitment process and added to the cost of the study. Five interviews were conducted by telephone as the geographical distance precluded face-to-face data collection (over 120 miles distance).

5.4.6. Digital Recording and Transcription

A personal password protected laptop was used to record the interviews, but laptops are large pieces of equipment and could have been seen to be a barrier between the researcher and participant. To reduce this potential barrier, the laptop was placed at a sufficient distance to the side of the interviewee and interviewer, with the interviewee's agreement, so it was not the focus of the physical interview set-up (Holloway and Galvin 2017). The interviews were digitally recorded using *Audacity*® software (version 2.2.1) on the laptop. *Audacity*® is a free and easy to use, open-source cross-platform audio software mainly used for editing music but useful for any type of recording. The functionality of *Audacity*® enabled the recording of interviews and provided editing options including slowing the recording to a desired speed and playing it back as a looped track allowing for easier transcription. These functions were useful for clarifying the participant's exact words and carefully deciphering local dialects and phrases.

Transcribing the interview recordings facilitates the development of a close understanding and the diversity of circumstances and characteristics of the raw data (Ritchie et al. 2014). This is in keeping with an interpretive descriptive approach (Thorne, 2016a) and is also part of the familiarisation process recommended within Framework analysis (Spencer et al. 2014). As some funding was available, five of the 17 interview recordings were sent for external transcription by L.S Transcription to enable efficient time management. LS transcription provided a confidentiality agreement ensuring participant names and details were kept strictly confidential (Appendix XX). Transcriptions were securely stored on the University "R" drive, which is a network shared folder purposefully enabled for secure storage of research data. The interviews I transcribed enabled me to become further immersed in the data. This was a time-consuming process taking between 6-8 hours per hour of recorded interview to complete. However, transcribing was a valuable process allowing me to engage with the content in greater depth (Ritchie et al. 2014). I re-listened to the recordings and re-read the transcripts of the five externally transcribed interviews to ensure I was re-familiarised with their content. The PhD study supervisors listened to the first three recordings and reviewed and discussed transcripts to enhance the study credibility. This process was fully discussed with the PhD team and no adaptations to the interviews, topic guide or the transcription process were required. Once the transcription process was completed, the digital recordings were deleted from the laptop.

In addition to re-familiarisation with the data, I was able to take a critical perspective on my interview technique and effectiveness as a listener, the language I used and my role as a co-creator of data (Mishler 1986). I could then consider how, what I learned from each interview could be taken to the next interview to improve the data obtained and to enhance the quality of the interview experience for the participant. I aligned this learning with field notes in order to be more reflexive in how I interviewed (Deggs and Hernandez 2018). I noted during early transcriptions, that I would sometimes ask prompt questions too quickly, and move the topic of conversation on without fully exploring the topics already raised, so I was able to improve this aspect in later interviews. The iterative improvement of my interview technique as I gained further confidence, ensured a greater efficiency and skill during the final few interviews. I was cognisant that Thorne (2016a) notes, that the researcher should, where possible, refrain from using language such as 'I agree' or 'that's good' as these value laden prompts would direct the participant interaction and this approach serves no role within an interpretive descriptive methodology.

5.5. Data Management, Abstraction and Interpretation

As in pilot study, Framework analysis was used to guide the data management, abstraction and interpretation stages of this study and the Framework process detailed in Table 5.1 (Ritchie et al. 2014). Once again, it was not possible to further develop the analysis to determine single typologies along the continuum of the data, but this might be possible with some variables in a larger study or as more qualitative research emerges on the topic (Ritchie et al. 2014).

Table 5.1 - The Framework Analysis Process

Steps	**Process**	**Data Management Activity**
Step 1	**Familiarisation**	Immersion in the data by listening to recordings, the transcribing process, reading and re-reading transcripts, and incorporating field notes to gain a sense of whole interviews. In doing so I was clear about the diversity of circumstances and characteristics in the data (Spencer et al. 2014). Dividing them into sections and identifying and listing recurring ideas and issues into topics that were relevant to addressing the study objectives. PhD study supervisors reviewed the first three recordings and the transcripts and provided feedback to enhance the study credibility. This informed the subsequent discussion of the initial themes.
Step 2	**Constructing an initial thematic framework**	The recurring topics identified in step 1 were developed and transferred to NVivo as nodes. This was the initial thematic framework applied back to and used to label the data. Thorne (2016a) promotes the grouping of data rather than initially coding at this point (Appendix XXI).
Step 3	**Indexing and sorting**	The thematic framework developed in step 2 was systematically applied back to the transcripts and notes made on which theme was reflected in each specific section. Labels were applied back to chunks of data where they were determined as being about the same thing and attached to the nodes in NVivo (charting) and verbatim quotes were attached to each theme (Appendix XXII). The coding and indexing process was reviewed and discussed with the principal PhD study supervisor by broadly looking across the sorting process. Coding was discussed and small refinements were made before continuing the coding process.
Step 4	**Reviewing data extracts**	The coherence of the labelled data in NVivo was checked here and amended and reapplied where necessary to alternative labels to ensure authenticity of the data. This process continued throughout the entire data management phase with frequent review and discussion with the PhD supervisory team (Appendix XXIII).
Step 5	**Data summary and display**	Data were reduced into brief summaries of participant transcripts for important topics relevant to the study objectives within the labels used in NVivo. These were managed in an Excel spreadsheet under the themes tabs and quotes were highlighted and italicised. Reading across and between cases and themes in the framework matrix to develop the

		analytic strategy and return to research objectives (Appendix XXIV) and these were reviewed and discussed with the principal PhD study supervisor prior to interpretation.
Steps	**Process**	**Data Abstraction and Interpretation Activity**
Step 6	**Constructing Categories**	This stage allows for comparison of themes and sub-themes and double checking against original transcripts, field notes, and audio recordings to ensure appropriate context. In this stage the charts are reviewed to see the whole data set, which includes checking the summaries on the charts against the original data and comparing the themes and sub-themes with each other to see if any further changes or merging was required. Creating elements, dimensions, categories and higher order classifications (Appendix XXV). A number of changes were made to the location and coding of some data items. These were moved, dispersed or condensed with other relevant items to make them fit more closely within established nodes, e.g., Impact of COPD on others in the workplace had two references although one was not directly relevant to the section and another which was recoded to advice and support. Employer's responsibilities had five references and two moved to psychological and five went to advice and support. Both the benefits of working and alternatives to employment nodes had 10 and 16 references respectively and on inspection looked similar and were therefore merged. The creation of elements, dimensions, categories and higher order classifications required the researcher to stay close to the data (authenticity) and use appropriate direct quotes (transferability). Analytical checks were undertaken by the PhD principal supervisor through frequent review and discussion to enhance the research credibility and trustworthiness of the study (Thorne 2016a).
Step 7	**Synthesising data by mapping and interpreting**	Conceptual mapping and interpretation of the data through identifying linkages and accounting for patterns. Here the charted data was compared, searching out the patterns, connections and relationships that offered explanation. Returning to original transcripts to retain context where required. Selected the best quotations to address the research objectives. All these steps were made explicit to enhance transparency of decision making as documented throughout the data management and analysis stage to achieve a high-quality and trustworthy study.

5.5.1. Research Rigour

The concepts of dependability and credibility were outlined and discussed in the pilot study. Reliability is about the replicability of findings. Debate ensues around the desirability of such an aim and indeed the likelihood of similar truths being possible due to the individual variability in context and experience in the qualitative field (Ritchie et al. 2014). It is suggested that the collective nature of the phenomena that study participants might generate, and the specific meanings attached to them would probably be repeatable and more importantly, whether data have been consistently and rigorously interpreted (Lewis et al. 2014).

Credibility in this study is also demonstrated through prolonged engagement with participants, their recordings and transcripts, using appropriate direct quotes representing the breadth and depth of participant experiences, and the search for clear description and analysis of their meaning (Thorne 2016a). To enhance study dependability and in the spirit of interpretive description with respect to representative credibility, I have provided transparency of the study design and conduct, and in the evidence of data processing from the initial index of terms through to the coding and determination of the elements, dimensions, categories and classifications, demonstrated analytic logic (Thorne 2016a). Dependability was further established through the PhD study principal supervisor reviewing and discussing samples of coding and analysis of decision making around the elements, dimensions, categories and higher order classifications (Harvey and Land 2017). These quality processes were used to ensure the research process and quality checks are transparent and auditable (Thorne 2016a; Coughlan, Cronin and Ryan 2013).

Further measures of research credibility can come from respondent feedback. Respondent feedback can enhance the validity of interview content through clarification of points, addressing typographical and grammatical errors and rebalancing some of the power imbalance through respecting the interviewees' views and giving them some control over the written word (Birt et al. 2016; Torrance 2012; Mero-Jaffe 2011). Member checks might also be considered therapeutic for some participants, particularly if reminded of previous challenges when there has since been improvement in health (Birt et al. 2016). This might add to the timeframe for data analysis and feedback and influence the researcher's interpretation (Birt et al. 2016) and participants might not respond or feel they have psychologically 'moved-on' (Mero-Jaffe 2011). Respondent validation was not carried out in this study because as Thorne (2016a, p.175) indicates, member checks are not advised as they could lead to false confidence in confirming thoughts or potentially derailing sound analytic interpretation.

5.6. Description, Findings and Discussion

5.6.1. Description of the Participants

A total of 17 interviews were conducted lasting between 45 and 75 minutes. Seven participants were currently employed and ten had ceased employment because of their COPD. Participant characteristics, their pseudonyms, interview type, employment status and source of recruitment are illustrated in Table 5.2.

Table 5.2 - Participant Characteristics

Pseudonym	Age	Interview Type	Employment status Job Group	Source of Recruitment
Ivan	62	Telephone	Employed part-time Self-employed electrical contractor	Press release
Diane	62	Face-to-face	Employed part-time Carer	Press release
Zach	61	Face-to-face	Employed Self-employed CEO	Press release
Kim	57	Face-to-face	Employed part-time Admin/reception	Press release
Debbie	51	Face-to-face	Employed Healthcare	Press release
Charles	56	Face-to-face	Employed part-time Supermarket	Press release
Julian	53	Face-to-face	Employed Security services	Press release
Colin	63	Telephone	Not employed Retired early at age 59 - ill health Healthcare	Press release
Julie	63	Face-to-face	Not employed Retired early age 61– ill health Administrator	Press release
Jeffrey	62	Face-to-face	Not employed Retired early 59 - ill health Aviation & health/safety	Hospital clinic
Rita	62	Face-to-face	Not employed Retired early age 58 – ill health Social Worker	Hospital clinic
Isaac	62	Telephone	Not employed Retired early age 56 – ill health Supermarket	Press release
Harry	58	Face-to-face	Not employed Retired early age 55 - ill health Electrical supervision	Press release
Brenda	50	Telephone	Not employed Animal worker	Press release
Joe	50	Face-to-face	Not employed Stone mason	Press release
Larry	49	Telephone	Not employed Forklift truck driver	Press release
Susan	45	Face-to-face	Not employed Retired early age 42 - ill health Animal Healthcare	Hospital clinic

5.6.1.1. Notes About Two Participants

Susan was interviewed in the pilot study two years previously and wished to participate again. Participation was discussed with Susan to determine whether this was appropriate. In the pilot study, Susan had recently ceased employment and stated that at that time that she was still feeling very angry at the way she had been treated by her employer. Having taken some time to reflect on her experiences and adapt to her new retired lifestyle, she felt she had more to contribute to this study. Her inclusion was therefore considered appropriate.

Colin disclosed at the start of his interview that he was yet to have a physician confirmed diagnosis of COPD and therefore did not appear to meet the inclusion criteria. However, he described moderate breathlessness, fatigue, sputum production, and a tight chest, which all caused a significant negative impact on his ability in the workplace and was the reason for him leaving his employment. Appreciating that there are large numbers of people with existing undiagnosed COPD in the population, and that diagnosis could take many months to achieve, his inclusion in the study was also deemed appropriate.

5.6.2. Higher Order Classifications

This section describes and discusses the findings from the 17 interviews conducted with working-age people with COPD. Data analysis resulted in numerous dimensions which were grouped into 23 categories, which in turn contributed to six higher order classifications. The six higher order classifications and their categories are illustrated in Table 5.3. Direct quotations follow the convention of being incorporated within the discussion text in italics when under 40 words in length and indented separate from the text in italics when greater than 40 words (Goldberg and Allen 2015). The use of ellipses (…) indicates where words have been removed. Square brackets ([ ]) are used to incorporate additional text where I have added any necessary clarifications. The following abbreviations are used throughout: Name = Pseudonym; E = Employed; RE = Retired Early; SE = Self-employed; NE = Not employed; Age.

Table 5.3 - The Higher Order Classifications and Their Categories

Categories	**Higher Order Classifications**
Variability of COPD Symptoms	**1. COPD Symptoms in the Workplace**
COPD is a Hidden Condition	
Work Activities Induced COPD Symptoms in the Workplace	
COPD Symptoms Impacted on Workplace Activities	
Going to Work Unwell and Feeling Unwell at Work	
Personal Actions for Managing COPD Symptoms in the Workplace	**2. Workplace Strategies and Actions**
Personal Strategies for Managing COPD Symptoms in the Workplace	
Workplace Adjustments Made by Employers to Accommodate COPD	
Workplace Adjustments not Facilitated by Employers	
Disclosure of COPD in the Workplace	**3. Communication, Advice and Support**
Discussing COPD in the Workplace	
Employer Support for COPD in the Workplace	
Colleague Support for COPD at Work	
Perceived Support Needs for Health-related Employment Concerns	
Emotional Experiences	**4. Psychosocial Aspects**
Feelings of Stress	
Anxiety and Depression	
Treated Differently	
Financial Challenges	**5. Financial Aspects**
Financial Solutions	
Ending Employment	**6. Employment, Retirement and Unemployment**
Reflecting on Leaving Employment	
Future Employment Plans	

5.6.2.1. COPD Symptoms in the Workplace

Five categories contributed to this higher order classification (Table 5.3): Variability of COPD symptoms; COPD is a hidden condition; Work activities induced COPD symptoms in the workplace; COPD symptoms impacted on workplace activities and Going to work unwell and feeling unwell at work.

Variability of COPD Symptoms

Most participants discussed the impact of COPD symptoms in relation to their employment. Symptoms including coughing, gasping, chest tightness, breathlessness, producing sputum (phlegm), heavy legs, lack of energy and fatigue were common. Day-to-day symptom variability and unpredictability of how well or otherwise participants are on any given day was a challenge for most; this concurs with findings reported in the pilot study. On some days participants could feel relatively well, but other days were not so good:

> *"On good days you could go to work, and it is not a problem and it is a brilliant day. But then there is a lot of really crap days and they are worse than the brilliant days and then you take a job on full-time and take a couple of days off sick and people do not want you coming back after two days off" (Joe NE 50yrs).*

> *"It is still the same today, although far more extreme, it is about how you never knew how you were going to be on a daily basis. It was like when you phoned me a couple of days ago, that would have been quite a bad day for me" (Rita RE 62yrs).*

> *"I'm feel I'm quite drained today actually. I was ok yesterday. I was working Wednesday night, Thursday and Thursday I just didn't feel too great, then … Thursday, I virtually didn't do very much at all on Thursday, and I was OK at night, you know what I mean, I was fine" (Charles E 56yrs).*

COPD symptoms are similarly reported in the literature as varied and unpredictable with some individuals experiencing the greatest impact from morning breathlessness, a constant cough and a need to expectorate sputum (Stephenson et al. 2015). However, other studies record a wide variation in severity of COPD symptoms across a wider 24-hour period (Miravitlles and Ribera 2017). Holland and Clayton (2018), in a systematic review of individuals with musculo-skeletal problems (MSK), suggested individuals might be perceived by colleagues as being a fraud, as they doubted the authenticity of their limitations when having a 'good day' because they looked so well. Symptom variability seemed to cause the participants in the current study some concern in relation to their employment, as they never knew how fit they would feel from day-to-day. As a result, there was doubt as to how their health would subsequently affect attendance at work, how they were feeling trying to complete the day's work and how that could subsequently affect others in the workplace.

Variability of COPD symptoms was also linked to the weather, particularly during the cooler seasons:

> *"Some days are really fantastic, other days it's rubbish. That is the nature of chronic obstructive pulmonary disease, so it is depending on the weather, your health, lots of things, going out into the cold, or going into the heat" (Diane E 62yrs).*

> *"I always think it is to do with weather and pressures. Yesterday the cloud was really high, and it was quite a good day. As soon as I open my eyes in the morning, I have an indicator of … before I open the curtains, I know what sort of day it is because I can feel it. I always said to myself that I was going to start taking a note. You get weather indicators, you can get them online, I was always wanting to see myself if there was a link there, because there is definitely something in relation to that. Temperature as well, because as soon as it gets cold, I struggle" (Rita RE 62yrs).*

Extremes of weather including cold, moist, raw air and hot weather in temperate climates has also been recorded as problematic in inducing fatigue in those with

COPD though not specifically in relation to employment (Stridsman, Lindberg and Skar 2014). Seasonality related to exacerbation is also an important factor with weather and temperature likely influencing viral variation and increasing the COPD exacerbation risk and potentially affecting sickness absence (Hicks et al. 2018; Jenkins et al. 2012). Julie reported on her annual exacerbation experience as the winters drew in:

> *"Every October was usually when it hit and some days I could not get out of bed. It was as though my body just shut down because at one point, I thought I maybe had Fibromyalgia. I woke up in the morning and everything was just so heavy, and I could not physically get up" (Julie RE 63yrs).*

The current study findings are typical of the experiences of people with COPD in relation to their 'struggle' with the weather and colder temperatures in a northern European climate. However, although there are many weather-related studies on COPD illuminating the increased morbidity through exacerbations between November and February (Donaldson and Wedzicha 2014). Alahmari et al. (2015) found that physical activity, a critical factor in maintaining health and well-being in people with COPD, was also reduced on cold, wet and overcast days. Bad weather can therefore have a double effect in that it adversely affects COPD symptoms and restricts opportunities for outdoor physical activity and working. Indeed, the literature reports that variation in lung function is also evident in healthy individuals as well as with COPD and that variability is most pronounced in the cold, damp environment of winter (Donaldson and Wedzicha 2014; Jenkins et al. 2012).

Participants in the present study seem to have found it challenging to deal with the impact of their symptom variability and the effects of the weather on their COPD and general well-being. This appears to create a complex situation, as participants cannot always predict how able or otherwise, they might be for their work on a given day, which is likely to pose challenges for others in appreciating and understanding the situation, creating further uncertainty. COPD variability and weather factors are likely to pose greater difficulties for individuals who work outdoors. There is a need for employers and colleagues to be aware of the potential influences and impact on work performance and attendance and be prepared to be flexible in the workplace and adjust expectations accordingly.

COPD is a Hidden Condition

Many of the participants considered COPD as a largely unseen illness with the impact of the condition and its systemic effects, not always visible to others. Participants explained that they did not often portray being needy or 'disabled' and as far as possible tried to normalise their daily working lives. The negative aspect of the unseen condition for one participant was a feeling that her colleagues had *"absolutely no appreciation whatsoever what was entailed in her managing her workload"* (*Susan RE 45yrs)*, meaning she perceived that the effort she made to function normally in the workplace went unnoticed. Several participants also acknowledged COPD was a difficult condition to fully understand unless you have or know someone with COPD or asthma. Another perspective was that, because COPD is an umbrella term for several lung conditions, people *"assumed everybody's functioning is at the same level" (Rita RE 62yrs),* which Rita felt was an obstacle to understanding an individual's illness experience.

The hidden nature of COPD as a condition was felt to be a barrier to effective working and healthy colleague relationships. Participants in this study reported little empathy from colleagues for a condition that was not as visible, for example, as having a missing limb. Previous studies have also highlighted the hidden nature of the disease; for example, Dorland et al. (2016), Mal'ouf (2016), and Kanervisto, Kaistila and Paavilainen (2007) found that the effects of COPD are not always visible to others and individuals can appear healthy and well to people around them. As a result of the hidden nature of some symptoms, others may not appreciate the seriousness of the current health status of persons with COPD, which concurs with the above studies.

Participants in the current study also indicated that COPD was more than just the symptoms they experience, which they felt do not fully represent the effect that COPD has on them and their lives. Joe felt that in relation to his employment challenges, even doctors:

> *"Do not know the total effects of COPD, and there is no energy, nothing inside and doctors do not really look at it hard enough and consider it as serious. It is a pretty serious thing to happen and how it totally affects your life and work and your health, not just one aspect"* (Joe NE 50yrs).

The implication is that COPD is a variable, systemic condition causing more than just the breathlessness and constant cough sometimes apparent to others, and for Joe, now feeling empty of energy, COPD had negatively affected every aspect of his life.

Several participants noted that their COPD went largely unnoticed by the wider workforce, and only colleagues they worked with closely tended to know about their COPD. On noticing Julian using nasal oxygen one day, a colleague whispered to another *"what is wrong with Julian, he is wearing this thing on his face?" (E 53yrs).* Julian had worked with this colleague on many occasions previously, although not when using his oxygen. The other colleague replied, *"oh that is his oxygen … do you not know he is disabled*?" *(E 53yrs).* This experience was amusing to Julian and reinforced that he did not portray himself as being disabled or helpless in the workplace and, as a result, few colleagues knew of his COPD. Like many other participants in this study, Julian's example captured the physical effort and personal resilience required to sustain a stressful job in a professional manner.

Similar experiences have been found in workers with MSK disorders who note the invisibility of most symptoms makes it difficult for colleagues to comprehend the challenges of their working experience (Holland and Clayton 2018). Sudden limitations in work tasks brought on by pain or physical decline leads to doubt and disbelief from colleagues who wonder how individuals with MSK disorders, who look healthy, cannot deal with everyday tasks as they usually could (Holland and Clayton 2018). The uncertain nature of COPD can therefore create an unstable work identity, and individuals could find they are unable to fulfil their work-related responsibilities. The findings from the current study appear to be congruent with findings from previous research on other health conditions such as MSK. It is likely that there are lessons we can learn from these studies that might be useful for people with COPD, and that there is a need to reduce barriers in communicating and understanding the challenges that individuals with long-term conditions might encounter in the workplace.

Work Activities Induced COPD Symptoms in the Workplace

In the workplace, participants reported that their COPD symptoms were more pronounced when undertaking various workplace activities including walking, bending, lifting, carrying weight, stretching, pushing, pulling, crawling, climbing stairs, rushing, talking, stress, manual work, extremes of temperature, wind, smoke and exposure to VGDF. The experience of breathlessness was a recurrent theme for many participants. Breathlessness occurred most often when participants were undertaking manual activities. Instances including walking to work, walking briskly, climbing stairs and bending and lifting were described as inducing levels of breathless in the workplace that participants would have to actively manage and control. Colin recounted: *"I was already breathing heavy and would become more breathless carrying the heavy medical kit. The breathlessness did not become more frequent, but it became more disabling" (Colin RE 63yrs).* Breathlessness made conversing with people in the workplace challenging when speaking to clients face to face or by telephone:

> *"Especially if I'm going into a meeting - which is quite often the case where I have to do a lot of the speaking, then I find myself getting breathless … Then I'm sort of 'huh'* [takes a deep breath]*, which I don't like to do in front of customers" (Zach SE 61yrs).*

Susan recalls working as a veterinary nurse and how being breathless during consultations with pet owners also made her professionalism feel compromised:

> *"If I was doing consults I would find I would have to catch my breath before I would bring the next client in, because if I had a chest infection or I was recovering from a chest infection, just by speaking I could get out of breath… so, you had to pace yourself speaking to people during the consultation so that you did not come across as not knowing what you were talking about because you were taking lots of pauses in between. So that*

> *you came across as you should as a clinician in a consulting room" (Susan RE 45yrs).*

The uncomfortable feelings Susan had about her professionalism being compromised when experiencing breathlessness was similar to that found by Mal'ouf (2016) in interviews with women indicating that COPD induced breathlessness made participants feel vulnerable at work. These feelings of vulnerability subsequently undermined participants' authority when reprimanding others at work, as they felt colleagues might perceive their breathlessness as a sign of weakness (Mal'ouf 2016). Breathlessness was also noted to cause difficulty when communicating with the public for several participants with COPD interviewed by Watson (2015). In this study, participants found that when they were talking at work, they were not taking in enough oxygen and found talking tiring and they felt their body was working twice as hard as others (Watson 2015). This suggests that people with COPD might find working in occupations where there is a high demand for communication more difficult to manage and, if breathless, it might compromise their confidence and professionalism. Additionally, if a large proportion of the work activity requires talking, then colleagues with COPD may become hypoxic and easily fatigued in the workplace.

Other participants in the present study noted they could barely speak without coughing if, for example, they had recently had pharyngitis or during or after a common cold, which produced the unpleasant lingering cough and constant throat pain. Additional instances were noted about making gasping and grunting noises when breathing heavily when under pressure at work**.**

Walking had a negative impact on breathing which caused some concern for several participants. Walking and climbing stairs affected Jeffrey *(RE 62yrs)* who worked on health and safety inspections and was exposed to daily aviation fumes in aircraft hangers, which caused frequent breathlessness and loss of focus:

> *"Every day involved a lot of walking and stairs because I had six buildings. Coming back from doing an inspection or a walk about, and of course then*

> *I'd be susceptible to the fumes, and the hangar has always got fumes in it anyway. You can't get away from them. It clears a bit when the doors are open, but you've got things like aviation fuel hanging about"*
>
> *"I felt very heavy headed until things could clear* [due to aircraft fumes in the hangars]*. It would be the next day, mid-afternoon or something like that before my head could clear again" (Jeffrey RE 62yrs).*

Although Jeffrey could organise his diary and prioritise his own workload, the walking activities still needed to be completed as he was required to visit various buildings around the worksite. Walking was also noted to be difficult for those with COPD in the Mal'ouf (2016) study on working-age women, who reported that it made them breathless at work. Other workplace activity such as climbing stairs was similarly noted as problematic by Stridsman, Lindberg and Skar (2014) who found it caused breathlessness and fatigue, and for which participants with COPD had very low endurance for. Mal'ouf (2016) also found that participants altered their tasks to avoid needless stair-climbing or avoided this activity altogether in the workplace if they could. Findings from the current study reinforce findings from previous studies and confirm that occupational activities requiring walking and stair-climbing might induce additional episodes of breathlessness in people with COPD. If walking and climbing stairs are integral to employee's roles, this could potentially cause problems where the employee has a low level of work flexibility.

Whilst Brenda could normally walk the dogs from her dog boarding kennel business outdoors, this became more challenging as her lung function deteriorated and symptoms worsened. She recalled one experience of breathlessness when walking the dogs in one direction with the wind behind her and then turned to head home facing into the cold wind:

> *"It was a tightness across my chest, and my throat as well, and just a burning feeling down my throat and just not able to breathe. And, I am thinking I have to get back there* [to the kennels] *and what is more I have another 5 dogs to walk … and that was a horrible sinking feeling, and it was a case of one step at a time and headed back as slowly but as effectively as*

> *I could. Subsequent dogs would not get walked as far or I would exercise them in the shed depending how bad I was feeling" (Brenda NE 50yrs).*

Another participant recalled that she found different workplace tasks (those new to her) and walking around the office building affected her breathing:

> *"I did not realise how far I walked in a day, going along the corridor and going upstairs and sometimes if I was asked to do something different or stressful, or something that I would have previously taken in my stride, I would find I could not breathe properly" (Julie RE 63yrs).*

Susan provided further examples of how some of the work activities had a significant impact on her breathing:

> *"Restraining animals was difficult, if you're restraining a big German shepherd to get bloods taken and it's not happy about it. That was really difficult. Cleaning the kennels, bending down and mopping the floors, which was all part of my duties, those were the things that physically tasked me, drained me of oxygen and left me really breathless" (Susan RE 45 years).*

And Ivan also developed issues with his supermarket job:

> *"When deliveries arrived, I was responsible for taking them into the back of the shop and getting them ready to go out on the shop floor to get put out on the shelves. I worked with pallet trucks and then there were the big metal cages that you had to pull about. There wasn't a lot of room in the back shop, and you were stacking shelves. I would be climbing up and down these shelves. I was always fairly fit, and it wasn't a problem to shift these things about, and then all of a sudden it started to become more difficult than previously … because of shortness of breath" (Ivan SE 62 yrs).*

Several participants described events where they were close to physical collapse and seriously unwell as a result of work activities inducing breathlessness. Whilst most participants were able to suggest ways of coping and strategies for dealing with their COPD symptoms in the workplace (discussed in the following higher order classification), there were instances where they pushed themselves to their limit because of the importance of the jobs and tasks they were undertaking. In this excerpt Debbie, a community psychiatric nurse, was visiting a patient in an environment in which she had no control:

> *"I went inside, and the heating was up full blast and the house full of smoke* [cigarette] *and when I had finished the interview, I thought, 'Jesus'. Got out to my car and was beginning to toil. I drove away and did not want him to see I was puffing … waving to him 'bye, bye', 'puff, puff, puff' heading along the road taking my inhalers. Oh no, nothing is happening, I got* [drove] *further along the road and was coughing so much I could feel my eyes getting all blurry. I thought no point keeping on driving so I pulled off the road and got out of the car because I needed to stand up … which helps if you stand straight to open your lungs up. I was leaning on the car like this, hands either side* [demonstrates her position]*, but I was coughing and coughing and thought no, the fresh air is helping, concentrate on breathing. Then, I managed to get my breathing back under control and said, thank the Lord" (Debbie E 51yrs).*

Although Debbie portrayed an optimistic perspective in how she coped with extreme breathlessness when discussing this example, a sense of fear was noted in her facial expressions, animations (hands patting her chest), and the tone of her voice, indicating these instances caused her grave concern. Fear of losing their breath and a need to control breathing was a feature found in people with COPD by Clancy, Hallet and Caress (2009), who noted that participants often felt claustrophobic and frightened due to breathlessness and a lack of oxygen. Although not related to employment or workplace tasks, the findings suggest an individual's awareness of breathing and breathlessness, which people with COPD may encounter daily and be associated with physically demanding work activities (Clancy, Hallet and Caress 2009). Whilst people without respiratory compromise might not be aware of their breathing, people with COPD appear to always have breathing on their radar which might occupy their thoughts or focus at work.

Susan, a senior veterinary nurse, gave another extreme account of breathlessness in the workplace:

> *"I was wrestling with a stupid Staffy* [Staffordshire bull terrier] *and it was hauling me up and down the corridor. I just could not catch my breath. I was greying out and the blackness was coming in and my legs were feeling cold, and I was almost going down. I called for my head nurse, who said 'I will be there in a minute', and I shouted, 'take this f***ing dog!' and they came and took the dog. I was still hanging onto the dog and the table to stop myself from going down and managed to stay on my feet. One of the girls knew that my oxygen was in my car, so she took my car keys and got my oxygen. I had some oxygen and caught my breath. I recovered and went home, but that was a close call" (Susan RE 45yrs).*

Feeling panic when undertaking work activities was a recurrent theme raised by participants in association with breathlessness in the present study, and some wondered if they would ever be able to catch their breath:

> *"There are times when I feel like, will I ever get another breath and that is the worst feeling because most of the time I can recover, but this illness* [COPD] *can panic you sometimes, and even with the best strategies, you are still going to have horrendous days. I guess, with my relaxation and stuff, I can recover it* [breath]*"(Debbie E 51yrs).*

The cyclical nature of panic and breathlessness was recognised where panic can bring on breathlessness and when individuals were breathless, could feel a panic developing:

> *"It brought on … like a panic attack where you cannot breathe and you panic, you panic and you cannot breathe, so it is a vicious circle. But that only happened about twice in the factory" (Larry NE 49yrs).*

For some, manual aspects of work which involved crawling around in confined spaces when working in attics induced breathlessness. When things pressed on Ivan's chest it could cause panic attacks:

> *"The place I noticed it more was when I was probably pressing my chest, might be working in attics, maybe even lying in attics … it was almost like getting a panic attack with the lack the lack of breathing. It felt that breathing was a difficulty and … it got to the stage where it became a panic attack that I felt, and I had to get out of there"*

> *"Well, you're just bending, catching cables and could be stuck, under a kitchen worktop bent almost double reaching under floors and connecting pipes so it is bending all the time, it is bending work constantly and I couldn't carry drums of cable or heavy stuff" (Ivan SE 62yrs).*

Isaac would worry about feeling panic at work in the supermarket which caused gasping breaths and chest tightness:

> *"If I was in on my own and I felt a tightness in my chest, I would panic. Then, the sweat would be running off me and it would be hard to catch a breath, and you would think, "Oh god, what do I do now?" (Isaac RE 62yrs).*

Panic can be seen in this study as causing some distress to participants in a variety of work-related contexts. Panic has also been recognised in the wider COPD literature as resulting from breathlessness induced by physical activity and fatigue, but not specifically related to employment (Stridsman, Lindberg and Skar 2014; Barnett 2005). These examples illustrate a variety of situations where participants experienced panic brought on by work activities and had to take action to improve their breathing and prevent further panic.

Several participants explained that their COPD symptoms were also brought on by other factors in the workplace including being busy, being on their feet all day and extremes of temperature. Some focus was also given to discussing fatigue, which again was unpredictable and often dependent on the quality of their preceding sleep. Stridsman, Lindberg and Skar (2014) also reported that physical activity led to breathlessness and fatigue in a general study on COPD. Although not related to employment tasks and with an older population (Mean age 72), their participants described fatigue as a feeling of 'total exhaustion and body pain' (Stridsman, Lindberg and Skar 2014, p. 133), which was also echoed by participants in the current study. Whilst participants reported they were permanently tired at work, some indicated that they had to leave work or go home exhausted early from a night shift, as the work was so physically draining, they could not continue. This emphasised the physical toll that work could put onto participants when their health is already compromised. Watson (2015), in an exploratory study of older people with COPD, found that some of the working individuals perceived that eight-hours at work could feel like a double-shift, as it was so exhausting. This finding also reflects the experiences of some of the participants in this study.

COPD Symptoms Impacted on Workplace Activities

The symptoms of COPD, when experienced in the workplace, affected daily work activities and in many cases the participants had to stop what they were doing or slow down their productivity. Many of the examples demonstrate presenteeism and a loss of productivity due to breathlessness: an electrician leaving the attic to get fresh air and catch his breath, another coughing so much it caused stars in her eyes, some who had to slow down what they were doing or stop walking because of a stitch in their chest, another pulling over when driving, or dealing with an urgent phone call by calling back later.

Rita had concerns about her ability to focus on her work as a social worker:
"Yes, because the concentration bit is certainly a bit that I have noticed a deterioration in recent years. I would say that it does affect your cognitive ability" (Rita RE 62yrs).

Concerns around cognitive and mental function as a result of treatment or treatment effects are also recognised as a potential burden at work for individuals with other chronic physical diseases. De Jong et al. (2015), in a systematic review on employees with chronic physical disease and quality of life, found that fatigue and cognitive and mental impairment negatively affected participants' work efforts and the quality of individuals' working lives, whilst Dorland et al. (2016), found that in people with cancer, fatigue led to mistakes in the workplace. These physical and cognitive deviations from their usual state for participants in the current study, caused by the effects of COPD, might cause them concern and could inhibit normal work activity and affect their confidence in carrying out their role in the workplace effectively.

The breathlessness brought on by the exertion of walking to work for Debbie meant she would be unable to take urgent phone calls on arrival at work. She could be panting away trying to catch her breath and being asked to take an urgent call as the following quote highlights: *"I will get to you in a minute 'can you give me an answer for so and so who is on the phone?' I cannot, I cannot breathe, I will phone them back" (Debbie E 51yrs).* Lim et al. (2015) noted that 39% of their 1,841 participants in an Asian survey indicated that COPD even limited their normal activities including walking. COPD clearly has a negative impact on any walking requirement and, if a core part of a working role, may require the person with COPD and their manager to reprioritise working activities and reorganise planned walking within their role.

In working with COPD, some participants in the current study took actions to try to reduce energy consumption and prevent breathlessness and fatigue at work by not walking to work, taking an elevator to avoid climbing stairs or reducing the amount of physical labour they did. Another indication of the impact of COPD on his job was provided by Joe, who explained how his productivity had reduced because of the deterioration in his respiratory function and general health. He provided a quantified account of how, as a bricklayer involved in heavy manual construction work, his work rate and physical ability was not the same as it used to be because of breathlessness:

> *"I was building dry stone walls at 15-20 metres (300 bricks) per day initially when we moved to France to work but started gradually getting slower and slower and I was only managing about 5 metres (50-60 bricks) per day recently. My body seemed to not work the same anymore as I physically could not work as hard as I used to. I was used to working seven days a week on 12 hour shifts and was quite happy with that, but COPD was just taking effect and I could feel myself slowing down. I felt as though I was losing control of what I was doing" (Joe NE 50yrs).*

Joe's dramatic loss of physical ability to build his usual quantity of dry-stone wall represents presenteeism (Kirsch et al. 2019; Garrow 2016). Presenteeism is well documented in the COPD literature, and Lim et al. (2015) reported productivity to be reduced to 72% on an average working day but fell as low as 45% on days when COPD was at its worst. Joe would appear to have a greater loss of productivity when his COPD is at its worst of up to 80% (60 bricks compared to 300 bricks), which is understandable given Joe was undertaking heavy manual work in construction. Ding et al. (2017) also recorded the negative impact of COPD symptoms on productivity in a European wide study on individuals with COPD using the Work Productivity Activity Impairment tool. Their findings suggested that the more severe the COPD symptoms, the greater negative effect on productivity. Participants in the current study, who reported the most severe COPD symptoms in the workplace (Joe, Susan, Charles, Harry, Brenda and Larry) might have experienced the greatest productivity loss in the workplace, although this was not measured objectively.

Despite individuals with COPD working hard to maintain their productivity levels, the realisation for participants that they could no longer achieve as much as before in the workplace was disheartening. Many participants worked hard to make a living, despite their high COPD symptom burdens. Further elaboration of Joe's experience of trying to battle-on found him in uncomfortable situations:

> *"I cannot bend down and do this right now because I am really out of breath … but I cannot let these people down that are standing beside me, you know, so you are thinking about other people and not putting yourself out, so you are trying to get back to what you used to be" (Joe NE 50yrs).*

Participants considered being less productive than others around them at work and discussed guilty feelings. Collins and Cartwright (2012) explored managers and employees' perceptions of workers going to work unwell and found they considered a variety of factors including an individual's personal work ethic, wanting to complete their work tasks and not wanting to let their colleagues and employer down were important to them. These factors, highlighted by Collins and Cartwright (2012), mirror Joe's and other participants' attitudes to completing the work activity they have committed to do. Shortly after this instance, Joe reached a point where he could no longer keep pushing himself and left his job, indicating the desire in those with severe COPD to maintain a workplace presence. This drive to work keeps them in the workplace beyond the time in which they may still be physically capable of undertaking their job responsibilities effectively.

Other participants were equally frustrated by their productivity declines and worked around their limitations at work:

> *"I get a stack of bread in a delivery; it normally takes about 20 minutes to put it out on the shelves and now it is taking me the best part of an hour now, 45-50 minutes maybe to do. But work are okay with that, because if it is not done by the morning, I still can go home and someone can take over; it is very seldom that I've left anything for anybody to do because that is just my work ethic" (Charles E 56yrs).*

Other participants worked with a more relaxed attitude to productivity:

> *"The supermarket was a really nice place to work. There was no pressure put on you from either internally or from any of the higher management* [coughs]. *The likes of the area manager used to come in on a regular basis and there was never any pressure put on you to make sure you were doing X, Y, and Z, in such an allotted period of time. That was good" (Isaac RE 62yrs).*

Presenteeism was evident in several participant accounts and concurred with findings from Boot et al. (2016) who recorded that those with depression, osteoarthritis and cardiovascular disease, didn't accomplish much in the workplace at certain times, although some had the autonomy in their roles to make changes in their workplace to buffer the effects of the condition (e.g., to take a break). Presenteeism raised aspects of conscientiousness as participants in the current study reported their desire to perform at their very best at work. This appeared to be due to their work ethic in earning an *'honest living'*, and wanting their colleagues and managers to perceive them positively.

The examples provided by Joe and Charles also demonstrate resiliency attributes in their effort to satisfy their internal values and beliefs which are reconciled with positivity, rather than adopting a negative state of helplessness or hopelessness (Reich, Zautra and Hall 2010). Positive affect, or optimism (Wu et al. 2013), was demonstrated by Joe and Charles who would push themselves at work with an expectation of coping, sometimes leading to them having to leave work as they had become too unwell to continue working their shift. An expectation of coping for Joe and Charles was likely as a result of their internal attributes and beliefs in producing resilient responses to their workplace challenges. This pushing was perhaps too far at times for them physically but reflects the attitude to their work that has enabled them to maintain their employment status thus far. Presenteeism was an issue for many participants in the current study and is also discussed in the following section, although it pervades through many of the categories in this thesis.

Going to Work Unwell and Feeling Unwell at Work

Whilst discussing COPD symptoms in the workplace, many participants described the times they became unwell at work or when they went to work already feeling unwell. As in the above section on COPD symptoms impacting the workplace, this section illustrates presenteeism and absenteeism. Being unwell at work was a common occurrence for participants and reports of going to work with a chest infection, fatigue through poor sleep and being breathless which they found draining, were described. Although examples of presenteeism were numerous, participants in this study noted the many times they were at work and not fully productive but that these productivity losses did not seem to be measured or recorded by their employers. Gerich (2015) notes that sickness presence (presenteeism) is likely to cause greater loss in productivity compared to sickness absence. This is an important consideration for employers.

Often feelings of being unwell were brought on by the workplace conditions and work activities as already described. Some participants also acknowledged going to work feeling unwell and, despite their challenges, showed tenacity in their effort to remain at work:

> *"I've often gone to work feeling very unwell, perhaps with a chest infection because I used to plod on until I got really ill and work away until I was so ill that I needed antibiotics" (Rita RE 62yrs).*

Rita's justification for working when unwell was that she did not want to 'screw' the system (and have sickness absence), so she felt psychologically better working when unwell. Collins and Cartwright (2012) found a similar work ethic with personal pride and commitment where employed individuals with chronic illnesses didn't want to let their colleagues down and felt guilty that colleagues would have to pick up their work, giving them extra to do. Feelings of guilt towards colleagues and employers was noted to have a negative impact on the work contribution of individuals with various chronic physical diseases in the workplace, in a systematic review looking at quality of life (De Jong et al. 2015). Participants in the current study appeared to be very driven to attend their work despite feeling unwell and were frequently prioritising their job (and finances) over their health. It creates an impression that there could be internal conflict between what is good for the individual and what may be good for the employer or workplace.

Getting to work at the start of a shift was also difficult for some participants who reflected on the levels of energy expended in getting ready for work (washing, dressing, and eating), and travelling to work (the physical journey). Further challenges were noted to be around preparing for commencing work (putting on a uniform, work clothes or personal protective equipment), which took considerable effort, and even physically arriving at work had some participants feeling exhausted:

> *"My oxygen was in the car because I used it in the morning going to work" (Susan RE 45yrs).*

> *"I have used up a huge amount of energy before I even get out that door in the morning … my doctor says I am doing a triathlon every day with the effort I make to get to work and working a long shift" (Julian E 53yrs).*

Some participants found work exhausting and, if accompanied with poor sleep patterns, was so physically draining that going to work *"felt like jet lag" (Julian E 53yrs).* As days off would sometimes be utilised to recover physically from work and prepare for the next working day, there was no time for proper downtime or leisure. Julian further explained that he would like to have a foreign holiday, but it takes so much out of him it is not worth it, so balancing the pace of his work-life balance is a challenge.

Several participants gave accounts of being unwell at work and having to go home from their shift. Charles was found to be breathless by one of his colleagues who reported it to his line manager and was told to go home: *"No, no, you need to go home, you have given it your all, you are trying your very best, you need to go home now" (Charles E 56yrs).*

Larry noted that on several occasions he had gone to work unwell or became so breathless at work, his wife had to collect him and take him straight to the hospital:

> *"I was just trying to get to the department. I couldn't even walk down the corridor without having to stop and lean against the wall and everything and I don't think I even made it into the department as it was a long corridor".*
>
> *"I would go to work and make the effort even if I felt ill, I am old school* [laughs] *… yip you would feel unwell but, you would have breathing problems, but you would just calm down, take the inhalers, get relaxed and give them time to work" (Larry NE 49yrs).*

Larry recognised that pushing himself beyond his physical capability was not conducive to him managing work effectively. Boot et al. (2016), in their interviews with people with depression, cardiovascular disease and osteoarthritis, found that understanding the personal limits of their individual conditions was an important factor in continuing employment. Balancing energy with how individuals felt their general health was at work on any given day helped them to maintain an effective employment presence (Boot et al. 2016).

This could be achieved through careful self-mastery of their condition and symptoms and the efficient use of workplace and social resources (Boot et al. 2016). These ideas are also conceptually close to those involved in developing and enacting resilience where individuals use social support and self-regulation to cope with life and workplace challenges (Wu et al. 2013). Taking account of personal limitations on a day-to-day basis in the workplace based on health and using available appropriate resources might be a strategy worth considering in sustaining employment for people with COPD.

Other examples of being unwell at work came from the challenge of getting to work by participants who had problems having to park their car some distance from their workplace. This problem occurred because of the geographical workplace set-up and remote parking areas rather than by participant design. Walking from the car park to work was distressing for some participants:

> *"I would park the car and walk up a hill… not far, possibly a quarter of a mile, but far enough if you were having breathing problems or the weather was rubbish* [wind, rain, cold]*. By the time I got to the office I was just knackered, just drained. Was not just the physical thing, it was affecting my mental health, it was affecting everything, just horrible. The parking situation had an impact on my ability to do my job. Initially when I first got into the building I might be soaked through, or could not breathe right, chest tightness or whatever. No problems with the COPD once settled into the office and going about the building" (Diane E 62yrs).*

> *"Some of these mornings are almost killing me coming to work. My boss knew, because she walked with me some mornings as we met each other on the way. I would say to her, 'Oh Emily, I have to stop. I feel I am out of breath" (Debbie E 51yrs).*

Walking to work and at work was explored in the section above and noted by Lim et al. (2015) as being problematic for those with COPD in everyday activities. When additional factors were introduced for the participants in the present study e.g., distance to walk and unfavourable weather, this challenge became more difficult for them to manage at their work.

Feeling unwell at work was also linked to feeling tired at work, which was also a concern for Charles who felt *"COPD was making me tired and that I just do not have the go about me"* (*Charles E 56yrs).* Charles's fatigue was related to poor sleep and constant exhaustion. Sleep quality in individuals with COPD is not well understood and its impact on work and productivity has received little focus in the literature. McNicholas, Verbraecken and Marin (2013) highlighted in a review of research, that poor sleep quality caused by COPD is likely to cause chronic fatigue, sleepiness and a reduced quality of life. In those with severe COPD participating in a 106-participant strong sleep quality study, poor sleep was thought to cause deleterious physiological effects (e.g., daytime hypoxaemia) which could potentially negatively impact on an individual's work ability and productivity (McSharry et al. 2012). In addition, poor sleep was noted by Shorofsky et al. (2019) as being likely to lead to an increased risk of COPD exacerbation, which was also relevant to Charles's history. Having a quality sleep would seem to be a key requirement in both helping to preserve states of well-being and preventing exacerbation and a more productive and effective working experience for those with COPD.

5.6.2.2. Workplace Strategies and Actions

Four categories make up this higher order classification (Table 5.3): Personal actions for managing COPD symptoms in the workplace; Personal strategies for managing COPD symptoms in the workplace; Workplace adjustments made by employers to accommodate COPD and Workplace adjustments not facilitated by employers.

Personal Actions for Managing COPD Symptoms in the Workplace

Various personal actions and strategies were used by participants to control or recover from their COPD symptoms in the workplace. Actions were often instant reactions to how they were feeling at any given time, whereas strategies were broader and tended to be planned in anticipation of encountering problems. Participants often stopped their work activity and sat down or stood up, especially when they were breathless. Sitting down to catch their breath, standing still to take inhalers, and coming indoors from the cold weather were also commonly reported. Most actions were focused on self-management in regulating breathing and controlling coughing, and using relaxation techniques:

> *"I can recover my breathing if I focus really hard, but there have been many times when I've had a bad chest infection and started coughing, so trying to actually stop the coughing and focus on my breathing can be really difficult" (Debbie E 51yrs).*

Dropping to the ground for fear of collapsing was an action that Harry took for extreme breathlessness, fearing *"bashing on with work and down you go, and everyone gets involved, well, I did not want that to happen" (Harry RE 58yrs*). In trying to regulate his breathing he would drop to the floor and colleagues would ask *"what are you doing down there? … oh, oh I am just getting my breath"*. Some participants carried on working although slowed down their pace of work, and others would stop walking and rest or leave the office and go into the corridor to recover from coughing or breathlessness. Debbie became breathless on entering a patient's home which was hot and full of cigarette smoke. She recalled the patient saying, *"Oh God, I forgot you were coming, and she immediately goes and opens all the windows*" (*Debbie E 51yrs).* These actions were considered helpful when dealing with breathlessness and illustrate problem-focused coping, which reflects the rational task-oriented behaviours adopted to relieve participants stress or distress (Lazarus and Folkman 1984).

Examples of personal actions taken to self-manage COPD symptoms in the workplace is also captured in the literature. Mal'ouf (2016), in a study of working-age women with COPD, found participants adopted helpful personal actions to manage their COPD at work with some pacing themselves, walking and speaking more slowly or taking their breaks when feeling unwell; others adopted specific breathing techniques to control their breathlessness at work. Participants in the current study appear to be coping with their COPD symptoms by taking small and manageable personal actions in the workplace.

Participants also discussed using their inhalers to gain relief from breathlessness at work:

> *"You would have breathing problems, but you would just calm down take the inhalers, get relaxed you know, and give them time to work" (Larry NE 49yrs).*

> *"I've got a Ventolin inhaler, but I never think they make any difference. I used them ... sometimes I used them quite a lot, but I always felt when I was using them that you can't use them more than you should" (Julie RE 63yrs).*

When breathlessness occurred during indoor working, participants would go outdoors to get some fresh air and clear their head. When breathlessness occurred during outdoor working, as in the case of Brenda, a dog boarding kennel owner, she would return indoors if it was windy, cold and or wet:

> *"I could be quite bad and then come indoors and have a cup of hot tea and warm up, and I would improve maybe in about half an hour or so later - and taking a puff of formoterol and that would help too. I would have to sit quietly until it all warmed me up and I came to. On good days, I would walk several miles, on bad days very little. On a warm enough day, I would happily do several miles by the time I walk all the dogs. I would take them the longer circuit, but if I was not feeling well then, I am afraid they got the short circuit. And that was just the only way I could cope. The hot drinks, the scarves, and I had a de-humidifier in the bedroom which helped" (Brenda NE 50yrs).*

When Brenda did not manage to recover well from these events, she would later walk the dogs in a heated shed, or her family would help her with the outdoor workload. Other actions included having a drink available for a dry mouth, catching breath in between clients, putting someone on hold on the phone until they caught their breath and carrying lighter physical loads. Several participants explained that because of their COPD they often had to stop and rest:

> *"I have gotten to the dyke* [wall] *when walking to work and just had to sit down because I cannot go on. I feel it in my legs, it is like a clamp around my legs, and it is like walking through sludge. So, I have to stop because if*

> *I do not stop something is going to happen* [collapse]*. I have to be sensible and have control" (Debbie E 51yrs).*

Extremes of damp and dry conditions made Joe's breathlessness worse which he found difficult to control:

> *"I stopped four or five times, at least, and that was really unusual for me, as I was usually the first person that goes there in the morning and last to finish at night, and that is what I do. I do not stop, and I hardly eat at all. Now I was getting out of breath, so I had to stop and rest more than I used to because I would not stop most of the day" (Joe NE 50yrs).*

Similarly, Mal'ouf (2016) also noted in her small qualitative study that working women used a variety of personal actions to relieve their COPD symptoms in the workplace by taking their inhalers to ease breathlessness, leaving work early if symptoms became extreme, resting at home to ensure they were fit for the following day's work and trying to remain fit through undertaking physical activity at the gym. With the unpredictable nature of COPD and its symptoms, employed people in the current study appear to be able to effectively self-manage their symptoms in the workplace through the adoption of a variety of personal actions. Effective self-management, where people with long-term conditions make decisions and take actions to manage the factors that affect their health and well-being, is a key component of many government strategies (Scottish Government 2021), and it is crucial to employment success that these skills are appropriately applied in the workplace context (Russell et al. 2018). In addition, effective self-management may enable individuals to achieve greater workplace satisfaction, as it has a positive influence on an individual's health-related quality of life (Russell et al. 2018).

Personal Strategies for Managing COPD Symptoms in the Workplace

The personal strategies adopted by some of the participants to cope with their COPD in the workplace were predominantly focused on planning work activities ahead, building a routine and being organised in the workplace. Other strategies were linked to their workplace demands such as varying their workload, wearing light layers of clothing, wearing warm layers of clothing, using an elevator rather than climbing stairs, parking close to the workplace building, working different and varied hours, manipulating workload tasks and, using oxygen at lunchtime and *en route* home to relieve hypoxia. An example of working different hours came from Diane who had parking issues in the morning and tried to overcome them:

> *"I was predominately trying to work from 8-4, but they* [employer] *started being awkward and she* [line manager] *said, 'well that is fine I can make allowances maybe a few times if she had to work till 5' ... But you* [employer] *are offering flexible working why cannot I do it permanently* [8-4, but they wanted her in from 9-5]*. So initially it was that, but then they started putting restrictions on this other area so that when I went in at 9 there would be a space, that was not a problem, I could just zip into the space and leave my car there all day… until they started becoming obsessive about this where you could not be there and that is when they started giving people tickets" (Diane E 62yrs).*

Despite planning ahead to ease her parking challenges, approaches such as this did not appear to be successful for Diane where there was no employer buy-in, and they chose not to work to their policy.

Many of the participants adopted ways of working, which they felt would accommodate their challenges and meet the employer's needs through minimising disruption to their daily work. However, these strategies were not always noticed or appreciated by the employer as illustrated above with Diane, and in the next example:

> *"I had a mini oxygen concentrator, so I would go… and because it was in my car, as I used it in the morning going to work and when I was coming home from work. So, at lunchtime, if I was particularly tired or if I had maybe had a chest infection or was feeling it had been a busy morning, then I would have my lunch and sit in the car for 20 minutes, and have my oxygen for a wee while … I could get peace and quiet myself sitting in the car and just shut my eyes, even for 20 minutes" (Susan RE 45yrs).*

Another participant, who also used oxygen at work when his chest felt tight, often pushed himself to the point of exhaustion and would sit in his car to administer oxygen before setting-off to drive home. Hiles et al. (2018), in a cross-sectional survey with over 500 patients, found that participants with severe asthma were *'pushing through'* at work despite feeling unwell, which was a coping strategy to help them keep-up with others in the workplace. This strategy also implied presenteeism in being at work unwell and the risk of *'overdoing it'* physically. Holland and Collins (2018) also found similar in a qualitative exploratory study with 11 working participants with rheumatoid arthritis, who, in their desire to continue working, pushed themselves physically in the workplace. Participants in the current study often go above-and-beyond what is required of them at work so as to not cause disruption in the workplace, complete their job requirements and to keep up with others.

Other participants avoided rushing at work by arriving early to get settled-in and prepare for daily meetings:

> *"I do not run around as much as I used to do. In the mornings if I have a meeting at 9 o'clock, I will make sure I am here at 8:15 so I can settle down, have a cup of coffee. I prepare physically and mentally if you like. What I do not like to do, and I have noticed it more since the diagnosis, is I do not like to jump out my car, jump into a conference room and start a meeting because I am a bit breathless, so I like to come and settle down to the state I am in now" (Zach SE 61yrs).*

Being organised and orderly, knowing what to expect and not having things thrust upon them was a common theme that participants considered as beneficial to help them cope with their COPD. Planning the working day was felt to be an important strategy, particularly by participants who had some flexibility to be able to vary their workload and activities. For example, planning all phone calls to clients in the morning when COPD symptoms were usually less of a problem was adopted as a strategy. Kalirai (2016) noted in interviews looking at what influences adjustments at work, that flexibility in work tasks (and working hours) was important in having some control over work. Hjärtström et al. (2018), in interviews with the Swedish Public Employment Service helping match jobseekers with employers, also noted that participants reported that they felt they had good workplace flexibility, so if they felt unwell at work they could leave and go home to rest preventing sickness absence. This would seem important for a variety of work tasks to enable them to pace themselves and do more challenging tasks when they are feeling at their best and doing less demanding activities when they are not.

Other strategies included a participant using her iPad for explaining educational and support materials for her patients, so she did not have to carry heavy folders and documents back and forth to their homes every day. Other participants used days off work to sleep and recover from their working days, which was also a strategy found by Holland and Collins (2018) in people with rheumatoid arthritis.

Enlisting colleague support was also considered beneficial during heavy workload times and elements of bargaining were used to enable this. When expected to lift 100kg kerbs when building new roads, Joe negotiated workload tasks with his younger workmates:

> *"Lifting them all day it is a lot of work and there were younger guys and I thought well they can cover for me for a wee bit you know but it is not going to last for long ... I would just say look, I am older, you are younger you pick the kerb up and I will put the cement around it. The guy I worked with was good because once I explained exactly what happens to me with COPD, he says well okay then you have got something wrong with you. There were much younger guys around me, and we got on perfectly together and we worked well like that" (Joe NE 50yrs).*

This strategy was effective for a short period of time and like other participants whose work involved quantifiable production e.g., bricklaying, shelf stacking, and administration, the participant's overall effectiveness and decline might be evident to everyone.

Those who were self-employed appreciated their flexibility, which was helpful for days when they needed a slower pace, but others feared a more restrictive experience in the controlled environment of having an employer. Being able to *"vary things a wee bit did help"* and looking forward to the potential for starting a new business on relocating to a warmer climate, Brenda explained that *"It is not like I will have an employer breathing down my neck, because that would really worry me" (Brenda NE 50yrs).*

Ivan also appreciated his self-employed electrical contractor status:

> *"Erm, not initially as there was so much work that you could almost pick and choose* [being self-employed] *there was almost a backup of say smaller jobs or there was just totally different jobs as there was so much work at the time, and some jobs you could actually refuse" (Ivan SE 62yrs).*

Another strategy adopted to help participants cope with COPD symptoms was through hiding and deception. Participants sometimes hid their symptoms from colleagues. For example, Ivan hid his COPD and breathlessness from others he worked with because "*you did not want to have to admit to them you could not do anything" (Ivan SE 62yrs)*. A more extreme example of hiding COPD in the workplace involved manipulating workplace situations. Having worked in positions of seniority for many years as a supervisor, superintendent and manager of between 20 to 150 men, Harry, an offshore electrical manager, manipulated the workforce and work activities to hide his breathlessness from others. He felt he had to hide his condition or he would lose his job and admitted that, before retiring early, he did not have full-control of his work. Hiding COPD was a feature highlighted from the interviews with women with COPD by Mal'ouf (2016). This was done to prevent embarrassment and shame and try to prevent being judged by them. Avoiding situations where others may see individuals struggling with symptoms is a common strategy.

In deciding not to disclose his COPD to his employer or colleagues, Harry found ways to cover and conceal his breathlessness at work when anyone asked: *"Oh, eh, I have had a chest infection" (Harry RE 58yrs).* He also describes how he controlled various situations when working on offshore oil and gas installations or floating production storage and offloading units (FPSO):

> *"I was a supervisor, and I would manipulate when I had to go out* [of the office and onto the main section of the oil rig]. *I would go out and get everything that needed my physical input and presence done in the morning. I am still buggered but can manage a bit more in the mornings. The afternoons and nights could then be allocated to my paperwork. Because I had been out and seen situations in the mornings, I could just delegate without having to go back out. That is the way I manipulated that" (Harry RE 58yrs).*

> *"Or I could manipulate it and say to the workers, 'I will meet you at the job site after lunch or after teatime' … but I would be using that teatime to get to the job site myself so I was there when they arrived, and all this was under control. Then I could return at my own leisure without them. But I could not walk with them to the job site … just even at a normal walk as I would be 'peching' and 'panting' and needing a break" (Harry RE 58yrs).*

Harry considered that he was good at his job, was able to *'cover his back'* and thrived on workplace pressure, though he admitted he was not capable of undertaking the manual aspects of his job. He further noted:

> *"But me.… go into the store for a bag of bolts… but they could have went and got three bags themselves in that time, you know that kind of thing and that is when I manipulated the times" (Harry RE 58yrs).*

Harry used manipulation as a strategy to protect his job and avoid stigmatising experiences by covering up and concealing the extent of his COPD symptoms from colleagues in the workplace. Berger, Kapella and Larson (2011) found this was also a strategy adopted by those with COPD when they conducted in-depth interviews with 16 people in relation to stigma. They found some participants would 'play the game', by underplaying their work activity and symptoms, or 'backing down' so that others did not perceive them as being disabled or crippled (Berger, Kapella and Larson 2011). It is possible that controlling the immediate workload and situation is useful in helping those with severe COPD maintain their employment status in the short term. This strategy appears to have been successful for Harry for a period of time; however, this strategy might have caused him greater stress and created health and safety implications for himself, his colleagues, and the safety critical industry he worked in.

Overall, participants noted that they learned what they were capable of and understood how their bodies responded to workload demands, and they learned to pace themselves in the workplace to cope with their COPD ensuring the impact of COPD on their productivity was minimised. Most importantly, they knew what activities used most effort at work and when not to waste their energy, and as far as possible would try to control the more demanding activities themselves. Similarly, Mal'ouf (2016) reported that women with COPD paced themselves and took regular breaks from workplace activity to avoid exacerbation. Pacing workplace activity and knowing how their condition reacts to workplace challenges and effectively self-managing their condition to cope with the challenges of work might be a useful strategy for individuals in sustaining employment. This fits well with the Health and Well-being at Work report (CIPD 2020) and the Good Work review ambitions (Taylor 2017) that call for an emphasis on workplace well-being to be enabled. However, engaging in detrimental self-management strategies through prioritising work over their condition is evident in people with diabetes as found in a study by Ruston, Smith and Fernando (2013). For example, if people with COPD did not pace themselves, or delayed inhaler administration, or avoided time out for pulmonary rehabilitation this might contribute to poorer health outcomes and reduced employment success.

All employed participants expressed a strong desire and drive to remain in employment, and the strategies they adopted demonstrate resiliency skills and attributes. Participants used active coping mechanisms and trial and error, with the belief of their own capability in creating positive, rather than negative outcomes (Reich, Zautra and Hall 2010). These concepts are reflected in participants' efforts to plan and pace their work, embrace flexibility and to change their plan if required, depending on their health in order to maintain their employment status. Being successful in applying various strategies to facilitate employment seems to rely on those with COPD proactively integrating actions and strategies into their specific work contexts either independently or with employer and colleague support.

Workplace Adjustments Made by Employers to Accommodate COPD

Although some participants felt they did not know how to request adjustments at work, many provided examples of changes made by their employers to accommodate their specific needs. Some participants noted the need for employers to be supportive and accommodate COPD as a disability and make allowances for those with deteriorating health but who were still capable of undertaking most of their working role. Suggestions included changing the location of the place of work, working from home, reducing their hours, allocating lighter duties, and relieving some of the workplace stressors. Not all participants were offered reduced hours, and if that was an option available to them, some would have to change job, or workplace location, or drop a pay grade. Simply issuing temporary parking permits would have helped some participants feel the employer was doing their best to support them with little or no cost to the employer. This was a particularly sensitive issue for those whose employers openly published flexible working policies but seemed reluctant to make reasonable adjustments for the workers requesting them. This may have been as a result of the employer or manager not fully understanding the entitlements of employees with physical impairments under the Equality Act (2010).

Conversely, self-employed participants agreed that it was easy for them to implement any necessary adaptations, as they had complete autonomy over their jobs and the workplace environment. One participant could be selective of the electrical contracts he accepted, was able to minimise ladder climbing, reduced carrying equipment and crawling around in attics, thereby making his work less physically taxing. Another participant had carte-blanche for flexible working for all employees in his company, for example, in enabling workers to access physiotherapy if they had work-related MSK issues. In addition, he could implement flexible working for the workforce, such as changes in hours or days worked and shift changes if required, without much disruption to the company (Isaac RE 62).

There was a sense of missed opportunities for some participants, as they had not been offered, nor asked for alternative roles from their employer as their

COPD deteriorated. Participants reflected on alternatives roles and aligned them to their knowledge and skills, and some felt it a considerable loss of expertise for their professions when they left their jobs:

> *"It was never ever offered, and I was the most experienced veterinary nurse we had at the time. I had 20 years' experience under my belt at an advanced level, and they just let you walk away, which is crazy. There was nothing offered, there was no alternative offered, which they could have done, because I could easily have done clinical work plus lab work and reception work" (Susan RE 45years).*

Susan felt her skills were valuable to her employer and could have been redeployed in reception, fundraising, training or upskilling the veterinary nurses, student nurses or mentoring care assistants. Jeffrey in contrast, felt he had the skills to suit other roles but knew there was nothing else for him as his employer had previously moved him from an engineering role into safety and compliance. Jeffrey wanted to remain employed but appreciated his health was suffering in continuing to work. Feeling that their knowledge, skills and expertise were being cast off left many participants with a sense of loss.

Boot et al. (2016) found in interviews with participants with depression, osteoarthritis and cardiovascular disease, that they considered work as part of their identity, and it was important to them. This perspective mirrored the value participants in this study placed upon their knowledge and experience and the subsequent loss they felt when a workplace presence could no longer be maintained. Being able to channel their skills and expertise into other industries or commercial ventures with less of a physical demand might be important alternatives for participants to consider to their normal roles.

A variety of workplace adjustments implemented by employers were evident from participant accounts. These included a reduction of working hours from full time to part-time, avoiding long shifts and night shift, reduced workload, lighter duties, shift changes, day shift from night shift, working at home, flexible lunchtimes, stepping down from pressured roles and time off for medical appointments. Most adjustments were informal, local agreements made with either the employer’s management or directly with line managers who could enable some degree of workplace flexibility. Flexibility was offered in allowing longer lunches for medical appointments and physiotherapy and in making small parking concessions. Mal’ouf (2016), found similar in women with COPD where there were some allowances to take time off to attend hospital appointments such as pulmonary rehabilitation. Some employers denied this flexibility with the employer only honouring medical related appointments or insisting on making up time or using annual leave for this purpose (Mal’ouf 2016). The lack of standard practice from employers illustrates the varied approach to supporting those with long-term conditions and falls short of achieving a supportive workplace culture that values health and well-being in their employees.

A few participants in the current study had received formal Occupational Health assessments, and the employer and employee received advice and recommendations on which workplace adjustments or accommodations were advisable. These reports also included those workplace activity limitations which might prevent further work-related problems for example in the case of lifting load weights and avoiding dusty workplace environments. Kalirai (2016) also found that general practitioners were involved in providing useful fitness and work-related advice to those with COPD to enable workplace conversations of appropriate adjustments to participants’ roles.

Several participants had local workplace personal support plans implemented as a result of the occupational advice provided, although not all aspects were always closely adhered to by employers. These ensured both the employer and employee had a shared understanding of what was expected on a daily basis - for example, in attending work, working hours or aspects of work which are flexible. Additionally, ongoing monitoring, the need to discuss changes in health status and reporting-in once on duty on current health and well-being was incorporated. This approach mirrors the UK Government’s ambition for the development of collaborative approaches to workplace challenges for those with long-term conditions to maintain a workplace presence and sustain effective employment outcomes (Taylor 2017). Having healthcare professionals, employers and employees share an understanding of work integration or re-integration plans following absence was considered vital for those with chronic disease, according to a systematic review conducted by Esteban et al. (2018). Although the evidence on this finding from the systematic review was low in confidence, the need for general agreement of a plan and collaborative working was considered important and appears to be a sensible starting point for negotiation. Participants in the current study were encouraged in having a plan in place but were aware that it might be considered a paper exercise when not adhered to by both employer and employee. There is a need, therefore, for participants to ensure they are being assertive in regularly checking-in with their manager with regards to their plan and their current health status and that they ensure they have an active voice in the communication process.

As part of their individual workplace support plan, several employed participants discussed their adjustment latitude. Several participants were able to exercise flexibility in how they approached their work, adjusting the hours or days they worked, as well as other aspects of the job such as when to visit certain patients or when a telephone call would be sufficient, and the speed they worked at. These aspects of flexibility were also emphasised as important for *'Good Work'* in a modern economy, aiming for employers to engage with those with long-term conditions, carers and retirees to continue to have some presence in the labour market (Taylor 2017). Fulfilling flexibility intentions, however, is more difficult for some employers and in certain industries to facilitate and is dependent on the job demands, specific workplace constraints and role requirement contexts. The benefits from workplace adjustments appeared to be most beneficial around the reduction in hours worked which, when taken with her pension *"was exactly the same financially ... and dropping to 3 days per week was so much easier and made a big difference" (Julie RE 63yrs)*. Other examples where participants benefitted from workplace adjustments, was in reducing the hours worked per week and stepping down from a management role - Charles felt he was then able to manage his work better with less pressure, and he also indicated that his employer would be accommodating, they would make a job for him and that they were able to craft hours and different roles so they could still offer the employee options for continuing their work. Charles, having worked for his company for 22 years felt that if he:

> *"Went to them and said, I have tried this and this, but I am not coping on nightshift, I need to get onto day shift, I know that within a week I would have a job, they would create a job for me" (Charles E 56yrs).*

Reduced workloads were also helpful for a few participants but when carried out to the extreme, caused real concern for Julie. Having gone from being a perfectionist at work, working longer hours during busy times, she was now reduced to *"sitting twiddling her thumbs" (Julie RE 63yrs).* Although she knew her boss was being kind and thoughtful in reducing her workload considerably, she felt guilty and although *"I could have sat there till I was 65 and 3 months to get her state pension and took the money. I really did feel awful trying to make myself look busy when I didn't have anything to do" (Julie RE 63yrs).* Having very little to do for weeks on end, whilst her colleagues were working flat-out, became a moral issue for Julie and the guilt contributed to her leaving her job when she did. Bosma et al. (2021) conducted an exploratory study with occupational physicians and organisational representatives and noted that workplace accommodations that impacted on co-workers often caused feelings of resentment and jealousy when they observed those with long-term conditions taking advantage of the benefits. Clear communication between those with long-term conditions and colleagues may help prevent similar scenarios where reasonable adjustments are somewhat helpful but also impact relationships and might reduce sense of workplace satisfaction. In Julie's situation, colleague jealousy was not an issue, although she still felt guilty at work.

Lighter duties were often implemented in the workplace for participants either through negotiation with helpful colleagues or formally agreed through management. In some instances, colleagues agreed to support with some of the more strenuous roles such as cleaning animal pens and kennels and using chemicals to do so and in lifting heavier loads. An insight of lighter duties implemented on return from sickness absence, was offered by one participant requesting extra help from her employer:

> *"I would say, look, do you mind if I do a week on reception when I come back to work? It was the worst place in the world … but least taxing of duties. So, I used to do that and somebody else would be happy not to do*

> *reception and do other stations (kennels, theatre, consultations and lab work) so it was a win-win that way. I would just say I was really struggling and I cannot do that, or it is really knocking my chest" (Susan NE 45yrs).*

Boot et al. (2016) noted that implementing workplace adjustments was difficult and complicated for those with osteoarthritis, but more positive experiences were found in those with depression and cardiovascular disease. No specific detail of these difficulties was provided in the Boot et al. (2016) study; however, the implementation of adjustments to accommodate individual needs might be more closely related to individual circumstances and workplace situations rather than related to specific conditions.

Another example of adjustments agreed with her employer was in the fitting of a stair lift to ensure Susan could join her colleagues in the staff room which was located on the upper floor. This was so she could attend staff meetings after a period of exclusion. This was made possible by her searching for funding grants to facilitate its implementation and reported it as a constant fight with her employer to get to that point. Adams and Oldfield (2012) in a survey of people who were disabled or had long-term conditions found that their knowledge of access to work schemes that provide funding for adjustments of this type in the workplace was very low.

Even although adjustments were made and some flexibility was offered by the employer, she felt she was a problem and *"because they did not know how to deal with you, they wanted rid of you, as you were too much of a liability" (Susan RE 45yrs).* In other words, she felt that everything was made more difficult for her in the workplace in order to get her to leave her employment.

De Wind et al. (2013), found similar experiences when they conducted interviews with 30 people who had retired early due to health-related reasons. Participants claimed the employer suggested they retire early, threatened to dismiss them, or created such disagreeable workplace situations in which participants felt continuation of employment was thereafter impossible. In making employees' lives difficult, employers clearly risk losing valuable skills and assets if skilled workers leave their jobs and is contrary behaviour to research on chronic disease which suggests implementing workplace adjustments could potentially reduce sickness absence enabling employers to retain their expertise (Boot et al. 2013). This perspective was compounded by Bosma et al. (2021) who, in an exploratory study which interviewed occupational physicians and organisational representatives, found negative organisational attitudes towards those employees with chronic conditions. Further, that despite the widely acknowledged added value that experienced workers are reported to offer to an employer (Bosma et al. 2021), it appears there is often an unwillingness to try to provide support and retain employees with long-term conditions by some employers of participants in the current study. Vooijs et al. (2018) conducted focus groups with participants with various chronic conditions, but not COPD, and found that communicating their value to their employers and being clear about what they cannot do in the workplace was an important theme. This was something that participants in the current study did not do regularly and perhaps missed opportunities to have frank discussions about gaining a balance.

Larry was supported by his employer to reduce his hours and went on to lighter lifting loads following an Occupational Health medical. He was not allowed to lift more than 10kg because the exertion of lifting heavy weights could induce breathlessness. Covered under The Equality Act (2010), the employer made it clear it was Larry’s responsibility to follow the recommended advice. Subsequent actions taken by accommodating employers were considered helpful by participants in this study, facilitating an enduring workplace presence for those with severe COPD and easing the impact of workplace activities on their physical well-being.

Workplace Adjustments Not Facilitated by Employers

Where participants had no Occupational Health service involvement, informal requests for reasonable adjustments to their roles, responsibilities or conditions had unpredictable outcomes. Subsequently, adjustments often occurred at the discretion of the line manager or their colleagues. Where participants had access to an Occupational Health service through their employer, this provided clear workplace adjustment recommendations and advice that they could discuss with their employers. Participants reported several adjustments that were easily made to their work as listed above including a reduction in hours, changes of shift and lighter duties. There were, however, a few examples of employers who did not appear to demonstrate commitment towards supporting their employees with COPD in not implementing the reasonable adjustments. These were usually around the more complex recommendations which were difficult to implement company wide and in specific circumstances. In some cases, the constant exposure to workplace air pollutants (flour and aviation fumes) were impossible to minimise further or eliminate from the workplace, so nothing else could be done by the employer. Having already had role, responsibility and or shift pattern changes, some employees with no other options subsequently left their employment. In Colin's case, he felt the Occupational Health service was exceptional and, following their assessment, recommended he be transferred to lighter duties. This recommendation was not facilitated by his employer, so Colin left his job.

Having workplace adjustments implemented following expert Occupational Health advice is not always straightforward for employees or employers. Boot et al. (2016) found that people with osteoarthritis felt that having workplace adjustments implemented was complicated and sometimes refused by employers. Those making changes in the workplace were careful in explaining them to colleagues to avoid being perceived as selfish. Further research from Boot et al. (2014) also suggests that older workers (age 55-62), with low psychosocial resources (low autonomy, task variation and supervisor and co-worker support), are more likely to stop working. This suggests that successful navigation of workplace adjustment options requires effective communication, social support and personal resilience. This perspective concurs with the resiliency construct of efficient self-regulation, which might be required to ensure any adjustments that are implemented can be successful (Wu et al. 2013). However, even although the employer, employee and medical and workplace assessments are in agreement, making the adjustments work in practice will take a willingness on all parties to ensure they are sustained.

Not being registered as disabled from a driving perspective also posed barriers when requesting employer support with local disabled parking, as one participant was told she *"cannot do that because you do not have a Blue Badge" (Diane E*

62yrs). Diane followed this through with a disability assessment but was unsuccessful, as she did not meet the requirement for parking concessions. She was subsequently warned with the issue of parking tickets by her employer if she continued to park in disabled or visitor spaces. She claimed *"they were not up for being flexible. What is the point of saying we can do flexible working then* [and have a flexible working policy] *if you are going to be like that"* and proceeded to receive a £40 parking ticket in mid-winter *(Diane E 62yrs)?* Others had similar experiences in requesting parking spaces, which were eventually awarded after a long fight and leaving them feeling judged for asking *(Debbie E 51yrs).* Other solutions suggested by the employer (other than close parking) were unworkable in some cases as they did not understand the responsive nature of the community nursing service, load carrying requirements and drop off suggestions which incurred greater time and energy demands. In this sample, therefore, it appears informal reasonable adjustment requests were more likely to be successful in attracting some level of management support.

5.6.2.3. Communication, Advice and Support

Five categories make up this higher order classification (Table 5.3): Disclosure of COPD in the workplace; Discussing COPD in the workplace; Employer support for COPD in the workplace; Colleague support for COPD in the workplace; Perceived support needs for health-related employment concerns.

Disclosure of COPD in the Workplace

There were mixed views about the disclosure of COPD in the workplace. Some participants were explicit in telling their employer and colleagues about their COPD and the challenges they faced with their condition. Others suspected the employer and fellow workers would be aware of their deteriorating health over time or even told colleagues after they have improved following an exacerbation. The scepticism around withholding health information appeared to be linked to privacy and fear. However, participants widely acknowledged the benefits of disclosure as being to enable flexible working and adjustments, to maintain safety for themselves and others in the workplace and to help employers understand the needs and challenges of working with COPD. Because of the presence of symptoms such as breathlessness and a husky voice and the close co-working with people in the workplace, colleagues often knew of the existence of a respiratory condition. Having work colleagues know about their COPD was considered beneficial should assistance be required. Joe offered an example:

> *"The guy I actually worked with … really understood once I sort of explained to him exactly what happens to me … and he says well okay … you have got something wrong with you … I think you have to be* [open with colleagues] *because if anything happened to me and I took a breathing fit that I could not get out of, and well somebody's got to know what to do with me, so yea I told … most of the guys actually (NE 50yrs).*

Another perspective was offered from Debbie *(E 51yrs)* who worked as a community mental health nurse and told her patients about her COPD on first visiting them. She recounts an example of a patient hearing her husky voice:

> *"Oh my God, have you got the cold, nurse? ... and I will say … no, no, it is a form of asthma. So, from time to time you might hear me choking a wee bit or I might be a wee bit breathless, but do not distress yourself, I have my inhalers" (Debbie E 51yrs).*

Disclosure for Debbie was for the benefit of others and to prevent potentially embarrassing or alarming situations for her patients and herself. Similarly, a small sample of working women in the Mal'ouf (2016) study oversimplified their COPD by telling work colleagues it was asthma. Other examples in the present study related to comments made by colleagues in direct conversation when they noticed another participant's breathlessness in an open-plan office: *"Have you got a chest infection?" "No…" "Oh, but I heard your chest rattling?" "Oh, yea I have got COPD" "Oh right then, I thought you sounded a bit sort of whistly" (Kim E 57yrs).*

Overhearing this conversation, comments from another colleague validated Kim's COPD, miss-associating it with the ageing process and *"oh that is what happens when you get old, all bits and pieces start falling off" (Kim E 57yrs)*. Kim did not challenge this comment to underplay the visibility of her symptoms and prevent embarrassment to her colleague. Participants in the Mal'ouf (2016) study preferred to explain what COPD was and the COPD symptoms they experienced to colleagues in the workplace to save having to keep repeating it. Bosma et al. (2021) found in interviews with occupational physicians and organisational representatives, that there was a greater likelihood of people with long-term conditions disclosing their condition in the workplace when they worked in a supportive environment. In the current study, disclosure has benefits for both the participants and those around them who have some awareness and understanding of their colleagues' health issues, and they took actions to support them at times.

Other participants preferred to keep their COPD private and did not want to broadcast their illness to others. There was also the notion of not wanting to attract the attention of colleagues to the fact they had symptoms. Disclosure was also linked to the stigma of having a long-term condition and being observed by others in the workplace. Reflecting on how disclosure could have made her feel singled out, Diane indicated: *"I did not mind telling others what was wrong, but I was not really wanting to put a big flashing light on the top of my head … it is like pointing the finger again" (Diane E 62yrs).*

Hesitancy to disclose their condition was also noted by Kalirai (2016) when exploring interventions implemented to improve work productivity, in interviews with people with COPD. Individuals thought disclosure of their COPD would be interpreted as a sign of weakness, particularly in older workers (Kalirai 2016). Revealing a condition where there is a potential for stigmatising experiences, such as with the symptoms of COPD, might be threatening for individuals and negatively affect their self-esteem and be dependent on the work context. The stress caused in trying to hide symptoms in the workplace was also noted by some to be reasons for disclosing their COPD to others and another who would only disclose to colleagues if his COPD was clearly *"affecting his position or ability to do his job" (Zach SE 61yrs).* Another participant who had lost his job after a period of sickness absence due to an exacerbation of COPD, recounted his efforts when looking for another job. Joe recalled mentioning his COPD at an interview (for construction work), and it became clear to Joe that the interviewers were no longer interested in him, feeling they saw him as a liability. Conversely, he attended a job interview and did not disclose COPD and *"felt* *guilty as I never told them I had COPD" (Joe NE 50yrs)* making him feel worse. He subsequently did not commence jobs for fear of COPD affecting his productivity and being sacked, putting his family closer to the breadline.

Various perspectives on disclosure of COPD in the workplace are evident in the current study. De Jong et al. (2015), in a systematic review looking at quality of life of employees with a chronic physical disease, found that the non-disclosure of a long-term condition is a barrier that could prevent employers developing an awareness of an employee's condition, leading to unrealistic expectations being placed upon the employee. Bosma et al. (2021), in conducting interviews with occupational physicians and organisational representatives, found that non-disclosure of a long-term condition likely inhibits access to the specialist assessment and support needed to enable vulnerable employees to effectively maintain a workplace presence. Oldfield et al. (2016), in their interviews with women with fibromyalgia, found that illness disclosure was selective based on risk (if empathy was unlikely) and managerial trust (being marked as different from then on). Some participants in the current study articulated clear benefits in disclosing COPD in the workplace for theirs and others' benefits should there be a problem or others become concerned, although these are context dependent. For example, as Joe has no contract for employment and no employment rights, he is devoid of a platform to discuss and negotiate his support needs.

Discussing COPD in the Workplace

Discussion about COPD in the workplace came from several perspectives including colleagues commenting on symptoms, individual workloads and returning from sickness absence. Mostly colleagues demonstrated their concern for people with COPD, although less helpful examples were included. Workplace colleagues frequently asked after their well-being. As a way of showing concern and support, colleagues would comment on COPD symptoms of breathlessness by asking *"are you alright?" (Jeffrey RE 62yrs)* and pointing out a hacking cough *"that sounds terrible" (Debbie E 51yrs)* and after returning from sickness absence asking *"how are you getting on?" (Charles E 56yrs).* In one case, a supportive colleague pointed out breathlessness when aware of it by saying *"have you heard your breathing? I wasn't actually aware of it. It was like a rattle, and it's still like that" (Diane E 62yrs)* and *"oh have you been rushing to get to the phone?" (Rita RE 62yrs)*. When colleagues called the office and commented on Rita's breathless, she would reply:

> *"No, no, I was at the other side of the room", or "I had just been at the toilet and heard the phone ringing" or "I was just coming back into the office and heard the phone, and so you speed up to do those things" (Rita RE 62yrs).*

Rita felt that her colleagues knew the extent and impact of her COPD and had read her well, as she was indeed breathlessness without exertion, in the workplace.

Comments from others in the workplace situation were not always positive or encouraging. Colleagues made negative comments on seeing a colleague with a workload designed to accommodate lighter office duties as part of her reasonable adjustments making Julie *"feel guilty doing nothing compared to them, like she was sitting twiddling her thumbs with nothing to do … and asking for something to do as I have not got enough"* [which was a reduced workload] (Julie *RE 63yrs).* In addition, ambulance crew workers made negative comments about their colleague who they thought was *"trying to get his retirement"* [early retirement through ill-health] *… and was trying to work his ticket" (Colin RE 63yrs)*. Another employee [a veterinary nurse] was labelled as *"Teflon"* following a grievance meeting she called to formally request reasonable adjustments to her job and to have a stair lift installed in the workplace to try to prolong her employment *(Susan RE 45yrs).* She considered the derogatory term as unhelpful and was told that within the company she could not be *'touched for anything anymore'* as previously noted in the *'treated differently'* section above. Occasionally, colleagues were embarrassed by comments made towards individuals with COPD, as they often backfired not appreciating their colleague was disabled due to having severe COPD:

> *"Oh, you have taken the lift up one floor … and they realise that he is taking the lift because he suffers with COPD and chooses to take the lift*

> *because it does not put his lungs under strain going upstairs … then they are embarrassed" (Julian E 53yrs).*

Another participant defended himself with colleagues when he was given a lighter role as part of his workplace adjustments. In moving to a less manual role, he was focused on driving the forklift truck and no longer allowed to lift heavy loads. In the workplace he was faced with accusation of *"you are standing there with your arms folded while we are doing all the work" (Larry NE 49yrs).* This didn't make him feel good but defended it by saying *"you are paid to do the lifting and I am paid to drive the truck"* but did not feel he should have to justify his actions to his colleagues.

In addition to colleague comments, clients, customers and patients also asked after the welfare of participants in the workplace context. Knowing she had COPD, a patient being visited by community mental health nurse Debbie *(E 51yrs),* said: *"Your breathing … it is cold today … I will get you a drink of water"* felt supportive to her. Another example was with business clients who noted that Zach was breathlessness at work whilst walking briskly through an airport. His clients, who were all younger, dealt with the situation by stating: *"ah, it is just the old man is getting old" (Zach SE 61yrs)*. The clients were either making light of his breathlessness to save embarrassment or associated getting older with a lack of fitness and shortness of breath. No examples of colleagues discussing COPD in the workplace could be located within the COPD literature and therefore these findings further add to our understanding.

Employer Support for COPD in the Workplace

Participants generally felt there was a lack of support with regards to their COPD from employers and managers. Some participants thought the barriers to support were around employers and managers not understanding what COPD was or the limitations it may cause in the workplace. Others felt that the business and making money came first before employee health and well-being. Some participants had a balanced view seeing it from both perspectives, and others felt the employer overall was not supportive, but a few thought that managers were helpful at times. The converse was also apparent with other participants thinking that their employers were broadly supportive of people with long-term conditions, but some managers were being deliberately unhelpful or obstructive.

Most employed participants did not feel well supported by their employer or manager in the workplace and thought they were just another number and could be easily replaced. Some felt that the full impact of COPD is relatively unseen and not acknowledged like other conditions in the workplace e.g., cancer, pain or osteoarthritis (where there was potentially open access to chiropractor and physiotherapist); therefore, the employer was not interested in them or their respiratory problems. At times, participants could use this perspective to balance their feelings of commitment to their job or remorse for sickness absence for example by saying *"whether I am here, or you are here, the stores not going to fall down without us" (Charles E 56yrs)*.

Certain issues around parking locations close to work buildings had some feeling they were of little value to their employer and finding solutions to their issues were being obstructed by management. In Debbie's case*,* working as a nurse in a caring and compassionate profession was left wondering *"why no-one was giving a toss about the fact I was struggling with things (parking)"* and that the best she could get from the employer was her boss being told to *"send her somewhere else"* away from her team *(E 51yrs)*. This was despite her line manager trying to influence the employer to offer her better support and backing this up with a letter for reasonable adjustments from the Occupational Health assessment.

Attitudes expressed to participants by managers making individual requests for adjustments in the workplace had one suggest that employee was not alone in wanting things their *'own way'*, and that other employees have conditions that must be considered. This signalled resentment from management that certain employees could have concessions made for their workload or flexibility to their working patterns. Holland and Collins (2018) also found, in a study of people with rheumatoid arthritis, that there was co-worker jealousy for those with adjustments in place to the extent they were sometimes withdrawn. Reactions to colleagues in this way demonstrates a lack of empathy and willingness to work together to support those with long-term conditions in the workplace and might lead to sick leave or increased presenteeism. They may also lead to conflict in the workplace and further discrimination against those with long-term conditions. Further, negative organisational and managerial attitudes and practices, such as withholding flexibility in the workplace, might inhibit the implementation of workplace practices designed to help people sustain their employment. This could reflect a lack of management's understanding of the limitations of some people with health challenges and implicate the need for greater training and awareness to help them understand various conditions, and how to effectively enact more favourable and fair employment retention strategies for the workforce.

Several participants felt that in working with larger employers, making money was the prime focus and expressed this as *"let us get the job done, now, how is your health?" (Charles E 56yrs*). Meaning employee health and well-being was seen as a lower priority than making money and getting the work done. The employees felt working for small private employer would likely have people who cared more about individuals' health and well-being. For example, Harry (RE 58yrs) felt there were broad policies for substance misuse and psychological issues but little for long-term conditions in working with a large multi-national oil and gas company.

Susan *(RE 45yrs)* felt that her employer had no concept of how hard she worked on a daily basis, turning up at work and doing her job and trying to not let her COPD disrupt her workload. As she worked in a small team, any disruption would fall onto her colleagues. However, her goodwill and effort in not taking regular sickness absence or making too many doctor or physiotherapist appointments during working hours went unseen by her line manager. Instead, the employer was monitoring what she could not do in the workplace, e.g., mopping the floor and using cleaning chemicals, causing her concern that they were about to terminate her employment.

Consideration for the health and well-being of people with long-term conditions appeared important for many employers and managers according to some participants in the current study. One CEO stated that his company would seek to provide support for *"any employee who came to them with specific issues would be looked at and addressed to see what can be done to help" (Zach SE 61yrs)*. Others gave different examples of considerate managers and colleagues making a small positive impact on workplace experiences. Knowing how the cold weather negatively impacted on her COPD, Julie's *(RE 63yrs)* manager called her at home one snowy morning telling her not to come to the office that day and to work at home, as the boiler was slow to warm up the cold office. On particularly cold days, colleagues would turn the office heating up for her and have hot tea ready for her when she arrived at her desk.

De Jong et al. (2015), during interviews with individuals with a variety of long-term conditions, found they were fearful of asking for work accommodations or did not know how to go about requesting them. This was mainly due to communication at the organisational level being challenging. Hjärtström et al. (2018), in their interviews with the Swedish Public Employment Service, found that participants did not know how to request aids for their work or did not take time to request them. The successful and sustainable implementation of workplace adjustments rely on a supportive and transparent relationship between the employee and employer, with the employer fully understanding the limitations of an employee and the measures that would best enhance productivity outcomes. Bosma et al. (2021), investigating Occupational Health Physicians and organisational representatives on individuals with chronic conditions, found that relationship building, and trust was essential in developing a culture that can facilitate appropriate employee support.

Participants in the current study did not always have sufficiently open communication channels with their employers, which perhaps contributed to the feelings of mistrust and concern. In addition, short lines of managerial communication were thought to make efforts to implement workplace adjustments easier, as might working in smaller organisations (Bosma et al. 2021). Dorland et al. (2016), in focus groups with 29 cancer survivors and Occupational Health professionals, also found that the importance of the manager employee relationship was a key factor in positive employment outcomes. Therefore, short lines of communication with a manager with whom you have a good working relationship based on trust and concern may contribute to positive workplace outcomes. Holland and Clayton (2018) also noted in their meta-ethnography looking at navigating employment retention, that informal, local arrangements with line managers who could offer workplace flexibility might lead to better employment outcomes than going through more formal Occupational Health assessment channels. Either way, what is important is the need for a willing employer, cooperative and sympathetic colleagues and an employee who can effectively communicate their challenges and needs in the workplace (Holland and Clayton 2018).

There were several instances in the present study where participants raised points about the positive and helpful support provided by their employer as a whole or that they received from the managers who they reported to. Personal knowledge of respiratory conditions either directly (e.g., by manager having asthma), or indirectly (e.g., manager's father having severe COPD), made managers more likely to be empathetic and helpful in the workplace. Levels of manager understanding in these cases was high with commensurate levels of a problem-solving attitude (e.g., just do what you can when at work) and in sending employees for an Occupational Health assessment or facilitating the implementation of minor adjustments with ease. This can also be linked to the idea that people working with a larger employer felt managers might be less interested in an individual's well-being. In the Kalirai (2016) study, the interventions implemented to support productivity for individuals with COPD were often extended beyond the advice and guidance provided in the Occupational Health assessment. An example of this is in offering an extended break at work. This could be perceived as the employer being helpful and amenable to changes in their agreement, if required, to ensure productivity can be sustained at an acceptable level and to make the employee feel supported.

Charles' manager regularly checked on his well-being when arriving on night shift*,* knowing that he was often at work not feeling *"one hundred percent".* Having gone home breathless after three hours on night shift, his manager demonstrated appreciation for the effort made in getting to work: *"do not worry about it, you have made the effort to come in and done your best, and I can accept that" (Charles E 56yrs).* These actions made Charles feel valued and supported and felt his manager really understood his situation and his physical limitations, knowing he was working at his best some nights.

Bramwell, Sanders and Rogers (2016) conducted 40 interviews with employers and managers involved in supporting people with long-term conditions in the workplace. A key finding was that managers had to cope with conflicting demands in facilitating productive outputs and had to balance the needs of the business with those of the employee. Several important pressures were identified which influence the perspectives and behaviours of managers, including fear of the law, co-workers' needs, employee personality, discerning tangibility and questioning legitimacy, and having difficult conversations. This represents a complex set of factors for an employer or manager in managing and building relationships with an employee with a long-term condition and might be integral to the negotiation of what is acceptable and permitted in any workplace situation. In the current study, as in the example with Charles and other participants, there is extensive evidence of presenteeism, which is endorsed and supported by managers. This provides a perspective that employers (or managers) are prepared to support valued employees to remain in employment accepting they are working less than other employees (Kirsch et al. 2019; Igarashi et al. 2018; Holland and Clayton 2018). It is also highlighted by Garrow (2016) that presenteeism is both voluntary (an individual's interest and professionalism) and involuntary (cost of absence is too high for the employer, hard to replace employee and job insecurity).

Bramwell, Sanders and Rogers (2016) also uncover the important emotional challenges involved for managers in the support of those with health concerns in the workplace, who may experience guilt as a result of their decisions. It might be, that successful flexibility in the workplace for people with long-term conditions is partly dependent on the relationships they build with their managers, and how the manager copes with the emotional aspects of negotiating, implementing and enabling employee support. Successful employment outcomes, where workplace adjustments are required, may also rely on the manager being resilient in terms of their emotional awareness, values and ethics, as well as the employees seeking support, being resilient in self-efficacy and sense of purpose (Reich, Zautra and Hall 2010). What is evident from the examples in the current study is that the relationship between the manager and employee is important, and the manager’s role is crucial in facilitating successful employment outcomes.

Participants in the current study also felt supported through the medicals and physical assessments undertaken by Occupational Health services when referred to them. However, it was often more challenging for the guidance and workplace adjustments they suggested, to be accommodated and implemented into the workplace:

> *“They put me to Occupational Health and at that time Occupational Health was known for … if you ended up in Occupational Health you were going to lose your job. So, you withheld going to them as long as you could. But I met a very, very nice lady and she was exceptional. She explained to the ambulance service that this man is fine for light duties, such as driving the patient transport service… It did not happen” (Colin RE 63yrs).*

> *“This is what you, as a company, should be doing for your employee. HR refused to implement some of the Occupational Health company pointers. Things like, I would be expected to have more sick days and on bad weather days where I would have trouble walking in the snow, I should be provided with a taxi. There were a couple of items which they would not agree to. I just thought it was a waste of space* [asking for adjustments]*” (Jeffrey RE 62yrs).*

And for Susan, advised by Occupational Health that she could request a stair lift for her workplace:

> *“That is what the grievance meeting was about … I was told that I had to source my own stair lift. So, I had to do the legwork and find out who … does stair lifts* [locally] *and send it to HR for them to make the decision. I even looked into grants* [financial] *for them” (Susan RE 45yrs).*

Several participants in the current study accessed wider support from their spouse, Human Resource department (HR), the Jobcentre and the Citizens

Advice Scotland. Support was for financial, pension and job search purposes. In a few instances, husbands and wives supported their spouse by searching for benefits and financial grants to supplement the household income which was found to be helpful. In other instances, they were supportive financially if their spouse or partner had to give up working completely or reduce hours.

In some instances, work was noted to be helpful, particularly the human resource departments who would help with organising reasonable adjustments, Occupational Health medicals and pensions. Jeffrey found HR to be *"very helpful, to see which route would be best for him to go down"* and *"was sent straight to the insurance company"* for assessment for ill health retirement following a poor outcome from his Occupational Health medical *(Jeffrey RE 62yrs).* However, from the wider literature, (Hjärtström et al. 2018), there was less clarity around what Occupational Health services could offer working people with long-term conditions, as they were hard to access from an employee perspective. This might be because Occupational Health services are usually paid for by the employer for the purpose of ensuring people are fit and well for their work, and that they are the best equipped healthcare professionals to make proposals for workplace adjustments based on perceived and assessed employee capability.

Participants in the current study also praised the support provided by Citizens Advice Scotland (CAS) and felt they had been given practical advice and guidance to support the application for benefits including claiming PIP (personal independence payment) (CAS 2021; GOV 2021). Employee lack of awareness of what they are entitled to under the Equality Act (2010), was found to be poor in a survey of disabled people and people with long-term conditions in relation to work adjustments and support (Adams and Oldfield 2012). Although the report illustrated a greater awareness was evident in public sector employment due to more prominent policies, there was an overall sense of people not knowing how to take their requests forward or who to have discussions with. This reinforces the findings in the current study, that a greater focus is required by the employer and employee in highlighting the specific aspects of an individual's workplace situation and capabilities to help optimise employment outcomes through appropriate modifications.

Colleague Support for COPD at Work

There were some differing perspectives on the support received from colleagues. In some instances, colleagues were broadly supportive, but there were occasional examples of unkind comments.

Most participants offered examples where their colleagues were helpful and considerate towards them. Colleagues offered their support in a variety of ways including lending a hand and offering to help with workload, helping with heavy lifting or cleaning, and telling them to take a rest or break. This was particularly the case if they were breathless or struggling with something (e.g., carrying heavy weight, or wet or cold from the weather). Colleagues also showed concern by regularly asking how they were feeling or how they were keeping. Colleagues appeared more understanding and empathetic if they had some personal knowledge of COPD or appreciated the impact of the symptoms and the effort their colleague put into their work. This was also shown to be a factor in the qualitative study by Kalirai (2016), looking at feasibility of workplace interventions, who found that those who had similar personal health issues, better understood and appreciated their colleagues.

Most participants in the present study indicated that their fellow workers would help them out in the workplace if needed, although one participant noted:

> *"I actually felt relieved not to have to go to work and not to have … it is probably just me because I have never been one for saying, 'Can you help me? Can you do this?' I have always had an independent streak and admitting to people that you actually had something wrong with you I think was quite embarrassing" (Rita RE 62yrs).*

As she had always been the one to help others as part of her job, Rita recognised that not asking for help when she needed it held her back, although she was reluctant to seek support. On the other hand, Charles *(E 56yrs)* knew that colleagues would be doing extra to help him because they had been told to do so by the manager but did not feel under too much pressure:

> *"I feel they have to be … instructed by the line manager to go and give Charles a hand ... certainly if I asked my line manager, they would probably put somebody down to help me or just say look, we are tight here as well just do what you can" (Charles E 56yrs).*

Seeking or receiving support from others in the workplace further reflects presenteeism, indicating an individual is not able to fulfil their role completely (Kirsch et al. 2019). Boot et al. (2016) noted instances of presenteeism in people with depression, where a manager understood that productivity could be reduced on days when their health was bad. However, the more support people with COPD receive from colleagues, the more presenteeism will exist, and this may cause conflict with colleagues who have to take on more work.

Colleague support was also noted to be important for the participants in the Kalirai (2016) study exploring interventions to improve work productivity. Positive support in the workplace and helpful, sympathetic teamwork made for a more favourable situation to help improve productivity. Colleagues had, on occasion, offered to carry equipment for Colin, where fellow ambulance crew would jokingly say *"Goodness sake Colin, you are unfit, let me carry that for you",* as he was considered the old man of the station and *"I will do this, I will do that",* which he felt was supportive at times *(Colin RE 63yrs)*.

There was one instance where a participant felt colleagues were directly unhelpful and had a negative effect on him. Colin *(RE 63yrs),* who worked as an ambulance technician, was under investigation for respiratory symptoms and awaiting a firm diagnosis of COPD. His behaviour at work [avoiding heavy lifting and carrying where possible and sickness absence] was putting a burden on his colleagues and he knew they were saying he was *"swinging his leg"* [skiving or being idle and avoiding work due to illness] behind his back during periods of sickness absence. Colin felt there was a constant barrage of negative comments about his condition and behaviour at work:

> *"Yes, the weather is getting worse, the dark nights, yes, you will be going off* [sick] *soon Colin" and "oh come on Colin, I come to work with a cough and I can manage, what is wrong with you?" and "oh that is a hell of a*

> *cough you have got Colin, our staff can work with worse coughs than you" (Colin RE 63yrs).*

These comments were made from both colleagues and line managers and, whilst some were made in jest, they were hurtful to him. He felt there was nobody approachable at work, and he was bemused as to why they lacked empathy when they work in a healthcare context with patients with similar symptoms to him. Negative or passive working relationships were also found not conducive to having workplace changes implemented (Kalirai 2016). Conveying an understanding and empathy towards those enduring long-term conditions through the adoption of positive organisational relationships and a non-threatening culture, might contribute to improved employment outcomes to employed persons trying to maintain a workplace presence and be beneficial to employers.

Perceived Support Needs for Health-related Employment Concerns

Negative perspectives on the lack of practical job-related and financial support from employers and other agencies were recorded by the participants. Harry felt there was a general lack of transparency with regards to COPD and where and who he could get help from to survive if here were to give up work:

> *"If I'd appeared with other symptoms or whatever … an enlarged heart or cancer, there's a system in place for it, medicinally, financially you know. When I started this PIP thing to get help, I still don't see it* [COPD] *anywhere, I have got it, but I couldn't find anything, you know you could find cancers and various other things but no COPD" (Harry RE 58yrs).*

Some participants who had retired early were frustrated that the human resources department never followed workplace plans or sickness absence follow-up and just let them leave work with no support. Participants felt their employer had a duty not just to always put the company interests first but to look after all their staff with health conditions and *"help their employees as best they can" (Diane E 62yrs),* and *"do you know, there comes a point where HR should be looking after the staff, not the company" (Susan RE 45yrs).* There was also further thinking about employers having a responsibility to actively find out more about individual conditions and work with their employees to understand how to get the best from them for mutual benefit:

> *"The managers could look into health conditions more to understand what the implications are with having an illness and what the capabilities are of that employee to carry out their job role. Understanding illness would help the employer because they would know what COPD can do to you and what it can restrict you from doing" (Charles E 56yrs).*

This would, in some sense, bridge the gap between some basic knowledge and understanding the capabilities and limitations of each individual with a chronic illness. In bridging this knowledge and understanding gap, Susan felt employers would be able to construct the optimum workplace plan having determined what the employee can achieve and hinted at a trial-and-error process: *"Well, we could try this, or you could do that" (Susan RE 45yrs),* which, she felt, could potentially help individuals maintain their employment and have a longer working life. The support aspect was further expanded to indicate advice that participants would have benefitted from around their work life on specific employment and job-related options: *"Okay, so you can keep on working and here is what you can do, here is where you can go and anything like that" (Debbie E 51yrs).* Thinking back to when times were challenging, Susan thinks she *"should have demanded more from human resources and requested options from them and when they did not phone her every fortnight* [during periods of sickness absence], *demanded, well, why they are not doing that" (Susan RE 45yrs).*

Several studies investigating the support provided by employers in engaging with employees with several long-term conditions to facilitate job retention and re-integration are evident in the literature (Bosma et al. 2020a; Bosma et al. 2021; Pransky et al. 2016; Haafkens et al. 2011). Many active work reintegration programmes reinforce the points made by the participants in this study, including the need for managers developing a greater understanding of specific employee's needs and employers being more willing to work in partnership with employees to comprehend their capabilities and workplace needs. Partnership working appears key to determining the best plan for both the employee and employer to ensure the goals being set are achievable.

Pransky et al. (2016), also suggests that a de-medicalised and pragmatic approach could be taken to work out what is best for both parties in this situation. Left to flounder without appropriate employer support, many participants in the present study had poor workplace experiences and exited the workplace dissatisfied and sooner than intended. Although a de-medicalised approach to the implementation of appropriate interventions may be a useful default position, perhaps during the holistic assessment and provision of support for people with long-term conditions by healthcare professionals, perspectives of their employment challenges could be incorporated since employment is of great significance to individuals of working age. This might be beneficial to a public health approach where health and well-being optimisation, including enhanced workplace functioning, could be prioritised.

Employer counselling support specifically around sustaining employment with a chronic illness was also thought to be important for some participants in the present study. Some stated that they would have liked an independent person to provide them with the time and to discuss their employment and health situation and help them consider their options. Debbie felt that she *"just needed somebody completely away from it all. So, even if you felt like a 'greet'* [cry], *you could have that greet, and you know it is within these four walls (Debbie E 51yrs).* This was thought to be important where the employee was in the younger age bracket: *"somebody to touch base with or counselling for somebody as young as me, might be helpful" (Debbie E 51yrs).* This type of independent advice meant that individuals would not have to rely on family and friends to support them with their employment challenges and that they could access unbiased practical and psychological support separate from the workplace.

A wider perspective was also offered to suggest that employees with chronic conditions require help to consider options for work when they have to consider leaving their trade or industry:

> *"There are not many people out there to help you even consider it* [working with COPD] *because you do not hear about COPD ... if it was like about cancer or whatever, it is all around everywhere, but you do not see the severity of COPD it is like lethal, it will kill you. More help is needed to suggest things* [work activities] *to people because if they suggested it to you, they might try it. I do not know, it would be good if somebody could convince them* [the Jobcentre and potential employers] *to say yea this guy, he has got all this experience and he can go down to this site and do …" (Joe NE 50yrs).*

Participants felt that people with COPD have knowledge and skills (e.g., bricklayers, nurses), that could be developed and applied in other roles in alternative industries. They implied that if negotiation could take place to support them, this would prevent a loss of expertise, which might facilitate retention of employment. For example, Joe protests that:

> *"I can do things around the building trade, I can do all around the building trade, I can do the easy jobs and the hard jobs, but the hard jobs are really hard for me now and the easy jobs are probably really easy for me now" (Joe NE 50yrs).*

There was also a notion from some participants that having fewer people involved in workplace fitness and employment issues relating to chronic illness was better for individuals in order to provide a more streamlined approach. Short lines of communication were discussed above and may help this process. One employer was interacting between the general practitioner, Occupational Health Physician and the respiratory consultant, requesting letters and assessments before one avenue had been thoroughly explored; this was considered:

> *"Supportive in one way and interfering in another" (Jeffrey RE 62yrs).*

Returning to employment was considered a challenge, as his previous experience with the Jobcentre on becoming initially unwell left him feeling that they *"treated him like dirt" (Larry NE 49yrs)* as he had lost his job and there was nothing they could do to help him. Larry felt there was something missing from the system in terms of support.

Kaye, Jans and Jones (2011) recorded many reasons for employers not hiring people with disabilities. These included the costs of accommodations, being stuck with workers who could not complete essential job functions, lack of understanding of the condition and how to deal with their requirements and difficulty determining productivity (Kaye, Jans and Jones 2011). Despite these potential barriers to employment, examples provided within the current study suggest that individuals with COPD want to remain in employment and are prepared to make whatever changes they can to facilitate this. This should not be to the detriment of their health or finances. Further, that there is a need for employers to become more knowledgeable on the health and well-being of their employees and to seek wider support to enable them to do this. Having this appreciation of what affects workforce well-being will become more crucial as the population ages (Silvaggi et al. 2020).

5.6.2.4. Psychosocial Aspects

Four categories make up this higher order theme (Table 5.3): Emotional experiences; Feelings of stress; Anxiety and depression; Treated differently.

Emotional Experiences

Participants described a range of emotions and feelings from past and current employment experiences related to their COPD. Many experiences were associated with their experience of COPD symptoms at work. Emotions including anger, fear, frustration, guilt, sadness, embarrassment, stress, shame and worry were all noted in describing their reactions to workplace conversations or events.

Several participants reported feeling embarrassed by symptoms as a result of breathlessness and being generally unfit. This embarrassment was usually associated with breathlessness occurring in front of colleagues (or when they were unable to hide it) or it occurred in open-plan working environments with colleagues looking on: *"Colleagues could not help seeing it* [coughing] *and we were sitting in rows with people next to me" (Diane E 62yrs).*

Some participants felt there was an element of shame having colleagues observe them in a physically unfit state, especially the male participants working in predominantly male oriented environments such as the oil and gas industry or construction. The deterioration in their health felt more pronounced if they had been previously fit and healthy and were now *"peching and panting"* around the workplace in front of colleagues *(Harry RE 58yrs).* Or another participant, who was previously sufficiently fit to be part of a mountain rescue team, but now did not want others seeing *"I could not do what I used to be able to do"* at work *(Ivan SE 62yrs)* and was embarrassed by the way he now presented himself. Rita reflected back to when she finally ended her employment and had an exacerbation of her COPD:

> *"About a month later* [December] *I got really ill, and I wasn't well again until the March. What I did feel then at that point with being that ill for that length of time was relief that I wasn't working, because there was no way. I would have been so embarrassed to have actually been off work all that time, and I think I would have been off sick for that length of time, and I've never been off for that length of time before" (Rita RE 62yrs).*

In addition to embarrassment, participants also articulated wider perspectives on their emotional experiences relating to guilt, fear, anger, worry, sadness and in feeling demoralised. Participants expressed sadness and reflected back to a time before their COPD diagnosis and how different life used to be, as indicated here: *"let us just say that nothing's as good now ... as it was" (Harry RE 58yrs).* Feeling demoralised was also a feature of not being able to do what they previously could in the workplace whilst some claimed they felt guilty that colleagues would have to pick up further work if reasonable adjustments were implemented or they had periods of sickness absence:

> *"If I got a chest infection… I was off for weeks on end and that sort of played on your mind as well, the fact that if you are not there somebody else is picking that up* [workload] *to meet workplace demands at busy times" (Julie RE 63yrs).*

This played on Julie’s mind as she felt she was not pulling her weight compared to other colleagues.

Emotions included worrying about the future or dying from COPD, to anger and frustration that COPD threatens their job after building skills and expertise throughout their careers. Thoughts of dying are illustrated in the following quote from Debbie on the impact of COPD, particularly at a younger age, which affects everything she does as a community mental health nurse, and she is worried about the future:

> *“At times, it does cross your mind, Christ, will I die some day from this, do you know what I mean? It is because I cannot recover my breath” (Debbie E 51yrs).*

The examples discussed in the present study convey the sense that whilst COPD can slowly develop and the decline might be insidious, there are times when individuals question whether they can survive a sudden episode of severe breathlessness. Thoughts of severe episodes of breathlessness heralding their last breath was also captured by Clancy, Hallet and Caress (2009), who interviewed nine people with COPD. Although not related to employment experiences, participants in that study recalled thoughts of times when they were ‘losing their breath’ and how this induced fear and panic when breathless and one participant exclaimed: “you think, Jesus is this it?” (Clancy, Hallet and Caress 2009, p.82), similar to Debbie in the current study. These accounts reinforce how distressing breathlessness can be and the efforts Debbie was making to avoid these extreme experiences of her symptoms at work. If employers prevent the implementation of reasonable measures to improve the lives of those with health challenges, they may experience distressing events as described which again does not fulfil the aims of a work culture that promotes enablement of the workforce.

Feelings of Stress

Whilst some individuals were fearful of losing their job, concerns were also expressed around the impact that continuing to work was putting on their health and well-being:

> *"I think a lot of it is to do with the fact I am getting a bit older eh, and I feel as though I am slowing down a bit because I am aware that I don't want to put too much pressure on my body too* [due to stress of work] *because I am worried again about my job" (Julian E 53yrs).*

Julian was conscious about the job stresses on him and the need to balance the risks of working with severe COPD (fatigue and effort) with the benefits of working (money and occupation). This balancing act is also captured in the literature on health influences on early retirement by De Wind et al. (2013), when they interviewed 30 people who had retired earlier than planned. Good health influenced early retirement, as individuals thought they could enjoy their life whilst they were relatively healthy, predicting a future health decline. However, the pathway to early retirement was less clear but possibly influenced by personal finances and employer insurance and pension arrangements (De Wind et al. (2013). Similar influences and attitudes towards exiting employment are found in the current study indicating that the concepts of physical and psychological stress may be transferrable across conditions and work contexts. Several participants in the present study felt that stressful experiences in the workplace were detrimental to them and that they were not able to cope. Even a slight increase in stress and or workplace demands could induce a worsening of their breathlessness and cause them problems:

> *"If I am a bit breathless, I just take my time and get on with it, and I find that when I get a bit stressed, I get a bit anxious and I start thinking ... so I try to keep things on a wee bit even kilter" (Kim E 57yrs).*

> *"The previous chest infection just sits dormant and then the next thing it comes up again and then it manifests itself a lot worse if you are under a*

> *lot of stress at work and you know you put your body under more stress and pressure in a way" (Julian E 53yrs).*

> *"Look you know with the stress and frustrations of being a manager I canna cope with this managerial job or being full-time … I found that one had to go you know what I mean so …" (Charles E 56yrs).*

> *"It felt stressful. Like I say, I had to arrive really early because I could not rush. This is the thing, I felt I could not rush. I had to walk there slowly, at a decent pace, because this crushing thing started to happen" (Debbie E 51).*

Harry, (RE 58yrs), considered *'living two lives'* as stressful, because at home he could relax and be himself, whereas working on an offshore oil platform, where he had not disclosed his COPD, he felt he had to live up to the physical and mental demands of the job and manage his workforce. This caused him stress, as he knew he was not in control of his job and felt considerable pressure from senior management to meet demanding production deadlines and financial targets. Returning to the offshore platform after each two-week rest break at home caused him to feel some *"distress going back offshore" (Harry RE 58yrs)*.

Although pressure from colleagues was cited as a source of stress for several participants, the main sources of stress were related to parking issues when coming to work, the busyness of work and as a result of symptoms such as feeling breathless. Pacing themselves and controlling breathing were seen as strategies for preventing the cycle of stress – breathlessness – anxiety for some participants. For Julian, feeling relaxed with a loose chest was important for working effectively:

> *"When my lungs, when that is feeling … not as relaxed and I am tight you know … that then has an effect, but once I am in* [the workplace] *I get caught up with events and get going and push myself forward" (E 53yrs).*

Another participant noted that stepping down from a managerial role and reducing his hours to part-time [21 hours] considerably reduced his workload stress and pressure of being a manager:

> *"In terms of my work and all the stress and everything, yes, it is a lot better definitely within the change* [going part-time and dropping managerial role] *because I start at my start time and finish at my finishing time and do not do extra hours so not needing to worry about the place, you know what I mean" (Charles E 56yrs).*

Another participant spoke extensively about consciously and actively destressing from her workplace stressors in her downtime. This was achieved through undertaking relaxation activities including weekends away, playing scrabble, doing tapestries and upholstery, visiting salt caves and occasionally using essential oils. This provides some balance to her stressful working life and eases her symptoms:

> *"If I am stressed, 'Let's have a game of scrabble' he will say* [husband] *and he will get out his I-Pad so that the two of us can have a game of scrabble" and "whatever you can do to destress, I mean, we joined a class last week and that is for essential oils. We are looking at ways that we can use some of the essential oils that might help" (Debbie E 51yrs).*

Stress was caused by many work-related factors for the participants in this present study. Participants in the Mal'ouf (2016) study also learned to manage stress themselves and taking on a less demanding role and running their own company was considered less stressful than working for someone else. Reducing stress through making changes to role and responsibility might be a way to reduce work pressure, enabling individuals with long-term conditions to cope more effectively and balance work-life demands. In addition, employers could make better use of external resources in offering employees independent counselling opportunities for their workforce.

Anxiety and Depression

Participants stated that their work kept them mentally occupied and that the routine of getting out of the house or enjoying the social aspects of having company at work prevented them feeling depressed. Conversely, others felt that the pressures of work and the symptoms experienced in the workplace placed a burden on their mental health and well-being. Anxiety was noted by several participants as being caused by work issues. In some examples, work issues negatively impacted on individuals to the extent they were: *'physically and mentally drained' (Julie RE 63yrs)* and in some instances, work and COPD affected every aspect of their lives:

> *"It is a pretty serious thing to happen to someone and how it affects somebody's life and how it totally affects all aspects of your life and not just one aspect* [mental well-being] - *health wise as well" (Joe NE 50yrs).*

> *"I think everybody kind of thinks themselves invincible, that you'll be able to carry on, you do not expect something to creep up on you to that extent and stop you outright" (Brenda NE 50yrs).*

For other participants, the pressures from colleagues caused added stress, making their breathlessness worse due to being worked up about difficult workplace relationships. An example of this came from a manager who told an employee that his colleagues said they *"were all wary of working with you" (Colin RE 63yrs),* due to him being unfit and being breathless on a regular basis. Colin described a cycle of colleague pressure and the stress it caused which then this made the anxiety worse and, in turn, made his breathlessness more pronounced. In other examples, participants felt greater anxiety in trying to hide the symptoms of COPD from colleagues in the workplace: *"well it causes even more anxiety trying to hide it" (Debbie E 51yrs).*

Participants also spoke about being dragged down in mood by symptoms and working with a persistent cough that subsequently caused broken sleep had a knock-on effect on tiredness at work during night-shift work. *"My mental state* *was such that I was bordering on depression, and I had just had enough" (Colin RE 63yrs)*. Other participants questioned their fitness to do their jobs in their entirety as a result. One participant, who used oxygen for up to 10 hours every day, noted the support received from colleagues as a result of their close team working relationship that was needed in a stressful security role. The following excerpt illustrates Julian's understanding of the effect of hypoxia on his mental state and how his colleagues perceived his mood:

> *"You do not work close with somebody ... with every nick-knack and argument … and they know when I am not firing on all thrusters, they know when I am feeling blue and vice versa and there are days when I am in work and feeling a bit down. COPD does affect the brain because of the lack of oxygen, that is the problem and unless you understand it you have no idea you know" (Julian E 53yrs).*

Julian suggests the need for working in a close supportive team and for transparency with colleagues understanding the challenges people with COPD have in the workplace. Feeling anxious or stressed prevented him from working effectively in his high-pressure job, and it was of concern to him and his colleagues that him feeling stressed was not conducive to good outcomes for any of the team because of the critical nature of the job they were doing.

Participants considered the role of employment in providing occupation and keeping their minds active important for protecting their mental health and well-being. One participant, who was close to ceasing employment, had concerns about what it would be like when he leaves work. In the following example, he ponders over the prospect of no longer working and his mood being affected:

> *"There are days when I am not working and I am sitting there and not sure if I am bored, or lonely, or fed up and I am sitting there all day, and it is peeing rain and it is wintry and I think to myself… Oh God, could I do this seven days a week? That is what I am holding onto because work gets me out of the house and keeps me going mentally" (Charles E 56yrs).*

Another participant concurs with the perspective of work providing occupation and motivation and emphasises the isolating nature of COPD as a result of losing his job and routine:

> *"I have turned night into day and I stay awake all night and I sleep during the day you know it is just a cycle I did not want to get into and living in an environment like this in a block of flats, there is not much to do is there, there is no place to go, but what do you do?" (Joe NE 50yrs).*
>
> *"How have I gone from being this person that works 12 hours a day without any problems to not being able to go out? It is unbelievable, it gets you down and depressed. It locks you away from other people because you do not want to tell them you have a problem, it is difficult. Where do you go with it all? What to do with it all?" (Joe NE 50yrs).*

Although there is extensive literature on anxiety and depression in COPD, there do not appear to be studies addressing it in relation to employment (Marsh and Guck 2016; Yohannes and Alexopoulos 2014). Yohannes (2021), notes that around 40% of people with COPD have depressive symptoms and 36% exhibit symptoms of anxiety which potentially challenges the work ability and employment experiences of participants in this study. The societal lockdowns and social isolation required for shielding during the COVID-19 pandemic for those with long-term conditions, may also have had deleterious effects on the experiences of anxiety and depression for those with COPD, and in relation to their employment. Indeed, many may have, or have not been able to switch their working roles to working at home depending on their job type. However, clearly many will be employed in roles that are not amenable to home working. This present study adds to the literature in helping to understand the effects of anxiety and depression in employment contexts and how work, or the lack of it, might affect people with COPD's mental well-being.

Treated Differently

Stigma and discrimination were raised by participants as a result of how they felt they were treated because of their COPD. Stigma was noted by some in relation to having an illness like COPD and articulated that they *"felt a bit, ah you know, I have got an illness type thing … it is like a stigma really you know" (Kim E 57yrs).* Another gave a general illustration of how being registered disabled and having a blue parking badge was of no benefit to him as he *"refused to use it when parking in town or at work" (Charles E 56yrs*) because he did not want people he knew to see him as disabled as he felt *"deep down there was a stigma"* attached to having an illness like COPD. Others refused to wear masks at work on a construction site or factories for fear people would be looking and wondering what was wrong with him. This suggests that participants did not want to stand out from others or be treated differently.

Discussion around discrimination stirred up feelings of anger, although varying perspectives were offered as contributing to these feelings. Participants commented on experiences such as feeling singled out or considered different and feeling isolated and segregated from colleagues. For some of the participants, their main issue related to parking close to their workplace and experiencing the challenge of not being able to park their car within a short walking distance from their workplace building. This caused problems at the start of the day and when they went out to visit their clients. Diane, a social care worker, felt she was being discriminated against by the response to her request for favourable parking. This parking concession would prevent her having a long walk to work which could leave her feeling fatigued, cold, wet and breathless in the morning. Diane reported that requests for a parking space were blocked by management, which was based on her having mild COPD and not being officially registered as disabled:

> *"They were making my life difficult because I had a disability is bad ju ju and I did not know if it stopped at that level* [of management] *or not as she never took it any higher … it is still raw" (Diane E 62yrs).*

As she was working for a local council with publicised flexible working policies, she thought they *"should help their employees as best they can and not be blocking them and making their lives difficult' (Diane E 52yrs).* Another participant gave an illustration of being refused permission to park closer to her workplace, which was a considerable distance away from the car park. However, she later indicated that she did not feel she had suffered from any type of discrimination. She was reluctant to label her experience as direct discrimination, although she described a situation where she was overtly treated differently to others by her senior management and her line manager was told to *"send her elsewhere to work" (Debbie E 51yrs).* She articulated these feelings as *"I was seen as some sort of leper that I could not work with my team* [in the same location]*" (Debbie E 51yrs).* Her employer expected the entire community nursing team to relocate to an alternative building to overcome her parking difficulties. This request drew further attention to her and as a result, there were numerous back and forth requests from her line manager to senior management, making her feel like *"an object of scrutiny" (Debbie E 51yrs).* Feeling an object of scrutiny and being treated like a leper made Debbie so exasperated she cancelled the parking request: *"Oh for the love of God, just stop it. I will walk. I would rather die than keep doing this" (Debbie E 51yrs).*

These unfavourable examples cast some light on issues that could appear to be relatively simple and straightforward for employers to resolve but are blocked (by e.g., Social care department with a local council and an NHS Board), potentially making the working lives of people with COPD more difficult. Stigma is represented in the COPD literature although not related to employment. Sixteen participants were interviewed in a qualitative descriptive study by Berger, Kapella and Larson (2011) to explore the effects of COPD on social relationships and experiences. Participants noted that people with COPD were almost treated like 'lepers' and unlike those with any other illness as people spoke about them in a negative way behind their back (Berger, Kapella and Larson 2011). The use of the word 'leper' was raised several times by participants in the present study. This occurred in different workplace contexts, and they referred to it with disgust as that mirrored how they felt they were being treated. This clearly had a negative impact on their psychological well-being and forced them into potentially stigmatising situations through exposing symptoms and limitations. This type of practice would seem to further discourage illness disclosure and prevent individuals gaining the appropriate support to help maintain a workplace presence.

Another extreme account of being treated differently was offered by Susan, who was physically separated and isolated from her colleagues in a work environment with no accessibility to the upper floor of the workplace. As there was no elevator in the building, stair climbing several times a day to access the staff area upstairs, was a barrier to her being integrated with her team during break times and for staff meetings. Her colleagues located to the staff room at break times, and she was left in a tiny partitioned-off area on her own, in a downstairs office. Feeling totally segregated by this arrangement she explained that *"it was awful. So, that is a whole hour at lunchtime that you are completely isolated and segregated, so it makes you stand out like a sore thumb" (Susan RE 45yrs).*

A grievance process was instigated by Susan to try to acquire a stair lift so she could gain access to the upper floor but, following this process, she was labelled *'Teflon'* by her manager. The implication being that she could now get away with anything she wanted (as she had requested reasonable adjustments) and nothing would stick. These examples provide some understanding of how simple and practical requests by those with COPD could be construed as major issues by employers. The subsequent barriers put in place make working life more challenging and single people out and appear to treat them differently from others. This resulted in Susan having feelings of isolation, resentment and discrimination and did little to foster effective working relationships with her employer. Whilst some employers might have felt they were being helpful by suggesting practical measures for their employees, there is a need for employers to have an awareness of the impact of their suggestions and support, and the outcomes from workplace adjustments should these potentially have negative implications for the employee. The negative outcomes from poorly thought through adjustments may have a more negative effect on those with long-term conditions than not implementing adjustments in the first place.

5.6.2.5. Financial Aspects

Two categories made up this higher order classification (Table 5.3): Financial challenges; Financial solutions.

Financial Challenges

Financial concerns were around regular income, pension shortfalls and social security and disability benefits. As all participants had either dropped to part-time hours, retired early through ill health or were facing that prospect, discussion of their fears of paying for the basics such as food, housing and utility bills were common. Participants less commonly discussed the financial aspects of hobbies, leisure and travel. Although participants were not asked directly for details of their financial status, many spoke about the fears that having a career limiting condition had created on their financial situation. Participants described their financial status in terms of money being a *"hellish worry" (Harry RE 58yrs)* and *"money was a very big worry" (Charles E 56yrs)*, "money is *a serious worry ... and if I reduce hours, I will drop a pay grade" (Debbie E 51yrs)* and that she had been *"feeling very apprehensive about finances initially"* before retiring early *(Diane E 62yrs)*.

Many participants had changed roles or jobs in the workplace or reduced hours and had lost out financially in income as well as pension contributions, meaning they were less well-off financially in both the short and long-term. Taking early retirement and claiming a pension earlier than planned due to ill-health would disadvantage individuals financially both in terms of lump-sum entitlements and reductions in monthly pension income. The thought of part-time wages or giving up her wage entirely was a serious worry for Debbie who described her nurse's wage as *"not fantastic at the best of times" (E 51yrs)* and, in addition, she was still looking for a mortgage to buy a home following her recent marriage.

Several participants commented on not knowing where to go to seek financial advice, particularly with regards to the impact of their COPD on sustaining employment. Some referred to having no household income for long periods of time because they were caught between the process of becoming registered *'disabled'* and not yet entitled to disability benefits, nor able to maintain their usual work or secure employment of the type they were experienced in. This happened for Larry (NE 49yrs) who had worked as a forklift truck driver and Joe (NE 50yrs) who worked in heavy construction.

Alternative types of work were not available, and Larry's wife became his carer, as he lost his job due to ill-health; she accessed a carer's allowance in order to support her family (Larry NE 49yrs). His COPD deteriorated quickly thereafter, and he required a lung transplant. Losing his job and having a reduced income meant the family had to sell their home to pay off accumulating debts and they moved into a council house. As this happened at the age of 45, Larry had not had time to build up savings and had young children, so the poor financial outcomes seemed to him to be particularly punishing. This was similar to Oliver's experience of losing his business and becoming homeless as reported in the pilot study.

Fletcher et al. (2011) in a large multi-national study found that those with COPD have considerably reduced lifetime incomes mainly due mainly to early retirement and that the majority of participants were concerned about their financial situation. Boot et al. (2016) also noted that work was considered important for income in those with osteoarthritis, depression and cardiovascular disease, which also concurred with the Rai et al. (2017) study on people with COPD. This suggests that the younger the employee with COPD, the more urgent their need is to gain support to maintain their job and income, in order to limit the risk of low incomes in the future.

However, single parent commitments motivated some women with COPD to sustain their employment longer in the Mal'ouf (2016) study to remain in employment. Irrespective of the motivations people have to remain in employment, physical well-being and employment type appears to have a considerable influence on an individual's presence in or exit from the workforce in this study. Also, people with COPD are likely to be at greater risk for and experience the most serious effects of the SARS-CoV-2 virus if infected (Sunkara et al. 2021) and might be disproportionally impacted financially due to working in sectors unable to work at home or sustain their jobs (e.g., manual labour or personal services) pushing them into, or further into poverty (Francis-Devine 2021).

Financial Solutions

Participants deliberated over the financial options available to them and their family including cashing in pensions early, relying on spouse's earnings, applying for PIP (Personal Independence Payment), employer insurances and social security benefits. Some participants were able to leave employment at a time suitable to them, as they were financially secure or had accrued sufficient funds in their pension to ensure they would be financially comfortable in their retirement. There were examples of individuals accessing their pensions 12 years before they had intended (e.g., at age 55 rather than age 67) and paying off their mortgage and others having invested in additional property and having that income to fall back on if needed. Being awarded PIP, tax credits, carers allowance or claiming AVC's (Additional Voluntary Contributions) also provided extra income for some participants. One participant spoke about the process of applying for PIP and going part-time:

> *"Did a bit of digging, filled out all of the forms and scored 'top marks'* [meaning COPD had a considerable negative impact on health] *and I got the full PIP payment. Having the pension and the PIP every month is a really big help. That gives us piece of mind as well that the mortgage is paid off … so you know you've to cut your cloth to suit and I was probably £1000 a month pay cut, so it is a lot… and you need to manage it but the money helped take a lot off my mind" (Charles E 56yrs).*

Spousal support in relation to financial security was an important factor for several of the participants ceasing employment, retiring early or reducing their hours. Spouses provided financial support for their family and were often able to supplement the household budget with earned income or additional savings and pensions. Larry noted that: *"the financial side of it was a challenge and for years my wife worked part time because she was my carer and she got carers allowance as well as her wage" (Larry NE 49yrs)*; and from Joe: *"well, what we live on now is my wife's earnings, some tax credits, some working tax credits which we get it since March this year and there's nothing out with it" (Joe NE 50yrs).* Harry also considered his wife's contribution to the household:

> *"It's my job to look after everybody and I did that, but now it's a role reversal and we live on my wife's wage, and that's it … we canna pay a phone bill or a gas bill out of that and they have to come out of anything we've got stashed" (Harry RE 58yrs).*

Financial security enabled some participants to work part-time and not be under pressure continuing full-time. Other participants were working towards having pensions to look forward to ensuring they would be financially comfortable, which reduced the pressure on them in continuing with their employment. Julie made an agreement with her husband that she would work part-time until the end of the year of her 64th birthday: *"so we could bank some more money for our retirement" (Julie RE 63yrs).*

Spouses also provided psychosocial and practical support: "*My wife has been very supportive, very helpful and she's looked into a lot of things for me and nothing was too much bother for her. So I couldn't ask for anyone better…" (Charles E 56yrs).* Financial challenges affect the entire family of a person with COPD and the psychosocial and financial support from a spouse appears to be crucial in maintaining financial stability and through the process of planning changes in working patterns and managing their lifestyle.

Some participants in the Mal'ouf (2016) study also felt that as they had worked in low-paid roles they were financially poor in heading to retirement, whilst some participants in the Watson (2015) study found their previously poor income from working was less than the state benefits they then received when retiring early. For some individuals, leaving employment meant they could create a more financially stable existence if social security benefits are higher than their previous wage although this was not a finding in the current study. This financial opportunity would appear to encourage people with COPD to leave the workforce earlier than they would have planned and although they do not miss the financial benefits of employment, they lose the psychosocial aspects of occupation, camaraderie, satisfaction and contributing to society.

5.6.2.6. Employment, Retirement and Unemployment

Three categories made up this higher order classification (Table 5.3): Ending employment; Reflecting on leaving employment; Future employment plans.

Many of those in employment offered accounts of issues currently of concern to them including health and financial and employment contract aspects. Those who had left the workforce expressed regret at no longer being able to work and the events that contributed to them leaving the workforce. Several references were made by those reflecting on their situation in regard to ending employment and becoming unemployed (through not being able to continue in their job) or retiring early (either voluntary or without choice). These reflections were mainly centred on psychological relief and loss. The findings from those no longer employed are presented first followed by those who are employed.

Of the participants not currently employed, seven had retired early and three were open to future work options. Retiring early meant the participants had either retired from paid employment before they intended to or retired before they could claim the national state pension but had personal pensions and other finances to rely on. The process of leaving work was either made on a voluntary basis as a preferred option or in having no other choice because of the participant’s physical health or practicalities related to the job or environment.

Ending Employment

Several participants who had left their employment expressed a desire to have maintained their workplace presence for a longer period of time. Some noted they would have wanted to have continued working, partly from a financial perspective and also because they enjoyed the work they did. Anticipating that there would be imminently no choice but to leave work due to their deteriorating health, a few participants left work as they suspected their employer was going to end their contract, which might have left them with fewer options for the future (e.g., no part-time or ill-health pension):

> *"My health was deteriorating and if I had not gone on the sick in 2012 they would have terminated my employment and I would not have got any pension, I would have got nothing because I would no longer be an employee" (Susan RE 45yrs).*

> *"The only ones that were part-time were pregnant women. I spoke to the ambulance services to say that I did not want to retire and wanted to go onto patient transport services, they made it very difficult. Mainly because if I went onto that side of it on health grounds, they would have to pay me my full salary for two years, which they did not like doing" (Colin RE 63yrs).*

The contribution of employment in providing a purpose in life is well reported in the general literature (Taylor 2017; Black 2008) and in the COPD literature (Masters 2018; Rai et al. 2018; Boot et al. 2016; Palmer et al. 2015) and in those with dementia (Chaplain and Davidson 2016). In some examples in this study, the continuation of employment creates a focus for individuals and enables a distraction from their condition or symptoms.

The ending of employment earlier than planned came with some regret for some individuals and was often preceded by Occupational Health medicals, exacerbation of their COPD or long-term sickness. Annual medical examination where certification on work fitness is required by the employer for health and safety purposes for the worker to continue in an offshore environment, was the main driver for one participant who was:

> *"Sure, his employer would see all aspects of his medicals and survival course efforts and so I got out before it was a case of … forget it! … but I have been a stupid boy* [being a heavy smoker*] and you can see I was buggered and eh … I had to cut the line" (Harry RE 58yrs).*

In addition, suspecting that his contract would be terminated soon, Harry reflected on the impossible task he had relating to the offshore safety and survival course he must complete every two years. He described in detail that he was to be submerged underwater in an open side vessel and hold his breath and escape fully clothed in a fire retardant and waterproof suit. He recalled:

> *"I have been at sea all my life and I am terrified of water, I canna swim and trying to hold your breath … and going under, and the rebreather nonsense and I started to panic the last one, 'dinna panic ... dinna panic' and I knew there was no way on this earth I could do it again, in this,* [pointing to chest], *cause you're meant to breathe and I cannot breathe, even properly so it … it would have turned into a farce in front of the whole class and instructors … and I was not willing to play that game" (Harry RE 58yrs).*

Colin *(RE 63yrs)* requested a move from a high-pressured emergency ambulance technician role to patient transport services, which was refused, and he subsequently left his employment early on ill-health grounds. Jeffrey attended an Occupational Health medical following a period of sickness absence due to a COPD exacerbation and was told by the doctor "do not go back into work" and he considered: *"When I got so breathless, I knew then it was time to go".* (Jeffrey RE 62yrs).

Some of the participants in the COPD focused study by Masters (2018) were employed in physically demanding roles and worked long, anti-social hours often with toxic fumes. In these instances, leaving work was perceived positively as work had offered them little satisfaction or financial reward. Leaving employment that has been physically hard, in job situations with little actual or perceived employer support and COPD causing declining health, may bring some relief to those who have struggled such as Colin and Susan.

Bosma et al. (2020a) suggests that all stakeholders involved in an employee's well-being should share responsibility for pro-actively identifying barriers and opportunities for employees with chronic conditions to gain employment support. They also indicate that Occupational Health Physicians should be involved as early as possible in helping to address the barriers to securing tailored advice and supporting the development of interventions aimed at helping those with chronic conditions stay in work (Bosma et al. 2020a). These suggested proactive actions could have potentially prolonged employment for many of the participants in the current study.

When Susan was undertaking heavy veterinary nurse's duties, she asked to do more support in nurse education or alternative roles but got no buy-in from her employer to do so. The final realisation that Susan could not continue in her job came when she found out her employer was monitoring what she was '*not doing*' in the workplace (e.g., heavy lifting or cleaning which involved manual work and the use of noxious chemicals) rather than what she was capable of doing, which was all other workplace activities and tasks. She found this concerning:

> *"I got wind that they were starting to track the things I could not do, not what I could do, and if they could put forward that I was doing less than 30% of my actual job, they could terminate my employment. If proven, I would have walked away with nothing as I was under 55 and could not take normal early retirement. So, I would have got nothing, which is why I pushed for the ill-health retirement" (Susan RE 45yrs).*

Feeling under scrutiny in the workplace was discussed by Chaplin and Davidson (2016) in relation to individuals with early dementia. Participants who were interviewed in that study felt they would have preferred to have been consulted about the process rather than being watched by their employer covertly (Chaplin and Davidson 2016). The covert nature of being watched in the present study, and hearing this second hand through colleagues, was not conducive to a shared partnership between Susan and her employer where they could proactively work together to enhance her capabilities through consultation and trying out various adjustment options. For Susan, this way of monitoring bred further mistrust in her employer and was not conducive to building a supportive relationship. Being unable to keep up with the physical job demands and colleagues and feeling forced into early retirement because of their COPD is not uncommon, and this can be found in the study of COPD by Masters (2018). Other studies confirm these findings, although the evidence is unclear on the exact variables involved (Wacker et al. 2016; Fletcher et al. 2011; Clancy, Hallet and Caress 2009). The participants in the examples given above wanted to continue working, albeit in situations more favourable to their capabilities, but little support was provided by their employer. These findings illustrate a lack of employer understanding and willingness to accommodate those with COPD. Employer support, as discussed throughout this thesis, is crucial to positive employment outcomes in most instances.

Several participants intimated they had left work voluntarily and at a convenient time due to their COPD because their individual circumstances allowed. Another participant left his job at a heliport as he was surrounded by aircraft fumes making him more breathless and requiring inhalers 7 to 8 times per day.

Individuals with COPD can attribute having to leave their employment due to their worsening COPD affecting their ability to undertake their job, which when balanced with risk of continuing, gives them impetus to leave. Watson (2015) also found in interviews conducted with people with COPD that their respiratory problems contributed directly to them leaving their jobs which involved substantial talking.

Brenda *(NE 50yrs)* accepted she could not carry on with her dog boarding business as the winter months were punishing for her. An opportune change of circumstances enabled her family to move to a warmer climate with less troublesome winds. She reminisces on her decisions and the end of her dog boarding business:

> *"The house was right by the sea and there could be days when it was not windy, that would have a cold wet haar* [cold sea fog] *which was difficult too … my husband needed to move south for his work, and the final trigger to make me accept that we had to move was my health, it came down to that. I kept trying to work out, oh there must be ways that we could do this, but no, I had to accept that I could not carry on with the job I was doing" (Brenda NE 50yrs).*

The working environment was clearly a major driving force for Brenda giving up her career, although other participants had different motivators including one who became a house husband to look after his children, leaving his supermarket job as his wife became the breadwinner. Mal'ouf (2016) also found that individuals with COPD would reallocate life and work priorities and use their time and energy for things that were important to them.

Some industries, such as contracting jobs on building sites, had managers who did not appear interested in employing workers who had a long-term condition, and after a short spell of sickness absence Joe was told not to return to the site. He felt disposed of by the employer because of his COPD as word had got around he was not keeping well and felt they just *"want to get rid of you" (Joe NE 50yrs)*. A key reason for this could have been a belief that the worker is not able to do the job (Kaye, Jans and Jones 2011). Other potential reasons for employers not retaining employees with long-term conditions were around concerns of them becoming liabilities and costing the company money as a result of workplace adjustments and a lack of understanding of what the worker's needs are (Kaye, Jans and Jones 2011).

A few of the participants recalled the leaving process and how it materialised. Some had offered or been given notice periods of three and six months by their employer. One managed to work 10 of the 12 weeks' notice offered by the employer before the employer terminated his contract due to sickness absence, whilst another worked a six-month notice period, which she regretted. She wished she had left months earlier, as it was a struggle to get to the end point, which correlated with payment of a superannuation pension and her birthday. One went off sick and didn't return to her employment and another received no financial payment after working 16 years with his employer:

> *"Erm, quite demoralising, you are not able to do the job you are doing, and you know that they are looking to see whether they are going to be able to find you something else … eventually I was told that there was no role for me … and gave me 12 weeks' notice end of contract ... so it was not even a case you know you have got 12 weeks' notice and then you can go, it was a case of I worked 10 of the 12 weeks, there was no payments … and that was after 16 years full service" (Larry NE 49yrs).*

Those participants were disappointed that the experiences they had at the end of their working lives were not ideal and felt some angst in this respect.

The ending of employment can be a sudden and traumatic event as experienced by Joe and Susan. Although they are very different in their contracts and professions, both had little time to plan and prepare for a loss of job and income. The traumatic cessation of work was a commonly reported theme in a systematic review on employment in people with dementia and mild cognitive impairment conducted by McCulloch, Robertson and Kirkpatrick (2016). This traumatic cessation also had financial, emotional and interpersonal consequences for the individuals involved. Bevan et al. (2018) also note that retiring from employment is now more of a process than a specific event, and that individuals often transition through stepping-down stages to leaving employment. This is thought to involve psychosocial planning and practical actions. Participants in the current study were unable to take advantage of this approach, which was unfortunate as they were both at a young age. This disadvantage caused financial hardship and a psychological impact; support offered to those with deteriorating lung function should include practical and psychosocial support to help them transition.

Reflecting on Leaving Employment

On reflecting over their employment coming to an end, participants felt a relief in that stopping work gave them the long break they needed from relentless working but also a regret at losing a social aspect from their life. Finding a convenient end point to employment was important for a few individuals and was commonly aligned to the end of the calendar year or a birthday as a landmark in time. Julie reflected:

> *"I half expected to be walking out the door, because I had been there 22 years, and I thought I am going to be so upset, and I walked out of there and it was just such relief, such a relief and never regretted it, not for a minute. It is just all the pressure has gone" (Julie RE 63yrs).*

Julie noted that her health to have improved instantly on retirement as she found she could pace herself better and not have to rush, and the day ran on her terms rather than her employers. Another participant recorded how she was unwell after retiring and would have had an extended period of sickness absence if she had continued in employment.

Looking back on their employment, many participants noted that they missed the people at work and the buzz of the social interaction, and a participant noted that retiring early form work *"was a bad day … Very tough"* as he felt he was *"giving up a huge chunk of his life and a job he enjoyed very much" (Jeffrey RE 62yrs).* The final decision was not his and came from the Occupational Health Physician who had reviewed his medical assessments and considered him not fit to undertake his job. He had previously changed roles from one where he was breathing in aircraft fumes each day to a more health and safety related role where he had a lot of talking with people face to face and by phone, indoor and outdoor walking and stair climbing. Whilst the employer had been accommodating with his requirements to a point, they ran out of workplace options, and he was still challenged by the demands in the workplace and environment.

Another participant had his employment contract terminated, as the lighter duties allocated were not sufficient to help him, and he felt this was the best and worst experience that had ever happened to him. For Larry, the loss of his job was:

> *"Devastating, when you have worked all your life you know and then you find you cannot work, I miss the financial aspects, the camaraderie, comradeship of working with people … because you become quite isolated when you are ill and just actually having something to do … I am not bone idle and I fill my time quite well now, but it is not the same as working" (Larry NE 49yrs).*

Larry noted here the camaraderie he previously had at work and clearly missed the social interaction of the workplace. His feelings of needing something to occupy him and be involved in activities was important and is also reflected in the COPD focused studies conducted by Masters (2018) and Mal'ouf (2016). Participants in these studies also felt that work gave them structure to their day and purpose in life and that they enjoyed interacting with their colleagues so did not like it when they had to work from home (Masters 2018; Mal'ouf 2016). Even when leaving employment is the best decision for an individual at a given time, they might still recognise what they have lost and have regrets about it.

Reflecting further on the loss of his job gave Larry mixed feelings, as his family subsequently had to sell their house to pay off their debts, as the family income had substantially reduced. He also considered it inevitable that, shortly after leaving work, he experienced a severe exacerbation and became sick enough to be placed on the lung transplant list (*Larry NE 49yrs)*.

Future Employment Plans

Of those still in employment, most agreed that work took a lot out of them in terms of energy and physical effort. The re-evaluation of life priorities balanced with income was important for many. Health was put into perspective for Debbie when considering the pressure that continuing to work with declining lung function puts on her body:

> *"I was always going to take my pension, even before this health issue. I was always going to do that because a lot of my colleagues have never gotten the good of their pension* [as they had died young]. *So, I had always intended to leave at fifty-five, but this kind of puts it into perspective for you because I know I am putting pressure on my other organs" (Debbie E 51yrs).*

Most employed participants wanted to remain in employment, although they had thoughts about how their employment and retirement plans would play out in the future. A few expressed their wish to continue working as long as possible but accepted the challenges that working with COPD brought them and anticipated that they would likely retire from their job earlier than expected. Reducing either the amount of work they took on *"I am trying to do as little as possible for as long as possible"* (*Ivan SE 62yrs)* or reducing the number of hours worked or *"offering flexible hours"* (*Zach SE 61yrs)* were options available to certain workers. However, it was unclear as to whether this was to reduce the impact of work on their COPD or to reduce the impact of COPD on reduced productivity, or perhaps both. Another participant had a clearer plan to retire within the next year knowing that having been previously advised by his doctor to give up work, felt that he *"just had to fight on"* (*Charles E 56yrs)* and that fighting on was also dependent on the quality of his sleep.

For one participant, the end to a nursing career appeared imminent in the next year because of the COPD deterioration. Debbie had planned to retire at age 55 and then work two nights per week to supplement her nursing pension, but that plan *"had all changed in the blink of an eye" (Debbie E 51yrs).* She was mindful of wanting to enjoy her retirement and considered working as placing a strain on her health due to her stressful role and the additional stress she had experienced caused by a parking issue. Participants deliberated their concerns about maintaining their job and that they would retire if their financial situation allowed them to, but knowing they were still capable of doing their job. Others prioritised whether they were able to sustain their role effectively into the future on health grounds. One was forced to leave her job and secure another because of the parking difficulties faced and the poor level of support from the employer.

Finally, Larry, who, having had a lung transplant and several years of pulmonary rehabilitation, finds himself returning to employment following successful lung transplantation and thinks:

> *"He has a lot to lose to get back into work. Looking for a role where I am earning enough to cover what I will lose as well. Could not lose everything I have* [social security benefits] *for 15 hours pay, so really need to get a reasonable amount of hours before I could even think about a position" (Larry NE 49yrs).*

Fadyl et al. (2020) found that poor income, through losing existing benefits, is recognised as a barrier to employment in a systematic review about engagement in paid work by people with long-term conditions. There is a risk that gaining part-time work may reduce an individual's income, and that some people may be more financially secure in not being employed.

5.7. Summary Discussion

This study set out to explore the employment barriers and facilitators for people with COPD and consider the available support and the support required. The preceding discussion of the study findings (Section 5.6) reveals that several facilitators and barriers to maintaining or sustaining employment exist for people with COPD. Six higher order classifications were developed from the findings: COPD symptoms in the workplace; workplace strategies and actions; communication, advice and support; psychosocial aspects; financial aspects and employment, retirement and unemployment. This summary discussion is structured to incorporate the support aspects of the research objectives within the discussion on the main facilitators and barriers. The key findings and considerations are italicised and the original contribution to knowledge is emphasised.

5.7.1. COPD Symptoms in the Workplace

Variability of Symptoms

The current study found symptom variability is common, and how well or otherwise people with COPD could feel at work is unpredictable. In addition to individual variability, *symptoms also appear to be affected by the weather with the cooler seasons or environmental extremes including hot, dry, moist, windy and dusty conditions causing distress.* Symptom variability in people with COPD is reported in the literature (Stridsman, Lindberg and Skar 2014) as is the effect of weather, especially on COPD exacerbation (Hicks et al. 2018); although there is no literature relating specifically to employment. Therefore, these findings are the first to be reported in an employment context.

A consequence of COPD symptom variability is that the employee presents an unstable work identity to their employer which affects productivity or impacts others in the workplace. *This finding was particularly relevant to people with COPD working outdoors or in physically demanding roles. There is a need for employers to appreciate that people with COPD might need to work flexibly to ensure they are not unfairly disadvantaged in the workplace.*

Hidden Condition

This study also found that COPD is considered a hidden condition, and colleagues and employers might have little awareness of the person with COPD or their symptoms. Employed people with COPD often downplay the effects of their symptoms to present themselves as ‘healthy’ to others to maintain a workplace presence and will often work above and beyond what is required of them to compensate. This poses challenges for colleagues and employers, as they might not appreciate the effort people with COPD make to maintain a workplace presence and remain fully productive. These findings concur with those from Dorland et al. (2016) in some patients with cancer and Mal'ouf (2016) who indicate the invisible nature of COPD does not reflect the potential seriousness of health status and the current study further highlights *a need to reduce barriers for individuals communicating the working experience to employers whilst discretely self-managing COPD in a workplace context.*

Work Activities Induced COPD Symptoms in the Workplace

Breathlessness and cough as a result of physical exertion and environmental factors in the workplace were common symptoms experienced in this study. People with COPD frequently reported pushing themselves to their limit inducing extreme breathlessness and coughing caused by the physical, psychological and environmental factors in their various workplace contexts. Extreme breathlessness at work could sometimes cause panic. This finding is not reported in existing COPD research in relation to employment.

Speaking as part of a job also causes breathlessness, as it reduces oxygenation and subsequently increases breathlessness. Breathlessness reduced confidence and self-esteem leaving individuals with COPD feeling less professional and vulnerable in the workplace. This finding was also reported by Mal'ouf (2016) who noted breathlessness to be a sign of weakness in the workplace, and by Watson (2015) who found that individuals who had jobs involving communicating with the public felt their work was difficult due to their breathlessness and contributed to early retirement. *People with COPD who experience breathlessness might find working in occupations requiring a high communication workload challenging to manage and be better suited to roles that are not public facing.*

Walking and climbing stairs in the workplace were challenging, and the impact on fatigue and breathlessness was context dependent. Other studies indicate that people with COPD had a low endurance for climbing stairs and walking (Stridsman, Lindberg and Skar 2014) although not in relation to employment, and Mal'ouf (2016) found that walking was difficult for working-age women in the workplace. *The current study findings extend the depth of understanding on the effects of the physical nature of work on COPD symptoms.*

Fatigue and physical exhaustion were found to be important in the current study induced by intense workplace demands which could be physically draining for individuals with COPD. Being very busy, on their feet all day and extremes of workplace temperature were cited as causes. Although Watson (2015) reported that working eight-hour shifts felt like 'double shifts' in a few participants who were 'older workers', several similar reports are found in the current study which extends the understanding of the challenges for people with COPD in undertaking physically and mentally demanding roles. *The negative impact that fatigue and exhaustion have on people with COPD as a result of physical and psychological job demands, must be taken into consideration by employers.*

COPD Symptoms Impacted Workplace Activities

This study found that COPD symptoms frequently impact on work activity and, if severe, might affect productivity. A reduction in the amount of work individuals could accomplish is frequently noted and the effort to maintain work integrity is evident. Reprioritisation of workload by reorganising certain activities later in the day or avoiding or minimising challenging work activities is required as a result of the effects of COPD symptoms. People with COPD would leave their immediate environment to get fresh air or privacy, interrupting their workflow. Findings from the current study demonstrates presenteeism, particularly as a result of breathlessness. Presenteeism is well reported in the COPD literature, although it is unclear as to the extent of how COPD may contribute to a poorer workplace performance than in those with other long-term conditions (Rai et al. 2018; Lim et al. 2015). There are, however, links to presenteeism in people experiencing severe COPD symptoms and in those who have frequent exacerbation of their COPD (Solem et al. 2013). *It seems essential to understand more about the factors related to presenteeism to inform supportive workplace adaptations to optimise workplace conditions to help sustain employment for people with COPD.*

Despite considerable constraints in the workplace and the productivity challenges for people with COPD in the current study, many indicated a strong commitment to remain in employment and perform to the best of their ability. This optimism and professional attitude towards sustaining their employment demonstrated personal resiliency attributes through their positive affect and an anticipation of being able to cope despite challenges (self-efficacy) (Cannon et al. 2018). Resiliency in this context may be what enables individuals to maintain a workplace presence often beyond which their health status and symptom burden might suggest is possible. *There does not appear to be any research focused on resilience in people with COPD related to employment therefore this finding contributes to the knowledge base.*

Going to Work Unwell and Feeling Unwell at Work

In this study, people with COPD went to work feeling unwell or became unwell at work and subsequently delivered reduced productivity or returned home taking sickness absence. The effort taken to journey or walk to work or prepare for work, with for example protective clothing, could leave people with COPD exhausted by the time they commence work. *Recognising individual limitations was considered important to balance managing work effectively with use of energy.* Although a study by Boot et al. (2016) notes the impact of balancing health with energy in the workplace, this was in relation to people with depression, cardiovascular disease and osteoarthritis, and the current study adds to our existing understanding.

People with COPD might also prioritise their work over their health so as not to let their employer and colleagues down or take sickness absence. This practice might create internal conflict for people with COPD because what is best for an individual might not be desirable for the employer (presenteeism). A similar work ethic is reported in studies on other long-term conditions (Collins and Cartwright 2012) and feelings of guilt towards others in the workplace for reduced work contribution having a negative impact in the workplace (De Jong et al. 2015). *However, the current study appears to be the first to report on the commitment to work and feelings of guilt in relation to COPD and employment.*

Quality sleep was also considered helpful in preventing fatigue and a better work experience by optimising a feeling of well-being in the workplace. Sleep quality has been explored in relation to quality of life in people with COPD (McNicholas, Verbraecken and Marin 2013), but no studies have focussed on poor sleep relating to employment; therefore, the findings from the current study contribute to our understanding.

5.7.2. Workplace Strategies and Actions

Personal Actions for Managing COPD Symptoms in the Workplace

This study found that learning to pace work activities was important in remaining productive in the workplace, and various personal actions to cope with COPD and the challenges involved in work are adopted. These findings demonstrate that individuals actively and effectively self-manage their COPD symptoms and make small adjustments to modify their situation or tasks independently of their employer's input which are helpful to sustain employment. Using inhalers was similarly reported by Mal'ouf (2016), although findings from the current study provide depth to the employment context and detail of the extent of the challenges. *Successfully implementing personal actions to self-manage COPD also highlights personal resiliency attributes in coping in the workplace and recognised as crucial to employment success* (Scottish Government 2021; Russell et al. 2018; Reich, Zautra and Hall 2010).

Personal Strategies for Managing COPD Symptoms in the Workplace

Personal strategies for managing COPD symptoms in the workplace involved forward planning, building a simple routine and being organised. Mal'ouf (2016) also recorded pacing and planning as important aspects of managing employment and these findings build on this further. *Applying various strategies to facilitate employment seems to rely on those with COPD proactively integrating actions and strategies into their specific work contexts either independently or with employer and colleague support.* Extreme accounts illustrated hiding COPD from others and manipulating the workplace through delegation and management to extend the employment period. Strategies and actions are mainly incorporated into job requirements to minimise disruption on the employer and colleagues although these are not always noticed by others. *Where there is a high level of adjustment latitude afforded to the employee to adapt work commitments by varying and reprioritising work activities to suit individual capability is possible, this is helpful and might prevent sickness* *absence.* Being self-employed offered additional flexibility to role adaptations to enable self-management of COPD symptoms and flexibility in role function was also reported in the study by Kalirai (2016) and Masters (2018). Adjustment latitude is not discussed in any depth by Kalirai (2016), as the focus is on workplace interventions, so the current findings are important in developing a clearer picture of what works for people with COPD in navigating health challenges in the workplace. *Crucial to the success of these strategies is the person with COPD understanding their individual limitations and capabilities and being realistic about which work activity causes them greatest challenge and using their active coping mechanisms (resilience skills) to manage these*.

Workplace Adjustments Made by Employers to Accommodate COPD

The findings of this study suggest there is no standard practice from employers in conveying the support they can provide for people with long-term conditions and fails to promote a supportive workplace culture explicitly valuing the health and well-being of employees (Taylor 2017). It was likely that not all employers fully understood their employee's entitlements under the Equality Act (2010), and where employers understood their requirements, they were sometimes reluctant to comply with the necessary changes. *Employer support is vital in enhancing employment outcomes; therefore, there is a need for developing a broader awareness of organisational policies including the potential adjustments that individuals can make to accommodate health requirements whilst maintaining productivity.*

Various workplace adjustments made by employers to accommodate people with COPD are evident in the findings from this study and whilst many were informal local agreements, others were operationalised as a result of Occupational Health medical recommendations. Adjustments mainly included reducing hours or workloads and some flexibility in role function and tasks were evident in the studies by Mal'ouf (2016) and Kalirai (2016) in respect to flexibility of hours worked and tasks undertaken. The findings from the current study further develop the context and detail of how these adjustments are operationalised in a variety of work contexts and the challenges involved in making them successful. Personal support plans were used with varying commitment to review their success and *it appears that people with COPD need to ensure they are being* *assertive in regularly checking-in with their manager with regards to their plan and their current health status, and that they can develop an active voice in the process.* This approach fits well with the 'good work' aim where employer engagement is seen as key to this process (Taylor 2017). Not all adjustments are hassle free and resentment and jealousy can be a concern where changes to role are poorly communicated, and colleagues acquire an unfair workload as a result. *When it is clear employees can no longer function effectively in their current role, being able to channel expertise and skills towards alternative industries that are less physically demanding might be important options for participants to consider to their normal roles and support from employers to do this is important.*

Workplace Adjustments Not Facilitated by Employers

The findings from the current study indicate that workplace adjustments to accommodate the health requirements of people with COPD are not always possible to implement either formally or informally. This is due to the workplace environment and the industry type (e.g., dusty environment and oil rig). In order to implement successful adjustments, Boot et al. (2014) in their study of older workers with various long-term conditions suggests the need for individuals having high psychosocial resources including autonomy and manager and co-worker support. *This indicates the need for personal resilience and clear communication in negotiating adjustments with a willing employer to ensure successful implementation*.

5.7.3. Communication, Advice and Support

Disclosure of COPD in the Workplace

Whilst some people with COPD in the current study were comfortable disclosing their condition to an employer and colleagues, others were more sceptical wanting to protect their privacy. Disclosure was seen to facilitate an understanding for the employer to enable the negotiation of flexible working conditions and from a safety perspective for others who might be able to help in an emergency. Many people with COPD, however, do not want to draw attention to their condition and avoid disclosure fearing it as a sign of personal weakness making them vulnerable to stigmatising situations or losing their job. These concerns were similarly captured in a COPD study by Kalirai (2016) in relation to workplace interventions.

Non-disclosure of a long-term condition to an employer can create obstacles for people in gaining appropriate support to accommodate their health needs. Bosma et a. (2021) also notes the employer may have unrealistic expectations of an employee where there is no understanding of personal circumstances. *Employers need to have appropriate sources of help and the resources available to provide timely employment support to enable workers to maintain their workplace presence when people disclose a long-term condition.*

Discussing COPD in the Workplace

COPD was raised by colleagues in the workplace and they often showed concern for the well-being of people with COPD. Negative and derogatory comments were also noted around reduced workloads, carrying lighter loads or as a result of implementing workplace adjustments. Colleagues also made light of breathlessness when symptoms were observed presumably to prevent embarrassment. *There does not appear to be any research illustrating conversations about COPD in the workplace, so these findings add to our understanding.*

Employer Support for COPD in the Workplace

Although the findings overall were mixed, there was a general feeling that support for COPD from employers and managers was lacking with most not understanding COPD or the limitations it may cause in the workplace. Instances of managers being deliberately unhelpful or obstructive were reported, and some lacked empathy or a willingness to work with the employee to develop mutually beneficial workplace outcomes. There were general feelings that employers had no interest in the health and well-being of employees and had little insight into their condition, their challenges or potential workplace solutions.

There were also examples of employers being broadly supportive and enabling job adjustments and were related to having a supportive line manager or a manager who understood the condition. This finding concurs with that found by Kalirai (2016) which suggests *information and education about health conditions* *and their management may be important in developing knowledge and skills of managers supporting people with long-term conditions in the workplace.* Bosma et al. (2021) also found that building open and trusting relationships between employers and employees was vital to create and develop workplace cultures conducive to enhancing productivity outcomes and a positive workplace experience for employees with long-term conditions.

Findings indicating positive experiences when working with a smaller employer who would treat people with any condition on an individual basis and support their needs in the workplace were also apparent. *However, people with COPD were not always clear about what support they could ask for and who they could have discussions with about their health needs at work.* This is similar to the findings from a study on disabled people conducted by Adams and Oldfield (2012).

Some employers were effective in helping employees access wider services such as human resource departments, Occupational Health services and pension-related support through finance, but these were in the minority. *These findings indicate a need for employers and managers to gain a better awareness of the health conditions that challenge their workforce through awareness training and use the resources available to them to support people with COPD and other long-term conditions in the workplace effectively.*

Colleague Support for COPD at Work

The current findings highlighted that work colleagues frequently asked after their colleagues' well-being and offered their help, although people with COPD were often reluctant to accept or ask for help. *Colleagues seemed to be more empathic if they had knowledge of COPD or had experience of similar personal health issues or symptoms.* This agrees with and extends the findings from the Kalirai (2016) study relating to workplace interventions where supportive colleagues led to improved productivity.

There were examples of colleagues lacking in empathy towards the person with COPD, and in some instances the employees felt isolated, alone and with nobody to turn to in the workplace for advice or support. Kalirai (2016) also noted that passive or negative relationships with colleagues would not enhance opportunities for employment modifications.

Perceived Support Needs for Health-related Employment Concerns

This study found that transparency in what employers' obligations are to provide job related and financial support, what specific support is available in the workplace and how to discuss and organise this support for people with COPD was lacking. People with COPD largely felt that employers have a responsibility to support employees with health concerns to remain as effective in the workplace as they can.

There were illustrations of Occupational Health medicals being completed with accompanying workplace recommendations either not followed through or the support plans implemented but not completed. *Working with inadequate or no support leads to poor work experiences and adopting a trial-and-error approach to find the best-fit between capability and task might help people with declining health remain in employment. Early career advice could be helpful where transferable skills can be considered relevant to other industries and job types.*

Findings that further support the above reported the *need for employers to be better informed regarding employee health concerns came through strongly, and subsequently a greater commitment to work collectively to facilitate job retention is required*. This reflects perspectives established from research on other long-term conditions which supports the need for active engagement in job retention and re-integration (Bosma et al. 2020a; Pransky et al. 2016; Haafkens et al. 2011), although the current research appears to be the first to report on COPD. *There also seems to be a need for an independent professional to provide space for employment to be discussed and this might be possible within a holistic patient centred assessment and consultation by healthcare professionals,* although this is likely to be less of a priority during the post COVID-19 recovery period for the National Health Service.

5.7.4. Psychosocial Aspects

Emotional Experiences

The current findings report on a range of emotions and feelings experienced by people with COPD in relation to employment. *Embarrassment and shame were commonly reported around the visibility of COPD symptoms in front of colleagues, as was anger about not being able to do their job as well as they could previously. Worrying about the future and fearing death from an acute episode of breathlessness and COPD was also a concern*. There do not appear to be any studies addressing the emotional aspects of COPD in relation to employment; therefore, these findings are important in drawing attention to this important aspect of the working lives of people with COPD. There is, however, some focus on severe episodes of COPD-related breathlessness heralding a last breath in a study reported by Clancy, Hallett and Caress (2009). Although this study was not in relation to employment contexts, their findings support those found in the current study.

Feelings of Stress

Stressful situations in the workplace, the nature of the specific work or job and worrying about keeping their jobs was detrimental to people with COPD. *When people with COPD are stressed at work COPD symptoms can develop or worsen*. *Reducing work-related stress by stepping down from management roles and preparing and pacing the workload carefully were all adopted as successful strategies for managing stress.* Mal'ouf (2016) also reported that working-aged women with COPD also managed their own stress in the workplace and also took on less demanding roles, which concurs with the current study findings.

Anxiety and Depression

Although there were some reports of the protective nature of work keeping people with COPD mentally occupied and enjoying the social aspect of working in others company, *reports of the pressures of work and the symptoms experienced in the workplace often posed a burden on individuals mental health and well-being*. *Reports on feelings of stress preventing effective working were notable and could lead to poorer work-related outcomes.* Although there are many studies that address anxiety and depression in people with COPD (Marsh and Guck 2016; Yohannes and Alexopolous 2014), there are no studies that incorporate this from an employment perspective and these initial findings may broaden perspectives on how employment affects mental health and well-being.

Treated Differently

The findings from the current study suggest that being treated differently and experiencing stigmatising situations in workplace are common. *Multiple examples of people with COPD trying to avoid standing out from others were apparent and included, not wearing a mask on a building site, not being allowed role adjustments, hiding symptoms of COPD from colleagues and employers and being segregated in the physical workspace exposing their differences and vulnerabilities.* Discrimination against parking close to the workplace building was also noted in several cases even although employers have flexible working policies in place. *This type of treatment is likely to discourage illness disclosure and prevent individuals gaining the appropriate workplace support.*

Despite this, there is a reluctance for people with COPD to label issues as direct discrimination although many did. The term 'leper' was raised many times by people with COPD with reference to how they felt as a result of the way they are treated in the workplace and generated feelings of disgust, contributing to a negative psychological well-being. Berger, Capella and Larsson (2011) also found in a study of people with COPD that others spoke about people with COPD with disdain behind their back and that they were viewed as 'lepers', which was unlike those with other long-term conditions.

Other examples in the current study illustrate the barriers that might present for people with COPD in their perception of stigma as a result of being treated differently. Although some workplace adjustments may appear to be helpful, those which single out and highlight differences in people with COPD might create unintended negative employment outcomes as a result. The risk of facing stigmatising situations in the workplace might also discourage disclosure of illness to an employer and consequently deny people with COPD opportunities for gaining appropriate workplace support and jeopardising long-term employment. The findings from this study add further depth to the published research.

5.7.5. Financial Aspects

Financial Challenges and Solutions

These research findings identified that financial concerns in covering basic needs, including food, housing and utility costs as a result of reducing to part-time hours, stopping working or retiring early, are a concern for many people with COPD. *Losses in regular income and reduced pension contributions added to a financial disadvantage in the short and long term meaning a reduction in lifestyle for some and is a common concern for people with COPD.* Similar reports of the considerably reduced lifetime incomes of people with COPD, particularly due to early retirement are evident in the COPD literature (Rai et al. 2018; Fletcher et al. 2011). Fletcher et al. (2011) noted that whether individuals were working or not, loss of income was a worry for people with COPD and most reported decreases in their income and substantial lifetime income losses in retiring early. Individuals with other long-term conditions (osteoarthritis, depression and cardiovascular disease) also found work vital to sustain their income (Boot et al. 2016). Accessing pensions, PIP, tax credits and allowances and other savings are key to being able to maintain lifestyles. However, the current *study findings indicate that financial and career advice for people with COPD is not easily accessible from employers or external agencies and people with long-term conditions might benefit from actively seeking support at the earliest opportunity to optimise the conditions for maintaining their employment and their income.*

This current research also found that the support provided by a spouse was key for maintaining their household financial stability; this appears to be the first study to report on the importance of spousal support in relation to financial stability. *Partners can therefore play a significant role in providing general support, guidance and financial stability when the person with COPD's employment intentions and plans are challenged and their income reduces or is likely to reduce in the future.* Healthcare practitioners and others with a role in decision-making and advice giving for people with COPD in relation to their employment could *involve partners in the assessment and planning of practical and social support options.*

5.7.6. Employment, Retirement and Unemployment

Ending Employment and Reflecting on Leaving

Work can be physically challenging for people with COPD, and re-evaluating future working life and health priorities through balancing the risks and benefits of continuing work is an important consideration*.* The current study findings suggest that a lack of employer support for people with COPD is implicated in ending employment and, conversely, that too much employer support in implementing extreme workplace adjustments draws attention to significantly altered workloads. *Most people with COPD in the current study wanted to continue working as long as possible, however many encountered pressures to leave their employment from their colleagues or employer*. *Ending employment can cause feelings of regret and personal loss when leaving employment following a period of sickness absence, exacerbation of COPD or health deterioration, or as a result of recommendations from Occupational Health medicals. People with COPD leaving employment may also experience a loss of social interaction and camaraderie and miss the daily routine and structure and having something to do with their time* which was also found in the studies on people with COPD by Mal'ouf (2016) and by Masters (2018). *However, the current study also found that for some people with COPD, leaving employment may bring some relief especially if they are not satisfied with their work remit, if work is too physically and mentally demanding, if they are working long hours and if there is little employer support*. Similar findings were reported by Masters (2018) with respect to long hours and work being physically demanding. The current study builds on the limited existing research on ending employment.

A sudden and unpredictable ending to employment can be disappointing and traumatic for people with COPD is congruent with research on people with dementia and mild cognitive impairment (McCulloch, Robertson and Kirkpatrick 2016). A stepping down transition towards ending employment for people with long-term conditions is recommended by Bevan et al. (2018) involving practical and psychosocial support. Although many in the current study were not able to take advantage of this type of support, *self-help resources and talking therapies enabled by the employer, might be helpful in the transition to retirement.*

5.8. Chapter Conclusion

This study has explored the experiences of people with COPD in relation to employment, and the findings provide a foundation to better understand people's contexts and indicates the support and interventions that might be helpful. The findings provide a detailed description and analysis of the varied contexts in which the participants sustain employment with COPD or have left their employment because of COPD and is considered in relation to existing literature on various long-term conditions. The study has also explored how employment might be enabled or constrained by an interplay of complex factors that influence employment success including unfavourable working conditions, poor workplace relationships, fear of losing one's job, lack of employer and employee understanding, disregard for guidance, and a lack of employment policy or policy enactment on supporting people with long-term conditions.

One of the key messages, expressed by most of the participants, is the need for COPD to be recognised and respected by employers and colleagues as a condition that creates varying and challenging health issues for people in the workplace. Despite most of the employed participants in this study wanting to maintain a workplace presence, and those who had ceased working, wishing they could have extended their working lives, they felt that it was a struggle to do so despite their best efforts.

Chapter 6 re-states the key findings from this body of work in relation to the thesis aims and objectives and considers the strengths and limitations of the research. The original contribution to knowledge is also highlighted. The implications this research has for healthcare professionals, people with COPD, and employers, as well as for research, policy and strategy are presented. Finally, the research dissemination plan is detailed, and reflexivity concludes the thesis.

6. Conclusion and Recommendations

6.1. Introduction

This final chapter concludes the body of work on the two studies contained in this thesis: *The Psychosocial and Physical Factors Influencing Employment in People with COPD and The Employment Experiences of People with COPD.*

6.2. Chapter Structure

The thesis aims and objectives are re-stated and the key findings from both studies, which were fully discussed and related to the literature in chapters 4 and 5, are further summarised and related to more recent research. The strengths and limitations of the research are considered and the original contribution the research makes to the subject is made explicit. The main recommendations for healthcare professionals, people with COPD, employers, research, and policy and strategy are also considered. Finally, the dissemination plan for the research is explained, and researcher reflexivity concludes the thesis.

6.3. Thesis Aims, Objectives and Key Findings

The aim of this thesis was to explore employment aspects in people with COPD in order to understand the factors affecting employment and people’s experiences of remaining in or leaving employment. Thus, the thesis findings might inform and influence the development of recommendations for research, guidance and or interventions to support people with COPD in relation to employment.

6.3.1. Thesis Objectives

The thesis objectives were:

1. To conduct a pilot study to test recruitment and study procedures to enhance the design of a later study;
2. To identify the psychosocial and physical factors that may influence paid employment in people with COPD;

3. To explore in-depth the perceptions and experiences of people with COPD who sustain or cease employment;
4. To understand, from the perspective of people with COPD, the facilitators and barriers to sustaining paid employment;
5. To understand the support required for people with COPD to sustain paid employment;
6. To use the evidence generated from objectives 2-5 to make recommendations for developing guidance and/or interventions to help support people with COPD in relation to employment.

6.3.2. Key Findings and Discussion

The broad findings from the cross-sectional study provided valuable information on the recruitment procedures implemented, the questionnaire and documentation designed and used to conduct the pilot study and are appropriate for use in a future similar scalable study. The questionnaire used in the pilot study generated data on several psychosocial variables and demonstrated that people with COPD are keen to contribute to research on health-related topics and employment. Future studies could be scaled-up with modifications to the process and questionnaire dependent on the study design and the support of additional resources. No modifications were required to the research processes during the conduct of the pilot study other than taking account of the reduced sample size and managing the tight timeframe.

The quantitative survey was the first step in the explanatory sequential mixed-methods study. The questionnaire and documentation used in the study were effective in eliciting the intended data on the psychosocial and physical factors potentially influencing the employment of people with COPD and no previous similar studies have been conducted in the past. Broad trends have been descriptively reported in Chapter 4, as statistical analysis was not possible due to the small sample. The main results indicated that COPD had a detrimental impact on participants’ well-being on the day the questionnaire was administered, although the impact was less for employed participants compared to those not employed. Employed participants were healthier on the visual analogue health scale compared to those not employed and, overall, they had a better quality-of-life, but both groups were below the expected population markers indicating the substantial loss of health because of their COPD (Encheva et al. 2020). However, it was evident that some participants could still maintain their employment status despite a health compromise.

Satisfaction with life and self-perceived mental well-being and anxiety and depression was generally higher in those employed compared to those not employed. Although the sample size is small and no statistical analysis could be made, the exploration of well-being measures warrants further investigation, as these factors might be important employment influencers. Greater levels of resiliency were also evident in the employed participants, and, as indicated in Chapter 1, resilience appears to be a construct worthy of further investigation in relation to COPD and employment (Cannon et al. 2015). Lower resilience is correlated with a lower quality of life, level of satisfaction with life and depression and anxiety in people with pulmonary disease according to a study conducted by Isokaanta et al. (2021). Indeed, the presence of high resiliency might be protective in supporting the maintenance of a workplace presence (Keil et al. 2017). A future study exploring the relationship between resilience and employment in people with COPD would therefore be worthwhile in order to better understand these relationships and to inform the development of interventions and practices to support people to remain in employment where possible. Some of the employed participants had a high level of flexibility in their role and absenteeism and presenteeism appeared minimal at this time, which might be related to the high level of workplace flexibility. Although there was an intention by the researcher to conduct a larger similar study, the remainder of this thesis, however, focussed on exploring the lived experience in more depth.

Participants showed a willingness to engage with research exploring their experiences of COPD in relation to employment. The main qualitative study built on the categories generated in the pilot study and further developed a breadth of themes. Resilience was a theme that continued throughout both studies. Several barriers and opportunities to more effective productivity and an enhanced sense of work satisfaction were established. The overriding message was that people with COPD want to continue working as long as possible in whatever capacity they can. However, some participants encountered pressure to leave their employment from colleagues or their employer or did not gain sufficient support from the employer to remain in employment. In addition, there was a feeling that employers and colleagues needed to respect COPD as a condition that creates varying and challenging issues for employees in the workplace. Respecting health status and the challenges individuals experience in the workplace is a clear imperative indicated in the CIPD (2022) guide on *Managing and Supporting Employees with Long-Term Health Conditions.* However, this study highlights that respect and support for employees with health concerns is not being provided in many situations because of lack of knowledge, lack of flexibility, rigid and flexible ways of working and poor management and leadership. It is evident that further work is required on this aspect to improve the conditions for people with health concerns in the workplace. The remainder of this discussion further highlights and discusses the key themes from the qualitative studies.

COPD Symptoms in the Workplace

People with COPD are optimistic and try to cope with their condition and workplace tasks and sometimes prioritise their work over their health. People with COPD are also committed to their work or career and often go to work unwell. Symptoms of COPD are well reported in the literature (Stridsman, Lindberg and Skar 2014) and are variable and unpredictable and the person with COPD might present an unstable work identity due to poor sickness-absence patterns or low productivity levels. Severe COPD symptoms are further highlighted in a review by Hicks et al. (2018) as causing fear of exacerbation during the colder winter months in the UK.

In addition, physical and psychological job demands, sleep deprivation and inclement weather induced fatigue and exhaustion in and negatively affected the productivity and motivation at work of participants in this study. Lower workforce participation is also reported in the literature on chronic breathlessness (Clark et al. 2022). Clark et al. (2022) found that employees with more severe breathlessness (grade 2-4 on the Medical Research Council scale) were less likely than those with lower grades of breathlessness to be employed. This related to both part-time and full-time employment indicating the extent to which COPD can have a negative effect on employment. Knowledge and understanding of the multi-faceted factors influencing the person with COPD’s employment experience is important to ensure work colleagues and employers can help maintain their employment status.

Workplace Strategies and Actions

Despite the challenges people with COPD face with symptoms and/or challenging workplace conditions, they demonstrated resiliency in coping through self-management, and recognised the need to be aware of their limitations and balance work tasks with their energy levels. Self-management approaches are considered a way forward in supporting people with long-term health conditions in the workplace to optimise employment outcomes (Silvaggi et al. 2020). People with COPD successfully implemented personal actions and strategies to prioritise tasks, either independently or with employer support, highlighting the resiliency attributes of a can-do attitude that might be crucial to employment success. However, individuals undertaking jobs requiring high levels of communication or physical effort might experience a worsening of symptoms and must recognise this and set realistic expectations for themselves.

The findings in this study also suggest that some employers might have no, or inadequate, organisational policies and practices in place to support people with COPD and those who do might not always operationalise them fully or appropriately. The CIPD emphasise that employers should make available the company policies and opportunities for workplace adjustments to employees with long-term health conditions (CIPD 2022). Having workers with a high degree of adjustment latitude where employees can adapt workplace tasks and deadlines themselves or have implemented formal reasonable adjustments are helpful; however, some people with COPD might feel guilty taking on a reduced workload compared to others.

A recent study conducted by Shaw et al. (2022), used a ‘Manage at Work’ intervention for employees with a variety of chronic conditions including back and neck problems, hand/arm problems, asthma/bronchitis or emphysema, mental health disorder, diabetes, cardiovascular disease and other conditions.

Employees accessed coaching, education, and skill development to help them self-manage their conditions in the workplace. The results were mixed with a slight improvement in workplace engagement in the intervention group and a slight decline of engagement within those in the control group (Shaw et al. 2022). This confirms the challenges in determining the best occupational rehabilitative measures and adjustments for employees with varying and intermittent symptoms and further data is required for people with chronic respiratory conditions. When adjustments are not possible, or the adjustments implemented are not effective, support from the employer for reskilling or redeployment can be useful.

Communication, Advice and Support

People with COPD can be embarrassed when their COPD symptoms are visible to work colleagues and colleagues often initiate conversations about COPD in the workplace on noticing symptoms, although not all interactions are considered helpful by the person with COPD, and they might try to hide them often because of the fear of stigma. Disclosure of COPD by participants in this study is varied and individuals may not disclose their condition fearing it as a sign of weakness or disclose it as a way of informing others and opening up to the offer of support from others and the employer. Hemming, McDermott and Munir (2020) suggests that disclosure of health concerns in the workplace is the gateway to opening up a variety of opportunities for support, advice and adjustments, although they acknowledge the challenges involved including signalling weakness and the potential for stigmatisation. Exploring the reasons for non-disclosure of respiratory disease might be worthy of further consideration to determine the main influences.

Managers and colleagues of people with COPD show more empathy and understanding when they have knowledge of the condition or experience of similar personal health issues or symptoms. Positive and trusting relationships in the workplace appear to be conducive to better employment and productivity outcomes for people with COPD. Conversely, the lack of workplace support leads to poor work experiences; however, people with COPD might not know who to speak to about their health needs at work or what support they can request from employers. This is closely linked to the broader need for implementing self-management programs in the workplace for people with long-term conditions (Silvaggi et al. 2020; Hemming, McDermott and Munir 2021).

However, workers who engaged with the support from Occupational Health services, human resource and finance departments find them helpful. Employers were mainly supportive of requests for workplace adjustments, although some employers appeared to have little interest in the health and well-being of the workforce or their health challenges in the workplace. These findings resonate with reports from physicians, company managers, supervisors and human resource representatives (Bosma et al. 2021). Numerous barriers are cited to providing support including negative organisational attitudes towards employees with long-term health conditions, employees' reluctance to disclose or collaborate with employers in dealing with work-related problems, physician lack of visibility and a lack of utilisation of support (Bosma et al. 2021). It is clear that more work is required to increase the awareness of the specific support available to people with COPD in terms of where they can access it and how it might be of direct benefit to them.

There was an overall lack of transparency in what employer's obligations were to provide job-related support for people with long-term conditions and greater awareness is needed. When the person with COPD was active in expressing their workplace needs and became a co-participant in the support process by voicing their challenges and needs and updating their current health status to their manager, improved employment experiences were achieved. Shaw et al. (2022) also indicate the promotion of assertive communication about health status and workplace needs as part of a self-management strategy is essential in achieving positive employment outcomes. Being well informed and assertive takes time and effort to develop and is not always easy to achieve for many individuals. Assertiveness skills development might be useful tools for people with health concerns to help them have more positive discussions with their managers in the workplace.

Psychosocial Aspects

The pressure of work demands, the variable symptoms experienced in the workplace and stress pose a burden on the mental health and well-being of people with COPD and could prevent effective working. Work induced stress is managed by people with COPD adapting their role, stepping down from high-pressured roles and self-caring, although some might feel anger at not being able to do their job effectively. Similarly, Mal'ouf (2016) noted that participants in her study also managed stress by taking on less-demanding roles, although clearly this cannot always be achieved in every case.

People with COPD might also face workplace discrimination where they do not have a supportive employer or colleagues, or the employer does not understand their legal obligations around the provision of support to employees with long-term conditions. Fear of encountering stigmatising situations may lead to non-disclosure of COPD, which might further reduce opportunities for building healthy and transparent workplace relationships and implementing the best support possible in the workplace. These issues can cause people with COPD ongoing career worries, as too few employees seek support for these needed work adjustments (Yarker et al. 2020). Particularly relating to mental health issues, workplace adjustments reportedly enabled employees to manage stress in the workplace and perform well (Yarker et al. 2020).

Financial Aspects

People with COPD have concerns about having a low income and a reduction in pension contributions if they work part-time or become unemployed and might lead to them becoming financially disadvantaged. As COPD is more likely to affect people in the lower socio-economic strata, lower levels of employment in those with the most severe symptoms further extend the disproportionality of the negative financial effect and is seen in this study also (Clark et al. 2022).

Important financial and career advice is not easily accessible either through an employer or external agencies. Partners and spouses of people with COPD play a vital role in providing general support, guidance and financial stability when the person with COPD's employment intentions are challenged or income is reduced, or is likely to reduce in the future. Partners and family of people with COPD are therefore crucial to the assessment, support and planning of their future financial health.

Employment, Retirement and Unemployment

Most people with COPD want to continue working and value their jobs and careers. A sudden and unpredictable ending to employment can be traumatic for people with COPD and might cause feelings of regret and personal loss. In other instances, a sense of relief was found which was similar to that reported in the study of people with COPD by Masters (2018). The access to general employment advice or support is lacking for people with COPD, although being pro-active in seeking support at an early stage of their condition might improve their opportunities for remaining in employment in the long term. Employment issues are important for people with COPD and their families, and people with COPD would like an independent person to provide support for their health-related workplace challenges and decisions that need to be made. There are opportunities for healthcare professionals to enhance employment outcomes for people with COPD. Gardener et al. 2019 suggests this is made easier during healthcare professionals' interactions with people with COPD through using the Support Needs Approach for Patients (SNAP) tool to help identify and express their perceived support needs.

6.4. Strengths and Limitations of the Research

6.4.1. Strengths of the Research

Maintaining employment status and workplace effectiveness is of growing importance in society, and the qualitative findings presented in this thesis provide a valuable insight into the various issues that are important to individuals with COPD. Conducting in-depth qualitative interviews and maintaining a person-centred approach enabled the prioritisation of the issues and generated the themes that were important to people with COPD.

Another strength of the thesis is that it was responsive to the initial pilot findings and reoriented the focus of the planned research objectives to prioritise the conduct of a robust qualitative study, focussed on the employment experiences of people with COPD. This was done in order to address what matters most to individuals with COPD and to inform the wider knowledge base, rather than following the original study plan for a cohort study addressing the psychosocial and physical factors influencing employment.

Another strength of the study is in the Framework approach taken for data management and analysis that provides a detailed audit trail of the research and analytical processes, decision making and researcher reflexivity throughout. This ensures transparency in how the categories and classifications have been developed and illuminates me as a developing researcher within this process. Using robust sampling methods and producing sufficient data to provide credible and trustworthy research, the findings present divergent viewpoints and experiences to fully represent the participants' voices on COPD and employment.

Another strength of the research is in its originality in taking a pragmatic approach in utilising interpretive description to illuminate a relatively unexplored area of COPD management and support.

A final important strength of the research is that the questionnaire was developed specifically for the cross-sectional study, using a combination of validated and non-validated health and well-being tools to investigate the psychosocial and physical factors in relation to employment. This questionnaire can be further adapted for future large-scale studies with amendments made to the types of tools incorporated, depending on the constructs to be measured. On further reviewing the literature on coping in a post-COVID-19 world, it might be that resilience is prioritised as one of the most important constructs for people with COPD in relation to employment.

6.4.2. Limitations of the Research

A limitation of the research is in the widely acknowledged difficulty in accessing and interpreting the subjective world of human experience through interviews. Participants might have offered versions of the experiences which they thought I wanted to hear rather than reflect their 'true' experience of pressing importance to them. However, through prolonged engagement and building trust in often lengthy interviews, participants' specific issues were prioritised, which enabled a depth of exploration and many new themes to be generated.

Another limitation of the study is that the psychosocial measures employed in the pilot survey were not utilised in the main qualitative study. In hindsight, some further data on demographics could have enabled me to describe the population more fully and the use of the resilience scale, for example, could have been informative during the thematic analysis stage.

A further potential limitation is that this was a Scottish-wide study and there was no ethnic diversity within the study population, as all participants were Caucasian. Therefore, the perspectives, findings and recommendations presented here might not be directly relevant in other contexts and cultures with different healthcare practices and social security measures. However, as the purpose of the research was to gain a better understanding of the employment experiences of people with COPD, some of the findings and recommendations might have relevance for others in similar situations and settings.

An additional limitation of the study was that some of the interviews were conducted by telephone, meaning the usual nuances of face-to-face interviews, including body language and facial expression, were missing. This aspect did not, however, seem to prevent the participants from fully engaging in the process and freely discussing their personal experiences and challenges.

A further limitation is that the focus of this study was on paid employment and the findings therefore do not capture the many people who work in unpaid, voluntary and carer roles. Attention on unpaid workers is a neglected area of research and must receive attention in the future, as it is potentially of greater concern to society post-COVID-19 where healthcare services are stretched and skilled manpower is lacking.

Another limitation of the research is that the literature review search strategy and literature utilised in the discussion may not have located all the relevant studies. The initial literature search was completed in the early stage of the PhD process and continuously developed thereafter. As I developed my research skills and with hindsight, the search strategy could have been constructed in a different way and there is always a possibility that pertinent literature may have been missed.

Limiting the search strings to abstracts only could be perceived as a weakness; however, early searches were conducted with and without limiting by abstract and the difference in terms of the number of hits was very small. The body of research on employment for people with long-term conditions is extensive, and only a relatively limited sample of literature could be incorporated into the discussion of the findings in the main qualitative study. However, I endeavoured to use the literature most relevant to the population under study.

A final limitation is that I was a relative novice in conducting interviews, although I had previous experience with focus groups. I gained experience through the pilot interview process, which was beneficial in the main qualitative study interviews. The main qualitative study interviews were subsequently longer and enabled a deeper exploration of relevant issues, which also demonstrated my development as a researcher.

6.5. Original Contribution to Knowledge

This is the first study to provide an in-depth account of the employment experiences of working-age people with COPD and makes an original contribution to our understanding of important contexts and issues as illustrated in Section 5.7. This study extends and enhances the current body of knowledge and represents participant voices in terms of barriers, facilitators and the support required in trying to achieve successful employment outcomes for people with COPD. The study findings and recommendations are of potential value for anyone involved in providing support for people with COPD.

This study is also novel in that it has piloted a questionnaire suitable for a larger study of working-age people with COPD in relation to the psychosocial and physical factors that may influence employment. In addition, the study used a mixed-methods approach to ensure that the priority to generate the best evidence to address the real-life issues around employment was achieved.

Feedback from presentations of the preliminary study findings demonstrated there is a wide interest in the topic from a variety of healthcare professionals. Study participants also commended the effort being made to illuminate their voices valuing the importance placed on the topic with one saying *"Oh, I don't want to stop. I want to speak, because the questions you're asking are the questions that should be put forward for other folk because it is the poor cousin, and it has been for a long time".*

This thesis illustrates how the research achieves the academic, economic and societal impacts highlighted by The Research Council UK as being essential for a contemporary, quality research output (Table 6.1) (Research Council UK 2019).

Table 6.1 - Academic and Economic and Societal Impacts.

Pathways to impact evidenced in this thesis	
Academic	Academic advancement through research training, utilising theories, technology and developing real-world research skills to develop my intellectual capability
	Enhances the knowledge of the research community by increasing the number of Doctoral nurse academics to develop the art and science of healthcare subjects
Economic and societal	Might contribute to the health and well-being of people with COPD
	Might influence organisational culture and practice
	Might attract further research investment
	Might influence national strategies and guidelines

(Research Council UK 2019).

6.6. Recommendations

Recommendations relating to the optimisation of health and well-being and the employment experience of people with COPD are relevant to healthcare professionals, people with COPD, employers, research, and policy and strategy.

6.6.1. Recommendations for Healthcare Professionals

The maintenance of employment for working-age people is a key aim in the UK Government’s objectives for the management and support of people with long-term conditions. Healthcare professionals involved in working with people with COPD and their families have a pivotal role in valuing employment in relation to an individual’s health and well-being. Incorporating employment aspects into a person-centred assessment might enhance self-management capabilities and improve employment outcomes.

Healthcare professionals can provide more tailored support to patient management for people with COPD when fully understanding their motivations for self-management and adhering to treatment plans based on employment barriers and drivers.

6.6.2. Recommendations for People with COPD

The person with COPD must understand their individual workplace limitations and capabilities and be realistic about what work activity causes them greatest challenge and use active coping mechanisms (resilience skills) to manage these.

Job activities might require reprioritisation where they cause a worsening of COPD symptoms in the workplace, and it is important that individuals learn to pace themselves and do more challenging tasks when they are feeling at their best and do fewer demanding activities when feeling less well.

People with COPD might find working in occupations requiring a high communication workload or those in physically demanding jobs challenging to manage and might be better suited to sedentary roles that are not public facing.

When gaining support from an employer, the person with COPD must be assertive in the communication process and be clear in negotiating adjustments and consider what reasonable accommodations they think could be effective in the workplace.

Adopting a trial-and-error approach to find the best-fit between capability and task appears to help people with deteriorating COPD remain in employment.

6.6.3. Recommendations for Employers

There is a need for employers to be pro-active in reducing the barriers to communicating and understanding the challenges that individuals with COPD and other long-term conditions might encounter in the workplace.

Employer support is vital to enhancing employment outcomes for people with COPD. Therefore, there is a need for managers to develop a broader awareness of organisational policies, upskilling in long-term conditions and become knowledgeable about the workplace adjustments that might be implemented to accommodate the health conditions that challenge their workforce.

There is a need for employers and colleagues to be aware of the potential influences and impact of COPD symptoms on productivity and attendance and enable flexibility and adjustment latitude in the workplace and adjust their expectations accordingly.

Employers need to have appropriate sources of help and the resources available to provide timely employment support to enable workers with long-term conditions to maintain their workplace presence.

Employers would also benefit from developing their understanding of the challenges that COPD makes on individuals’ working lives and equip themselves better through further training and support to ensure they are able to optimise productivity and enhance the overall experience of work. This could involve making transparent what organisational policies and practices are available for people with long-term conditions and encouraging early, mutually respectful conversations around specific issues with employees.

Referral to self-help resources and talking therapies enabled by the employer might be helpful in the transition to retirement for people who are likely to have shortened careers.

6.6.4. Recommendations for Research

A study looking at the factors that promote successful adaptation in the workplace irrespective of COPD severity, type of job and other relevant variables could be useful for informing employers and people with COPD.

Research focused on investigating the role of resilience in people with COPD in relation to employment could provide valuable insight into the protective skills that could be useful in helping to sustain employment.

It seems essential to understand more about COPD-related presenteeism to inform supportive workplace adaptations and optimise workplace conditions at the earliest opportunity.

A qualitative study specifically focused on communication aspects of COPD disclosure, workplace relationships and reasonable adjustments in employed people with COPD is warranted to determine the most successful ways of negotiating effective adjustments and employment outcomes.

Research using a case study approach with a small sample of currently employed people with COPD, to consider employment experiences and perceived support needs, would add further depth to the findings in this current study. This could be triangulated by including their employer/manager and healthcare professional (respiratory physician/Occupational Health Physician/GP) to gain a 360-degree perspective and greater depth.

A systematic review illustrating the types of interventions which have been shown to facilitate successful work adaptation or vocational rehabilitation is urgently required to focus on the needs of people with COPD. This could lead to investigation of these interventions in workplace contexts, or to the production of guidance on the best forms of support for employers, people with COPD and other healthcare professionals.

6.6.5. Recommendations for Policy and Strategy

The recently launched Respiratory Care Action Plan 2021-2026, is the strategy for health and social care services related to respiratory conditions in Scotland (Scottish Government 2021). Although two sections of the strategy are dedicated to Diagnosis, Management and Care (Section 2) and Supporting Self-Management (Section 3), it does not refer to employment. There is an opportunity to influence future policies, guidelines and strategies with important employment-related knowledge as the population ages and increasing numbers of people must work for longer with long-term conditions, including COPD. There is evidence of positive research and collaboration in the political, academic and practice fields on the topic of supporting people with long-term conditions with respect to their employment challenges. However, consolidation and a more integrated approach to working is required to align policy with practice and research in respiratory conditions.

6.7. Dissemination

Throughout the duration of the study, I have presented updates to Chest Heart and Stroke Scotland (CHSS), British Lung Foundation (BLF) and academic colleagues and researchers during meetings, workshops and seminars. The findings from the research have also influenced my academic practice, informing my teaching. The following section presents the completed presentations and future dissemination plan.

6.7.1. Completed Presentations

Invited Workshop Speaker - The Health Care Professions Conference: Person Centred Respiratory Care: BLF. Stirling, May 2018.

<u>The employment experiences of people with COPD</u>
Presenting to a knowledgeable audience provided an opportunity to review the study progress and reflect on the value of the interim findings. Respiratory Physicians, General Practitioners, Respiratory Physiotherapists, Respiratory Specialist Nurses, and Nurse’s evaluations indicated:

- This is an important area to study, and healthcare professionals need to build this element into their holistic assessment and support of people with COPD
- This is one aspect of patient support I do not cover during consultation; I will include it from now

Changes delegates will make:

- Ask patients questions about any workplace challenges they have experienced and any adjustments they have made
- Look at ways to help people with COPD who are still working

Seminar Presentation – Post-Graduate Research Student Seminar, RGU, Aberdeen, September 2018.

<u>Employment experiences of people with COPD: some early findings</u>
Presentation to an academic research group including PhD students. Developed research ideas and knowledge based on question-and-answer session.

6.7.2. Future Dissemination

Findings from this research will be disseminated in several ways:

- Present the findings at local and national workshops and conferences and feed directly into the Cross-Party Group on Lung Health: Scottish Government
- Provide a lay summary for the CHSS whose funding supported the conduct of the pilot study
- Provide a lay summary for the participants who requested feedback
- Prepare an academic paper to capture the main themes from the qualitative study and submit for publication in a peer-reviewed journal. Submission to a suitable journal will occur within two months of the finalisation of the PhD study.

6.8. Reflexivity

Throughout the research journey and recorded in all chapters, I have ensured transparency of the four general evaluation principles required to judge how qualitative research is theoretically, epistemologically and technically sound, within an interpretive descriptive approach. Although there is some overlap with the credibility and rigour addressed when detailing the Framework approach to analysis, this section serves to reinforce the overarching principles. In relation to Thorne's evaluation criteria (Thorne 2016a, p.234-235), knowledge construction is based on a sound rationale justifying the research and having *epistemological integrity* in the approach adopted. Further, that *representative credibility* is achieved through sampling and in adopting a credible method for in depth exploration of the participants' issues. Additionally, this study demonstrates *analytic logic* through the explicit and transparent inductive reasoning process adopted, which is made evident in the findings and analysis of interview data (Thorne 2016a). The documentation of the research method is made sufficiently visible, and the analytical decision making and audit trail are reported in a way to allow the reader to confirm or reject research credibility. I believe that this approach, in addition to reflexivity, demonstrates sufficient rigour and credibility to enable relevant findings to be translated and related to clinical and employment contexts where appropriate.

A final key marker of research validity and relevance to practice is through determining *'the thoughtful clinician test',* introduced by Thorne (Thorne, Kirkham and O'Flynn-Magee 2004, p.8). If subject matter experts assert that the findings of research broadly agree with their *'clinical hunches'* in developing new perspectives and relationships relating to a phenomenon, then the research is said to have *'disciplinary relevance'* (Thorne 2016a, p. 110). This disciplinary relevance has been established during the BLF workshop presentations, affirmed by the participants and in wider feedback from colleagues. This research journey has been long and challenging and, at times, emotional, when hearing participants' struggles with their health and employment challenges. It has also been a privilege to be entrusted with the participants' personal stories and emotive experiences. Debriefing with my principal supervisor was helpful in strengthening my professional resilience and research objectivity. This thesis highlights my intellectual and personal journey and is my original contribution to the knowledge base on employment factors in people with COPD.

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8. Appendices

I Pilot Study - Permission for Non-Commercial Research

Research and Development
Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB

NHS
Grampian

Ms Pamela Kirkpatrick
Faculty of Health & Social Care
Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QG

Date	25/10/2013
Project No	2013RG001
Enquiries to	Lynn Massie
Extension	53846
Direct Line	01224 553846
Email	grampian.randdpermissions@nhs.net

Dear Ms Kirkpatrick

<u>Management Permission for Non-Commercial Research</u>

STUDY TITLE:	Psychosocial and physical factors influencing employment in adults with Chronic Obstructive Pulmonary Disease (COPD)
PROTOCOL NO:	V1; 27 September 2013
REC REF:	13/NS/0139

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately, and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments – substantial or non-substantial (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

Susan Ridge
Non-Commercial Manager

c.c. Professor Peter Robertson, RGU

<u>Sponsor</u>: Robert Gordon's University

NHSG-RD-DOC-019 – V3.1 – R&D Management Permission Letter (Non CTIMP)

II Pilot Study - Participant letter from Respiratory Consultant

Chest Clinic
Clinic C
Aberdeen Royal Infirmary
Foresterhill
Aberdeen AB25 2ZN
Secretary 01224 551214

Dear xx

With colleagues in Robert Gordon University we are carrying out research into Chronic Obstructive Pulmonary Disease (COPD). We are interested in testing the feasibility of undertaking a national study to find out how COPD affects the lives of people in relation to their employment and what factors help them return to work. As you are potentially eligible for this study I am writing to invite you to consider taking part. Before you decide whether to take part, we would be grateful if you could read the enclosed participant information sheet. A decision not to take part, will not affect the standard of care you receive.

I hope you find all the information you need in the participant information sheet, but if you have any questions about the study, please contact either myself or Pamela Kirkpatrick at the address given on the participant information sheet. Should you wish to take part please contact Pamela or send her the reply slip in the enclosed stamped addressed envelope.

Yours sincerely

Professor Graham Devereux
Respiratory Consultant

III Pilot Study - Participant Information Sheet

ROBERT GORDON UNIVERSITY ABERDEEN

NHS Grampian

PARTICIPANT INFORMATION SHEET

Study Title: ***Psychosocial and Physical factors influencing employment in adults with Chronic Obstructive Pulmonary Disease (COPD)***

What am I being asked to do?
You are being invited to take part in a research study exploring psychosocial and physical factors influencing employment in people with Chronic Obstructive Pulmonary Disease (COPD). Before you decide, it is important you understand why the research is being done and what it involves. Please read the following carefully and discuss it with others. Ask if there is anything that is not clear or if you need more information. Take time to decide whether you wish to take part. Thank you for taking time to read this.

What is the purpose of the study?
COPD is a common condition that frequently affects people of working age. With the easing of compulsory retirement age, the issue of employing people with COPD is going to become a major issue that needs future planning consideration. We are interested in testing the feasibility of undertaking a national study to find out how COPD affects the lives of people in relation to their employment and what factors help them return to work. We are looking to include people who work and those that don't. We hope the outcomes may lead to the development of ways of supporting people to manage their COPD in relation to their employment.

Why have I been chosen?
You have been selected because you have COPD and are of working age. The study will be looking to recruit 30 people between the ages of 40 – 70.

Do I have to take part?
No, it's up to you to decide whether to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part in the study, will not affect the standard of care you receive.

What will happen to me if I take part?
Taking part involves completing a written survey (mainly tick boxes). In the survey, you will be asked about aspects of your life such as quality of life, satisfaction with life, coping, mental health and well-being, work-related productivity and control/adaptation as well as some questions relating to how your condition affects you. The survey will take around 30 minutes and the researcher can assist you with this. It will be completed in private and can be done at your next clinic appointment. If you wish, you can volunteer for a follow-up interview with the researcher to cover some additional areas of interest that come from the survey. Only 6 people out of the 30 people who complete the questionnaire will be asked to undertake the interview. This will be done in private in the clinic. This will be audio recorded and transcribed then the recording will be destroyed. The study will be completed over 5 months.

What are the possible disadvantages and risks of taking part?
There are no predictable risks for you in participating. It may be, however, that in answering the questions around your quality of life or other aspects may touch upon difficult issues for you. If you do not wish to answer certain questions, that is acceptable, and you can skip questions you don't want to answer. You can finish the questionnaire or interview at any time you wish. Every care will be taken to ensure that you are comfortable with the content of the questionnaire and interview. Should the questions about your mental well-being produce a score that is recognised as being above the anticipated population limits, with your permission, the researcher would wish to notify your General Practitioner so they can initiate further discussion with you.

What are the possible benefits of taking part?
Taking part in the study will offer you no direct benefit and will not affect your care or treatment in any way. The research provides you with an opportunity to contribute to a process of sharing knowledge, experiences and needs regarding people of working age coping with COPD. The information collected will help professionals learn what tools best measure factors affecting employment. It will also allow us to determine whether it is worthwhile conducting a larger national study on the topic. This could help professionals and Health Policy makers make decisions about healthcare in the future.

What happens when the research study stops?
Once the study is completed the researcher will analyse the results and with the study team determine what possible interventions could be offered to people with COPD to help improve their situation. A report will be published illustrating anonymised findings from the study. This will be sent to Chest Heart and Stroke Scotland in a report.

What if something goes wrong?
If you have a concern about any aspect of this study, you should speak to Pamela who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. The contact details are: Feedback Service, NHS Grampian, St Martin's House, 181 Union Street, Aberdeen, AB11 6BB, phone 0845 337 6338.

Who is carrying out the study?
A nurse researcher (Pamela) from Robert Gordon University is leading the study and is supported by a team specialising in Respiratory Medicine (Professor Graham Devereux - NHS Grampian) and Psychology (Professor Susan Klein - Robert Gordon University). The study will form part of the researcher's PhD thesis.

Who is funding the study?
Chest Heart and Stroke Scotland have provided generous funds in the form of a 'Minor Research Grant' to cover some of the costs of the study.

What do I need to do next?
If you wish to participate in the study, please complete the reply slip in the enclosed stamped addressed envelope.

If you would like to discuss the research further please contact me on: 01224 262957 - Many thanks for taking the time to read this information

Pamela Kirkpatrick (Researcher)

IV Pilot Study - Participant Response Sheet

Psychosocial and Physical factors influencing employment in adults with Chronic Obstructive Pulmoinary Disease (COPD).

I am interested in taking part in this study at my next clinic appointment.

Name: ………………………………………………………………….…….

Signed: ……………………………………………………………….…..…

Phone number: ……………………………………………………….

Date: ……………………………………………………………………….

PLEASE RETURN TO PAMELA KIRKPATRICK USING THE ENCLOSED STAMPED ADDRESSED ENVELOPE

V Pilot Study - Consent form - Health and Well-being Measures

Centre Number:
Study Number:
Patient Identification Number:

Faculty of Health and Social Care
Garthdee Road, ABERDEEN
AB10 7QG, 01224 262957
p.kirkpatrick@rgu.ac.uk

Name of Researcher: Pamela Kirkpatrick

CONSENT FORM: Questionnaire

Study Title: ***Psychosocial and Physical factors influencing employment in adults with Chronic Obstructive Pulmonary Disease (COPD)***

Please initial in each box

1. I confirm that I have read and understand the participant information sheet dated ……………… (version …….) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Robert Gordon University, from regulatory authorities or from the NHS Trust/Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to my GP being informed of my participation in the study and if the Hospital Anxiety Depression Score is at or above the expected threshold.	
5. I agree to take part in the above study and being contacted for interview.	

Participant Name: -- **Date:** --------------

Signature: --

Name of person taking consent: Pamela Kirkpatrick **Date:** --------------

Signature: --

VI Pilot Study - Health and Well-being Measures

Study Title:

"Psychosocial and Physical factors influencing employment in adults with Chronic Obstructive Pulmonary Disease (COPD)"

QUESTIONNAIRE

Please answer **all** of the questions.

If you would like help completing these questions, please ask the researcher.

Participant ID: ....

Today's date: ...../...../.......

SECTION A: PERSONAL DETAILS

These questions are about you. Please answer them all.

Gender - Male ☐ / Female ☐

Age .... years

Marital Status *(Please tick one box only)*

Single, never married	☐
Single, through divorce/separation	☐
Single/widowed	☐
Living with partner (but not married)	☐
Married	☐
Civil Partnership	☐

Education *(Please tick the highest level only)*

No formal qualifications	☐
Standard Grades/O Levels/GCSE's	☐
Highers/A levels	☐
Vocational Qualification	☐
College (e.g., HNC/HND)	☐
University Degree	☐
University Higher Degree (e.g., Masters/PhD)	☐

What is your ethnic group?
(Choose one section then tick appropriate box to indicate your ethnicity)

White
Scottish ☐
Other British ☐
Irish ☐
Any other white background
Please write in ___________

Mixed
Any other mixed background ☐
Please write in ___________

In the last 12 months:

How many exacerbations of your COPD have you had? __________

How many times have you required antibiotics? ________________

How many times have you been in hospital because of your COPD?

Today's details: Date: .... **BMI:** .... **GP**: ....

Smoking status: .... **FEV1 (if known):** ....

GOLD classification: ....

SECTION B: COPD ASSESSMENT TEST™

For each item below, please a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example:

I am very happy 0 1 2 3 4 5 I am very sad

I never cough							I cough all the time
I have no phlegm (mucus) in my chest at all							My chest is completely full of phlegm (mucus)
My chest does not feel tight at all							My chest feels very tight
When I walk up a hill or one flight of stairs I am not breathless							When I walk up a hill or one flight of stairs I am very breathless
I am not limited doing any activities at home							I am very limited doing activities at home
I am confident leaving my home despite my lung condition							I am not at all confident leaving home because of my lung condition
I sleep soundly							I don’t sleep soundly because of my lung condition
I have lots of energy							I have no energy at all

Scale B = COPD Assessment Test^{TM} (Jones et al 2009).

SECTION C: YOUR QUALITY OF LIFE

This section asks you about the quality and satisfaction of your life in general.

*(Under each heading, please tick **ONE** box that best describes your health **TODAY**)*

MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g., work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

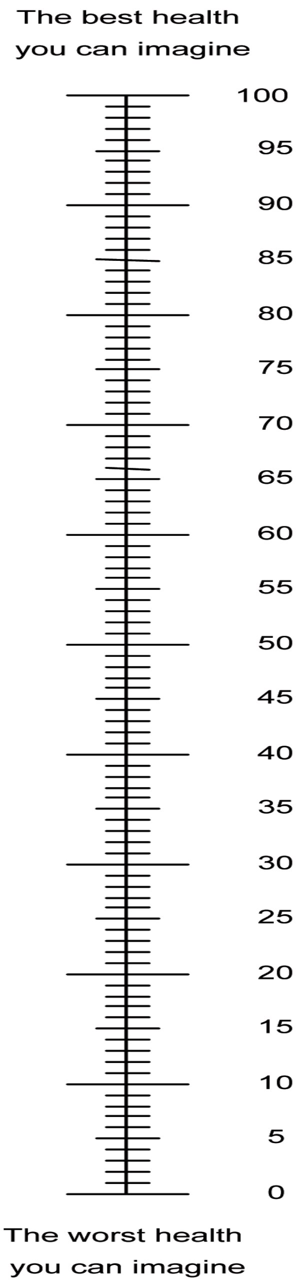
I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
- 0 means the <u>worst</u> health you can imagine.
- Mark an x on the scale to indicate where your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Scale C = EQ-5D-5L Quality of life questionnaire (EuroQol 1990).

SECTION D: YOUR SATISFACTION WITH LIFE

Below are five statements with which you may agree or disagree. Using the 1-7 score, indicate your agreement with each item by circling **ONE** score for each statement.

1 = Strongly Disagree; **2** = Disagree; **3** = Slightly Disagree; **4** = Neither Agree or Disagree; **5** = Slightly Agree; **6** = Agree; **7** = Strongly Agree.

Statement	**Score**						
In most ways my life is close to my ideal	1	2	3	4	5	6	7
The conditions of my life are excellent	1	2	3	4	5	6	7
I am satisfied with life	1	2	3	4	5	6	7
So far, I have gotten the important things I want in life	1	2	3	4	5	6	7
If I could live my life over, I would change almost nothing	1	2	3	4	5	6	7

Scale C = The Satisfaction with life (Diener et al. 1985).

SECTION E: YOUR WELL-BEING AND MENTAL HEALTH

This section asks about your mental health and well-being.
Below are some statements about feelings and thoughts - Please tick the box that best describes your experience of each over the last 2 weeks.

Statements	**None of the time**	**Rarely**	**Some of the time**	**Often**	**All of the time**
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had energy to share					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling good about myself					
I've been feeling confident					
I've been able to make up my own mind about things					
I've been feeling loved					
I've been interested in new things					
I've been feeling cheerful					

Scale D1 = The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)© (Tennant et al, 2007).

Please read the items below. Tick **ONE** response that comes closest to how you have been feeling in the **last 7 days**. Your immediate reaction will probably be more accurate than a long thought-out response.

I feel tense or 'wound up' Most of the time ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all ☐	**I feel as if I am slowed down** Nearly all of the time ☐ Very often ☐ Sometimes ☐ Not at all ☐
I still enjoy the things I used to enjoy Definitely as much ☐ Not quite so much ☐ Only a little ☐ Hardly at all ☐	**I get sort of frightened feeling like 'butterflies' in the stomach** Not at all ☐ Occasionally ☐ Quite often ☐ Very often ☐
I get a sort of frightened feeling as if something awful is about to happen Very definitely and quite badly ☐ Yes, but not too badly ☐ A little, but it doesn't worry me ☐ Not at all ☐	**I have lost interest in my appearance** Definitely ☐ I don't take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever ☐
I can laugh and see the funny side of things As much as I always could ☐ Not quite so much now ☐ Definitely not so much now ☐ Not at all ☐	**I feel restless as if I have to be on the move** Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all ☐
Worrying thoughts go through my mind A great deal of the time ☐ A lot of the time ☐ Not too often ☐ Very little ☐	**I look forward with enjoyment to things** As much as I ever did ☐ Rather less than I used to ☐ Definitely less than I used to ☐ Hardly at all ☐
I feel cheerful Never ☐ Not often ☐ Sometimes ☐ Most of the time ☐	**I get sudden feelings of panic** Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all ☐
I can sit at ease and feel relaxed Definitely ☐ Usually ☐ Not often ☐ Not at all ☐	**I can enjoy a good book or radio or TV programme** Often ☐ Sometimes ☐ Not often ☐ Very seldom ☐

Scale D2 = HADS: Hospital Anxiety Depression scale (Zigmond and Snaith 1983).

SECTION F: BELIEFS ABOUT YOUR HEALTH AND ASPECTS OF COPING

This section asks you about how you cope with challenges in your life in general. Please tick **ONE** box for each statement

	Not true at all	Rarely true	Sometimes true	Often true	True nearly all of the time
I am able to adapt when changes occur					
I can deal with whatever comes my way					
I try to see the humorous side of things when I am faced with problems					
Having to cope with stress can make me stronger					
I tend to bounce back after illness, injury, or other hardships					
I believe I can achieve my goals, even if there are obstacles					
Under pressure, I stay focused and think clearly					
I am not easily discouraged by failure					
I think of myself as a strong person when dealing with life’s challenges and difficulties					
I am able to handle unpleasant or painful feelings like sadness, fear and anger					

Scale E = Connor Davidson Resilience Scale (Connor and Davidson 2003).

Section G: WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT:

The following questions ask about the effect of your health problems on your ability to work and perform regular activities. By health problems we mean any physical or emotional problem or symptom. Please fill in the blanks or circle a number, as indicated.

1. Are you currently employed (working for pay)? ____ NO____ YES
   If NO, check "NO" and skip to question 6.

The next questions are about the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work because of your health problems? *Include hours you missed on sick days, times you went in late, left early, etc., because of your health problems. Do not include time you missed to participate in this study.* _____HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study? _____HOURS

4. During the past seven days, how many hours did you actually work?

   _____HOURS *(If "0", skip to question 6.)*

5. During the past seven days, how much did your health problems affect your productivity while you were working?

   Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. ***If health problems affected your work only a little, choose a low number. Choose a high number if health problems affected your work a great deal.***

Consider only how much health problems affected
productivity while you were working.

Health problems had no effect on my work	0	1	2	3	4	5	6	7	8	9	10	Health problems completely prevented me from working

PLEASE CIRCLE A NUMBER

6. During the past seven days, how much did your health problems affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If health problems affected your activities only a little, choose a low number. Choose a high number if health problems affected your activities a great deal.

Consider only how much health problems affected your ability to do your regular daily activities, other than work at a job.

Health problems had no effect on my daily activities	0	1	2	3	4	5	6	7	8	9	10	Health problems completely prevented me from doing my daily activities

CIRCLE A NUMBER

If you are not currently in paid employment you have now completed the questionnaire. Thank you. Please now read page 13.

If you are in ***paid employment,*** *please continue the survey.*

SECTION H: WORKING PRACTICES AND HEALTH

These questions are about your current work.

- How many hours per week do you do paid work? ……….. hours
- What is your job title/description of duties?
  …..
- How long have you been employed with your current employer? Years _____

This section now asks about how COPD affects you at work. (Please describe your work experiences during the last **4 WEEKS**. Please use the following scale and tick **ONE** response to each of the numbered questions to show your agreement or disagreement with the statements).

Please use the following scale
I strongly disagree with the statement; I somewhat disagree with the statement; I am uncertain about my agreement with the statement; I somewhat agree with the statement; I strongly agree with the statement.

	Strongly Disagree	**Somewhat Disagree**	**Uncertain**	**Somewhat Agree**	**Strongly Agree**
Because of my (COPD) the stresses of my job were much harder to handle.					
Despite having my (COPD) I was able to finish hard tasks in my work.					
My (COPD) distracted me from taking pleasure in my work.					
I felt hopeless about finishing certain work tasks due to my (COPD).					
At work I was able to focus on achieving my goals despite my (COPD).					
Despite having my (COPD) I felt energetic enough to complete all my work.					

Scale G = The Stanford Presenteeism Scale (SPS-6; 2001 version).

SECTION J: WORKPLACE CONTROL AND ADAPTATION

These questions ask about work adaptations relating to your **COPD** in the last **4 weeks**. Please circle either YES/NO and provide further information if applicable.

1. Does your employer know you have COPD? YES/NO

2. Have you taken time off your work for COPD treatment/appointments? YES/NO

(If yes – what was this for and how long did you take off? ....)

3. Have you had any adjustment to your working hours? YES/NO

(If yes – what changed? ....)

4. Have you taken a cut in pay because of your COPD? YES/NO

(If yes – what changed? ....)

5. Have you been able to be flexible in how you are working? YES/NO

(If yes – what has changed? ....)

6. Have you been able to change your job role, responsibilities or duties? YES/NO

(If yes – what changed? ....)

7. Have you been able to change any equipment/machinery in your job? YES/NO

(If yes – what did you change? ....)

8. When COPD MOST affects you at work what do you do to help yourself?

……

9. When COPD MOST affects you at work what makes things worse for you?

……

10. Finally, the purpose of this study is to understand more about how to support people with COPD in the workplace. Use the space below to add anything you feel important for us to know that we have not asked relating to your experiences.

    ………
    …….........

Willingness to participate in a follow-up interview

Much of this survey has been general and I have been selective in the items included to keep it manageable. However, to provide a more detailed picture, I wish to interview (one to one) a small sample of people who have completed this survey. The interview will provide an opportunity to develop issues not covered here. What you say in the interview is strictly confidential and no identifying information will be kept. I recognise this makes further demands on your time and efforts but if you were willing to be interviewed this would be very helpful and appreciated. I anticipate this would take up to 30 minutes, carried out in private, at a time and place convenient to you.

Since I don't yet know how many people will be willing to be interviewed, I can't at this stage confirm whether or not I would need to take you up on your offer. As you will appreciate, I have to be selective in terms of the representativeness of the interviewees as my timescale would not permit interviewing large numbers. If you were not selected for interview, despite your offer to help, this does not reflect upon you personally. If you are willing to be interviewed, I'd confirm if you are required within 4 months from today.

I am willing to be interviewed: Yes ☐ No ☐

Please write your name here

……………………………………………………………………………………....

Please tell me your contact details here

……

……

……………………………………………………………………………………….

Thank you for completing this questionnaire. Please look through your responses to check you have answered all the questions.

Scales

Scale B: COPD Assessment Test™ (CAT). Jones, P. W., Harding, G., Berry, P., Wiklund, I., Chen W-H. and Leidy, N. K., Development and first validation of the COPD Assessment Test. Eur Respir J 2009, 34: 648–654.

Scale C = The EuroQol Group. 1990. EuroQol-a new facility for the measurement of health-related quality of life. Health Policy, 16(3):199-208.

Scale D = Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. 1985. The Satisfaction with Life Scale. Journal of Personality Assessment, 49, 71-75.

Scale E1 = Tennant, R, Hiller, L, Fishwick, R, Platt, P, Joseph, S, Weich, S, Parkinson, J, Secker, J, Stewart-Brown, S., 2007. The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation, Health and Quality of Life Outcome; 5:63 doi:101186/1477-7252-5-63.

Scale E2 = Hospital Anxiety Depression Scale = HADS. Zigmond, A.S. & Snaith, R.P. 1983. The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 67, 361-370.

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983. This edition first published in 1994 by Nelson Publishing Company Ltd (now GL Assessment Ltd), 389 Chiswick High Road, London W4 4AL. GL Assessment Ltd is part of the Granada Learning Group

Scale F = Connor KM, Davidson JRT. Depression and Anxiety 2003; 18: 71-82. Copyright 2003 Wiley-Liss, Inc.

Scale G =Di Bonaventura, MD. Paulose-Ram, R. Su, J. McDonald, M. Zou, K.H. Wagner, J.S. Shah, H., The burden of chronic obstructive pulmonary disease among employed adults. Int J Chron Obstruct Pulmon Dis. 2012;7:211-9.

Scale H = Koopman, C., Pelletier, K.R., Murray, J.F., Sharda, C.E., Berger, M.L., Turpin, R.S., Hackleman, P., Gibson, P., Holmes, D.M., Bendel, T.J. Occup Environ Med. 2002; 44 (1): 14-20.

VII Pilot Study - GP Notification Letter

ROBERT GORDON UNIVERSITY ABERDEEN

GP Notification Letter

Date:
GP Address

Dear Dr
Re: Patient details – – DOB –

Study Title: "An Investigation of health and well-being factors influencing employment in adults with Chronic Obstructive Pulmonary Disease"

Your patient participated in the above study on xx.xx.xx. The study is investigating a number of health and well-being factors thought to be related to employment. As part of this study, your patient undertook a Hospital Anxiety Depression Scale questionnaire. The results from this have generated a score of - xx for xx construct, which suggests further follow up may be required by a medical practitioner. I have notified the patient that they should contact the surgery in the next few days to make an appointment to explore this further with you.

I have included the participant information sheet for your interest and if you require further information please do not hesitate to contact me.

Yours sincerely

Pamela Kirkpatrick
Nursing Lecturer and PhD student

p.kirkpatrick@rgu.ac.uk
01224 262957

VIII Pilot Study - Consent Form - Interviews

Centre Number:
Study Number:
Patient Identification Number:

Faculty of Health and Social Care
Garthdee Road, ABERDEEN
AB10 7QG, 01224 262957
p.kirkpatrick@rgu.ac.uk

Name of Researcher: Pamela Kirkpatrick

CONSENT FORM: Semi-structured interview

Study Title: ***Psychosocial and Physical factors influencing employment in adults with Chronic Obstructive Pulmonary Disease (COPD)***

Please initial in each box

1. I confirm that I have read and understood the participant information sheet dated ……………… (version …….) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Robert Gordon University, from regulatory authorities or from the NHS Trust/Health Board, where it is relevant to my taking part in this research, I give permission for these individuals to have access to my records.	
4. I agree to my GP being informed of my participation in the study.	
5. I am aware that the interview will be digitally audio recorded.	
6. I agree to take part in the above study.	

Participant Name: --- **Date:** --------------

Signature: ---

Name of person taking consent: Pamela Kirkpatrick **Date:** --------------

Signature: ---

IX Pilot Study - Interview Schedule – Not employed

Interview Schedule - Not employed

1. What prevents you from working?
    a. Any other detail about this?
    b. What other factors were involved?
    c. Further detail about COPD?

2. What caused you to stop working?
    a. Which was the most important factor?

3. What could have been done to help you work for longer?
    a. Anything else?

4. What difference would being able to work make to you?
    a. How would this help?

X Pilot Study - Interview Schedule - Employed

Interview Schedule - Employed

1. What helps you stay in work?
    a. Anything else about this?
    b. Further detail about COPD at work?

2. What difference would not being able to work make to you?

3. What might cause you to stop working in the future?
    a. What is your biggest challenge currently?

4. What else can be done to help you keep working for longer?
    a. Who can help with that?

XI Pilot Study - Draft of Elements, Dimensions and Categories

Elements	Dimensions	Categories
Condition varies day to day.	**Daily variability of health at work**	**Health and COPD symptoms**
Daily variability of condition.		
There is no pattern to how he feels on a daily basis.		
Weather affects how his lungs are at work.		
Alcohol intake can affect symptoms the next day.		
Fatigue is often an issue at work.		
Now focused on health instead of job.		
When frustration is too great turns into a horrible person.		
Expects COPD to get worse with age.		
Takes deterioration in condition for granted.		
Will have regular lung check-ups.		
Focused on health and well-being.		
Doctors advised wouldn't be able to continue to work much further.		
COPD is a hidden condition.		
Mornings were the best part of the day.		
Put himself first before job.		
Condition gradually deteriorated over last decade.		
The decline in health has happened gradually and now realises limitations.		
Can't work due to condition some days.		
Struggled physically at work for 2 years.		
Body can't keep up with mind.		
Daily variability of condition.		
Difficult to accept severity of illness.		
Not able to do things he knows he should be able to do.		
Could have exacerbation anytime and end up in hospital.		
Didn't predict sudden decline in condition.		
Doesn't think about what might happen if it gets worse.		
Frustrated can't do physically what can be done mentally.		
Uses inhaler if tight chested.		
Condition deteriorated suddenly and negatively impacted on work rate.		
Had no access to oxygen cylinders at work.	**Dealing with symptoms at work**	
Signs of oxygen depletion if worked 7 hours.		
Can go home if unwell.		
Face up to illness.		

Elements	Dimensions	Categories
Couldn't use oxygen at work.		
Close to collapse at work.		
Deterioration was constant.		
Health declined in a month and everything changed.		
Found deterioration difficult to accept.		
Easier to give in to bad days when unemployed.		
When working just had to get up and get on with it when not feeling good.		
Didn't expect to deteriorate so quickly.		
Went from being fit and healthy to not being able to walk upstairs.		
Having to push himself.		
Physical and mental attitude to lungs gets things done.		
Nothing would be achieved if didn't push hard.		
Pushes himself as hard as he can.		
Will seek support in the workplace if needed.	**Information, advice and support**	**Support in the workplace**
Not requiring support in the workplace.		
Difficult to predict the support that will be needed.		
Currently in control of work.		
Sent to Occupational Health when health issues cropped up.		
Fought for everything.		
Didn't ask anyone for support.		
Thought he was treated harshly.		
Not offered any help.		
Hospital consultant wrote letters to employer.		
Employers aren't familiar with COPD.		
Employers don't have a strategy for COPD.		
Requested information about pensions.		
Planned hospital visits to suit work times.		
HR didn't know systems and processes for early retirement and how to help.		
Need to be able to access easy to understand information on rights.		
Someone neutral to help would have been beneficial.		
Should have been more assertive knowing how poorly the treatment had been in the workplace.		
Advise others to stand up and don't accept poor treatment.		
Wasn't aware of disability rights or where to access support.		
Need information about COPD in the workplace.		

Elements	Dimensions	Categories
Independent support needed for establishing workplace adjustments.		
External support required for dealing with issues in the workplace.		
People don't know what their options are.		
Nobody able to help.		
Compromise was all one way.		
Put up with hassle at work.		
Wanted to get on with work.		
New line manager was better than previous.		
There's no help available.		
Not aware of any help.		
No support in work and experience wasn't good.		
Everyone needs different types of help.		
Works better under pressure.	**Work duties and role demands**	**Workplace challenges and solutions**
Having a lung transplant would mean a career change.		
Promoted the staff to take on more.		
Work has to be high quality all the time.		
Easy to do work in theatres standing up.		
More difficult to manage lifting animals.		
Some cleaning duties were a killer.		
The kitchen was hot, and it was fast paced.		
Reduced to part time hours but the job was still a physical one.		
Bending for cleaning was difficult.		
Gets depressed when runs out of puff and can't do things.		
Colleagues supported with low cleaning tasks.		
Standing still to do tasks was easier.		
Restraining animals was really difficult.		
Having control of tasks would have made things easier.		
Light duties may help do things slower.	**Workplace adjustments**	
Not achieving goals with light duties.		
Nothing can make job easier.		
Feels degraded and defeated by light duties.		
Get bored with little/nothing to do.		
Employees helped out with the workload.		
Reduced responsibilities less satisfying.		
Not giving enough in the workplace.		
Didn’t take wage as felt not working effectively.		
Adjusted role to justify position.		
Putting more hours in and benefitting less.		
Worked part time for a year.		
Couldn't work later shifts.		

Elements	Dimensions	Categories
Stair lift installed in the workplace eventually.		
Changes to cleaning duties were made begrudgingly.		
Changed cleaning chemicals as they caused choking.		
Working 5 mornings provided better consistency at work.		
Had to fight for everything at work.		
Nothing structured put in place.		
Worked for small company so not easy to do alternate role.		
A structured approach to adaptations would have helped everyone.		
Works flexible.		
Could have worked longer if job had been more sedentary.		
Tax complicates pension if working part time.		
Reduced hours to 2.5 days.		
Being off sick prevented employer terminating employment.		
Part time work negates the pension.		
Works around core business hours.		
Flexible hours would help depending on condition.		
Refused to work longer shifts which caused issues at work.		
Reduced working hours on advice from physio.		
Better working part time.		
Sedentary role means work isn't too difficult.		
Got a work stair lift by taking it to a grievance.		
Working some hours helps everyone.		
Flexible hours beneficial.		
Segregated from colleagues for meetings and breaks.		
Employer makes work area as good as possible.		
Didn't like being pampered.		
Staff began to pamper as noticed deterioration in condition.	**The impact of work adjustments on others**	
Staff worked extra to cover.		
Impact on staff was unfair.		
Saw tiredness in employees as they were working harder.		
Recognised as someone who had helped others.		
Attended hospital appointments during lunch hour.		
Hurried lunch to return to work duties.		
Put pressure onto colleagues.		

Elements	Dimensions	Categories
Let others take on the work.		
Colleagues (and friends) helped with difficult duties.		
Staff were doing extra work which wasn’t fair.		
Reluctant to affect employees career prospects and pathways.		
Separated from the workplace.	**Purposeful employment**	
Misses not using brain.		
Missed banter with colleagues.		
Would be happier working.		
Working provides financial choices.		
Forced to live in a poorer social situation.		
Helped employees develop themselves.		
Loved his job.		
Got pleasure from helping others progress their learning.		
Has no influence on people now.		
Doesn’t look for work any longer.		
Gone from being useful to useless.		
Would love to be working.		
Could do work at home.		
Might be seen as unreliable by potential employers.		
Known as someone who helped people.		
Wanted someone to notice skills and help get work.		
Could be teaching and educating others to work in the kitchen.		
Jobcentre looks at negatives rather than capabilities.		
Offered to do work for free.		
Not enough help for people losing job to poor health.		
Forced to retire as nobody accommodated condition.		
Working on makes you feel stronger.		
Helping others would have been satisfying.		
Could have worked on longer.		
No chance to try alternative work.		
Now out of touch with the workplace.		
Still feels he has plenty more to give.		
Once someone leaves the workplace, they've no chance of employment.		
Was open to any type of work.		
Work gives a person something to do.		
Keeping busy reduces feelings of depression.		
Part time work gives a person something to look forward to.		
Never too old to learn.		
People need helped into work without punishing them.		

Elements	Dimensions	Categories
Having a job benefits many people.		**Benefits of working and exiting employment**
A course is useful to train for other jobs.		
No point working if they stop benefits.		
Helped others and still prepared to do that.		
Still wants to help others learn.		
Potential employers should listen to applicant.		
Would still like a chance at work.		
Recognise what people’s skills are and match them to appropriate job.		
Everyone has a use.		
Give up on people too easily.		
People that try hard should get support.		
Part time hours reduced work continuity.		
Working 5 days a week gives working continuity.		
Working part time brings work-related challenges.		
Missed the structure and routine of working.		
Pension isn't big.		
Taking part time work would cause substantial tax issues.		
Staying in work is better.		
Work is important in people’s lives.		
Looked online for alternative work.	**Searching for alternative employment**	
Worked hard and deserved to be treated fairly.		
Wishes someone would recognise valuable skills.		
Need friends to help you into new job/role.		
People will stay healthier and happier with help to stay in work.		
Would have liked to do something else.		
Wanted someone to suggest other things to try.		
Signed on at 39.		
Understands why people don’t want to employ him.		
Not everyone is trying to take advantage of the system.		
Thinks condition makes him unreliable to potential employers		
Jobcentre staff saw him as lazy.		
Jobcentre tried to force him into work rather than try to help.		
Thinks he could go into kitchens as a problem solver.		
Could work as a consultant.		
There wasn't anything out there.		
Couldn't secure part time work.		
Still prepared to do some part time work.		

Elements	Dimensions	Categories
Should have had more of a voice to force the issue.		
Thinks he could teach and educate others.		
Unfair to give up on people too easily.		
Thought employers were put off by him having a condition.		
Should have made more noise to get noticed by prospective employers.		
Keeps motivation because needed by family.		
Children provide motivation for life.		
Might lose drive for life if gave up work.	**Exiting employment**	
Age limit for working would make stop.		
Giving up work would have a negative financial impact.		
Need to have money to live.		
If stopped working would be isolated in winter because of where lives.		
Had to stop working as couldn't keep up with fast pace.		
Not enough work in the business just to do the management.		
Loss of lifestyle as a result of bankruptcy.		
Sudden disconnect with workplace.		
If couldn't do the job well then wouldn't do it.		
No backup plan.		
Can't work if on a lung transplant waiting list.		
Business came to an abrupt end.		
Stopped taking a wage as wasn't earning it.		
Realised it was time to stop working when breathless communicating with customers.		
No option other than to leave work.		
Early retirement cost the company money.		
Difficult giving up everything worked for.		
Missed work when he left.		
Needs to keep active.		
Should have tried harder to keep job.		
Should have been more forceful and not given up work.		
Was time to give up work for physical reasons.		
Wasn't ready to give up work at that time.		
Couldn't cope with work now as on O2 24/7.		
Really missed working.		
Needed something constructive to do with time after giving up work.		
Would have got worse if kept on working.		

Elements	Dimensions	Categories
Own choice to finally leave work at that time.		
Someone could have recognised valuable skills.		
Would still like to use skills and do what capable of.		
Feels ignored and forgotten about.		
Helping others would be satisfying.		
Couldn't physically do the job anymore.		
Not in the real world now.		
Hasn't worked for years.		
Not contributing to society or socialising with others.		
Needs a reason to wake up in the morning.		
Needing to have something meaningful to do.		
Feel useless if I can't do anything.		
Would miss the financial and social aspects of working.		
Not worried about leaving work yet.		
Didn't want to be on benefits as would rather be in work.		
Given a lot to society and wants to be treated fairly.		
Still wants to earn a living part time.		
Husband advised to leave work.		
Lose touch with outside world.		
Something had to change to make the business sustainable.		
Gave up work when couldn't physically do it any longer.		
Work activity would take the monotony out of life.		
Boredom is a big life factor now.		
Suddenly felt alone.		
Not ready to give up work mentally.		

XII Qualitative Study - Ethics Approval - Health Research Authority

Health Research Authority
South West - Cornwall & Plymouth Research Ethics Committee
Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

08 August 2017

Ms Pamela Kirkpatrick
Academic Lead for Internationalisation
Robert Gordon University
School of Nursing & Midwifery
Garthdee Road
Aberdeen
AB10 7QG

Dear Ms Kirkpatrick

Study title:	**The Employment experiences of People with Chronic Obstructive Pulmonary Disease (COPD) (The TEMPO study)**
REC reference:	**17/SW/0168**
Protocol number:	**SHS/16/38**
IRAS project ID:	**216306**

Thank you for your letter of 03 August 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion, but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g., for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC, but you should do so at the earliest opportunity e.g., when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Sponsor Insurance]	V1	18 July 2016
Interview schedules or topic guides for participants [Interview schedule working]	V1	16 June 2017
Interview schedules or topic guides for participants [Interview schedule cessated]	V1	16 June 2017
IRAS Checklist XML [Checklist_03082017]		03 August 2017
Letter from sponsor [Sponsor letter]	V1	23 June 2017
Letters of invitation to participant [Consultant letter of invitation]	V1	16 June 2017
Other [Gatekeeper letter]	V1	14 July 2017
Other [Response to ethics]	V1	03 August 2017
Other [Participant information sheet National]	V2	02 August 2017
Other [Participant information sheet NHS]	V2	02 August 2017
Other [Social media draft flyer]	V1	03 August 2017
Other [Insurance document]		31 July 2017
Participant consent form [Participant consent form NHS]	V1	16 June 2017
Participant consent form [Participant consent form National]	V1	16 June 2017
REC Application Form [REC_Form_14072017]		14 July 2017
Research protocol or project proposal [Research Protocol]	V1	16 June 2017
Summary CV for Chief Investigator (CI) [PI CV]	V1	16 June 2017
Summary CV for student [PI CV]	V1	16 June 2017
Summary CV for supervisor (student research) [G Devereux CV]	V2	16 June 2007
Summary CV for supervisor (student research) [KC Summary CV May 2017]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics

Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/SW/0168 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

LRoberts.

pp.

Canon Ian Ainsworth-Smith
Chair

Email: nrescommittee.southwest-cornwall-plymouth@nhs.net

Copy to: Ms Jill Johnston
Dr Susan Ridge, NHS Grampian

XIII Qualitative Study – Ethical Approval - NHS R&D

Research and Development

Foresterhill House Annex
Foresterhilll
Aberdeen
AB25 2ZB

Ms Pamela Kirkpatrick
Robert Gordon University
Faculty of Health & Social Care
Garthdee Road
Aberdeen
AB10 7QG

Date	17/10/2017
Project No	2017RG003
Enquiries to	Lynn Massie
Extension	53846
Direct Line	01224 553846
Email	grampian.randdpermissions@nhs.net

Dear Ms Kirkpatrick

Management Permission for Non-Commercial Research

STUDY TITLE:	The Employment experiences of People with Chronic Obstructive Pulmonary Disease (COPD) (The TEMPO study)
PROTOCOL NO:	V1; 16.6.17
REC REF:	17/SW/0168
R&D REF:	2017RG003

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

1) **The R&D Office will be notified, and any relevant documents forwarded to us if any of the following occur:**
    - **Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).**
    - **A change of Principal Investigator in Grampian or Chief Investigator.**
    - **Any change to funding or any additional funding.**

2) **The R&D Office will be notified when the study ends.**

3) **The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.**

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

Susan Ridge
Non-Commercial Manager

cc: Dr Kay Cooper
Prof Graham Devereux
Research Monitor

<u>Sponsor</u>: Robert Gordon University

XIV Qualitative Study – Participant Information Sheet

PARTICIPANT INFORMATION SHEET

"The Employment Experiences of People with Chronic Obstructive Pulmonary Disease (COPD)

What am I being asked to do?

You are invited to take part in a research study exploring the employment experiences of people with Chronic Obstructive Pulmonary Disease (COPD) which has been reviewed by the Cornwall & Plymouth Research Ethics Committee and the School of Health Sciences Research Review Group in Robert Gordon University (RGU). Before you decide if you wish to take part, it is important you understand why the study is being done and what it involves. Please take the time to read this information sheet carefully and discuss it further with others if you wish.

What is the purpose of the study?

The study is looking at the employment experiences of people with COPD. It is being carried out to see what helps or what hinders people being able to work to their satisfaction. The study will include a mix of people with COPD who are currently in paid work and people who have given up paid work because of their COPD. The study has not received funding.

Why have I been chosen?

To be selected to take part you will be of working age (65 years old or under) and either working or have stopped working due to your COPD. The study is looking for around 16 people to take part in a short discussion (interview to take one hour) with the researcher.

Do I have to take part?

No, it is up to you to decide whether to take part. If you decide to take part, you will be given this information sheet to keep. You will also receive a participant consent form which I will read out to you and ensure you agree to all sections before proceeding. You may print, sign this and return to me for further verification of consent. If you do take part, you are free to withdraw at any time, without giving a reason for doing so. If you wish to withdraw from the study, you have the choice to also withdraw your data provided it has not reached the publication stage. No payment will be offered for taking part.

What will happen to me if I take part?

Taking part involves a short interview (discussion) with the researcher. This will be done in private and can be done at home, alternative venue or by telephone or Skype/Facetime if more convenient for you. The discussion will be digitally recorded and typed up. Once typed up, the recording will be deleted from the portable device once it has been securely stored on a password protected computer. All typed and printed data is securely locked and kept anonymous as only pseudonyms are attached to the data. Only the research team will see the transcripts. Anonymous quotes from the interviews may be used in subsequent publications in research papers and professional journals. Information will be collected and stored within the requirements of the Data Protection Act (1998) ensuring confidentiality at all times. In the unlikely event I uncover evidence that you are in physical or psychological danger at any point I will immediately breach our agreed confidentiality and contact a medical practitioner in order to protect your safety and well-being.

What are the possible disadvantages of taking part?

There are no predictable risks in taking part. It's possible however, that when discussing your experiences, we may touch upon sensitive issues for you. If you do not wish to answer certain questions, you can skip anything you don't want to answer. You can also end the interview at any time you wish, and you don't need a reason for doing this. Care will be taken by the researcher to ensure you are comfortable with the content and conduct of the interview and will progress it at a pace you are comfortable with.

What are the possible benefits of taking part?

Taking part will not offer you any direct benefit and won't affect the standard of care you receive. The research provides you with an opportunity to contribute to a process of sharing knowledge, experience and needs regarding working-age people coping with COPD. The information collected will inform healthcare professionals how to provide better support for people with COPD. It will also help determine whether it's worthwhile conducting a larger study on the topic to enhance employment experiences and sustainability. This may help healthcare professionals/Health Policy makers make supportive healthcare decisions and this information may benefit employed people with COPD in the future.

What happens when the research study stops?

Once the study is completed (within 6 months from this letter being issued) the researcher will analyse the results and with the study team determine what possible interventions could be offered to people with COPD to help improve their employment situation. A report will be written illustrating anonymised findings from the study. This will form part of the researcher's PhD thesis and will be published in professional academic journals.

What if something goes wrong?

The research (interview) is classed as low risk. If you are harmed in any way by taking part in this study, there are no specific compensation arrangements. If you have a complaint about the conduct of this study contact Dr Hector Williams, co-convenor of the School of Health Sciences Ethics Research Review Group – 01224 262961 or h.williams@rgu.ac.uk.

Who is carrying out the study?

The nurse researcher (Pamela who is a PhD student), from Robert Gordon University is leading the study and is supported by the NHS Respiratory Medicine colleagues and a research team who are also the academic supervisors from Robert Gordon University, Schools of Health Sciences and Nursing & Midwifery.

Participation and queries

Thank you for considering taking part in this study. If you've any questions or wish to take part, please contact me on **01224 263276** or email **p.kirkpatrick@rgu.ac.uk**

Thank you for taking the time to read this letter - *Pamela Kirkpatrick*

XV Qualitative Study - Consultant Invitation Letter

NHS
Grampian

Department of Respiratory Medicine
Aberdeen Royal Infirmary
Foresterhill
Aberdeen
AB25 2ZN

“The Employment Experiences of People with Chronic Obstructive Pulmonary Disease (COPD)

With colleagues in Robert Gordon University, we are carrying out research to understand more about the employment experiences of people with Chronic Obstructive Pulmonary Disease (COPD) and what factors help them remain in or cease paid employment. We know from the lack of research that there is a poor understanding of the impact of leaving employment. The outcomes from this study will help inform recommendations to improve the employment outcomes for people with COPD.

As you are eligible for this study, I am inviting you to consider taking part in a short discussion (interview). Before you decide whether to take part, we would be grateful if you could read the enclosed *Participant Information Sheet.* A decision not to take part will not affect the standard of care you receive in any way.

I hope you find all the information you need in this enclosed sheet. If you have any questions about the study or wish to take part, please contact Pamela, the PhD researcher, whose details are included.

Yours sincerely

Professor Graham Devereux
Consultant in Adult Respiratory Medicine

XVI Qualitative Study - Press release

Volunteers with Chronic Obstructive Pulmonary Disease (COPD) age 65 and under sought for a research study on employment experiences

Pamela Kirkpatrick, a lecturer and researcher in Robert Gordon University's School of Nursing and Midwifery, is recruiting people with COPD to take part in a short discussion (interview) to explore people's experiences of employment. The research team also includes Professor of Respiratory Medicine Graham Devereux, colleagues from NHS Grampian and Dr Kay Cooper, Emeritus Professor Valerie Maehle and Dr Sheelagh Martindale from the Robert Gordon University. Pamela said: "We know from the lack of research that there is a poor understanding of the impact of work on COPD and vice versa. Previous research highlights that 40% of people with COPD have given up paid employment sooner than those with most other chronic conditions and many lose out financially, becoming more socially isolated as a result".

"Support structures from the employer, human resource departments, support groups, family and friends and healthcare professionals is fragmented, not joined up and is inconsistent in facilitating workplace adaptations, flexible working or benefits entitlement. This means people with COPD often navigate through these elements alone and over a longer period of time which can be exhausting and not always to their long-term benefit. The outcomes from this study will help inform recommendations to improve the longer term employment outcomes for people of working age with COPD".

To be eligible for the study participants will be 65 years old or under, have COPD as their main presenting condition and be fluent in spoken English. The confidential interview (discussion), carried out in private, can be conducted face to face, by telephone or through the use of other media such as Facetime or Skype. The interview is expected to take under one hour. Recruitment to the study is underway and will run until February 2018. If you, or someone you know has COPD and are either employed or have given up employment because of COPD and may be interested in finding out more taking part, contact Pamela Kirkpatrick by email: p.kirkpatrick@rgu.ac.uk 01224 263276.

XVII Qualitative Study - Consent Form

Name of Researcher: Pamela Kirkpatrick

"The Employment Experiences of People with chronic Obstructive Pulmonary Disease (COPD)"

CONSENT FORM: Semi Structured interview

Please initial in each box

1. I confirm that I have read and understood the participant information sheet dated ……………… (version …….) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.	
2. I understand that my participation in this study is entirely voluntary and that I am free to withdraw at any time, without giving any reason.	
3. I understand that data collected during the study may be looked at by individuals from RGU, where it is relevant to my taking part in this research.	
4. I am aware that the interview will be digitally recorded and will be deleted from the portable device after it has been typed up and then securely stored on a password protected computer.	
5. I understand that anything I say during the interview will remain confidential and not be discussed out-with the interview.	
6. I agree that my anonymised verbatim quotes may be used for illustrative purposes in reports or presentations produced by the researcher.	
7. I agree to take part in the above study.	

Participant Name: -- Date: --------------

Signature: ---

Name of person taking consent: Pamela Kirkpatrick **Date: --------------**

Signature: ---

XVIII Qualitative Study – Interview Schedule – Employed

Experiences of people with COPD in employment

- How many hours paid work do you do each week? ………………….. hours
- What is your job title/description of duties?
  ……………………………………………..….…………………………….….……………………………..
- How long have you been employed with your current employer?
  Years .…………………….…..
- What did you do before this?
- What's it like to work with COPD?
    - How does your COPD affect your ability to work?
    - How does your work affect your COPD?
    - What does it feel like going to work?
- How do you successfully sustain working with COPD?
    - What helps in particular (Physical and psychological)?
    - In what way does this help?
    - Why does this help?
    - Are there any barriers in sustaining working with COPD (physical and psychological)?)
    - Why does this not help?
- Have you faced any challenges in the workplace because of your COPD?
    - What happened?
    - How did this affect you?
    - Can you forsee any barriers to working in the future?
    - How might this/these cause challenges to you?
- Do you know if there is any specific support available for you in the workplace?
    - What, if any support have you used to help you sustain working?
- What would prevent you from working in the future?
    - Why would that affect you?
    - What would that mean?
    - How would you feel about this?
- Who could help provide support in that process?
    - How might this help you?
    - Who else could help?

- Have you made any adjustment/s to your working hours or the jobs you do? YES/NO
  (If yes – what changed?..)

- Have you been able to change/adapt your job role or duties or equipment/machinery used in your job? YES/NO
  (If yes – what changed? ....)
  - Why did it change?
  - Who instigated this?
  - What was the outcome?
  - If not – why?
  - Was support required/other reasons?

- Have you needed to be flexible in how you are working in relation to your COPD? YES/NO
  (If yes – what changed?..)

- Have you needed to make any recommendations to colleagues/employers about your working conditions?
  - What were they?
  - How did they help?
  - If so, what's your feelings about them?
  - Any other recommendations?

- Is there anything else you thought I would ask you about but haven't?

- Is there anything else you'd like to say about this topic?

XIX Qualitative Study – Interview Schedule – Not employed

Experiences in ceasing employment due to COPD

Reasons for giving up paid employment because of COPD

- How many hours per week did you work immediately before stopping working?
  …………… hours

- What was your job title/description of duties?
  ……
  ….………..

- How long had you been employed with your last employer? Years……………..……….

- What was it like to work with COPD?
  - Did your COPD affect your ability to work to your satisfaction?
  - Did your work affect your COPD?
  - How did this make you feel?
  - What prevents you from working?

- How long did you manage to sustain working with COPD whilst you/your employer were thinking about stopping?
  - What factors best helped you do this?
  - What aspects hindered you working longer with your condition?
  - How did you feel about this?
  - What else helped?

- Have you ever made any recommendations or advised colleagues/employers about your condition?
  - What did you do?
  - Was this effective?
  - How did you feel?
  - What may have helped you stay in work for longer?
  - How could this have helped you?
  - Is there anything you didn’t try and wished you had?
  - Who/what else could have helped you?

- Who made the decision you would stop working?
    - How was this made?
    - How did you feel about this?
    - Did anyone support you with this process?
    - Was it helpful?
    - Did anyone support you with benefits/advice?
    - Thinking back, is there anything you would have done differently?

- What would life be like if you could work?
    - Is there anything you think you could be doing for work now?
    - What difference would that make to you?

- Had you made any adjustment/s to your working hours or the jobs you did? YES/NO
  (If yes – what changed?...)

- Had you been able to change/adapt your job role or duties or equipment/machinery used in your job? YES/NO
  (If yes – what changed?...)
    - Why did it change?
    - Who instigated this?
    - What was the outcome?
    - If not – why?
    - Was support required/other reasons?

- Have you needed to be flexible in how you were working (e.g., hours worked)? YES/NO
  (If yes – what changed?...)

- Is there anything else you thought I would have asked you about your work experiences but haven't?

- Is there anything else you'd like to say about your work experiences?

XX Qualitative Study - Transcription Confidentiality Agreement

Confidentiality Agreement

Between Pamela Kirkpatrick (Robert Gordon University)
& L.S TRANSCRIPTS

During the course of our working contract, **L.S TRANSCRIPTS** may have access to, gain knowledge of or be entrusted with medical and/or personal information concerning individuals. This information may include matters of a highly sensitive and/or personal nature.

1. The receiving party hereby agrees that all information, whether oral, written or otherwise communicated that is supplied by the disclosing party in the course of the project shall be treated as confidential.
2. The receiving party undertakes not to use the information for any purpose, other than for the purpose of working within the project specification.
3. This agreement applies to technical and commercial information, intellectual property, as well as goodwill and know-how contained within the disclosed information and supplementary or supporting data howsoever communicated between the parties.
4. This agreement does not apply either to any information that is in the public domain, nor to information which the receiving party can demonstrate was already lawfully in their possession prior to its disclosure by the other party.
5. On request from the other party either party shall return any documents or other information relating to this agreement. No unauthorised copies in any form are permitted to be retained and must be deleted or destroyed 7 days after return of completed transcription to disclosing party.
6. Signature to this agreement does not create a licence, title or interest in respect of any intellectual property rights of the disclosing party.
7. For a period of one year after the termination of services with the disclosing party the receiving party will not approach or attempt to solicit the clients of the disclosing party.

By the signatures below, we agree that **L.S TRANSCRIPTS** will not at any time, whether during or after the contract ends, disclose to any person or make use of such information. This duty includes keeping strictly confidential the names and other details relating to individuals making and keeping appointments.

Signed: L. Smith (Business Owner, on behalf of LS Transcripts)
Date: 22.12.2017

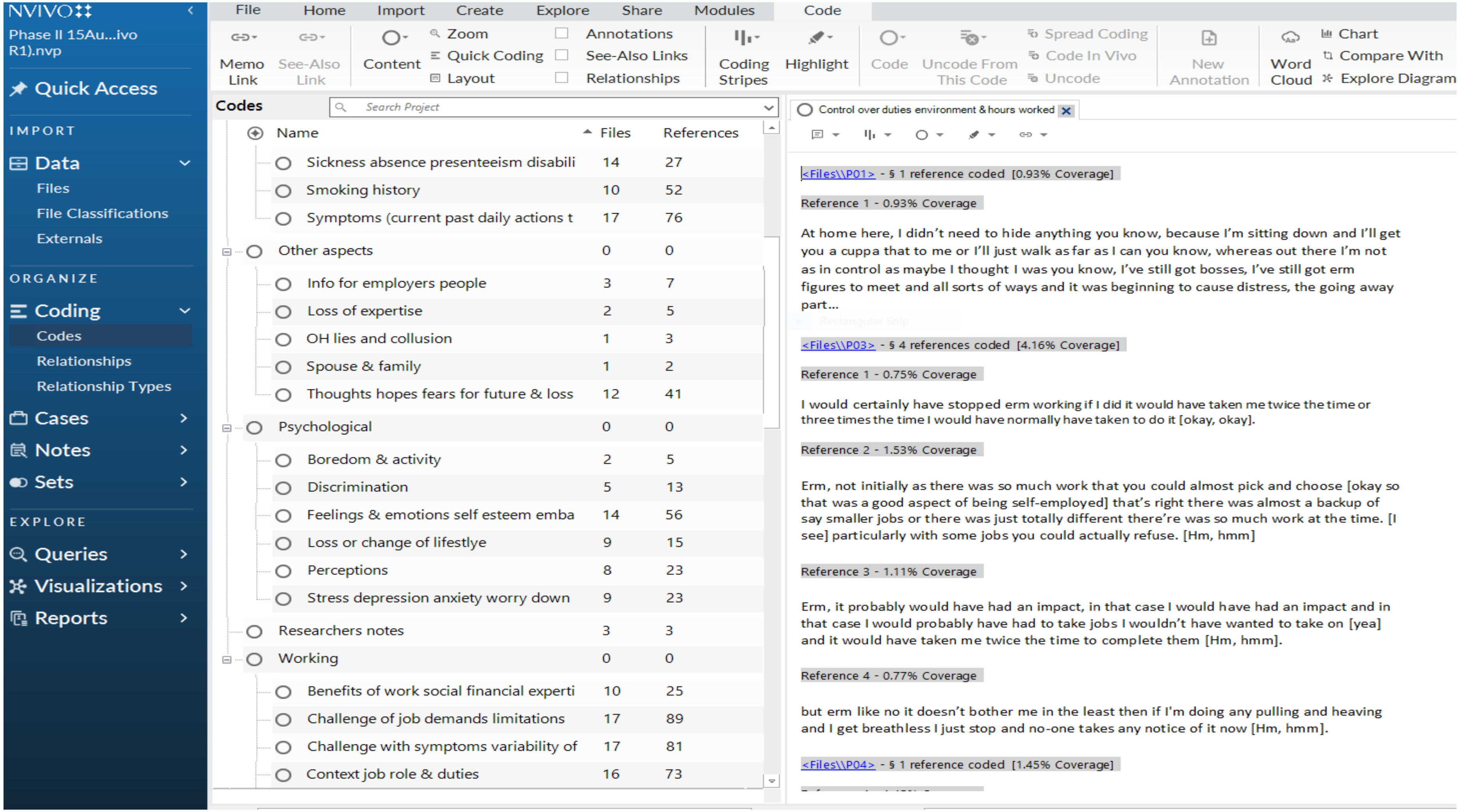
XXI Qualitative Study - Initial Thematic Index Applied to the Data

- Psychological
  - Fear
  - Depression
  - Denial
  - Self-esteem
  - Attitude
  - Frustration
  - Drive
  - Defeated
  - Boredom
  - Regret
- Loss of identity
- Social factors (including isolation)
- COPD/symptoms
  - Variability
  - Unpredictability
  - Individual nature
  - Environmental influences
  - Weather
  - Self-management
  - Coping strategies
- Work adaptations
  - Flexible working
  - Finance
  - Impact on others
- Employment
  - Job satisfaction
  - Employers’ responsibilities
  - Employers’ attitudes
  - Benefits of work
  - Type of employment
  - Work environment
  - Policy/entitlements
  - Cessating employment
  - Alternatives to employment
  - Impact on others
- Advice and support in the workplace
  - Health professional and HR
  - Community
  - Other organisations
  - Family
  - Colleague support
  - Pensions
- Other people’s understanding
  - Colleague attitude - others
  - Jobcentre staff attitudes

XXII Qualitative Study - Framework Themes and Sub-themes

Themes	Health & well-being	Working	Communication, advice and support	Psychological	Other aspects
Subthemes	Employer/boss/HR conversations/attitudes HCP conversations/attitudes Family/friends conversations/attitudes Colleague conversations/attitudes Community & practical Others (CAB) Financial (benefits (ESA/PIP) & pension) blue badge & practical advice	Context – job/role & duties Benefits of work (social/financial/expertise/satisfaction) Getting to work Challenges of job demands limitations/productivity/events Challenges with symptoms (variability of condition) Control over duties/environment/hours worked Coping strategies (Actions/covering/hiding/deceiving (double life) Workplace adjustments (other role/duties/flexible diary/PT/redeployment) Giving up work/retirement	Employer/boss/HR conversations/attitudes HCP conversations/attitudes Family/friends conversations/attitudes Colleague conversations/attitudes Community & practical Others (CAB) Financial (benefits (ESA/PIP) & pension) blue badge & practical advice	Feelings & Emotions (self-esteem/stigma/embarrassment/upset/shame/pride/self-blame/sadness/humiliation/embarrassment/demoralising/fear/guilt/denial Discrimination Stress/depression/anxiety/worry/down Boredom/activity Perceptions self/others/employer Loss of lifestyle	Spouse & family Hopes/fear past/future life (loss) What should/could be happening/reflecting OH lies/collusion Loss of expertise Info for employers

XXIII Qualitative Study – Example of the ‘Working’ Node Once Data is Indexed and Sorted in NVivo



Name	Files	References
Sickness absence presenteeism disabili	14	27
Smoking history	10	52
Symptoms (current past daily actions t	17	76
Other aspects	0	0
Info for employers people	3	7
Loss of expertise	2	5
OH lies and collusion	1	3
Spouse & family	1	2
Thoughts hopes fears for future & loss	12	41
Psychological	0	0
Boredom & activity	2	5
Discrimination	5	13
Feelings & emotions self esteem emba	14	56
Loss or change of lifestyle	9	15
Perceptions	8	23
Stress depression anxiety worry down	9	23
Researchers notes	3	3
Working	0	0
Benefits of work social financial experti	10	25
Challenge of job demands limitations	17	89
Challenge with symptoms variability of	17	81
Context job role & duties	16	73

○ Control over duties environment & hours worked

<Files\\P01> - § 1 reference coded [0.93% Coverage]

Reference 1 - 0.93% Coverage

At home here, I didn’t need to hide anything you know, because I’m sitting down and I’ll get you a cuppa that to me or I’ll just walk as far as I can you know, whereas out there I’m not as in control as maybe I thought I was you know, I’ve still got bosses, I’ve still got erm figures to meet and all sorts of ways and it was beginning to cause distress, the going away part…

<Files\\P03> - § 4 references coded [4.16% Coverage]

Reference 1 - 0.75% Coverage

I would certainly have stopped erm working if I did it would have taken me twice the time or three times the time I would have normally have taken to do it [okay, okay].

Reference 2 - 1.53% Coverage

Erm, not initially as there was so much work that you could almost pick and choose [okay so that was a good aspect of being self-employed] that’s right there was almost a backup of say smaller jobs or there was just totally different there’re was so much work at the time. [I see] particularly with some jobs you could actually refuse. [Hm, hmm]

Reference 3 - 1.11% Coverage

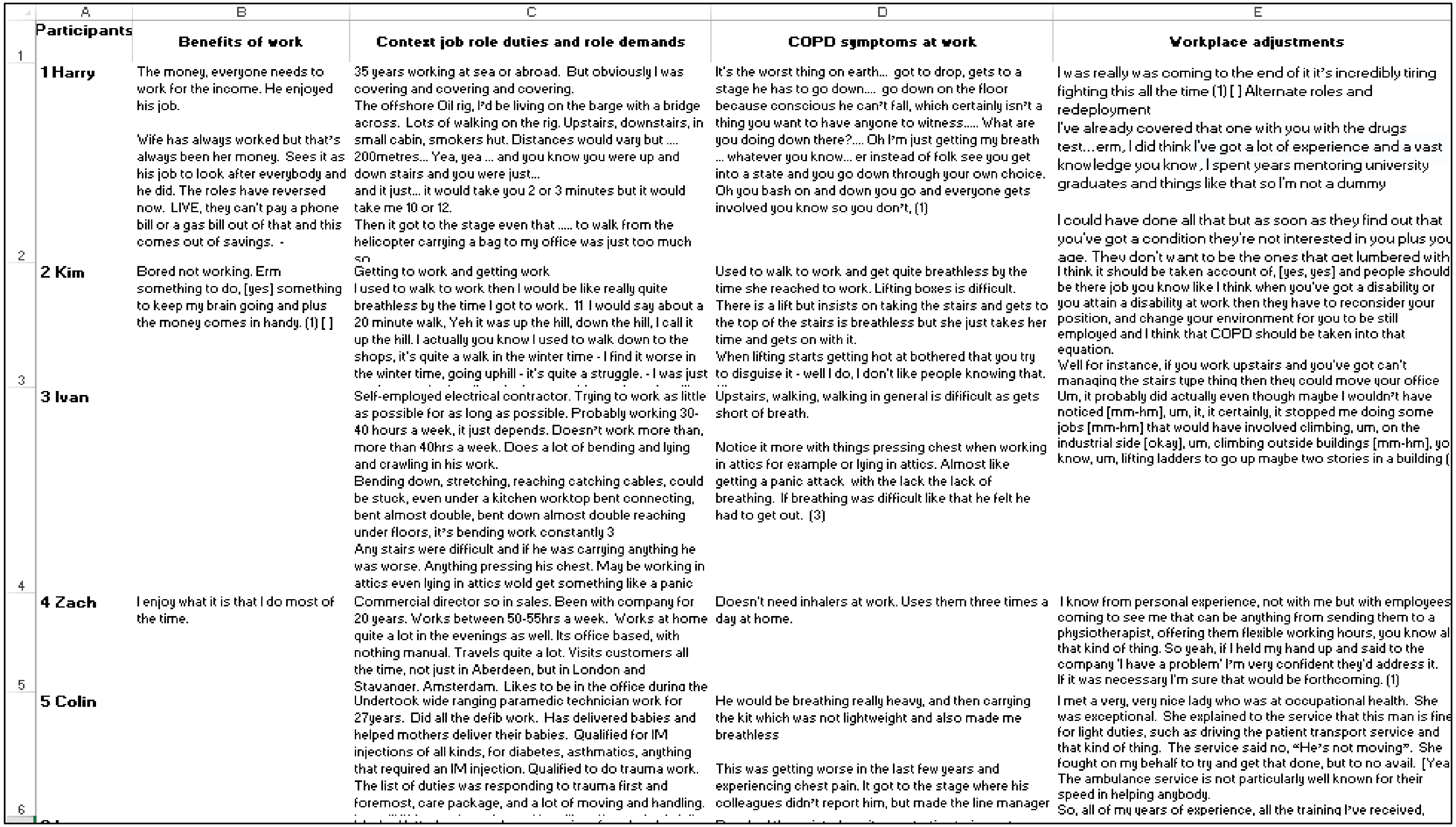
Erm, it probably would have had an impact, in that case I would have had an impact and in that case I would probably have had to take jobs I wouldn’t have wanted to take on [yea] and it would have taken me twice the time to complete them [Hm, hmm].

Reference 4 - 0.77% Coverage

but erm like no it doesn’t bother me in the least then if I'm doing any pulling and heaving and I get breathless I just stop and no-one takes any notice of it now [Hm, hmm].

<Files\\P04> - § 1 reference coded [1.45% Coverage]

XXIV Qualitative Study – Developing the 'Working' Elements Example of a Framework Matrix in Microsoft Excel



Participants	Benefits of work	Context job role duties and role demands	COPD symptoms at work	Workplace adjustments
1 Harry	The money, everyone needs to work for the income. He enjoyed his job. Wife has always worked but that's always been her money. Sees it as his job to look after everybody and he did. The roles have reversed now. LIVE, they can't pay a phone bill or a gas bill out of that and this comes out of savings. -	35 years working at sea or abroad. But obviously I was covering and covering and covering. The offshore Oil rig, I'd be living on the barge with a bridge across. Lots of walking on the rig. Upstairs, downstairs, in small cabin, smokers hut. Distances would vary but .... 200metres... Yea, yea ... and you know you were up and down stairs and you were just... and it just... it would take you 2 or 3 minutes but it would take me 10 or 12. Then it got to the stage even that ..... to walk from the helicopter carrying a bag to my office was just too much so	It's the worst thing on earth... got to drop, gets to a stage he has to go down.... go down on the floor because conscious he can't fall, which certainly isn't a thing you want to have anyone to witness..... What are you doing down there?.... Oh I'm just getting my breath ... whatever you know... er instead of folk see you get into a state and you go down through your own choice. Oh you bash on and down you go and everyone gets involved you know so you don't, (1)	I was really was coming to the end of it it's incredibly tiring fighting this all the time (1) [ ] Alternate roles and redeployment I've already covered that one with you with the drugs test…erm, I did think I've got a lot of experience and a vast knowledge you know, I spent years mentoring university graduates and things like that so I'm not a dummy I could have done all that but as soon as they find out that you've got a condition they're not interested in you plus you age. They don't want to be the ones that get lumbered with
2 Kim	Bored not working. Erm something to do, [yes] something to keep my brain going and plus the money comes in handy. (1) [ ]	Getting to work and getting work I used to walk to work then I would be like really quite breathless by the time I got to work. 11 I would say about a 20 minute walk, Yeh it was up the hill, down the hill, I call it up the hill. I actually you know I used to walk down to the shops, it's quite a walk in the winter time - I find it worse in the winter time, going uphill - it's quite a struggle. - I was just	Used to walk to work and get quite breathless by the time she reached to work. Lifting boxes is difficult. There is a lift but insists on taking the stairs and gets to the top of the stairs is breathless but she just takes her time and gets on with it. When lifting starts getting hot at bothered that you try to disguise it - well I do, I don't like people knowing that.	I think it should be taken account of, [yes, yes] and people should be there job you know like I think when you've got a disability or you attain a disability at work then they have to reconsider your position, and change your environment for you to be still employed and I think that COPD should be taken into that equation. Well for instance, if you work upstairs and you've got can't managing the stairs type thing then they could move your office
3 Ivan		Self-employed electrical contractor. Trying to work as little as possible for as long as possible. Probably working 30-40 hours a week, it just depends. Doesn't work more than, more than 40hrs a week. Does a lot of bending and lying and crawling in his work. Bending down, stretching, reaching catching cables, could be stuck, even under a kitchen worktop bent connecting, bent almost double, bent down almost double reaching under floors, it's bending work constantly 3 Any stairs were difficult and if he was carrying anything he was worse. Anything pressing his chest. May be working in attics even lying in attics wold get something like a panic	Upstairs, walking, walking in general is difificult as gets short of breath. Notice it more with things pressing chest when working in attics for example or lying in attics. Almost like getting a panic attack with the lack the lack of breathing. If breathing was difficult like that he felt he had to get out. (3)	Um, it probably did actually even though maybe I wouldn't have noticed [mm-hm], um, it, it certainly, it stopped me doing some jobs [mm-hm] that would have involved climbing, um, on the industrial side [okay], um, climbing outside buildings [mm-hm], yo know, um, lifting ladders to go up maybe two stories in a building (
4 Zach	I enjoy what it is that I do most of the time.	Commercial director so in sales. Been with company for 20 years. Works between 50-55hrs a week. Works at home quite a lot in the evenings as well. Its office based, with nothing manual. Travels quite a lot. Visits customers all the time, not just in Aberdeen, but in London and Stavanger. Amsterdam. Likes to be in the office during the	Doesn't need inhalers at work. Uses them three times a day at home.	I know from personal experience, not with me but with employees coming to see me that can be anything from sending them to a physiotherapist, offering them flexible working hours, you know al that kind of thing. So yeah, if I held my hand up and said to the company 'I have a problem' I'm very confident they'd address it. If it was necessary I'm sure that would be forthcoming. (1)
5 Colin		Undertook wide ranging paramedic technician work for 27years. Did all the defib work. Has delivered babies and helped mothers deliver their babies. Qualified for IM injections of all kinds, for diabetes, asthmatics, anything that required an IM injection. Qualified to do trauma work. The list of duties was responding to trauma first and foremost, care package, and a lot of moving and handling.	He would be breathing really heavy, and then carrying the kit which was not lightweight and also made me breathless This was getting worse in the last few years and experiencing chest pain. It got to the stage where his colleagues didn't report him, but made the line manager	I met a very, very nice lady who was at occupational health. She was exceptional. She explained to the service that this man is fine for light duties, such as driving the patient transport service and that kind of thing. The service said no, "He's not moving". She fought on my behalf to try and get that done, but to no avail. [Yea The ambulance service is not particularly well known for their speed in helping anybody. So, all of my years of experience, all the training I've received,

XXV Qualitative Study - Draft Elements, Dimensions and Categories for the Support Theme

Elements	Dimensions	Categories
Manager referred her for OH assessment Employer fought us all of the way. (12) Line manager suggests she goes to see Occupational Health. Said, *“Please don’t take me wrong, I am not trying to punish you or anything, but I think we need to get to the bottom of this, or at least to try and get you parking on site”.* The Occupational Health wasn’t because she couldn’t do her work or was failing at her job, or anything like that, it was purely to try and get parking on-site - that is when the nightmare began. No. Issue went on for months but her boss, God bless her, did not give up. She was absolutely adamant that this was not going to happen. She said, “*I am worried for you*”. “*Oh for the love of God, just stop it. I will walk, I would rather die than keep doing this*”, her boss was great. She said, “*Don’t be ridiculous*”. "	Employer fought against the issue	No support from employer
Employer didn’t appreciate she was trying not to let health disrupt her work (14) Employers didn’t appreciate she was willing to cause as little disruption to the team as possible, because it was a small team and it was her colleagues and friends that would bear the brunt of it. She felt there was a lot of goodwill on her behalf but not taken into account	Employer didn’t see goodwill	No support from employer
Heard boss was monitoring workload and activities she didn’t carry out (14) I heard that through word of mouth because my head nurse was starting to take a log of the things that I wasn’t doing. Like I had stopped using certain cleaning products because of my chest, I had stopped mopping the floor and getting somebody else to do it. So, there were certain things that I wasn’t doing that are start of the veterinary nurse duties and they were starting to log it.	Employer monitoring what wasn’t done	N
Struggled for years and her husband wanted her to retire earlier (14) That’s basically why I took it. Husband had been trying to get me to retire for years because I was struggling, and I had gone down to half, to working part time, and physically it was more demanding. I really was needing oxygen 24/7 by then.	Struggled for years in job	
Boss knows sometimes he is at work not feeling good (7) at down with boss as condition progressed. Made him feel better because it’s not just - Hi Charles, cheers. Last two weeks he left work to go home - boss says *"dinna worry about it, you’ve made the effort and came in and done your best and I can accept that he says"*, that was different to what it was before … Understands and listens to his health concerns	Boss understands and listens to health concerns	Supportive employer
Boss understands impact of condition (7) *"with the stress and frustrations of being a manager I used to be like that but, whether I’m here or you’re here, the stores not going to fall down without us, you know what I mean”, He* knows it’s true and understands a bit better and he’s listening to him. He told him about his medication and listened to him about the inhalers and nebulisers. Boss's dad has condition but thinks COPD worse.	Boss understands the impact of condition	Supportive employer
Company supportive of employees with health problems (4) As a director of the company he's aware that if any employee comes to them with a specific issue it will be looked at and addressed and see what can be done to help.	Company supportive of employees with health problems	Supportive employer
Line manager was considerate of her situation (11) Previous line manager would phone her up and say it's so cold and the heating had gone off or something and he'd phone her and say don't come in. She couldn't fault them at all. Hot tea on desk for her coming in on a cold day.	Line manager was considerate	Supportive employer
Colleagues switched up heating in the office when it was cold (11) Asked about heating, in the office because her office was quite cold. When she worked with a guy in the estates office, he was really good he used to put the heating on in the winter, he was always in early anyway, but he would always put the heaters on, the space heaters on in the office for me coming in, you know. Well obviously it wasn't so cold, so it wasn't such an effort to breathe, and you didn't get the chest pains because of the cold air and what have you. But I'd worked with him for a long time, so it was all those little things that made a difference.	Colleagues heated the office in the cold weather	

End of Thesis