

**The working-age experience of living with Chronic Obstructive Pulmonary
Disease (COPD)**

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Thesis declaration form

I 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 in the thesis.

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OVERVIEW

Living with COPD can have a significant impact on a person's quality of life. This thesis aims to understand age differences in quality of life for people living with COPD, and to learn more about the working-age experience of COPD. It is organised into three parts. Part 1 is a meta-analysis of the literature comparing quality of life in older adults and working-age adults with COPD. Overall, no significant difference was found in quality of life scores between these groups. What was striking was the high heterogeneity between studies. The majority of included studies had not controlled for confounding variables. Quality of life in COPD is complex, and there are likely to be many interacting factors contributing to differences in quality of life scores.

Part 2 presents the findings of a qualitative investigation which aimed to understand the working-age experience of living with COPD. Eleven working-age people diagnosed with COPD participated in a semi-structured interview, and a framework analysis was conducted. Ten themes were identified. Interestingly, the majority of participants did not make reference to concerns about their age, and issues around loss of employment were not raised. Participants did, however, speak about their distress at having to be cared for by family members. Overall, this study has highlighted the importance of providing a space for all COPD service users to discuss their quality of life, and their experiences of living with COPD, with a healthcare professional.

Part 3 is a critical appraisal that aims to reflect upon the role that class differences played in the research study reported in Part 2. The research was conducted with a group of working-class people. The appraisal discusses the relationship between socioeconomic status and physical health outcomes. It also considers how class may have influenced the responses given in the study, and reflects on differences in class identity between the interviewer and interviewees.

IMPACT STATEMENT

This research study was conducted in a London-based respiratory service. The service described seeing increasing numbers of working-age adults being diagnosed with COPD, and expressed the wish to better understand the needs of this group of patients. They reported anecdotally that this group appeared to be struggling with managing their COPD, and they were interested to know whether or not quality of life was impacted in a different way in individuals of this demographic.

A meta-analysis has been conducted which has brought together the research literature that compares quality of life scores between older and working-age adults. There is, of course, a clinical value to understanding whether there are demographic differences in quality of life, as this can help care providers target support and interventions aimed at improving quality of life. The findings of this meta-analysis suggested that decisions about clinical care and services provided should not be made based on age, but rather quality of life should be used as a clinical indicator of need. Quality of life assessment should be offered to all patients accessing COPD services.

The meta-analysis described is followed by a qualitative investigation into quality of life in a group of working-age adults with COPD. The findings of this framework analysis challenge the idea that care needs of the working-age group are different to those of older adults. Life stage factors, for example concerns around employment, were reported far less frequently than predicted. While participants did speak of COPD interfering with values specific to their age group, it is likely that COPD symptoms interfere with many goals and values. Older adults would be likely to experience a similar sense of conflict with their COPD, even though their values might be somewhat different.

What was particularly distressing for the working-age group described in this study, however, was needing to be cared for by family members. Services seeing increased numbers of patients from this age group are advised to focus interventions on supporting their patients in developing skills in independent living, and negotiating care in a way that does not diminish their sense of autonomy. This would speak to the needs of this group, and would therefore be likely to improve engagement.

This research also demonstrates the complexity of quality of life. While quality of life measurement goes some way to assessing these issues, it does not access the nuances of living with COPD, and the individual barriers to making lifestyle changes. Time and space should be made within COPD services for conversations about an individual's experience of living with COPD.

While the National Institute for Health and Care Excellence (NICE) guidance for the diagnosis and management of COPD (NICE, 2010) does acknowledge a role for identifying anxiety and depression, this is not specified as a key part of caring for an individual with COPD. Quality of life assessment is not mentioned in the guidance. Three specific groups are identified as being in particular need of screening for depression and anxiety on the basis of physical symptom severity. This research, however, suggests that opportunities to discuss quality of life should be available to all COPD service users. Services should aim to take a whole-person approach to the care of people living with COPD.

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Part 1: Literature Review

Quality of life differences between working-age and older adults with Chronic Obstructive Pulmonary Disease (COPD): A meta-analysis

ABSTRACT

Chronic Obstructive Pulmonary Disease (COPD) has a significant impact on quality of life. It could be argued that the impact COPD has on day-to-day life differs according to an individual's life stage. This research is a systematic review and meta-analysis of the COPD quality of life literature. Studies which have compared quality of life scores between working-age and older adults have been included, along with studies that have looked at age differences between individuals scoring high or low on quality of life measures. A total of ten studies have been included. Overall, there was no significant difference found between working-age and older adults with COPD on measures of quality of life. It is concluded that there are likely to be multiple other factors which impact quality of life in individuals with COPD, and these need to be considered in further depth.

INTRODUCTION

What is Chronic Obstructive Pulmonary Disease?

Chronic Obstructive Pulmonary Disease (COPD) is a term used to describe a group of conditions that affect a person's breathing, including both emphysema and bronchitis. These diseases come about as a result of damage being caused to the lungs. The typical cause of COPD is smoking, which causes inflammation in the lungs and narrowing of the airways. Individuals with a diagnosis of COPD would likely experience worsening breathlessness, wheezing, frequent coughing, and regular chest infections. Chest infections in individuals with COPD can be severe, sometimes requiring hospitalisation (NHS, 2017).

COPD is a chronic condition, meaning that there is no cure, but that medical professionals aim to help an individual manage the diagnosis. Often, inhalers are used to help manage COPD. In addition, many people with COPD now attend Pulmonary Rehabilitation (PR). This is a series of classes that help COPD sufferers learn how to increase their activity in a safe way, whilst developing skills at detecting, preventing, and managing flare-ups in their COPD. A 'flare-up' can be defined as a period of significant difficulty breathing, which is often caused by a chest infection (NHS, 2017).

The World Health Organisation's (WHO) Global Burden of Disease study (WHO, 2018a) has highlighted the scale of the problem of COPD. In 2015, it was the fourth largest cause of death globally, with 5.6% of all deaths being caused by COPD. It is projected that by the year 2030, COPD will be the third largest cause of death, causing 6.5% of all deaths globally. This highlights that COPD is a growing concern, and the global burden of COPD is increasing.

The impact of the disease can also be measured by disability-adjusted life years, which is a measure of years lost to poor health. In 2015, COPD was the seventh largest cause of disability-adjusted life years. This tells us that COPD is not only a prominent cause of death globally, but also has a significant impact on day-to-day life for many individuals living with the diagnosis (WHO, 2018b).

Who has COPD?

The National Institute for Health and Care Excellence (NICE) has estimated that three million people in the UK are currently living with COPD, two million of whom are undiagnosed (NICE, 2010). Prevalence research conducted by Snell et al. (2016) has estimated that 1.2 million people in the UK are currently diagnosed with COPD. These researchers compared this statistic to estimates made by the Department of Health in 2011, noting that the number of people now diagnosed with COPD is significantly higher than the predicted number of 835,000 people. COPD was the fifth largest cause of death in the UK at the time of this research being conducted. We can see, therefore, that the burden of COPD in the UK is an increasing problem, which is growing far beyond recent estimates.

An increasing priority of the National Health Service (NHS) has been around raising awareness of COPD and prioritising early detection. The NICE guidance for COPD now includes a requirement that all individuals aged over 35, who are current or ex-smokers with a chronic cough, should receive spirometry in order to aid early detection of COPD (NICE, 2010). A recent review conducted by Csikesz and Gartman (2014) has indicated that the most severe health decline in COPD patients occurs in the moderate stage of the disease. They have therefore emphasised the importance of early detection of COPD in ensuring that interventions such as smoking cessation support can be offered at earlier stages of the disease, in order to prevent significant deterioration. Therefore, while the COPD population in the UK

has not dramatically changed in recent years, the numbers of individuals under the age of 65 being diagnosed with COPD is increasing and the clinical population being seen by respiratory services in the NHS is changing (James, Petersen, Donaldson & Wedzicha 2011).

What is 'quality of life'?

In lay terms, quality of life can be defined as “the general well-being of a person or society, defined in terms of health and happiness, rather than wealth” (Collins English Dictionary, 2017). This definition is fairly broad. When bringing the concept of quality of life into a research discipline, we therefore have difficulty with its operationalisation. In the field of psychology, complex constructs such as this tend to be understood in terms of 'models'. There are many models of quality of life in existence.

The review of models of health-related quality of life (HRQoL) by Bakas et al. (2012) has pointed to a wide range of different models of this concept, making its definition difficult. This review found very little consistency in the use of models across HRQoL research, meaning that there is no consensus on a definition and further development is needed.

Farquhar's taxonomy of the varied definitions of quality of life (1995) identified four distinct types of definition of quality of life, all of which take a slightly different view on the construct. 'Global definitions' refer to quality of life as a broad concept; 'component definitions' focus on quality of life as several component parts; 'focused definitions' address specific component parts of quality of life in detail as particular areas of interest, such as HRQoL; and 'combination definitions' consist of more than one of the three types described: for example, quality of life as a broad construct that can also be broken down into several component parts. Farquhar (1995) also emphasised the role of culture in influencing definitions of quality of life.

The complex range of definitions given to this construct has obvious implications for measuring quality of life. Our view of what is important in understanding quality of life will have an impact on what areas are given more weight or influence when we are attempting to measure it. This ongoing difficulty has prevented the field from developing a 'gold standard' measure of quality of life.

In looking at the range of quality of life measurement tools available, Bowling (2004) has drawn attention to this concern. She highlighted that the theoretical perspective of the individual designing the measure very much influences what areas are investigated. For instance, if a researcher subscribes to a defined idea such as Maslow's theory of the hierarchy of needs, the tool developed would be likely to assess whether these specific needs are being met by an individual's current life circumstances. However, a researcher who takes a more phenomenological stance might understand quality of life as being defined by the individual in question. Quality of life measurement in this case would then involve asking about life satisfaction more broadly, or in areas defined by the individual being asked. If these two distinctly different measurement techniques were used with the same individual, the results would be inconsistent.

In the field of COPD alone, there are several widely-used HRQoL measures, including the St. George's respiratory questionnaire (SGRQ), the COPD Assessment Test (CAT), and the Chronic Respiratory Questionnaire (CRQ), all of which are commonly used in research and clinical settings. These instruments were all recommended as viable measures in a review which examined the psychometric properties of HRQoL instruments in COPD (Weldam, Shuurmans, Liu & Lammers, 2012). Each tool aims to measure the same construct, but approaches it differently. For example, the SGRQ asks about severity and frequency of symptoms over the past four weeks, and then about their impact on specific day-to-day activities. Space is also provided for the individual to list additional important areas of life that are affected by their COPD. The CAT, however, is a much shorter measure which

focuses on physical symptoms, and only asks very broadly about the extent to which the individual is 'limited doing any activities at home'. Of course, the choice of measure depends on the purpose of assessment and definition of quality of life, but each would yield somewhat different findings.

Quality of life is an important construct in COPD. A logistic regression has highlighted that quality of life significantly predicts hospitalisation and mortality in individuals with COPD diagnoses (Fan, Curtis, Tu, McDonnell & Fihn, 2002). In this study, lower scores on all subscales of the Seattle Obstructive Lung Disease Questionnaire (SOLDQ), a disease-specific quality of life measure, predicted risk of future hospitalisation for COPD care, and mortality. A similar finding was reported by Domingo-Salvany et al. (2002) who identified that in a sample of 321 male patients with COPD, lower scores on the SGRQ and The 36-Item Short Form Health Survey (SF-36) were independently associated with mortality. Therefore, quality of life is not only an important construct in understanding the impact of COPD on an individual's life, but it also predicts health outcomes.

The impact of COPD on quality of life

There is a range of research that describes the serious impact of having a chronic health condition on an individual's quality of life. In reviewing the literature around quality of life in patients with chronic disease, Megari (2013) has highlighted a range of important factors which contribute to poorer quality of life in patients with chronic ill health. These include symptoms, such as pain, physical limitations, and health complications. These symptoms interact in a complex way with an individual's context, with variables including socioeconomic status, ethnicity, and cultural beliefs, all also directly influencing quality of life in individuals with chronic health conditions.

With specific reference to COPD, a range of research has examined the complex interplay between having a diagnosis of COPD, and quality of life. A study

of over 10,000 patients with stable COPD has highlighted that, compared to the general population, individuals with a diagnosis of COPD have significantly impaired quality of life, even in the very early stages of the disease (Garrido et al., 2006).

Quality of life in COPD is heavily associated with depression and anxiety. Both depression and anxiety are prevalent diagnoses in individuals with chronic lung conditions, with the combined prevalence of anxiety or depression in a large sample of individuals with chronic breathing disorders estimated to be 80% (Kunik et al., 2005). A further study of over 8000 individuals with a diagnosis of COPD (Ohayon, 2014) has also offered evidence in support of the relationship between COPD and comorbid mental health diagnoses. Depression is four times more common in individuals with COPD than in the general population, and anxiety disorders three times more common. This study also highlighted that individuals with COPD and comorbid mental health diagnoses are significantly more likely to experience symptoms of insomnia than individuals in the general population with mental health difficulties, but without COPD. Systematic reviews have highlighted the link between anxiety and depression, and poorer HRQoL in people with COPD (Blakemore et al., 2014; Panagioti, Scott, Blakemore & Coventry, 2014), however the direction of the phenomenon is unclear and requires further understanding. Whilst we cannot make assumptions about causality, what we do know is that people diagnosed with COPD have a far greater chance of experiencing serious mental health difficulties. These problems are associated with needs, such as a need for psychological care, that might be overlooked by teams caring for the physical health of people living with COPD.

Qualitative research has explored the experience of living with COPD in great detail. It has been used in this field to understand the experience of COPD patients broadly, rather than exploring the meaning of COPD to specific subgroups of patients.

A thematic analysis of patients' understanding and experiences of COPD exacerbations (Kessler et al., 2006) has described patients as commonly experiencing an increase in anxiety with exacerbations, with worries about dying, suffocating, declining health, and hospitalisations. These researchers noted a significant impact on day-to-day life, with half of the study sample reporting that all activities had to be stopped, and 90% needing help from others to complete daily tasks. An impact on mood was also identified, with members of the sample raising concerns around feelings of depression, anger, bad temper, isolation, and guilt. A negative impact on social relationships as a result of these emotions was also reported. The researchers suggest that the psychological impact of exacerbations is an area commonly underestimated by physicians.

Kvangarsnes et al. (2013) used a narrative inquiry approach to further understand patient perceptions of COPD exacerbations, and relationships with healthcare providers and systems. Their sample consisted of ten participants aged between 45 and 85 years. Participants described a feeling of total dependence on others during exacerbations, and distressing nightmares and distortions in perception at these times. They described feeling that they needed to trust healthcare providers, and gave examples of times when they felt providers both could and could not be trusted. The researchers identified the importance of the power dynamic between service users and providers, with participants often describing a feeling of not being in control.

A meta-synthesis of eight qualitative papers investigating the experience of exacerbations in COPD has indicated two domains of understanding for individuals (Harrison et al., 2014). First, it identified a theme of the 'acute effect' of the exacerbation. This included subthemes such as: intense emotions related to a feeling of threat, body awareness and a focus on breathlessness, beliefs that visible symptoms legitimised need for help, passivity from members of the individuals'

social networks, limiting of activities in order to prevent breathlessness, and feelings of powerlessness and lack of control over COPD symptoms. The second theme was identified as 'sustained regulation'. Within this theme the researchers identified the following subthemes: an interruption to daily life due to hypervigilance for COPD symptoms, and avoidance of situations that might result in breathlessness, meaning that participants did not feel able to maintain independence. While participants were able to demonstrate an understanding of COPD and self-management, they typically described feeling ill-equipped to manage their COPD independently, and their attempts at self-management often resulted in withdrawal and social isolation in an attempt to minimise their perceived burden on others. There was, additionally, a reluctance to seek help, linked to urgency in help-seeking following exacerbation and associated fear of death.

In addition, a thematic analysis of research with a sample of 20 people of varied ages (median 69 years) has highlighted six areas of difficulty for people with a diagnosis of COPD (Schroedl et al., 2014). These were understanding COPD, the uncontrollability of symptoms, physical limitations, emotional distress, social isolation, and concerns for the future. Of particular reference to the current discussion, the researchers indicated that the emotional distress, fear, and isolation expressed by the study participants were rarely known by the care teams involved. In addition, many participants indicated that the information they were offered by care teams did not support them in feeling in control of their care and future.

Why is life stage relevant in discussion of quality of life?

Age has been demonstrated to be an important factor which impacts upon quality of life in many long-term health conditions. For example, studies have shown that younger individuals have poorer HRQoL in fibromyalgia, gastroesophageal

reflux, and also breast cancer survival (Champion et al., 2014; Jiao, Vincent, Cha, Luedtka & Oh, 2014; Lee, Chang, Chang, Kao & Chou, 2011,).

There are a range of models of ageing that can be used to generate hypotheses about different priorities and values of individuals of different age groups (Erikson & Erikson 1998; McGoldrick, Carter & Garcia-Preto, 2010; Vaillant, 2002). These models are widely referred to when discussing life stages and ageing, but do present a somewhat heteronormative and dated view of family. Nonetheless, they all interestingly suggest that 'middle-age' and 'later life' are two very distinct stages, wherein the individual is tasked with achieving entirely different goals and meeting different needs. The 'middle-aged' stage is often viewed as a time of productivity, achievement, and caring for both older and younger family members. Later life tends to be seen as a time of taking stock and integrating one's experiences, developing a sense of 'wisdom', and also adapting to changes in ability and health.

Alternative theories of ageing do not see life as a distinct set of stages or tasks, but rather as a continual process of development. For example, activity theory (Lemon, Bengtson & Peterson, 1972) has highlighted the importance of social inclusion for maintaining wellbeing in older individuals. This theory states that both middle-aged and older adults have the same psychosocial needs, yet older individuals might be limited in meeting these needs if they experience limitations to their health. This relationship has been demonstrated within a UK population (Knapp, 1977). Disengagement theory (Cumming, Dean, Newell & McCaffrey, 1960) follows a similar rationale, suggesting that an individual's self-perception changes in later life. People begin to see themselves as less sociable and less connected beings, which results in withdrawal, meaning that the individual starts to engage in fewer and less varied interactions as they age.

Of course there will likely be a role for personality in determining an individual's activity levels and overall life satisfaction during the ageing process, alongside other contextual factors.

More recent perspectives on ageing incorporate our growing understanding of biological changes that happen as part of the ageing process. There is a wide range of modern biological theories, which can be grouped into two categories: programmed theories, which suggest that ageing is part of a continual developmental process that we undergo from birth, and damage theories which understand ageing as being a process of built-up damage and injury to our bodies as a result of living day-to-day life. There is a wide range of these modern theories of ageing, with no agreed understanding at present. Research suggests that it is likely that a number of these theories need to be combined to reach a complete understanding (Jin, 2010).

Whichever theory or combination of theories of ageing one subscribes to, it is clear that the tasks, priorities, and goals of an individual in the later stages of their life may be very different to those of somebody who is middle-aged. Also, it is the social expectation in western society for an individual to be in paid employment in their middle-age, with the retirement age in the UK currently set to reach 66 by 2020 (Age UK, 2018). It is fair, therefore, to suggest that the impact of a specific diagnosis, such as COPD, would not be the same for all patients, but would have a different impact on an individual depending on life stage. Where there are increasing numbers of middle-aged adults presenting to services, better understanding is needed of how COPD specifically impacts on their quality of life.

Summary

As described, the population presenting to COPD services is changing, with increasing numbers of adults at earlier stages of their lives coming into contact with

services. COPD can have a significant impact upon quality of life for those with the diagnosis, especially during exacerbations. With working-age and older age being understood to be different life stages, wherein the individual is focussed on different goals and values, the impact of COPD symptoms on day-to-day life might differ accordingly.

Aim

The aim of this review is to develop an understanding of whether quality of life differs between working-aged and older adults with a diagnosis of COPD, with specific interest in the direction of this difference. This review will also discuss the different quality of life measurement tools used in quality of life research with people diagnosed with COPD.

The specific research question is:

- Is there a difference in quality of life scores between working-aged and older adults with COPD, and in what direction is this difference?

METHOD

Search strategy

A systematic literature search was conducted across three databases: PsychInfo, Medline, and Embase. The search terms covered three areas of interest – COPD, quality of life, and working-age populations. A combination of subject heading searches, and text searches were used.

The exact search terms were as follows:

COPD: COPD (Subject heading search), COPD (text search), chronic obstructive pulmonary disease (text search), chronic lung disease (text search),

chronic obstructive lung disease (text search), chronic respiratory disease (text search), chronic obstructive respiratory disease (text search).

Quality of life: Quality of life (Subject heading search), quality of life (text search), life quality (text search), well being (text search), wellbeing (text search), well-being (text search).

Working-age: Working age* (text search), young* age (text search), middle age* (text search), under 65 (text search), age* (text search).

All included papers were screened for relevant references that might also be included.

Inclusion and exclusion criteria

The inclusion criteria were that the study made a direct comparison between individuals with COPD of working-age and older age, or made a comparison between individuals with higher and lower quality of life where an independent variable was age. To be included, the study must have compared working-age and older adults, therefore only studies which split comparison groups at an age between 60 and 70 were included in this review.

Studies were excluded on the basis of not using a quality of life measure, not being available in English, or not being published as full journal articles. Finally, studies that did not clearly report a group mean for each comparison group were also excluded.

Data analysis

A meta-analysis was performed using the mean and standard deviation data from each paper. Where the paper included multiple age group comparisons, the

data were combined into two groups with an age split between 60 and 70 years prior to being included in the analysis.

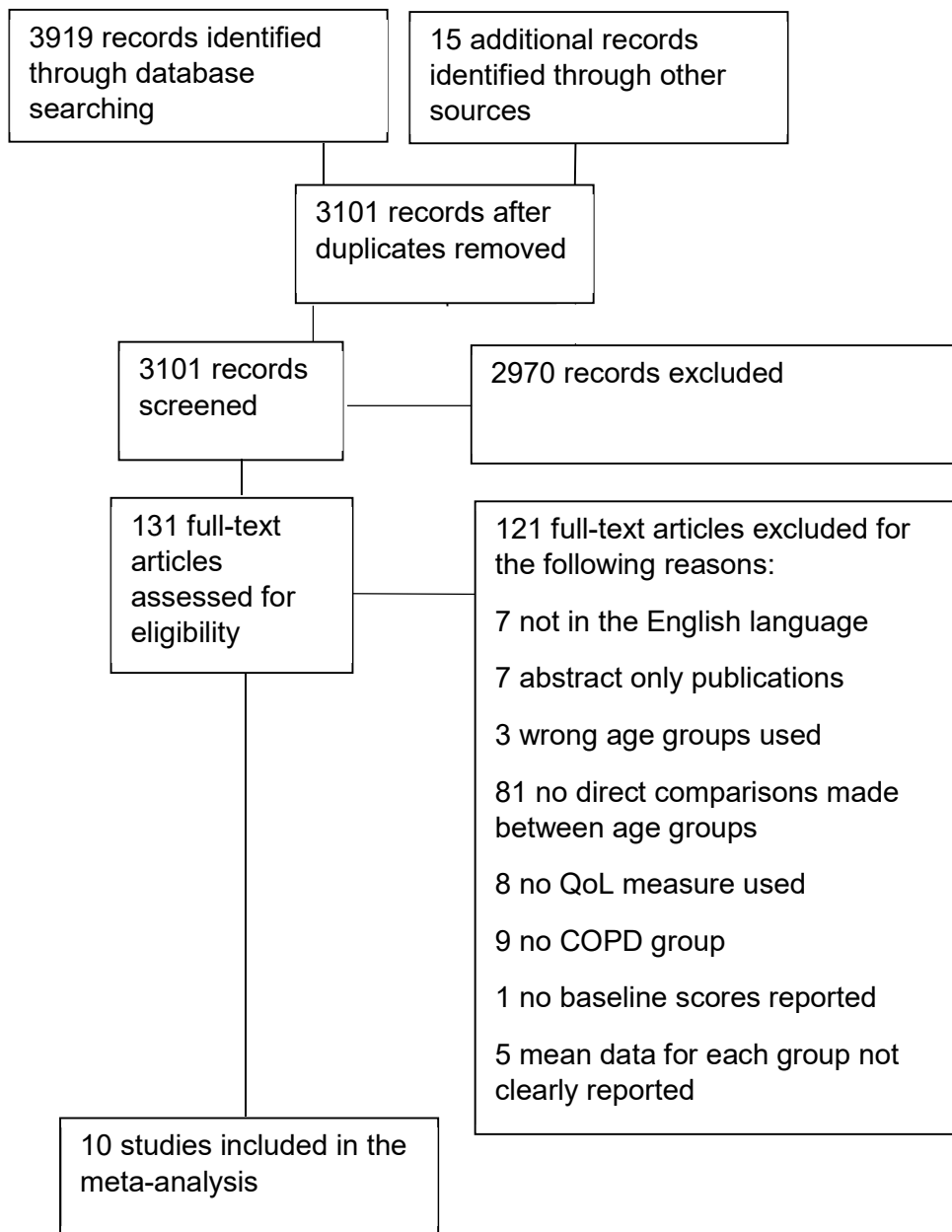
Two separate analyses were conducted, one for papers comparing age groups, the other for papers comparing quality of life score groups with age as an independent variable. For each analysis, an overall effect size was determined.

Review Manager 5 (RevMan 5) software was used to analyse the data. The data were assumed to have random error, and standardised mean differences.

RESULTS

A total of 3101 records were identified and screened following the initial search. 2970 records were excluded following the screening of paper titles and abstracts. 131 full-text articles were then assessed for eligibility, with a total of ten papers being included in the final meta-analysis. Please see Figure 1 for the full details of papers excluded.

Figure 1. Table of process.



Of the ten included studies, eight compared quality of life between individuals from working-aged and older adult age groups. The additional two papers gave average ages for individuals scoring high or low on quality of life measures. Separate analyses were conducted for these two groups.

Analysis 1: Comparisons of quality of life scores in working-aged vs. older adults

Please see Table 1 for a summary of all included papers, with additional details about how data from each was used for the purposes of this meta-analysis. As described above, some age groups were combined in order to ensure that only two age groups were compared for each study – working-aged and older adults. In addition, in cases where the overall quality of life score was not provided in the paper but component scores were given instead, the mental health component scores were included in this analysis. In cases where more than one quality of life measure was used, the more commonly used measure was selected for inclusion in this analysis. Scores for any quality of life measures wherein a higher score represented poorer quality of life, were reversed for this analysis. One paper included in this analysis, Martinez et al. (2016), conducted two separate analyses on two different COPD cohorts, the COPDGene cohort and the SPIROMICS cohort. Data from both cohorts has been included separately in this analysis.

Table 1. Data used from each paper included in analysis 1.

<u>Study</u>	<u>Number of participants</u>	<u>Country in which study conducted</u>	<u>Gender breakdown of participants</u>	<u>Age groups reported in original paper</u>	<u>Age groups combined for this meta-analysis</u>	<u>QoL measure used in original paper</u>	<u>QoL data used in this meta-analysis?</u>
Corhay et al. (2012)	140	Belgium	67.9% male 32.1% female	<65 65-74 >/=75	Means and standard deviations combined for the 65-74, and >/= 75 age groups	CRQ total score	CRQ total score
Corlateanu et al. (2016)	180	Moldova	65% male 35% female	< 65 </=65	Not applicable	SGRQ and CCQ component and total scores	SGRQ total score
Emery (1994)	64	America	54.7% male 45.3% female	</=67.5 >67.5	Not applicable	PGWBI component and total scores pre and post intervention	PGWBI total score pre intervention
Gupta et al. (2016)	716	Canada	60% male 40% female	<60 60-75 >/= 75	Means and standard deviations combined for the 60-75 and >/= 75 age groups	CAT total score	CAT total score
Henoch et al. (2016)	7810	Sweden	44.1% male 55.9% female	</=70 >70	Not applicable	CCQ total score	CCQ total score
Martinez et al. (2016) Data set 1 (COPDGene cohort)	4097	America	56% male 44% female	50-64 65-80	Not applicable	SGRQ component and total scores	SGRQ total score

Martinez et al. (2016) Data set 2 (SPIROMICS Cohort)	1522	America	56.4% male 43.6% female	50-64 65-80	Not applicable	SGRQ component and total scores	SGRQ total score
Moro et al. (2009)	1786	Spain	0% male 100% female	40-49 50-59 60-69 70-79 >=80	Means and standard deviations combined for 40-49, 50-59, and 60-69 to create younger group, and combined for 70-79 and >=80 to create older group	SGRQ component scores	Mental health component SGRQ score
Zhou et al. (2013)	6437	China	74.9% male 25.1% female	<=65 >65	Not applicable	CAT total score	CAT total score

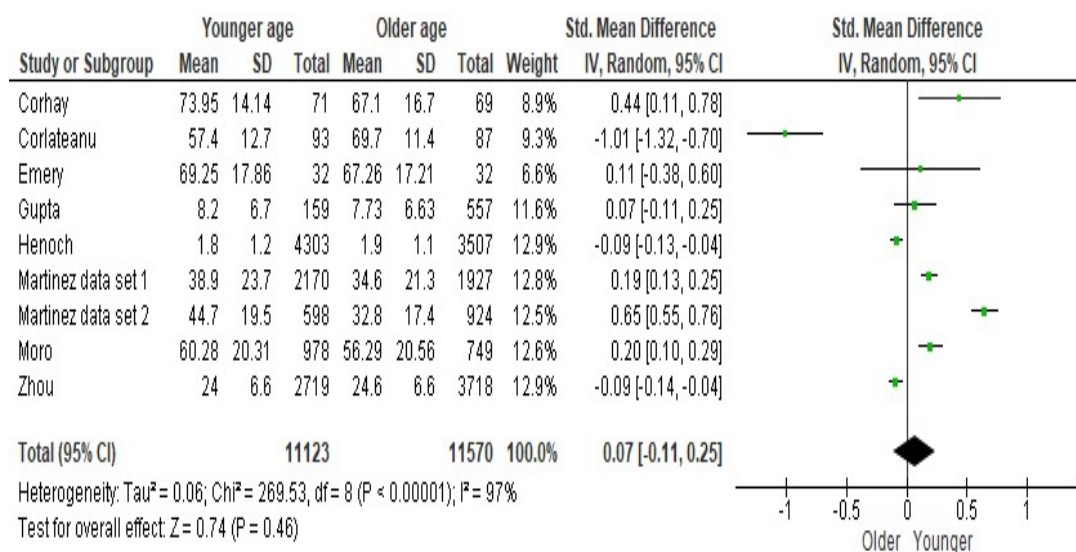
CAT (COPD Assessment test), CCQ (Clinical COPD Questionnaire), CRQ (Chronic Respiratory Disease Questionnaire), PGWBI (Psychological General Wellbeing Index), SGRQ (St. George's Respiratory Questionnaire)

The included papers are varied in their overall research aims. Two were studies directly aiming to identify differences between individuals with COPD on the basis of age (Corlateanu, Botnaru, Covantev, Dumitru & Siafakas, 2016; Martinez et al., 2016). One study aimed to identify whether a quality of life measure, the CAT, could be used to discriminate between subpopulations of people with COPD (Gupta et al., 2016). Another study used the Chinese translation of the CAT measure to draw conclusions about the relationships between CAT scores, other relevant COPD symptom scores, and demographic characteristics (Zhou et al., 2013). One study's aim was to better understand quality of life in women with COPD (Moro, Izquierdo, Anton, de Lucas & Martin, 2009). A further three studies aimed to review the use of COPD interventions across age groups. One of these investigated the impact of a six-month pulmonary rehabilitation intervention for COPD patients of different age groups (Corhay et al., 2012), whilst another similarly studied outcomes of a 30-day pulmonary rehabilitation intervention (Emery, 1994), and a final study was aimed at better understanding the distribution of valid COPD interventions across different demographic groups, including age (Hench, Strang, Lofdahl & Ekberg-Jansson, 2016).

In total, eight studies were found which compared quality of life scores across different age groups, one of which analysed two data sets, therefore nine separate data sets were included in this meta-analysis. When combined, these studies suggest no significant difference between the two age groups on quality of life scores ($p > 0.05$), $Z = 0.74$, effect size = 0.07, 95% CI [-0.11, 0.25], $I^2 = 97\%$.

Four of the included studies suggested poorer quality of life in the working-age adult group, three suggested the opposite, poorer quality of life in the older age groups, and two studies found no difference in quality of life scores between age groups. The heterogeneity score of 97% is very high, showing substantial between-study heterogeneity (see Figure 2).

Figure 2. Data set and forest plot for analysis 1.



Analysis 2: Comparisons of age across high vs. low quality of life score groups

Two studies were found that grouped individuals as having high or low quality of life scores, and compared age between groups. See Table 2 for details of the included studies.

Table 2.

Data used from each paper included in analysis 2.

<u>Study</u>	<u>Number of participants</u>	<u>Country in which study conducted</u>	<u>Gender breakdown of participants</u>	<u>Groups reported in original paper</u>	<u>Groups combined for this meta-analysis?</u>	<u>QoL measure used in original paper</u>	<u>Data used for this meta-analysis</u>
Miravittles et al. (2007)	222	Spain	95% male 5% female	High QoL, SGRQ score <39.5 Low QoL, SGRQ score >39.5	Not applicable	SGRQ total scores	SGRQ total score
Suetomo et al. (2014)	139	Japan	77% male 23% female	High QoL, CAT score <10 Low QoL, CAT score >10	Not applicable	CAT total score	CAT total score

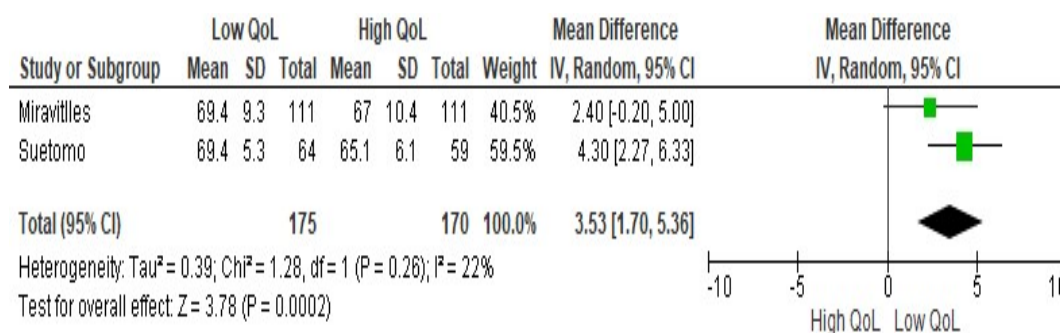
CAT (COPD Assessment Test), SGRQ (St. George's Respiratory Questionnaire)

Aside from reversing scores for any measures wherein a higher score represented poorer quality of life, none of the data from these two studies was manipulated for the purposes of this meta-analysis.

Both studies included in this second analysis had a similar research aim, which was to identify the factors related to quality of life impairment in COPD (Miravittles et al., 2007; Suetomo et al., 2014).

Overall, this analysis indicates that individuals with poorer quality of life scores are significantly more likely to be in an older age group ($p < 0.001$), $Z = 3.78$, effect size = 3.53 95% CI [1.7, 5.36], $I^2 = 22%$ (see Figure 3).

Figure 3. Data set and forest plot for analysis 2.



Summary of results

Overall, looking across both analyses, we see that there is no significant effect of age on quality of life in studies which have compared quality of life scores between age groups. However, a smaller analysis of studies comparing age in high and low quality of life groups, shows a significant difference in that individuals with poorer quality of life scores are significantly older than those with better quality of life scores.

Quality of life measures used in included studies

The included studies used a total of five different quality of life measures between them, the details of which are expanded below.

Chronic Respiratory Disease Questionnaire (CRQ): The CRQ has, in the past, referred to a clinical interview tool which is used to assess the impact of respiratory disease on quality of life. This interview covers four areas: dyspnoea, fatigue, emotions, and mastery. From this, a self-report version of the tool was developed which follows the same structure as the interview. In the dyspnoea section, the individual is asked to rank the five most important areas affected by their breathing. In the other three sections, the individual is asked to score the impact of their difficulties on a seven-point scale. Similar results are found between both the interview format and the self-report questionnaire on all sections of the measure, except for the dyspnoea section, where different findings are collected depending on the format of the measure used (Williams, Singh, Sewell, Guyatt & Morgan, 2001). This measure has been shown to have good internal consistency and convergent validity with the CCQ, but does not have strong convergent validity with spirometry scores (Reda, Kotz, Kocks, Wesseling & van Schayck, 2010).

Clinical COPD Questionnaire (CCQ): The CCQ is a ten-item questionnaire which is scored using a six-point scale. Six items relate to COPD symptoms, including impact on mood, and four items relate to limits in day-to-day activity levels. The respondent is asked to complete the scale with reference to the past seven days only. A 24-hour version of the measure is also available. This measure has high internal consistency and is able to distinguish between individuals diagnosed with COPD, and healthy ex-smokers. It correlates well with the SF-36 and SGRQ (Van der Molen, Willemse, Schokker, Hacken, Postma & Juniper, 2003).

COPD Assessment Test (CAT): This is an eight-item questionnaire measure which is designed to assess the impact of the physical symptoms of COPD. The participant is asked to rate, on a six-point scale, to what extent day-to-

day life is impacted by each symptom (CAT test user guide, 2016). Validation studies have compared the CAT to the SGRQ and found that the two measure comparable constructs. CAT scores have been shown to be able to distinguish a non-COPD sample, a stable COPD sample, and a group of people with COPD experiencing exacerbations. The CAT has high internal consistency and test-retest reliability (Jones et al., 2009). A systematic review has also supported the reliability and validity of this measure, with studies showing a clear difference in scores between COPD patients of different disease severity. Scores are also shown to reduce after pulmonary rehabilitation (Gupta, Pinto, Morogan & Bourbeau, 2014)

Psychological General Wellbeing Index (PGWBI): This is the only included questionnaire that is not designed for use specifically with a COPD population but rather, is a broad measure of quality of life. It is a 22-item measure which asks the individual to rate, on a six-point scale, the severity to which he or she has experienced a number of symptoms implicated in poor quality of life. The questionnaire focuses on six aspects of quality of life: anxiety, mood, positive wellbeing, self-control, health, and vitality. While not a measure of HRQoL, its user guide does advise that its use with a range of clinical health populations, including with individuals with respiratory diseases, is appropriate (Chassany, Dimenas, Dubois & Wu, 2004). The measure has good internal consistency and is able to pick up changes in overall wellbeing following intervention (Lundgren-Nilsson, Jonsdottir, Ahlborg & Tennant, 2013).

St George's Respiratory Questionnaire (SGRQ): This is a 50-item measure of quality of life. It starts by asking the individual to rate their overall health, and then asks questions about frequency of COPD symptoms in day-to-day life. The questionnaire goes on to ask the individual to state whether they have, or have not, experienced a series of difficulties a person might encounter with COPD. The focus is on activities, emotional impact, and medication. Finally, the questionnaire leaves

space for the individual to add his or her own statements about the areas of most importance for COPD impact. Scores are given for three domains: symptoms, activity, and impact. A total score is also given. SGRQ scores correlate well with a range of COPD symptom scores such as forced expiratory volume (FEV) score, six-minute walking test, and spirometry. Changes in SGRQ score also correlate well to changes in score on other measures of quality of life, for example, the SF-36. It is widely considered to be a reliable and valid measure of HRQoL for use with respiratory populations (Jones, Quirk, Baveystock & Littlejohns, 1992)

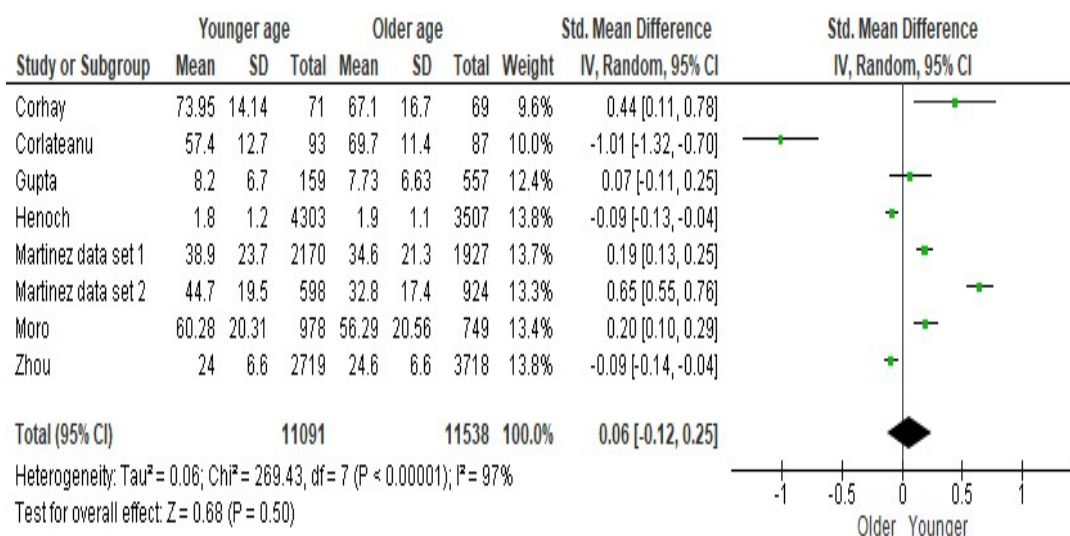
The four included data sets which suggested poorer quality of life in working-age adults all used COPD-specific measures of quality of life, the SGRQ or the CRQ. These measures aim to specifically record the level of quality of life impairment caused by COPD or chronic respiratory difficulties.

Of the further seven studies, three showed no difference between age groups, and four showed poorer quality of life in older adults with COPD. The quality of life measures used in the three studies showing no difference were the PGWBI in one study, and the CAT in the two others. The PGWBI is a generic quality of life measure, while the CAT is a COPD-specific measure.

The four studies showing poorer quality of life in older adults used only COPD-specific quality of life measures – the SGRQ, the CCQ, and the CAT.

Removing the study (Emery, 1994) which uses a generic quality of life measure, rather than a COPD specific measure, from analysis 1, does not make any meaningful difference to the findings. There remains no significant difference in quality of life scores between working-age and older adults ($p > 0.05$), $Z = 0.68$, effect size = 0.06, 95% CI [-0.12, 0.25], $I^2 = 100\%$. The high heterogeneity score in this analysis is not improved by the removal of this study (see Figure 4).

Figure 4. Data set and forest plot for analysis 1, after removal of Emery (1994) data



Overall, the majority of included research has used COPD-specific measures, and the research finding is not impacted by the removal of studies using generic quality of life measures. Therefore, the research is not biased by the inclusion of generic quality of life measures. The only included study which used generic measurement had a very small sample size, of 64 participants, and is also the oldest study, having been published in 1994. It appears that COPD-specific measures are being more widely used in modern research.

Quality assessment

To assess the quality of the included papers, the quality assessment tool for observational cohort and cross sectional studies from the National Heart, Lung and Blood Institute (NIH, 2018) has been used. This tool consists of 14 questions used to assess the quality of the included papers (see Appendix A for a full copy of the tool).

Each included study has been quality assessed using this tool. See Table 3 for scores and Appendix B for a more comprehensive table, detailing complete quality assessment results for each paper. Within the included research papers,

three of the quality assessment questions were consistently rated as 'not applicable', therefore the scores reported can be understood as being from a total score of 11 rather than 14.

Table 3.

Scores for each included study on the NIH quality assessment tool for observational cohort and cross sectional studies.

<u>Study</u>	<u>Quality assessment score</u>	<u>Overall quality</u>
Corhay et al. (2012)	9	Good
Corlateanu et al. (2016)	7	Fair
Emery (1994)	8	Fair
Gupta et al. (2016)	8	Fair
Henoch et al. (2016)	8	Fair
Martinez et al. (2016)	8	Fair
Miravittles et al. (2007)	8	Fair
Moro et al. (2009)	10	Good
Suetomo et al. (2014)	8	Fair
Zhou et al. (2013)	7	Fair

The two included studies rated as 'good' were both studies which found poorer quality of life scores in the middle-aged group. All other included studies were rated as fair. Looking at the quality assessment scores for each paper, items three, five and 14 are particular areas of the quality assessment where the papers are seen to differ. Item three asks whether a minimum of 50% of eligible individuals participated in the study. Nine of the twelve included papers scored 'yes' on this item, a further three did not report whether or not this was the case (Corlateanu et al., 2016; Emery, 1994; Zhou et al., 2013).

Item five asks whether a sample size justification was reported in the paper. Only one paper met this criterion (Moro et al., 2009). This paper used a large

sample size, of 1727 participants. Some of the included papers which did not report a power calculation have used much smaller sample sizes, particularly the papers authored by Corhay et al. (2012), and Corlateanu et al. (2016), and also both studies included in the second analysis, authored by Miravittles et al. (2007) and Suetomo et al. (2014). Whilst these papers do not calculate or justify sample size, we might assume that these studies were underpowered. This is not necessarily an area of concern in meta-analysis research as the studies are weighted based on their power, but it does help us make sense of the results of analysis two, where two possibly underpowered research studies have been combined and returned a result which is strikingly different to the finding of the much larger first analysis.

Finally, item 14 asks about whether the study has controlled for confounding variables. Only one of the ten studies scored 'yes' on this item. This was the study conducted by Moro et al. (2009), which controlled for gender as it was a study of female patients only. It did not control for any additional factors. The vast majority of the papers did conduct factor analyses, aiming to make sense of the various factors which account for variance in quality of life score, but the data used in this study was taken from the baseline research data from each study and so no controls have been applied. This helps us to make sense of the overall result of this meta-analysis. Overall, no significant difference in quality of life has been found between working-age and older adults with a diagnosis of COPD. There are very high heterogeneity levels in the data set and this may well be because the included papers have not controlled for potential confounding variables.

DISCUSSION

Two separate meta-analyses were conducted in this review, aiming to understand whether quality of life in individuals with a diagnosis of COPD differs according to age group. One analysis combined eight studies with a total sample

size of 22,693 participants, all of which compared quality of life across age groups, but found no significant overall difference in quality of life scores between working-age and older adults. The included studies presented conflicting results, with very high heterogeneity. The 95% confidence interval for this analysis is small, telling us that it is very likely that future studies looking at this phenomenon would also find a non-significant result.

The second analysis combined two studies with a total sample size of 345 participants. These were studies which had presented data regarding age differences between groups of individuals with COPD, who had scored either high or low on quality of life measures. The result of this analysis was a significant finding that people scoring worse on measures of quality of life were older than those scoring better. This finding therefore suggested that an age difference exists between quality of life scores for people diagnosed with COPD.

When looking at these two findings in combination, it is important to consider that the first analysis had a much larger sample size than the second, giving this result greater power. Therefore, taking an overall view of the data, we must conclude that there is no difference between working-age adults and older adults with COPD in terms of quality of life scores.

The quality assessment process highlighted that only one of the included studies controlled for possible confounding variables, with this study only controlling for gender. It is likely that no relationship has been found between quality of life and age because quality of life is a far more complex construct. Those included studies that have found significant results might be picking up on the impact of an uncontrolled confounder, rather than the effect of age differences alone. It may also be the case that age interacts in complex ways with a multitude of other variables which the studies have not controlled for.

The heterogeneity of the included studies is an important issue to consider. By looking at the two studies which give the most different findings, we can begin to think about why such distinct results might have been returned. The study conducted by Corlateanu et al. (2016) gave the strongest result suggesting that older people with COPD have poorer quality of life, while the second Martinez et al. (2016) dataset (SPIROMICS cohort) gave the strongest result indicating the opposite, that younger people with COPD have poorer quality of life. The Corlateanu et al. (2016) research study was conducted in Moldova, with a sample that was approximately 65% male. The SPIROMICS cohort data used in the Martinez et al. (2016) study was gathered from an American population with approximately 58% of the overall sample being male. Both studies included individuals of all disease severities. Neither study controlled for possible confounding variables. It might well be that the studies are not, in fact, picking up a difference in quality of life score which can be understood as being a result of age differences, as they have concluded, but rather the picture might be more complicated than this. Both studies are different in terms of the nationality of the sample, for example. Therefore, the findings from both studies are likely to have been influenced by cultural ideas about aging and coping which might well differ between Moldovan and American citizens. The relationship between age and quality of life in COPD is likely to be complex, and the role of factors such as culture needs to be explored in greater depth.

Both of these studies used the same measure of quality of life, the SGRQ. However, the use of different quality of life measures in different research studies might also account for some of the differences in findings. Looking across the four COPD-specific quality of life measures used in the included studies, the areas asked about are not vastly different. Questions tend to focus on COPD symptoms, ability to be active both within the home and outside, and ability to socialise with others. However, the main difference between the questionnaires is length and therefore

also, potentially, depth of assessment. The CCQ and CAT are both ten-item measures, the CRQ is 20-items long and the SGRQ is the longest, at 50 items. While the CCQ, CAT, and CRQ all ask fixed-response questions, the SGRQ also allows the responder to enter free text responses about their specific experiences and therefore allows for more individuality, within the realms of a standardised measure. It might therefore be that studies using different measures are also tapping into slightly different areas of quality of life. Given that quality of life is such a broad concept, this is fairly likely to happen in cases where the same measure is not consistently used.

Disease-specific measures, particularly the SGRQ, have been shown to be better able to discriminate different stages of COPD disease severity than generic quality of life measures, indicating that they may be more powerful tools for use in COPD research (Pickard, Yang & Lee, 2011). Given that COPD-specific measures have been used in the majority of research included in this meta-analysis, and have been exclusively used both in the research suggesting poorer quality of life in working-age adults, and the research suggesting poorer quality of life in older adults, it is fair to assume that the conclusions drawn in both categories of studies are comparable in terms of the quality of life measurement tools used. An analysis was conducted with the study that used a generic quality of life measure removed, and this made no difference to the overall finding.

Limitations

This review has included a total of ten research studies that compared quality of life in individuals with a diagnosis of COPD according to age. For some of these research studies, this was the main outcome of interest. For others, these statistics were reported as part of a wider research paradigm.

With regard to the included data, the ten studies included did not all define their age groups in the same way. For some of the included studies, age groups were combined in order that the data could be included in this analysis. All included studies divided age groups at a cut-off between the ages of 60 and 70, and any papers that split age groups at a point outside this age range were excluded from this analysis. This was to ensure that the comparison being made in this meta-analysis was one of older adults and working-age adults. The concept of 'working-age' is a flexible one and therefore, while in ideal circumstances all included studies would define their age groups in the same way, the approach taken in this analysis is a compromise reflecting what is available in the current research literature.

No studies were excluded on the basis of research quality, as the number of available papers was fairly low. Quality assessment was conducted and the majority of included papers were rated by the researcher as 'fair'. Included studies were only assessed by one researcher. If more resources had been available, it would have been preferable to cross-reference this with a second researcher to ensure reliability of the quality assessment process.

The quality assessment process in itself had some challenges as the majority of research quality assessment tools in existence are not applicable to the type of research studies included in this analysis; rather they are often designed for use with randomised-controlled trials. The tool used in this meta-analysis is the NIH tool for observational cohort and cross-sectional studies, which is the only available tool that is appropriate for use with this type of research. It is unfortunate that it has been chosen based upon issues around access and availability, rather than the usefulness of the quality assessment questions included. The conclusions drawn from this process must therefore be interpreted cautiously.

Whether or not the quality assessment questions asked by the tool truly tap into the quality of the research could be debated. For instance, the questions around

the appropriate reporting of the research question and sample selection process are more likely assessing the quality of the researcher writing style, rather than the research in and of itself. The answers to these questions tell us little about the actual quality of the research. Additionally, questions regarding the 'exposure' of interest have little relevance to epidemiological research, given that the 'exposure' in this case is a physical health diagnosis that cannot, of course, be manipulated in any way by the researcher. Equally, the assessment criteria regarding loss to follow-up, again, lacks relevance to research which has not been conducted longitudinally. The quality assessment has not been able to significantly distinguish between the included papers with the vast majority being rated as 'fair'. Unfortunately, it has therefore been able to add little in terms of really interpreting the data quality.

The lack of appropriate quality assessment tools for observational research designs has been discussed by Lang and Kleijnen (2010) who highlight the problems associated with there being limited tools for use in this area, and no agreed upon 'gold standard' tool for assessing research quality for observational designs.

Clinical recommendations

There is of course, an important clinical relevance to understanding the impact a person's COPD is having on his or her quality of life. Quality of life is significantly predictive of hospital readmission for patients with COPD (Osman, Godden, Friend, Legge & Douglas, 1997). Poorer quality of life is also linked with psychological distress and poorer coping strategies (Brien, Lewith & Thomas, 2016). Of course, quality of life is also an important domain in allowing us to understand how COPD affects an individual's ability to participate in day-to-day life in the way that they would want to. Poorer quality of life scores are also indicative of greater

disease severity (Amoros et al., 2009; Zamzam, Azab, El Wahsh, Ragab & Allam, 2012).

Understanding more about whose quality of life is more significantly impacted by COPD can help care providers target support and interventions aimed at improving quality of life in COPD patients, such as PR or psychology. PR is an intervention which has been shown to have a positive impact on quality of life in COPD patients (Moullec, Laurin, Lavoie & Ninot, 2011), and interventions such as this should be prioritised for individuals with poorer quality of life. The findings of this meta-analysis suggest that decisions about clinical care and services provided should not be made based on age, but rather quality of life should be used as a clinical indicator of need. Overall, services must ensure that holistic care, which takes a whole-person approach to the treatment of COPD, is offered where constructs such as quality of life are given equal weight alongside measures of disease severity. It is important that quality of life assessment is included in the care package delivered to all COPD patients accessing services.

Research recommendations

Overall, no difference has been found in quality of life scores between working-age and older adults with COPD. Heterogeneity was particularly high within this meta-analysis, telling us that there is substantial diversity among the research studies included. The included studies have not controlled for confounding variables that might also be contributing to quality of life scores, and therefore impacting these findings. Future research aiming to examine in further detail the age differences in COPD quality of life should make sure to control for confounding variables or to assess them directly.

It is important to also consider the complexity of the concept of quality of life. Further quantitative research which continues to look at possible predictors of

differences in quality of life in people with COPD might well fail to pick up on this complexity. Future research using qualitative research paradigms, with different groups of individuals with COPD, or indeed other physical health diagnoses, would also be valuable in continuing this discussion.

Future research could, for example, consider the use of qualitative research methodologies to further unpick the role of life stage in determining how COPD impacts quality of life. Much qualitative research in the area of COPD has investigated the ways in which COPD has impacted on life quality. However, these studies have investigated across age groups, and not specifically focussed on any one age group or drawn conclusions regarding the role that age might play in quality of life.

The studies included in this analysis used several different COPD quality of life measures, and the conclusions drawn will likely have been affected by the quality of life measurement approach used. Future research that compares COPD quality of life measures, to facilitate researchers in appropriately selecting the right measure for use for their purposes and population, would also make a valuable contribution to this field.

Additionally, quality assessment tools for use in meta-analyses such as this, which bring together epidemiological or observational research studies, are limited and the tools available fail to ask meaningful questions. Future research would be well-placed in developing meaningful quality assessment tools for use in future systematic reviews, or meta-analyses.

CONCLUSION

Overall, this meta-analysis of ten research studies has shown no age difference in quality of life scores in individuals with COPD. There is very high

heterogeneity within the research field and this is likely due to various factors, such as the lack of consideration for confounding variables, and the inconsistency in quality of life measurement tools used. This meta-analysis has also identified the limited availability of appropriate quality assessment tools for use in reviews of epidemiological or observational research studies, which limits the researcher's ability to draw critical conclusions.

Future research should focus on the development of meaningful research quality assessment tools for use with epidemiological or observational research. Additionally, comparisons of quality of life tools would be valuable in supporting clinicians and researchers in selecting the tool most useful for their purposes. Future research should also consider the complexity of quality of life as a concept, possibly using qualitative research paradigms to further investigate the impact that COPD has on quality of life, and the role that life stage plays in this complex relationship.

The finding of this meta-analysis has clinical implications for COPD services, which must ensure that quality of life assessment is being offered to all individuals accessing services, and that interventions targeted at improving quality of life in COPD, such as PR, are being offered to all individuals accessing COPD services, particularly those with poorer quality of life.

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Part 2: Empirical paper

The working-age experience of living with Chronic Obstructive Pulmonary Disease (COPD)

ABSTRACT

Numerous factors have an impact on quality of life in people living with COPD. Some of these are likely to be relevant to all people living with COPD, whereas others may have more impact on those of an employable age. This study reports the findings of a qualitative investigation of 11 working-age adults with COPD, aged between 52 and 63. The aim of this study was to understand in greater depth the impact that COPD has on quality of life for individuals of a working-age. A framework analysis approach was used, and ten themes were identified, which interact in complex and nuanced ways. Interestingly, the sample reported very few concerns specific to their age group. The majority of participants did not report concerns about loss of employment, for example. However, changes to their role within the family and the need to be cared for by their children were particularly distressing. Participants also reported complex relationships to making lifestyle changes, such as quitting smoking. Participants commonly reported a lack of 'readiness' for making changes, and experiencing services as disempowering when this sense of not being ready was not taken seriously. These areas need further exploration.

INTRODUCTION

Understanding Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a diagnosis used for the chronic lung conditions that were previously identified as emphysema and bronchitis. COPD comes about as a result of damaged lungs, the most common cause of which is smoking. Individuals with COPD experience breathlessness, wheezing, coughing, and chest infections. In cases where COPD is poorly managed or deteriorating, chest infections can require hospitalisation. While COPD is incurable, individuals can manage their symptoms by learning breathing techniques, using medications, getting fitter, developing skills in pacing, and giving up smoking. COPD services commonly offer an intervention called Pulmonary Rehabilitation (PR), which supports patients in developing these skills and making these changes (NHS, 2017).

COPD is commonly thought of as a disease of older age, with the majority of individuals diagnosed being over the age of 70. However, decreasing numbers of older adults are being newly diagnosed with COPD, whilst the number of diagnoses in individuals aged between 30 and 60 years old remains steady. This means that proportionally more individuals in younger age groups have been newly diagnosed with COPD in recent years, and are therefore increasingly represented among patients in COPD services (British Lung Foundation, 2018). There is value in better understanding this group of individuals with COPD who increasingly represent a larger proportion of the population of COPD service users.

Why focus on working-age adults with COPD?

A large scale study of over 10,000 Spanish patients with COPD has shown that it has a significant impact on quality of life (Garrido et al., 2006). Qualitative

research has been particularly valuable in helping us to develop our understanding of the meaning that COPD has to an individual living with the diagnosis (Harrison et al., 2014; Kessler et al., 2006; Kvangarsnes, Torheim, Hole & Ohlund, 2013; Schroedl et al., 2014). This research has often been conducted broadly, across people with COPD as a whole, rather than being conducted specifically within particular subpopulations.

The meta-analysis previously described has demonstrated that research does not show any overall difference in quality of life scores between individuals of working-age and older age with COPD. Of interest is the high heterogeneity in research findings in this area, indicating that there are likely to be several important and possibly interacting variables in this complex relationship. This is an interesting area with further exploration needed.

Given the interesting questions raised about the role of age in affecting COPD quality of life, and also taking into account the increasing representation of this group, this research study aims to investigate quality of life in this younger group of working-age adults.

Factors affecting quality of life in COPD

Quantitative research has advanced our understanding of the factors associated with poorer quality of life in individuals with COPD. For example, hospitalisation following a COPD exacerbation has been found to have a positive impact on quality of life, compared to those who try to manage exacerbations at home without seeking medical intervention (Narewski et al., 2015). In addition, greater physical impairment in COPD, as assessed by the six-minute walk test and levels of dyspnoea, is associated with poorer quality of life (Regan et al., 2015). The presence of comorbid physical health conditions also contributes to a worsened quality of life (Holle et al., 2015). Alongside COPD symptom severity, and the

presence of other physical symptoms, psychological factors such as illness perception and locus of control also play a role in quality of life for COPD patients. More optimistic perceptions of COPD and an internal locus of control are associated with improved quality of life. Symptoms of depression and anxiety are both predictive of poorer quality of life (Mewes, Rief, Kenn, Ried & Stenzel, 2016).

Coping style also affects quality of life, with research suggesting that problem-focused coping styles are linked with lower levels of distress in individuals with COPD. Those who endorse coping strategies such as 'I drew on my past experiences from similar situations I have been in before' are likely to experience less distress than those who endorse coping strategies such as 'I hoped for a miracle' (Andenaes, Kalfoss & Wahl, 2006). This finding has been replicated by Tiemensma, Gaab, Voorhaar, Asijee and Kaptein (2016), who additionally found that individuals are likely to use a more problem-focused or proactive coping style when they have a better understanding of their COPD diagnosis, and when their emotional response to living with COPD is less.

For COPD patients in marital or couple relationships, the coping style of the couple can also have an impact on health-related quality of life for both the COPD patient and his or her partner. In particular, signalling stress to one's partner can improve quality of life for individuals with COPD. Stress communication within the COPD population is much less than in the general population, and this is possibly in the context of spouses and partners 'covering up' or hiding their emotions so as not to overburden the partner with COPD. Both members of the partnership benefit from being able to take on tasks for the other, meaning that over time, as the COPD worsens, the non-COPD partner's quality of life might be expected to improve if the partner with COPD delegates tasks to him or her, whilst the partner with COPD would expect to see a decline in quality of life as a result of his or her decreased ability to take on delegated tasks from the non-COPD partner (Vaske et al., 2015).

Factors affecting quality of life in COPD for working-age adults

It could reasonably be predicted that factors such as coping style, symptomatology, hospitalisation, and comorbid mental and physical health issues might influence quality of life in people with COPD across all age groups. There are also, however, some factors that are likely to impact individuals of a working-age to a greater extent. For example, COPD has been reported to have a significant impact on an individual's ability to perform in the workplace, with high rates of mobility difficulties meaning that early retirement and workplace impairment are common in COPD cohorts (Igarashi, 2016).

Research conducted with a British COPD population suggests that only 31% of individuals with COPD who are of a working-age are in paid employment. Those who are able to maintain employment are those who have fewer physical symptoms and report better quality of life (Kalirai, Adab, Jordan, Fitzmaurice & Ayres, 2013). Further research conducted with the same cohort has explored the factors that are involved in the likelihood of an individual with COPD being in paid employment. Individuals with lower levels of prior education, worse COPD symptoms, and previous exposure to workplace toxins, such as fumes or dust, were less likely to be in employment. Age and gender also played a role in employment, with women and older members of the study sample less likely to still be working. Notably, researchers found that employment rates in this sample of individuals with COPD were far lower than in the general population, but also lower than employment rates for people with other physical health problems, or those classified as having a disability (Rai et al., 2017a). For people with COPD who are currently in work, worsened dyspnoea is the main predictor of absenteeism (Rai et al., 2017b).

The question of how COPD specifically impacts quality of life in working-age individuals has begun to be explored in a large-scale survey conducted with

individuals aged 45-67 across six different countries (Fletcher et al., 2011). Only 30% of the study sample were in paid employment. The mean retirement age for this group was 58, with 26% of the sample attributing their retirement to COPD. Those in work tended to report having reduced their working hours or changed their employment role to something less physically demanding. Those who remained in work also reported a reduction in productivity, and impairment of activities outside work. Twenty-two percent of the sample reported requiring regular care from a family member, friend, or neighbour. This working-age sample was found to have impaired quality of life, although the relationship between quality of life and factors around employment was not explored by the researchers.

Of course, the research literature on employment rates and absenteeism in people living with COPD does not consider individuals who are self-employed, or those formally caring for others, such as children or parents. This should be considered when interpreting these findings.

Given the societal expectations in British culture that a person of working-age is normally in paid employment or self-employed, and the value that employment can bring to individuals - for example, through providing structure and self-esteem - it is likely that the difficulties faced by individuals with COPD in maintaining employment would have an impact on overall quality of life. In addition to issues around employment, there are likely to be other age-specific concerns that might result in COPD having a different impact on those of a working-age. For example, an individual of working-age might still have children to care for, or have parents who require care.

Summary

Overall, there are many factors that influence quality of life in individuals with COPD. Some of these are likely to be relevant for people of any age, and some are

more likely to be problematic for the working-age group. It is likely that all of these factors, plus many others, come together in a complex interplay to affect quality of life. The aim of this research study is to gain a greater understanding of these complex and nuanced relationships, and how they function for working-age adults with COPD.

Research aims

This study is a qualitative investigation exploring the meaning of COPD, and the individual experience of having COPD, for service users of a working-age, defined as being under the age of 65. The specific research questions are as follows:

1. What is the individual's understanding of, and relationship to, COPD?
2. What priorities and concerns are important given his or her life stage?
3. Has COPD affected or changed his or her priorities or concerns?
4. Has COPD affected his or her ability to participate in day-to-day life in important areas?
5. Do services provide the help he or she needs to manage COPD?

METHOD

Recruitment

Participants were recruited from a London-based secondary care respiratory team. Referrals to this team typically come from general practitioners and hospital consultants. There are several treatment pathways within the respiratory service. The main pathway is the pulmonary rehabilitation (PR) pathway. PR consists of sixteen sessions providing exercise support, and education on COPD management. This intervention is offered to the majority of individuals accessing COPD services who are able to attend outpatient appointments. In addition, the service has an oxygen pathway, for those whose breathing has deteriorated to the point that their

blood-oxygen levels have lowered, meaning that long-term oxygen is needed. There is also an admissions avoidance pathway, which supports people at home whose health is deteriorating. The group accessing this part of the service would most likely be those who are regularly admitted to hospital with chest infections. The aim of the admissions avoidance pathway is to reduce the frequency of hospitalisations and support these individuals in their own homes. Therefore, the service users from the oxygen and admissions avoidance pathways tend to present as more physically unwell than those being seen in PR. The team also has a Clinical Psychologist and Occupational Therapist who accept referrals from all pathways within the service.

The following inclusion and exclusion criteria for this research study were specified:

Inclusion criteria. Diagnosis of COPD, currently under the care of the clinical team (have completed assessment with the service), aged between 18 and 65 years of age.

Exclusion criteria. Current hospital inpatient, unable to attend an outpatient appointment, unable to communicate verbally in English, current substance misuse, member of a vulnerable population e.g. pregnant, diagnosed with a terminal illness, diagnosed with a cognitive impairment or learning disability.

An opportunistic sampling strategy was used. All clinical staff in the team were informed about the research and the inclusion and exclusion criteria and asked to give information sheets (see Appendix C) to eligible service users at clinic appointments. The contact details of interested service users were collected at these appointments, along with consent for the researcher to contact the individual. Contact details of the researcher were also given. A minimum of 24 hours was given between the individual receiving the information sheet, and being contacted by the

researcher, in order to give time for them to consider the information before being asked whether or not they wished to participate.

No target sample size was determined in advance but rather, recruitment ended when the content of the interviews had reached 'saturation'. This is the point at which no new or different perspectives were coming through in the research interviews. To determine this, the researcher coded the first three transcripts early on in the data collection process. This helped the researcher gain a detailed understanding of the content of the early interviews, allowing saturation to be assessed.

Procedure

Following referral, those individuals who had consented to being contacted and provided their details were contacted by telephone by the researcher, who clarified information about the research over the phone. Research appointments were arranged for those expressing interest in participating. Research appointments were held at the hospital site where the respiratory team is based. All appointments took place during working hours (Monday-Friday, 9am – 5pm). The appointment began with a review of the information sheet and then participants were consented (see Appendix D for a copy of the consent form).

The participants then completed four standardised questionnaires. These were: the Public Health Questionnaire 9 Item Scale (PHQ-9), a depressive symptoms scale; the Generalised Anxiety Disorder 7 Item Scale (GAD-7), an anxiety scale; the St. George's Respiratory Questionnaire (SGRQ), a quality of life scale for COPD; and the Dyspnoea-12 (D-12), a breathlessness scale.

The PHQ-9 consists of nine items, each scored on a scale from zero to three. The maximum possible score on the PHQ-9 is 27, with higher scores

indicating more severe depression (Kroenke, Spitzer & Williams, 2001). The GAD-7 consists of seven items, again scored on a scale from zero to three. The maximum possible score on the GAD-7 is 21, with higher scores indicating more severe anxiety (Spitzer, Kroenke, Williams & Lowe, 2006). Both are widely-used measures. The SGRQ is a longer, 50-item measure which asks about the impact of COPD on day-to-day life. Scores on the SGRQ are out of a total of 100, with higher scores indicating poorer quality of life (Jones, 2016). This is both a valid and reliable measure of quality of life for use with respiratory populations (Jones, Quirk, Baveystock, & Littlejohns, 1992) The D-12 contains 12 items, scored on a scale from zero to three. The maximum possible score on the D-12 is 36, with higher scores indicating worse dyspnoea. It is a reliable and valid measure of dyspnoea (Yorke, Moosavi, Shuldham & Jones, 2010).

Following the completion of the questionnaires, the semi-structured interview commenced and was audio-recorded. See Appendix E for a copy of the interview schedule. Participants were welcome to take breaks whenever required. The maximum total research appointment time was 2 hours 30 minutes, with interviews being between 45 minutes and 1 hour 30 minutes in length.

Following the interview participants were invited to ask any questions they had, and a debrief was offered. The researcher was a Trainee Clinical Psychologist who was able to sensitively manage any distress that arose during the research interviews. The researcher was also able to make onward referrals to members of the clinical team, such as the Clinical Psychologist, following the research interview. Discussions around these issues were held during debriefing.

All participants were offered the opportunity to receive feedback on the findings of the research, and those who opted to receive this will be sent a summary of the research findings.

Participants

A total of 11 participants were included in the study. One further individual attended a research appointment but met two of the exclusion criteria (current substance misuse, and cognitive impairment). Of the 11 participants, ten were referred via the pulmonary rehabilitation pathway of the service, and one via the admissions avoidance pathway. The participants' ages ranged from 53 to 62. Five participants were male and six were female. All participants were British; nine were white British, and two black British. All participants were unemployed at the time of conducting the research interviews. Those who had been full-time carers were no longer caring for others. All of the participants had smoked at some point in their lives, and some continued to smoke. Two of the participants also reported high levels of workplace exposure to toxins which they believe was a cause of their COPD.

Situating the sample

Participant one: Participant one was diagnosed with COPD four years ago. He was previously employed in a field of manual work. Participant one had been a non-smoker for 25 years at the time of the interviews. In the past 12 months, this participant had not needed any hospitalisations. He had a diagnosis of a comorbid pain condition.

Participant two: Participant two was diagnosed with COPD under one year ago. In the past, she had been a full-time carer for family members. This participant stopped smoking at the time of her COPD diagnosis, and had not been hospitalised with her COPD in the past 12 months. She also had a diagnosis of depression, and was living with a comorbid pain condition.

Participant three: Participant three was diagnosed with COPD one year ago. He was previously employed in a field of manual work. He was not smoking at the time of conducting the interviews. He reported being hospitalised frequently with COPD, on an approximately monthly basis since diagnosis. He was diagnosed with a comorbid heart condition.

Participant four: Participant four was diagnosed with COPD 18 months ago. In the past, he had been employed in a manual field of work. He had a history of asthma and had previously been a smoker. He had since given up smoking. Within the past twelve months, he reported having had three hospitalisations with COPD.

Participant five: Participant five was diagnosed with COPD one year ago. She was previously employed in a healthcare profession. She had a history of asthma and had smoked in the past but stopped smoking several years ago, upon her first admission to hospital with breathing difficulties. She reported having been admitted to hospital six times in the past 12 months, as a result of her COPD.

Participant six: Participant six was diagnosed with COPD over 15 years ago. In the past, she was a full-time carer for family members. At the time of the research interviews, she reported being a smoker. She had had five admissions to hospital in the last 12 months.

Participant seven: Participant seven was diagnosed with COPD one year ago. He had a history of working in child care. He reported being a current smoker and had been admitted to hospital once in the past 12 months.

Participant eight: Participant eight was diagnosed with COPD eight years ago. She had a history of employment in a field of manual work, and had also been a carer for family members. She reported having recently stopped smoking. She had had two hospital admissions with COPD in the past 12 months.

Participant nine: Participant nine was diagnosed with COPD five years ago. She had a history of working in a field of manual work, and caring for family members. She was a current smoker, who had not had any hospital admissions in the past 12 months.

Participant ten: Participant ten was diagnosed with COPD one year ago. She had a history of working in childcare. She reported being a current smoker, and had not been hospitalised with COPD in the past 12 months. She was living with comorbid pain conditions.

Participant eleven: Participant eleven was diagnosed with COPD two years ago. He had previously worked in manual fields of employment. He had stopped smoking at the time of his COPD diagnosis, and had not been hospitalised with COPD within the past 12 months. He had a comorbid heart condition, and a pain condition.

As described, all 11 study participants completed four standardised questionnaires prior to completing the research interview: the PHQ-9, the GAD-7, the SGRQ, and the D-12 (see Table 1 for details of participants' scores). All scales provide a total score, and the SGRQ also provides component scores, for COPD symptoms, for activity levels, and for impact of COPD.

Table 1.

Participants' standardised measures scores

<u>Participant</u>	<u>PHQ-9</u>	<u>GAD-7</u>	<u>SGRQ Symptoms</u>	<u>SGRQ Activity</u>	<u>SGRQ Impacts</u>	<u>SGRQ Total</u>	<u>D-12</u>
P01	11 (moderate)	11 (moderate)	91.0	66.2	48.6	61.0	24
P02	24 (severe)	21 (severe)	53.8	85.8	61.9	68.1	29
P03	2 (none)	1 (none)	85.9	85.8	63.9	74.2	16
P04	7 (mild)	2 (none)	64.4	55.1	30.5	43.6	25
P05	10 (moderate)	7 (mild)	91.1	100.0	62.6	78.6	27
P06	18 (mod-sev)	18 (severe)	88.9	92.5	64.7	77.5	36
P07	6 (mild)	11 (moderate)	75.6	61.5	39.0	51.9	20
P08	12 (moderate)	4 (none)	100.0	93.3	61.7	77.5	16
P09	21 (severe)	18 (severe)	100.0	92.5	78.5	86.2	36
P10	4 (none)	5 (mild)	37.8	54.5	10.2	28.4	4
P11	4 (none)	3 (mild)	44.1	92.5	45.9	60.0	14

The scores for the PHQ-9 and GAD-7 have been marked as 'none', 'mild', 'moderate', 'moderately severe', and 'severe', based on clinical cut-offs (Kroenke et al., 2001; Spitzer et al., 2006).

Situating the researcher

The writer of this thesis is a Trainee Clinical Psychologist with no prior experience of working in COPD care, and no personal experience of individuals with a diagnosis of COPD. This researcher conducted all the research interviews and the research analysis. She attempted to approach this process with a perspective of 'not knowing', and an interest in the experience of living with the diagnosis of COPD. Whilst she had no prior assumptions about individuals living with COPD, she did enter the research with ideas about the lifestyles, likely values, and priorities of individuals in their fifties and sixties. These assumptions were based on her personal relationships with people in this age group. The assumptions were around people in this age group tending to be healthy and active, and often being in employment.

The researcher is also part of a younger generation who grew up at a time, and in a culture, where it was widely known that smoking was unhealthy and had serious long-term health implications. The researcher therefore does also hold biased beliefs about smoking being an unwise choice and believes that individuals 'should' attempt to stop smoking where possible. The researcher has tried to remain mindful of these assumptions throughout the research process, and to remain aware of their impact.

The research is being supervised by a Clinical Psychologist working part-time in the respiratory service where the research took place, and an academic psychologist with much experience of research in the field of health psychology, in particular, the area of chronic pain.

Analysis

The qualitative transcripts were analysed using framework analysis. Framework analysis is a thematic analysis approach, designed for applied research in contexts such as health settings. Framework analysis has been used in this study for several reasons. Firstly, it suits more question-focused qualitative research paradigms such as this. Framework analysis also lends itself well to both contextual and strategic qualitative research questions, such as those being explored in this study. Additionally, the transparency and relative accessibility of framework analysis research is important in allowing the conclusions of the research to be fully understood, and therefore effectively evaluated by the reader (Ritchie & Spencer, 1994). Framework analysis is also an accessible method of data analysis for novice qualitative researchers (Gale, Health, Cameron, Rashid & Redwood, 2013).

The stages of framework analysis as set out by Ritchie and Spencer (1994) were broadly followed in this research project. Any areas of difference between their advised steps, and the process followed in this piece of research will be clearly stated as the research stages are described.

Stage one. Familiarisation with the data: The researcher familiarised herself with the study data through a process of reading interview transcripts and listening to interview recordings. In this case, all interviews were transcribed by the researcher. The researcher therefore became familiar with the interview material as part of the process of transcribing the interviews.

Stage two. Coding: The first six transcripts were coded by the researcher. This was a process of identifying and recording the content of the interviews. Please see Appendix F for an example section of a transcript which has been coded in this way. One transcript was coded by an independent researcher (a Trainee Clinical Psychologist) in order to assess validity of the coding process. Codes were

compared between researchers and where differences were present, discussions led to conclusions about the most appropriate way to code the data.

In Ritchie and Spencer's (1994) suggested approach to conducting framework analysis, it is not required that the researcher formally codes transcripts as part of this stage, but rather the researcher is expected to identify the key content from the familiarisation stage. In this case, using a more formal coding approach was felt to be a useful tool to guide the researcher. Coding the transcripts allowed the researcher to ensure that the key issues identified for use in the coding framework (stage three) were closely linked to the study data.

Stage three. Developing the coding framework: The codes developed in stage two were brought together by the researcher, who identified common links between the codes and developed an initial framework of codes that would be used to classify the full data set. Please see Appendix G for a full copy of the coding framework used. This is a complex process, wherein the researcher is led by the research questions, familiarity with the research material, and, in this case, their psychological knowledge, to develop the content of the coding framework. The framework at this stage is seen as a working framework, with changes being made to it where needed to ensure the full data set is captured. An 'other' code was used, so that important information that did not fit the codes already decided upon would not be lost.

Stage four. Indexing: All transcripts were subsequently 'indexed' using the coding framework. Please see Appendix H for an example section of a transcript which has been indexed using the coding framework. As with stage two, a second researcher (a Trainee Clinical Psychologist) used the coding framework to index one transcript in order to assess the validity of the coding framework. Any difference of opinion about the content of the coding framework, or the use of the codes, was

discussed and conclusions were drawn about the best way to use, or adapt, the framework.

Stage five. Charting: Once the coding framework had been applied to all research interviews, the data were 'charted'. At this stage pieces of data, or specific quotations and references, were taken from the transcripts and entered into a large table, with each column representing a code and each row representing a participant. The main body of the table was filled with quotes from each participant that related to each code. The purpose of charting is to bring the data across all participants together and to help the researcher get a sense of the full data set. It is important that every participant is included and represented. Please see Appendix I for an example section of the charting table.

Stage six. Mapping and interpretation: This is the final stage of the analysis, wherein the researcher uses the charting process, alongside knowledge of the interview materials, and their understanding of the research questions, to identify themes within the data. The researcher in this case kept a note of the research questions, whilst studying the charted data. The researcher thought about similarities and differences between the experiences of participants in order to identify relevant themes. These were then discussed with a second researcher (supervisor) to support thinking around them.

Patient and public involvement

A focus group was held with four service users. Their input was sought in both the design of the study information sheet, and the interview schedule. They were shown the draft information sheet, and interview schedule, and asked for their feedback.

While feedback was welcomed on the content of the information sheet and interview schedule, the majority of feedback from the service users consulted

concerned the logistics of the interview appointment. An emphasis was placed on making the appointment a COPD-friendly space. For example, the focus group members emphasised the fact that talking for long periods of time can cause breathlessness and spoke about the importance of allowing participants to take regular breaks. The information sheet was amended to ensure that participants were clearly informed that they would be able to take breaks and to terminate the interview at any time.

Ethics

This study was sponsored by the University College London Hospital joint research office, and following favourable opinion from the North West – Preston Research Ethics Committee (REC reference: 17/NW/0454), was given ethical approval by the Health Research Authority (IRAS ID: 221004). Please see appendices J and K for copies of the REC confirmation letter and HRA confirmation of ethical approval.

RESULTS

A total of ten themes were identified in the data; each is described in relation to the relevant research question. The themes will be described with the aid of quotations from the research participants. Please see Table 2 for a summary of the themes. The themes relevant to research question two are pertinent to understanding the themes of research question one, and so will be discussed first.

Table 2.

Summary of themes

Research question two: What priorities and concerns are important given participants' life stage?

Giving back

Independence

Research question one: What is the individual's understanding of, and relationship to, COPD?

Conflict

Helplessness vs. agency

Research question three: Has COPD affected or changed priorities or concerns?

Complex relationship to health

Research question four: Has COPD affected the ability to participate in day to day life in important areas?

Self-efficacy

Loss of control

Resilience

Research question five: Do services provide the help needed to manage COPD?

Readiness

Empowerment vs. disempowerment

Research question 2: What priorities and concerns are important given participants' life stage?

Giving back. The first theme in regards to the priorities and concerns of this group of participants is one of 'giving back'. The majority of participants described themselves as the person to whom others come for support, and spoke about wanting to provide care and support when it was needed. This was particularly a feature of the interviews given by female participants who spoke about the importance of their roles as mothers and grandmothers.

It is worth noting that many of the study participants were parents of children under the age of 18 or in their young adulthood, or were new grandparents. They also had parents who were elderly and required care. Becoming a grandparent was often a difficult milestone for the participants, who had pictured themselves taking an active role in the care of their grandchildren, but were now struggling with the physical limitations of their COPD.

The participants valued providing both practical and emotional support to others but some also valued giving back in the sense of valuing employment, and making a wider contribution to society through work. Many of the participants appeared to define themselves in terms of their contributions or what they were able to offer to others such as family members, friends, and wider society.

My priorities are my children and my husband for the last 31 years. I don't, I don't consider myself very much, they come first. And now of course my granddaughter's here so it's the three of them (P10).

I've always been brought up with a work ethic, this is probably the longest time that I've been off work and I dunno, it, it gives you structure and purpose and all the rest of it and for me personally, for me, it's very important that I'm giving back something (P02).

Independence. This theme describes the emphasis that participants placed on being self-reliant. For many of the participants, asking for help was unfamiliar and uncomfortable. Rather, the participants valued coping alone. Many of the participants spoke about not wanting other people to see the extent to which they were struggling, either physically or emotionally.

My boy helps me a lot more, my son, and my wife, they help me a lot more than I used to, than really want now. I'd sooner be doing things for myself (P11).

I try to cope with things a lot of the time on my own without having to burden my family (P05).

Asking for help, from family members and friends, but also from healthcare services, was often described as uncomfortable. Many members of the sample reported times when they knew they had a chest infection, and needed antibiotics, but would delay visiting the GP, not wanting to 'bother' them.

I take after my old man. His head could be falling off and he wouldn't ask for help. He's always been like that (P04).

Some participants did, though, describe being able to ask family members or friends for help when needed, and they spoke about this being beneficial to them.

I look at it like a nice thing, they're there for me as well; I'm not on my own. I know I've got other people there so I ain't got to worry (P03).

However, for the majority, partners, family members, and friends were often left to work out if something was wrong. Some participants described that through knowing each other for many years, important others had developed the ability to 'guess' through their behaviour if something was wrong. Of course, this was not a wholly effective strategy, and would result in the participants feeling unnoticed or not cared about in circumstances where their distress had not been picked up on in the way that they hoped it would be.

When looking at both of these themes regarding values, it appears that they are likely influenced by the participants' life stage. In terms of giving back, participants generally spoke about wanting to be able to support family members, with this being an important task for a parent or grandparent of their age. With regard to independence, again, being cared for or supported by others was particularly painful for the participants in this sample, and this appeared to be related

to their age. Participants described it as being 'too soon' for their children to be providing them care.

There might also be a role for class in this discussion. Class structures within UK society can certainly influence value systems. When a person is from a working-class background, it is much harder for them to accrue wealth or property, and gain a sense of 'value' through personal capital. In these circumstances, value systems are developed based on relationships with others. Individuals from working-class backgrounds therefore tend to emphasise the importance of community connections and mutual support (Skeggs, 2011).

It is important, in understanding both of these themes, that the context of the interviews is also held in mind. A group of individuals who seemingly pride themselves on their independence and their ability to give back were being asked about the difficulties they face in day-to-day life. The interviewer was not known to the participants prior to conducting the interviews, and probably appeared to be a young, and relatively healthy, individual. This was possibly a situation in which the interviewee might have anticipated adverse judgement by the interviewer, given the stigma associated with a chronic illness like COPD, particularly one associated with smoking. It might be the case that these individuals wanted to convey something about themselves that was not just about their needs as a result of the COPD, but rather emphasised their prosocial values. Shame likely plays an important role here, in causing the individual to avoid simply being seen as taking support from others (Dolezal & Lyons, 2017).

Research question 1: What is the individual's understanding of, and relationship to, COPD?

Conflict. This theme describes the conflict that a person experiences when living with COPD. The participants described COPD as holding them back, or being

in the way, preventing them from achieving what they wanted to be achieving at this point in their lives. This links to the previously-described themes of ‘giving back’ and ‘independence’. These priorities were often in conflict with their COPD symptoms, which prevented individuals from being independent, or being able to provide for others in the way that they would like to. Please see Table 3.

Table 3.

Description of the factors at conflict in living with COPD when of a working-age

<u>COPD symptoms</u>	<u>Working-age values</u>
Breathlessness	Giving back
Being slowed down	Independence
Fatigue	
Concentration difficulties	
Pain	
Regular chest infections	

I'd like to be able to go round, help my daughter out, things like that. Now I don't think I could do it. It's just impossible (P06).

If I didn't have COPD I'd be working, I'd be going to the gym, I'd be doing things that I never thought I could do or that I used to do, I'd be going out with my friends, socialising, you know I'd be going on holidays but I just can't do it no more (P09).

Given the hypothesis that the values of giving back and independence are more predominant within a working-age group, and possibly also within working-class populations, it might be that this conflict is specific to individuals of this demographic. However, it is likely that COPD symptoms would impede most of the life values and goals an individual might have, and so it is likely that this sense of

conflict would arise regardless of demographic, but possibly not in the same areas of life.

Helplessness vs. agency. This theme describes the individual's response to the conflict of living with COPD. All participants appeared to reach a point of experiencing this sense of conflict with the COPD. For example, they might want to be able to do something but not be able to do so without help, or they might experience COPD symptoms when doing something that used to be physically undemanding. From this point, it seems that they either come to an understanding that:

(1) this is a worsening condition and I have no control over the trajectory of it
(helplessness)

As time goes by it just gets worse and worse and you go downhill and then you know the day will come when you know, you won't be able to do nothing (P09).

Or (2) this is a serious chronic condition but there are things I can do to manage the diagnosis and improve my quality of life (agency)

It's changing your way of life, it can be hard but it's got to be done, it's like self, I know me, I know I've got a problem and it's up to me, not to put it right because I know the problem won't be put right, but make the most of it. If you just lay back and do nothing it's going to deteriorate, that's the way I look at it (P01).

This theme can be viewed as a spectrum, where those demonstrating a greater sense of helplessness appear more likely to 'give up', and to sacrifice desires and goals as a result of a sense that the COPD has taken over. The individual with a greater sense of agency is more likely to retain some hopes and desires, and to find ways to work with, or manage, the COPD to ensure that he or she is able to meet their goals. There might be an important role here for being able

to adapt one's goals to something more achievable in light of the change to one's health context.

There are many models within the field of psychology that attempt to make sense of an individual's relationship to chronic health diagnoses. Moss-Morris (2013) has attempted to bring multiple models together, presenting an overall understanding of how an individual comes to a place of adjustment to a diagnosis of a chronic health condition. This model of adjustment categorises individuals as either 'successful adjusters', or those with 'adjustment difficulties', where successful adjustment involves finding equilibrium after the diagnosis. Those who struggle to adjust fail to return to a sense of equilibrium.

Within this study sample, those who experience more of a sense of helplessness with the COPD could be understood as struggling to reach this state of equilibrium. As independence and giving back are specifically important for the group of individuals interviewed, not regaining equilibrium following the COPD diagnosis might mean not being able to find ways to realise these values.

There appeared to be some factors that influenced an individual's response to COPD. In cases where the participant had already known or cared for a family member with COPD, he or she appeared to respond with more of a sense of helplessness, describing a sense of knowing what was coming and not being able to stop or slow what was felt to be inevitable.

This COPD is just, it's a killer, simple as that it is a killer at the end of it and where I've seen two deaths with it, I know what's what, I know all about it... I've seen it all, I know what it's gonna do. Yeah I do know it's gonna do it at the end so I think oh well it's there now so what can I do (P09).

The common sense model of illness representation (Leventhal, Phillips & Burns, 2016) argues that an individual's schematic understanding of the identity,

cause, timeline, consequences, and curability of a diagnosis affects his or her coping response. It is a possibility that seeing a relative living with COPD would bias someone's understanding of the diagnosis, making them more likely to see it as unmanageable if it was poorly managed in the case of the loved one in question. This might explain why this group was more likely to feel hopeless in response to COPD.

There is likely also a role for symptom burden here. The participants who verbally reported a high symptom burden and difficulty completing day-to-day tasks due to breathlessness, and who scored higher on the D-12, tended to be those who had poorer quality of life, as measured by the SGRQ. Of course, the SGRQ does focus on symptoms so this relationship might be due to the definition of quality of life in the measure used. We might, however, hypothesise that more severe symptoms, or a struggle to find ways of managing these symptoms, is linked to either a greater sense of conflict with the COPD, or a greater sense of helplessness in response to this conflict. It is possible that a more overwhelming symptom burden results in the individual feeling less able to live according to their values and goals and therefore developing a sense of helplessness. It appears that this is related to overall quality of life score. Of course this is a hypothesis and further research would be needed to establish causality here.

Participants who also had other comorbid chronic health conditions would seem to fall closer to the agency end of this spectrum, appearing to feel that they already knew how to manage a chronic condition, or already feeling able to cope with this challenge.

Because of the other conditions I have, I've been doing things a lot more, a lot slower and I do so much and then I have to sit and rest so it's all part and parcel. I do the same thing for this condition as I do for the other conditions (P10).

Research question 3: Has COPD affected or changed priorities or concerns?

Complex relationship to health. Participants described a complex relationship to their health which, for some, had changed, and for some had remained the same. Thinking about their health was new for many of the participants.

Before this you get up, you don't even think about your health it's the last thing on your mind, you've got to do this and you've got to do that. Not anymore (P04).

For some, accepting the seriousness of their COPD diagnosis enabled them to take steps towards safeguarding their health, while for others this was overwhelming and left them in a difficult situation of knowing they wanted to improve their health but not being able to take action towards this. There were lots of 'I should' thoughts expressed in this group about health behaviours. A third group of individuals had always prioritised their health. These were often those who had lived with chronic health conditions for many years prior to the diagnosis of COPD. Please see Table 4.

Table 4.

Summary of participants' relationship to health, which can be understood as fitting into three main categories.

Since being diagnosed I have started to see my health as more of a priority. 'I should' be making changes to support my health but don't feel able to. <i>Every year I do it for 6 weeks [stop smoking], every single year, put on a stone in weight and then I think oh no I can't (P09).</i>	Since being diagnosed I have started to see my health as more of a priority. I have been able to make changes. <i>I do like a 10 minute walk every day and then try to increase that by maybe 15 minute walks, so sort of focus on building up, sort of small goals really. So set myself small, achievable goals sort of daily (P05).</i>	My health has always been a priority <i>When I was young... I had a, what was it, stopped me from smoking. I think it was a burst ulcer, went into hospital... and they went, same thing, anything, you break your toe and they tell you to stop smoking, but anyway they told me and I did (P01).</i>
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In the COPD population, making changes to improve one's health usually involves at least one of the following: stopping smoking, improving fitness, or adhering to medication regimes. Making significant changes to one's health behaviour is very complex and a person's ability to make lifestyle changes can be impacted by a number of factors. These include cultural factors, social factors, and individual factors (Leventhal, Weinman, Leventhal & Phillips, 2008). In the case of smoking, participants described a culture of smoking being the norm, knowing many significant others who smoked, and for some, beliefs about their inability to quit smoking. This might explain why for some members of the sample making changes felt too difficult, even if they described wanting to make the change in question.

What was interesting is that all participants, to some extent, described wanting to make some form of lifestyle or behaviour change in the interest of their health. It must also be considered that these statements were made in the context of a research interview, to someone presented as a Trainee Clinical Psychologist and therefore, a healthcare professional themselves. It may well have been that the power dynamic that this context created made it impossible for any of the participants to openly say that they simply did not wish to make any lifestyle changes.

Research question 4: Has COPD affected the ability to participate in day to day life in important areas?

Self-efficacy. The role of self-efficacy in managing COPD was important. What emerged from the interviews was just how complex a concept self-efficacy is. It requires the individual to know his or her own body, know how to respond (skills), believe the response will work (outcome efficacy), and feel able to perform the helpful response (performance efficacy). Many participants faced difficulty at different stages of this process. Those who were able to achieve a sense of self-efficacy were more likely to be living life in the way that they wanted.

I try and control it but obviously I can't because [the respiratory service] obviously tell you how to try and control your breathing but when I get into an attack I can't you know what I mean, that's the main thing I try to do is calm myself down rather than think of other things. I try to think slow my breathing down but sometimes it don't work (P03).

I seen what COPD can do and I know I'm heading down that road in the future then, no I don't see any point anymore (P09).

Self-efficacy is a widely-used psychological construct, developed originally by Bandura (1994) who identified the role that an individual's sense of ability to do something has in determining whether he or she will make a behavioural change. This is influenced by four factors. The first of these is performance accomplishments, meaning that when an individual successfully performs a certain behaviour, and receives a desired outcome, their sense of self-efficacy increases.

Secondly, basic social learning principles apply. For example, if an individual observes others whom they feel are in a comparable situation, having a positive outcome from a specific behaviour, they are again, more likely to develop a sense that they too can perform this behaviour. This is called vicarious experience.

Thirdly, verbal persuasion from others can have a role in improving someone's self-efficacy, but to a lesser extent.

Finally, there is a role for emotional arousal in determining an individual's sense of self-efficacy. For example, when a person is highly anxious, he or she would be expected to struggle to develop a sense of self-efficacy in making behaviour changes. The participants in this research study described difficulties with anxiety, which could make managing COPD difficult. Many participants described how the breathlessness caused by COPD could result in panic attacks, with some very distressing thoughts such as 'I am going to die'. Some reported avoiding

situations that might cause an increase in breathlessness. This of course makes it very challenging to manage the COPD, for example, through exercise, and can also make living day-to-day life very difficult. Some of the participants had stopped doing important day-to-day activities which required even small increases in activity levels. This naturally had a significant impact on their sense of self-efficacy.

The first time I ever had a panic attack and I was in the house on my own and I think that's stuck in my brain, that's all I can think back to is why am I frightened to be on my own, to be in the house by myself, to be on the street by myself. The only conclusion is going back to the first time it ever happened is I was on my own and that, I think that's just stuck in my brain, the fear that went through me, it frightened me, I was that scared I thought I was gonna die (P06).

Certainly, within this small study sample, the participants whose GAD-7 scores were highest, were those who reported very little self-efficacy. These participants reported a sense of feeling 'defeated' by the COPD, and not being able to find ways to take control. They had very little sense of themselves as being able to make helpful changes to improve their overall quality of life. Participant six, for example, who provided the above quote, scored in the severe range on the GAD-7. She described severe and frequent panic attacks. Breathlessness was synonymous with dying for this participant. She had therefore not been able to engage in PR because she felt that doing exercise was dangerous. She couldn't understand the rationale behind this intervention in her case. This participant described often trying to avoid situations where she might become breathless. She would also avoid being alone due to her fear of dying. She had very little sense of self-efficacy in being able to manage her COPD differently day-to-day.

Loss of control. All participants described a sense of loss of control in their lives which was directly in conflict with their desire to be independent. Individuals found that they could not plan ahead due to the unpredictability of their COPD.

I would say, frustrated. Cos it's as if you're not in charge of your own body (P04).

They also spoke about a loss of control in a broader sense, for example, a loss of the ability to control situations in order to manage anxiety. This is therefore strongly associated with their sense of self-efficacy. Bandura (1997) highlights that if an individual can carefully control a situation, this can help him or her in managing emotional arousal, for example, anxiety, and can therefore improve their sense of self-efficacy. Many participants in this research study, however, described the unpredictability of their COPD. Sometimes they would become extremely breathless without being able to identify any reasonable cause. The COPD can flare up without explanation. This meant that for many of the participants, planning often felt redundant.

That's the reason as well you don't make no plans, in my head I ain't gonna be there, you know like Christmas, I probably won't be there anyway, oh I'm looking forward to summer, I probably won't be there, you know, you put yourself down before you can be there (P08).

Resilience. Resilience was another factor that could enable someone to move towards their priorities and goals, helping them to feel they had more agency over the COPD. This theme attempts to capture what, for the participants, was often described as 'positive thinking' or 'optimism'. When elaborated on, it appeared that the participants used these descriptions to mean helpful, rational thinking. Participants who focused on what they had, and what they could do, found that they were more able to manage day-to-day life and meet their values and priorities.

There also seems to be a role for setting manageable goals within this theme. Some participants seemed more able to adapt their goals to be more achievable following their diagnosis of COPD. These individuals were those

appearing to have a greater sense of resilience. It could be argued that a more resilient individual is able to let go of unachievable goals, in favour of their overall wellbeing (Wrosch, Scheier, Carver & Schulz, 2003).

Just trying to think positive, erm and you know, on the positive side of things sort of what health I have got rather than what health I've not got sort of thing (P05).

At times participants would get stuck in thoughts about what they had lost and, for some, this created a serious low mood that had the potential to undermine their sense of resilience against the COPD.

Every day you compare, when you sit down, there's times when you do sit down and you sit there and think God, before I could do anything you know, I could run around, like comparing myself from then to now, it's terrible (P06).

The developmental psychopathology literature has contributed to discussion around resilience, highlighting that resilience is a phenomenon wherein individuals living with adversity do not appear to respond with the distress that might be expected. Resilience is seen as developing over time. The factors that support its development are complex and varied, but some important factors include supportive family and peer relationships, and a sense of belonging to a community. An individual's development of resilience can be affected by early life adversity, for example experiencing traumas, difficult attachment relationships, or experiences of prejudice and discrimination (Luthar, Lyman & Crossman, 2014).

It is possible that those members of the sample who had been able to share some of their day-to-day difficulties with significant others were those with a more resilient coping style. Some participants had been able to find a way to seek support from others and found that this brought a sense of closeness to their relationships. They saw concrete evidence that they were loved by family members, through being

cared for. This was often helped by the individual with COPD being able to honestly share the diagnosis and difficulties with family and friends.

I'm amazed at how aware people are about it yeah a lot of friends as well know an awful lot about it... I've tried to inform them as to you know COPD and also how I deal with it so yeah I'm also passing on information to them it's not just about them trying to guess why I'm out breath you know (P07).

Others, however, described 'putting on a front'. This appeared to be a process of hiding difficulties to protect others, rather than acknowledging them and making helpful comparisons or seeking help in order to be able to make progress. These individuals tended to report feeling unsupported or misunderstood, and were struggling to develop their sense of resilience with the COPD.

I don't talk to anyone about things like that and whatever. It's all, it's all like a front really around family and friends, it's a dreadful thing it is. I make out everything's perfect and that when I'm at home (P09).

Research question 5: Do services provide the help needed to manage COPD?

Readiness. This theme describes the perceptions of the individual with COPD about readiness for change. Often participants would describe not being ready to make important changes, for example, giving up smoking. Participants were generally clear about the reasons for not being 'ready' and presented the passing of time as the main way to achieve readiness. Therefore, achieving readiness appeared to be a passive process.

That's the situation I'm trying to deal with now, because I know I should do something but it's do that tomorrow (P01).

Lack of readiness was often expressed in reference to smoking cessation. The stress-coping model (Lazarus & Folkman, 1984) can help in making sense of

this concept. This model asserts that there are two types of coping style an individual can use: problem-focused coping where the individual tries to solve the problem encountered, and emotion-focused coping, where the individual tries to resolve his or her problem-related emotional state. For the research population, especially those struggling to develop problem-focused coping skills, smoking was an important method of coping with their emotional experience. It offered comfort in a very difficult set of circumstances, and so it is possible that the idea of readiness, in regards at least to smoking cessation, references the individual's sense of not having other means with which to cope with their difficult emotional experiences or day to day stresses.

While, as discussed in the introduction, problem-focussed coping tends to be more effective at managing distress than emotion-focussed coping, this is harder to apply to chronic illness. Research conducted with people diagnosed with either COPD or cardiovascular disease has found that emotion-focussed coping is associated with reduced illness intrusiveness (Hundt et al, 2015). While taking a 'problem-focused' approach to acute illness is helpful, in chronic illness, using 'problem-focused' strategies alone can result in the patient managing their condition only at times when it has worsened, and not effectively managing the condition when they are not symptomatic. Therefore, emotion-focussed coping strategies can work effectively in combination with problem-focused coping in managing a chronic health condition.

However, for the participants, difficult emotional experiences were often managed through smoking. The participants described how much they enjoyed smoking, and the role that smoking had in offering them a sense of comfort, and helping them to manage stressful situations. Those who were no longer smoking were more likely to be those who had found other ways of managing their emotions, such as confiding in others, or those engaging in more helpful thinking styles. There

is, therefore, a complex relationship with smoking, where many participants are aware that smoking worsens their condition, but it is also one of their main coping mechanisms for dealing with the distress they experience at living with COPD.

People who have been living with COPD for longer tend to have a greater sense of perceived seriousness of the diagnosis, along with a reduced sense of personal control (Fischer et al., 2010). We might therefore expect more ambivalence from this group with regards to making lifestyle changes, and might hypothesise that the individuals within this sample who were more recently diagnosed would also be those with a greater sense of 'readiness'. Certainly many members of the sample reported having given up smoking at the point of diagnosis, when they might have a more 'acute' model of illness where change equates to cure. For those who had been diagnosed several years ago and had not been able to make important changes, there was certainly a sense of ambivalence. These individuals were more likely to endorse beliefs such as 'it's going to get worse anyway, so what's the point?'.

It is also the case that expectations of treatment impact on engagement in PR for people with COPD (Fischer et al., 2009). Therefore, we might assume that expectations of the benefits of lifestyle changes would also impact whether or not someone is willing to make them. Exercising (a core principle of PR) is fairly counterintuitive with a diagnosis such as COPD, as exercise results in significant breathlessness. If someone is therefore not convinced by the long-term benefits of improving fitness, they would likely feel sceptical about the rationale behind PR, and therefore be less likely to engage, possibly citing a lack of 'readiness' for this intervention.

We also know that low mood can have a significant impact on motivation, and also has a contribution to make in discussing this theme. Many of the participants reported losing their sense of motivation as part of an ongoing process

of feeling low in mood. They would describe not being 'bothered', and struggling to enjoy things that used to bring them happiness. They would withdraw from others which served to reinforce their lack of enjoyment and motivation.

I think I bottle it all up really, I think, and that's my mood really gets to a low point and then, it's hard to explain exactly how it, I feel like I've got a cloud over my head you know and it's just you feel like you're battling your way through it and you can't it's no, no light at the end of the tunnel. It just feels like it's sinking you down further and further, weighing you down (P02).

This quote comes from a participant scoring in the severe range for both the PHQ-9 and GAD-7. In the interview, she described a process of trying to hide her difficulties from others. This caused day-to-day stresses to escalate and become overwhelming. She therefore developed the belief that lifestyle or behaviour changes would not make a meaningful difference for her because the daily challenges that she faced were felt to be too unmanageable.

The role of mood in this theme is a phenomenon that we see in other participants too. Participants with the highest scores on the PHQ-9 were often those who had reported struggling to make or maintain changes. Interestingly, these also seemed to be the people who felt they had lost closeness in their relationships. Therefore, it is possible that there is a role for support from others in helping an individual to feel 'ready' to make and maintain changes. Alternatively, it may be the case that being unable to make changes prevents an individual from being able to continue with important activities. This group might then be less likely to maintain social relationships and connections with loved ones.

Additionally, as described for the theme of 'new relationship to health', it might also be the case that in the context of the research interviews, participants were faced with being asked questions about lifestyle changes they have been

encouraged to make but have not been able, or wanted, to work on. Telling the researcher 'I'm not ready yet', communicates both an acknowledgement that the change 'should' be made, whilst also communicating a more socially-desirable reason for not making it than 'I do not want to'. There are likely to be some individuals in the research sample who simply did not want to make difficult lifestyle changes, and it can be difficult to openly say this.

Overall, this is a complex theme. Some ideas have been discussed about possible reasons for participants' sense of not being ready to make changes, but no certainty about the reasons for lack of readiness came through from the interviews. This is an area that needs further consideration.

Empowerment vs. disempowerment. What particularly came across when participants described their experiences with services was the power that healthcare professionals have to either empower or disempower COPD patients. This is possibly also linked to an individual's 'readiness'. Participants reported feeling judged by some care providers. They spoke about feeling blamed for having smoked, and at times felt as though they were seen as 'stupid' for continuing with this behaviour despite being advised to stop. Please see Table 5.

Table 5.

Summary of participants' experience of services, which were felt to be either empowering or disempowering

<p>I'm given advice that I feel unable to achieve.</p> <p><i>I've never been an exercise person, I've never been a gym kind of girl, and it was like you know you've got to do this up the wall, do this there, and there's all other people there. I didn't like it (P08).</i></p>	<p>I'm offered relevant and helpful information that I feel I can apply to my day to day life</p> <p><i>Going along to the rehab and whatever else has been, yeah, very helpful. As I say, it's recognising different peoples' level and how they deal with it basically and their symptoms has been, yeah, very helpful (P07).</i></p>
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Participants would imply that readiness was something that care providers were not willing to understand or engage with. They felt they were often given advice by care providers irrespective of whether or not they were 'ready' to hear it. This puts healthcare providers in a difficult position. Healthcare providers are often obligated to offer advice, for example around smoking cessation. As discussed, their patients struggle to identify the exact reasons behind their sense of not being ready. Therefore, it is difficult to find a way to prevent unwanted advice being experienced as disempowering. If we were better able to identify the reasons for people not feeling ready for change, it is possible that care providers could offer support with resolving these, however at present these remain unclear.

I mean my COPD nurse is, she's brilliant, and she says like come and see me when you're ready and we'll, we'll try and help you through it, erm, whereas my GP, you've got to stop smoking you know, do you want me to refer you somewhere. At this moment in time, no not really (P10).

Readiness is a central theme in Motivational Interviewing (MI), an intervention designed to elicit motivation for behavioural changes. Within MI, readiness is either visualised as a series of stages or a continuum, the important point being that readiness is changeable and can be fostered. The task of the care provider offering MI is therefore to identify the individuals' current readiness, plans, and barriers to change, and use the techniques of MI to facilitate changing behaviour. Importantly, MI acknowledges both the pros and cons of any target behaviour when supporting an individual to consider changes (Rollnick & Allison, 1995). It is possible that service providers who use approaches such as this, acknowledging that there are benefits to any 'unwanted' behaviour, might be those who are seen as being more empowering. However, we cannot draw conclusions about this from this study. Further investigation into how important advice can be given in an empowering way is needed.

Bringing the themes together with the help of a case example

During one of the interviews a participant described, in depth, her struggle with her COPD. Her story will be used to help us make sense of how these themes can work in combination in complex and nuanced ways. Some details have been left out in order to ensure that this individual is not identifiable.

As with all research participants, being independent and providing support to others was emphasised. When asked what she valued, this participant said it was her family. She elaborated, however, that not only was she not able to support her family in the ways she would like to, but she was needing to be cared for by them (themes: giving back, independence). She struggled with being alone, due to the panic attacks she would experience. She also needed support with day-to-day tasks, such as shopping, cooking, cleaning, and sometimes personal care. This was a feature of many of the interviews, and something that this participant described as 'degrading'. This participant had felt unable to make any future plans, partly due to the unpredictability of her COPD, but also due to severe low moods which meant that she did not enjoy the things that she used to (themes: conflict, helplessness vs. agency, loss of control).

She had attempted to attend PR but did not complete the course as she found it embarrassing to exercise in front of other people. However, after a later hospital admission, she reengaged with the admissions avoidance team, who visited her at home and provided support individually. She was taught exercises she could perform at home (themes: readiness, empowering vs. disempowering services). She also spoke about the importance of her family relationships, describing a supportive family from which she would try to withdraw, but who would maintain contact with her anyway.

This participant had recently reached a point where she was hospitalised. She described being in incredible pain, and feeling very frightened that she might die. Following this admission, she made the decision to stop smoking. She described the pain she had experienced as being a motivating factor, alongside thinking about the things that she would like to be able to do with her family if she were able to regain some strength. While not identified by her, it is likely that there was an important role here for supportive others as well (themes: readiness).

Having been able to carry through her intention to stop smoking, this participant consequently noticed a dramatic improvement in her physical health. She described having proved to herself that she could take back some control, and she increased her hope for the future. She started to feel more positive and, as a result, spent more time with her family which was, again, a big encouragement for her to continue with her behaviour change. She started to set herself manageable goals and make plans for the future (themes: resilience, self-efficacy, complex relationship to health).

She described being mindful not to set herself tasks at which she might fail, and was careful as she made changes. She therefore allowed herself to experience increasing levels of success and to feel empowered. She was learning how to make plans that were manageable, rather than feeling that making plans was pointless. She was valuing her health and seeing both the importance and benefit of making changes to her health in new ways (themes: self-efficacy, resilience, complex relationship to health).

This participant continues to experience severe low mood and anxiety and describes herself as being at an early stage of a long journey. This case example demonstrates that the themes interact in complex ways that likely vary between individuals.

DISCUSSION

Ten themes were identified by this framework analysis and can be understood as individual ideas, but it is important to also consider how they interact. A case example has been used to illustrate this point.

Research participants reported valuing their independence and giving back to others. These values were reported in a context of shame and stigma about chronic disabling disease, so may demonstrate self-presentation. These are values specific to a working-age group but they may also be specific to working-class people. What didn't come through in the research interviews was a sense of distress arising from participants having to leave work. The members of this study sample were far more distressed at not being able to contribute actively to family life.

Participants reported conflict with COPD, which prevented access to goals and, ultimately, to living according to their values. We can hypothesise that this conflict arises for individuals regardless of their specific value system, but COPD does seem to be particularly at odds with the values named by participants within this research study. Participants responded to this conflict either with a sense of helplessness or of agency, moving between them depending on multiple factors. This study further identified self-efficacy, resilience, and readiness as important in helping an individual develop a sense of agency.

Self-efficacy, resilience, and readiness are complex constructs that were difficult for the study sample to define, but it is hypothesised that they are linked to psychological constructs such as motivation, and to mood states; namely anxiety and depression.

Participants described how they experienced services and their considerable power; services were experienced as empowering or disempowering their users. At this stage, this phenomenon needs further exploration. There is clearly a delicate

balance to be found, where service providers are obligated to offer advice, but some service users experience hearing it as disempowering. If we had more of a sense of why some service users identify themselves as not being ready to receive or act upon certain advice, we might be able to make further sense of this.

Alongside these themes, a theme of loss of control involved feeling unable to make plans due to the unpredictability of COPD. This, too, makes behaviour change difficult. Participants also reported complex changes to their relationship with their health. While some found it increasingly important and were able to make changes, others felt 'stuck' and, despite wanting to make changes, felt unable to do so. A third group, often those living with other chronic health conditions, had always valued their health.

It is important to note that all research participants described wanting to make lifestyle changes, whether or not they had been able to achieve this. It is likely, however, that some of the participants felt that they did not want to make changes to their lifestyle, but were unable to report this to the researcher given the power dynamic at play. We could predict that this dynamic is at play in the majority of appointments with healthcare providers.

Although not generalisable, some links were made between the scores on the standardised measures, and some of the themes. Quality of life appeared to be linked to COPD symptom burden, and the impact of symptoms, especially breathlessness, on day-to-day life. Higher D-12 scores appeared to be anecdotally linked to higher SGRQ scores, and participants with higher scores on these measures appeared to be those who experienced a greater sense of conflict and helplessness in response to the COPD. Mood appeared to be linked to difficulties in making and maintaining changes, and also a sense of loss in close relationships. These were difficulties commonly reported by those participants scoring higher on the PHQ-9. Links were made between low mood and the theme of readiness.

Anxiety, as measured by the GAD-7, seemed higher in individuals who appeared to have little sense of self-efficacy.

In introducing this piece of research, the variables cited as having an impact on quality of life for individuals with COPD included severity of symptoms, mood, anxiety, coping style, and employment. All of these factors were discussed in the research interviews, but what emerged was the complexity of their interaction in each individual.

While the themes of giving back and independence were related to life stage, very few of the later themes appeared to be linked to stage of life. As described, very few of the participants spoke about the loss of employment as being a concern for them. One of the assumptions of the researcher had been that employment would be an area of life that would give people satisfaction and improve life quality. While this was the case for a minority of the participants, most did not support this idea. This may be linked to the fact that most of the participants had been employed in manual roles. We know that employment improves quality of life, but not for individuals whose working conditions result in risks to both physical and mental health (Burgard & Lin, 2013). Many of the research participants previously worked in jobs with high physical demand, some inhaling toxins regularly, and they were also required to work antisocial hours, missing out on time with their families.

With regard to other aspects of COPD and its impact on day to day life, again the participants tended not to report concerns specific to their age group. For example, one might have expected services to be experienced differently by a younger age group, but the concerns raised by the participants regarding their interactions with service providers tended not to be about their life stage. There was little reference made to not wanting to depend on health care services, and feeling younger than other COPD service users. Overall, concerns around depending on others were mainly focussed on difficulties with depending on family members.

Issues raised about experiences of services tended to be around the way that advice was typically offered. Concerns were voiced around feeling judged by service providers, particularly around smoking behaviours. This is likely a concern of many individuals who live with COPD, not only those of a working-age.

Limitations

The themes described in this study attempt to summarise the experiences of a small sample of working-age people with COPD. Research conducted with eleven different individuals might return different results and so these themes are only one way of understanding the complex and nuanced experience of living with COPD. All participants in this research study were working-class individuals. Only two of the eleven participants were from a black or minority ethnic group; the remaining nine participants were white. All spoke fluent English; constraints on time and funding did not permit the use of interpreters.

It might therefore be the case that the research conducted here better represents the white working-class experience of living with COPD than others. We do know, however, that smoking and COPD are more commonly represented in the white British population, particularly among younger age groups (Martin, Badrick, Mathur & Hull, 2012).

Qualitative research is not statistically generalisable but does have its place in allowing us to make sense of the complexity of phenomena like quality of life, and broadening our appreciation of the range of variables and relationships that influence patients' health-related behaviours. Detailed descriptions of the study sample, and the researcher, have been provided in order to aid the reader in drawing conclusions about the relevance of this research to their setting.

Data collection was conducted over the winter months and this meant that there were further limits to the sample. Chest infections are far more frequent for

people living with COPD in cold weather (Donaldson & Wedzicha, 2014), and so ten out of the eleven research participants who were able to attend the interviews were from the PR pathway of the service. Individuals attending PR tend to be managing their COPD better, and experiencing fewer exacerbations and hospitalisations than patients being seen by the other pathways of the service. Whilst referrals were received from other pathways within the service, these individuals tended to be too unwell to attend a research appointment. It may therefore be the case that the data collected in this study represents the experiences of a group of COPD service users who are physically less impaired by their COPD than some other service users might be. However, many of the participants were being frequently hospitalised with COPD, and so their COPD cannot be described as being well-managed.

Elliott, Fischer, and Rennie (1999) outline a number of criteria by which qualitative research should be assessed. It is important to consider which of these the current research meets, and which are areas for concern. As discussed, the current research both situates the sample and the biases and perspectives of the researcher. Numerous examples and quotations from the original interview material have been included, ensuring that the research is sufficiently linked to the rich interview data gathered. The reader should, however, bear in mind the limits to validity checking in the conducted research. Both stages of coding were checked with an independent researcher, but no attempt has been made at validity checking with a member of the participant group at either stage of coding, or following the development of the themes. This decision was made in the interests of time. Having not done this means that there is less certainty that the themes identified by the researcher accurately capture the experiences of the participant group. Additionally, no attempt at triangulation has been made to validate this research, with no third data set being collected or found in existing research.

The final criterion, resonance with readers, requires the judgement of the reader. A summary of the findings of this research will be sent to those research participants who have requested further information, and will be communicated to the clinical team who hosted the research. The resonance of this research with these groups will be an important piece of feedback regarding the validity of the research. It will be beneficial for the researcher to either communicate the themes to participants in person in order to facilitate them giving their feedback on the themes, or to offer contact details so that feedback can be given by the participants to the researcher if desired.

Additionally, as commented upon during discussion of the themes, it is a possibility that complex power dynamics at play during the research appointments might have prevented some participants from being able to honestly express their views. In particular, these dynamics may have prevented participants being able to express a lack of willingness to make behaviour changes. The inclusion of more service user input in the research might have served to reduce the impact of this power dynamic. For example, service user researchers can be a beneficial resource and their use should be considered in future research.

Clinical recommendations

This study's aim was to make sense of the working-age experience of living with COPD. What was striking is that age was rarely mentioned as a concern by the research participants. This is important for service providers who might theorise that services need to change what they offer to better suit the increasing numbers of working-age adults accessing care. In actuality, this is unlikely to be the case based on the findings of this research study.

Participants tended not to be concerned about their loss of employment, as one might assume. Certainly this assumption was made by the researcher and is

likely to be made by other health care professionals. Given our experiences of working in professional roles and finding work rewarding, we tend to assume that employment is an important aspect of life for the people we see in our services. However, for the population of participants in this study who tended to work in low paid, manual roles, sometimes at antisocial hours, work does not offer the same sense of satisfaction. In fact, leaving work had been a positive experience for some of the participants. Services often place priority on helping people of working-age who are not in work get back into employment. Certainly, for the people who participated in this study, this was not a priority, nor would it be guaranteed to improve their quality of life.

Rather, what was very distressing for the participants was their dependence on members of their family. Given how upsetting this aspect of living with COPD could be for the participants, services could look to support patients in developing their skills at living independently. For some of the participants, services such as PR had been challenging to engage with. If services were advertised to patients as being designed to support them in this important area, engagement might improve.

What is also demonstrated by this research is the complexity of quality of life. Services often offer quality of life assessment to patients with COPD, in the form of a standardised measure, but this does not tell us the full extent of the problems that our patients experience. As an example, participant nine was the participant in the study population with the poorest quality of life score on the SGRQ. Her symptom score was highest, telling us that she might struggle with the symptom burden of COPD, and she also scored highly on measures of depression and anxiety. However, the interview data from this individual shows that she has previously tried to engage with services but felt uncomfortable exercising around others, and felt shame when asked to talk about COPD with other service users. This individual also described a sense of having 'given up' after caring for a sibling with COPD whom

she watched die. She felt resigned to the fact that her life would end in the same unpleasant way. This participant described feeling shame and embarrassment about some of her COPD symptoms, keeping her isolated from others. None of this important information about her experience of living with COPD is represented in a score on a standardised measure, yet it could be central to designing an effective intervention for her.

Therefore, clinical teams should take a whole person approach to understanding quality of life, with time and space offered for these concerns to be discussed. The suggestion that nursing and physiotherapy staff screen and identify psychological distress is not a new one. Hardy, Smart, Scanlan, and Rogers (2014) have demonstrated the efficacy of an intervention with COPD specialist nurses, teaching them to screen for depression and anxiety, and to use MI skills in their clinical practice. This intervention was well received, with staff expressing a willingness to develop these skills as long as they were given the time to do so. Despite studies such as this demonstrating the efficacy of this way of working, it remains the case that while the emotional strain that comes with living with COPD is increasingly discussed, guidelines for the care of individuals with COPD do not generally reflect this, and nursing staff are generally not supported to develop their practice accordingly (Dury, 2016).

The NICE guidance for the diagnosis and management of COPD in over 16s (NICE, 2010) does not acknowledge the need for quality of life assessment. It does, however, identify that screening for depression and anxiety are important in managing COPD. The guidance emphasises the importance of this for patients who are hypoxic, have severe dyspnoea, or have been admitted to hospital with an exacerbation. This study would argue that identification of depression and anxiety are an important part of caring for all individuals with COPD. Making the space and time for having conversations about quality of life is also highly important.

Research recommendations

This study has identified a difficult balance that exists between healthcare providers who are obligated to offer advice on mitigating risks to health, and patients who suggest they are not ready to hear or act on it. In being given advice at times when they do not feel ready, the participants of this study have reported feeling unheard and ultimately, disempowered. Future research that aims to further understand the patient experience of receiving unwanted advice would be valuable. If we can better understand the factors behind a patient's sense of not being ready to receive, or act on, medical advice we can better support services in offering recommendations that are sensitive and relevant.

It would also be interesting to identify whether this phenomenon exists for individuals with other chronic health conditions, or those being encouraged to make lifestyle changes without the presence of chronic illness. Research might also consider the role of power dynamics in healthcare consultations, and possibly even in research settings, and how these impact on a patient's response to being given advice or asked an opinion regarding health behaviour change.

Further research which explores how people with COPD develop a sense of self-efficacy or resilience, and how care teams can support this process will also be valuable. Future research that identifies practical changes that services can make to the way that advice and support is offered to patients would be particularly useful.

CONCLUSION

Overall, this research has studied, in depth, the factors which affect day to day quality of life for individuals of a working-age who are living with COPD. The research has identified ten themes which are important in making sense of quality of life for this group. Quality of life is complex, and there are several factors which must

be considered when making sense of it. Many of these did not seem to be specific to life stage, and it is possibly not necessary to view different age groups as requiring different care. Additionally, some of these themes remain unresolved, with further research needed to make sense of the factors which contribute to patient reports of a lack of readiness.

Overall these findings have important implications for care providers, including informal carers such as family members. It is important that the complexity of quality of life is thought about in care teams in order that effective and empowering care is offered. Services should be sure to offer interventions which focus on the areas of importance for their patients. For this group, an important area would be developing skills at managing COPD independently, without the need to be cared for by others. In order for service providers to gain a sense of the important aspects of living with COPD for their service users, space and time should be made for conversations about quality of life with all patients, regardless of demographic.

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Part 3: Critical appraisal

INTRODUCTION

While not specifically designed as a piece of research investigating the working-class experience of living with COPD, the demographic population with whom this research was conducted were members of the British working class. This likely influenced their responses to the research questions, along with their relationship with the interviewer. It was clear from the interviews that there was a cultural norm of smoking, and many participants reported family histories of COPD. This has led me, the researcher, to ask myself questions about the role of social inequality in the development of COPD, and the role of class in determining the content of the interview material.

This critical reflection will therefore discuss the role of social inequality in physical health outcomes, and how class may have affected the responses given in the research. Reflections will be offered regarding my own class identity, and how this may have created a sense of difference in the room during the research interviews. I will consider what this means in terms of my future work within the field of Clinical Psychology.

Social inequality and health outcomes

This piece of research was conducted in a London borough known to have high levels of social inequality. The borough in question has 39% of its residents living in poverty, which is one of the highest levels in London (Trust for London, 2018a). We know that social inequality can significantly affect both mental health and physical health outcomes. As an example of this, this London borough is also the area of London with the lowest life expectancy (Tinson, Ayrton, Barker, Born & Long, 2017).

Inequality can result in increased mortality, but also earlier diagnoses of disability. This means that people from poorer backgrounds are likely to die sooner, but also live a greater proportion of their lives with disability. There are certain areas in the UK with persistently low life expectancy rates. The borough in which this research was conducted is one of these. The reasons for persistent low life expectancy rates include employment deprivation, smoking, binge drinking, and low educational attainment (Buck & Maguire, 2015). We can see, then, that lifestyle factors are important in the relationship between socioeconomic status and health outcomes. The role of smoking is, of course, particularly relevant to discussion about the impact of class and socioeconomic status in this research, which was conducted with people diagnosed with COPD.

Additionally, mortality is significantly associated with employment grade, with individuals in professional jobs having lower mortality rates than individuals in non-professional roles (van Rossum, Shipley, van de Mheen, Grobbee & Marmot, 2000). This again shows us how social deprivation is linked with health outcomes.

Social inequality and COPD

COPD, which has been the focus of this research project, can certainly be argued to be a diagnosis of deprivation. Proportions of COPD diagnoses increase with levels of social deprivation (British Lung Foundation, 2018). Concerns around the role of deprivation in smoking behaviours and lung disease are increasingly being discussed, and The British Lung Foundation (BLF) have recently released a statement on health inequality in lung disease (BLF, 2017). This statement highlights the higher frequency of smoking, greater exposure to air pollution, poorer housing conditions, and greater occupational risks in people from lower social classes in the UK. These factors put this group of people at far greater risk of being diagnosed with COPD. The BLF argues for the need for an independent respiratory

health task force in tackling these inequalities, and taking a preventative approach to COPD.

Public Health England (PHE) have also published a report which highlights a similar role for socioeconomic status in smoking behaviours (PHE, 2015). This report points to increased childhood smoking in people from lower income backgrounds. It also points to increased smoking behaviours in adults with mental health difficulties, and lesbian, gay, bisexual or transgender people. Therefore, not only is smoking far more likely to occur in working-class populations, it is also more likely in groups of people who lack privilege based on other protected characteristics such as disability, sexuality, and gender identity.

Within populations of COPD patients, social deprivation can also influence health. For example, not being able to heat one's home to 21°C for a minimum of 9 hours per day is linked to worsened symptoms in people living with COPD (Osman, Ayres, Garden, Reglitz, Lyon & Douglas, 2008). Additionally, research has shown that people with COPD who died within a given 12-month period were significantly more likely to have lived in a socially-deprived postcode than those who survived. This is the case even when malnutrition, age, and disease severity are controlled for (Collins, Stratton, Kurukulaaratchy & Elia, 2010).

How class structures were communicated in the content of the interviews

As described, the research participants in the study conducted as part of this thesis were from a working-class background. The content of their interviews spoke to social deprivation and difficulty. For example, participants described working in difficult manual environments, their experiences of being single parents, and their constant struggle for financial security.

What also came across through the interviews was a culture of smoking. Many of the participants had started smoking as children. They had family members and friends who were smokers. Many also spoke about their use of smoking as a coping mechanism. In their hardest moments, smoking was something they would rely on to get them through. It was described by some as a comfort. Those participants who were continuing to smoke spoke about not feeling ready to stop smoking. This was often in relation to living with ongoing stressors.

A further common theme coming through from many of the interviews conducted was the importance of independence to the participants. The participants tended to be the types of individuals who considered themselves the 'go to' person in their families, wanting to provide care and support for others. For some this was even formal, with their main occupation being as a caregiver to family members. This made the transition to living with a chronic illness, and needing support from others, incredibly challenging and painful. It is interesting that this was a value for so many of the participants, and leads one to ask whether the working-class culture from which the participants came has influenced the development of this value system.

Class structures within UK society can certainly influence value systems. When a person is from a working-class background, it is much harder for them to accrue wealth or property. When this is the case, value systems based on relationships with other people, rather than an individual's relationship with themselves, are more likely to be developed. Individuals from working-class backgrounds report that they associate being middle-class with being uncaring and, through community connections, mutual support, and reciprocal care and love, distance themselves from what is seen as middle-class coldness. This difference particularly comes into play during motherhood, with working-class mothers priding

themselves on warmth and care for their children, seeing middle-class mothers as too focused on achievement (Skeggs, 2011).

Within families of lower socioeconomic status we might guess that, given the cost of formal childcare, there is a greater reliance on family members such as grandparents to support in caring for children. It was painful for many of the participants to not be able to fulfil this role, which we could understand as being a cultural expectation. It also likely has a financial impact for the children of people living with COPD, who cannot access childcare support from their parents, and who also need to invest more time in caring for them along with their children. There might then be a generational impact of COPD, wherein COPD is both caused by social disadvantage and also keeps social disadvantage going.

What was striking was the sheer number of odds stacked against the research participants. My prediction prior to conducting the interviews had been that the participants would speak about physical limitations due to breathlessness, and some distress surrounding this. I had not predicted that the level of impairment or level of distress would be as extreme as was reported. This was to the extent that some participants were reporting complete impairment, not even being able to engage in self-care activities. Some described a desire to bring an end to their life. In addition, the frequency with which some of the participants described having periods of breathlessness during which they believed they were dying was, again, far greater than I had imagined.

There was, therefore, a far greater physical and emotional toll of COPD than predicted. Alongside this, all participants I spoke to who had been employed, had been employed in manual roles. They spoke about having been unable to continue with work due to the physical demand of their jobs, and their lack of ability to keep up due to their COPD symptoms. Most participants, however, didn't speak of this as a loss. This challenged my assumptions about work bringing value to individuals. I

had assumed that the structure and self-esteem gained from work was a positive experience for everyone. I had not considered that, actually, for many people work is physically demanding, not enjoyable, and makes life harder, especially preventing some of the participants from seeing family because of the antisocial hours they would work.

My assumption had been that the participants would want to get back into work, and certainly if I had been working with this group clinically, I would have placed an emphasis on supporting them to find work again. In reality, this would likely have been considered unhelpful, and a demonstration of my lack of understanding of their day-to-day difficulties living with COPD.

It was striking that these individuals had little to fall back on in retirement, having worked in low paid roles throughout their lives. As a result, day-to-day life continued to be a struggle. Not only was there difficulty in managing their symptoms, but also in getting by day-to-day, possibly resulting in an extra burden being placed on family members. This, of course, was the last thing the participants wanted and, as discussed, they described very well the difficulty they experienced with needing to be supported by family members, especially their children.

The participants also described difficult experiences with healthcare services. They reported that interactions with care providers often did not meet their needs. Examples were given about general practitioners who were felt to not understand how difficult daily life can be. The participants often described feeling misunderstood. This was especially the case in regards to smoking, where it appeared that the participants were communicating something about healthcare services not understanding the role that smoking plays in helping them feel comforted within a very difficult set of circumstances. They spoke about receiving judgement about their smoking. They also spoke about services being disempowering in their insistence on behavioural changes that felt difficult to make.

This was difficult to hear. At times, my role as a Trainee Clinical Psychologist has required me to support someone in making behavioural changes. I wonder if at these times, I too might have been experienced as disempowering.

I have often viewed psychology as a somewhat different profession to our medical colleagues. We often have the privilege of getting more time with the people we work with clinically. I have always seen this as helpful, and can get caught up in my own assumptions about the value of sharing concerns and being listened to. For many of the research participants, however, this was not a desirable idea. Certainly, within this research sample, while some of the participants had engaged with the service psychologist, others were very reluctant to engage with talking therapies. They did not like the idea of sharing their thoughts and feelings with others. It might well be the case that previous experiences with talking therapists or healthcare professionals have resulted in them feeling blamed, or responsible for making change in areas of their lives that they have little power over in reality. There may well also be a role for class structures in making sense of this. As previously discussed, people from working-class backgrounds are more likely to use community connections to cope. It might be that individual interactions with care professionals, such as a Clinical Psychologist, simply do not meet their needs.

Reflections on the researcher's position

As described, the content of the research interviews was unexpected. This was especially in regards to the impact of COPD, but also when considering the experience of living in a working-class culture. This, of course, had not been the focus of the research being conducted, but it came through nonetheless. I brought several assumptions to the research, especially about health behaviours. A key one of these was around smoking. I felt that people who continued to smoke despite knowing the health risks were careless. Having not been a smoker myself, I lacked

insight into how hard making changes like giving up smoking can be, but also how important a role smoking plays in day-to-day life for a person who smokes.

As a Trainee Clinical Psychologist, I have spent three years learning about various forms of psychological therapy, the majority of which are offered individually. The therapeutic approaches I have learned about typically see 'dysfunction' as an individual problem, offering an individual solution. The person who is suffering is required to make changes in order to see an improvement. I have therefore developed, throughout the course of my training, a sense that an individual can take control of their situation and, through a process of 'empowerment' supported by the therapist, can make the changes they want to see.

This view also mirrors my experiences in my personal life. I come from a loving family who taught me that I am valuable to others, and who also had the financial security to support me to pursue further education and this career. I am also white, and therefore have not experienced oppression on the basis of race, but rather have benefitted from privileges that come with being a white person in British society today (McIntosh, 1989). I therefore have the privilege of being able to take control of difficult situations. If I encounter a difficulty, I have the means and social support to help me in finding and reaching a solution. My training experience has therefore reinforced my personal view that this is how change is achieved.

This, of course, has influenced how I offer help as a professional. I find working one on one with service users preferable. I feel frustration when service users appear 'stuck' and unable to make changes that, to me, seem obvious and easy. I would find it difficult to understand why, and attribute fault or blame with the individual. I might, for example, have made suggestions that they lacked motivation or 'readiness for change'. An example pertinent to this research is, of course, smoking. As described, I held beliefs about smoking being an unwise choice, and I know that smoking cessation support is available, so I imagined that if an individual

wanted to quit smoking, it was as simple as asking for support and making gradual changes. However, this view comes from my privileged position.

My position, of viewing the individual as responsible for change is also protective for myself. It offers me a sense of ability to support someone in making changes. In accepting that change is required on a societal level, and that redistributions of power are necessary, I must accept that my profession has limited reach in its current format. Individual therapy can only take us so far, and can only support a privileged subset of the wider population.

What I learned from conducting these interviews with a group of people with less privilege, was how hard it is to make changes for yourself when you lack the resources, either material or social, to help you move towards this. The research participants described to me a palpable sense of not being ready to make changes. They spoke about their difficult life circumstances, and I came to see how challenging day-to-day life could be for this group of people. Not only did they lack a considerable amount of power, but they were also living with a chronic health condition, and having to sacrifice some of their important values. Within this context, for some, smoking was just not something that was changeable. I came to understand this position in a way I hadn't previously.

The impact of differences in the room when conducting the interviews

Of course, the interviews were conducted within a social context and the position of the researcher will have also had a considerable impact on the conversations that arose. I wonder to what extent the fact that I come from a middle-class background, and presented myself as a young person engaging in advanced education, might have caused an unhelpful dynamic within the research interviews. There can certainly be biased beliefs between individuals from different class backgrounds and it is likely that these might hinder the authenticity on the part of the

interviewee, but could also bias the way the interview was conducted. For example, conversation might be shut down by the interviewer in circumstances where richer detail could have been accessed.

For instance, the research participants did not express any views about not wanting to make certain lifestyle changes. They instead would express knowing that they 'should' make changes, but were not feeling ready. This was difficult to make sense of, and it is possible that it actually represents an inability on the part of the participant to feel able to genuinely express a lack of desire to make changes within the power dynamic of the interviews. This may well be a dynamic that exists in the majority of contact with healthcare providers.

This was also the case for the values identified by the participants. Two very prosocial values were named, and it is again possible that in the context of a difficult power dynamic where the participants were speaking to a person who seemed fit and well, and might therefore offer adverse judgement, positive aspects of the self were emphasised.

How can the researcher carry this learning forward?

What has particularly struck me is that I had always seen myself as coming from a more working-class background. In the context of other Clinical Psychologists, and clinical psychology trainees, I had often felt less privileged. At times I had felt very different from the rest of my training cohort, given what I felt were very obvious differences in our backgrounds. However, I now see that in comparison to many of the individuals I work with clinically, I often hold a great many more privileges. In denying these privileges and choosing to focus on my lack of power, rather than the great amount of power I do have, I fail to use my privilege helpfully.

What has been described has been a process of learning about the social impact on unhealthy behaviours and physical health outcomes. Within psychology, there is often a pressure to work with people at the individual level, not focussing on many of these important areas that might make it difficult to achieve change. By doing this, we might actually perpetuate power dynamics that our patients experience in other areas of their lives.

It is difficult for those in the position of less power to acknowledge these power dynamics. Interestingly, while the participants in this research study spoke to factors that indicated their working-class experiences, they did not directly name this themselves. I also did not bring discussion around class, or class differences, into the room. This might have been an important way for these issues to be discussed. Openly thinking together about these differences can lessen their impact. Certainly it might have helped me understand their impact on the resulting data set, rather than hypothesising about this independently afterwards.

This is an important area, and with social inequality in London being an ongoing and stable problem (Trust for London, 2018b), it will continue to be pertinent throughout my career in Clinical Psychology. I therefore hope to find ways to bring difference into the room so that this can be explored and discussed. I see the role of a Clinical Psychologist as requiring more than simply offering psychological therapy. More and more, we have a responsibility to use our positions of power to advocate for change. This can be done in many creative ways, the Community Psychology approach being an example of how psychologists can work more effectively to challenge, rather than reinforce, unhelpful power dynamics.

CONCLUSION

This critical reflection has considered the role of social inequality and class in health outcomes. Social deprivation is very much linked to poorer physical health

outcomes, and individuals with COPD are far more likely to come from working-class backgrounds. Deprivation also plays a role in outcomes for people living with COPD, with mortality being predicted by socioeconomic status. Alongside discussion of this important relationship, I have reflected on my own class background and differences that were likely at play in the room when conducting the research interviews. Class structures tend to be a less thought-about social characteristic but in the case of this research study, the impact of social class has been significant. This is the case for both the content of the interviews, and the relationships which unfolded between the interviewer and interviewees, making some things difficult to discuss. I have used this critical reflection as an opportunity to consider how to helpfully work with these differences, and to consider the role of Clinical Psychology in working with complex power dynamics which might make changing behaviour difficult for the people we work with.

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APPENDICES

**Appendix A: National Heart, Lung, and Blood Institute Quality Assessment
Tool for Observational Cohort and Cross-Sectional Studies.**

All questions require a response of – yes, no, not reported, or not applicable. A score of 1 point is given for each answer of ‘yes’.

1. Was the research question or objective in this paper clearly stated?
2. Was the study population clearly specified and defined?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
5. Was a sample size justification, power description, or variance and effect estimates provided?
6. For the analyses in this paper, were the exposure(s) of interest measures prior to the outcomes(s) being measured?
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g. categories of exposure, or exposure measured as continuous variable)?
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
10. Was the exposure(s) assessed more than once over time?
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
12. Were the outcome assessors blinded to the exposure status of participants?
13. Was loss to follow-up after baseline 20% or less?

14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?

**Appendix B: Table of included papers and scores on each item of the NIH
quality assessment tool**

Study	Item number														Total score	Overall quality (good, fair, or poor)
	1	2	3	4	5	6	7	8	9	10	11	12	13	14		
Corhay et al. (2012)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	Y	N	9	Good
Corlateanu et al. (2016)	Y	Y	NR	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	7	Fair
Emery (1994)	Y	Y	NR	Y	N	Y	Y	NA	Y	NA	Y	NA	Y	N	8	Fair
Gupta et al. (2016)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	8	Fair
Henoch et al. (2016)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	8	Fair
Martinez et al. (2016)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	8	Fair
Miravittles et al. (2007)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	8	Fair
Moro et al. (2009)	Y	Y	Y	Y	Y	Y	Y	NA	Y	NA	Y	NA	NA	Y	10	Good
Suetomo et al. (2014)	Y	Y	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	8	Fair
Zhou et al. (2013)	Y	Y	NR	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	7	Fair

Appendix C: Copy of Participant Information Sheet

[UCL DEPARTMENTAL LOGO]

Information Sheet

Date:

Version:

Title of project: The experience of having COPD in working-age adults: A framework analysis.

We'd like to invite you to take part in a student research study. Joining the study is entirely up to you. Before you decide we would like you to understand why the research is being conducted and what it would involve for you. Please feel free to talk to others about the study if you wish. Do ask if anything on this information sheet is unclear.

Why is this study being done?

We would like to learn what it means to people to have a diagnosis of Chronic Obstructive Pulmonary Disease (COPD) when they are of a working-age (under 65 years). The reason we are interested in exploring this is because more people are being diagnosed with COPD at a younger age, and may have different problems from older adults with COPD. We hope that understanding younger people with COPD can help us provide the support they need.

What would taking part involve?

You will be asked to fill in some questionnaires, and then to be interviewed by a Trainee Clinical Psychologist for approximately an hour and a half. The interviews will take place during working hours (Monday- Friday 8am-5pm) at [hospital site] at a time that suits you. You will be asked questions about your experience of having COPD. We anticipate that completing the questionnaire measures and the interview will take a maximum of 2.5 hours in total. You can take breaks at any point whilst participating in the research.

How do I participate or learn more?

If you would like to find out more about participating in this study, please leave your contact details (either an email address or telephone number) with the member of your care team who has given you this information sheet. Alternatively, you are welcome to contact the researcher directly using the contact details below. You are very welcome to contact the researcher before making a decision about whether or not you would like to participate. You can take your time to decide if you would like to participate in this study. We hope to have collected enough information by early 2018, so please let us know your decision by then.

Email:

Telephone:

Am I eligible to participate?

In order to participate you must:

- Have a diagnosis of COPD and currently be under the care of the [name of respiratory team hosting research study]
- Be aged between 18 and 65 years old
- Be fluent in speaking and understanding English

You will not be able to participate if you have any current substance misuse difficulties, are a hospital inpatient, are unable to attend an outpatient appointment, or are currently considered a 'vulnerable person' e.g. if you are pregnant, terminally ill, or have any cognitive impairments or learning disabilities.

What are the possible benefits of taking part?

We hope that talking about your experience of living with COPD could be beneficial for you. We also hope that the researchers will help us better understand what it means to have COPD for people under the age of 65. We hope that if we understand this better, this group of people might receive care that better meets their needs in the future. To thank you for your time, we offer a £10 Marks and Spencer voucher, and your travel expenses, including parking, will be repaid up to a maximum of £10.

What are the possible disadvantages and risks of taking part?

Discussing your experiences could be boring for you. It could also feel intrusive, or be upsetting. Should this be the case, you will be provided support by the researcher. You would be able to end your participation in the study at any point. The interviews will take place during working hours and so you may lose pay if your employer does not support your participation.

What if I don't want to take part?

You do not have to take part in this study. You are also free to withdraw at any time and you can do so without disadvantage to yourself and without any obligation to give a reason. If you choose to withdraw from the research, all of the data from your participation would be deleted. Whether or not you choose to participate will not affect your care in any way.

Will the information I share be confidential?

All data will be anonymised so that you will not be able to be identified in the report of the study. All data will be collected and stored in accordance with the Data Protection Act 1988.

How will my information be stored?

The interviews will be audio recorded. You will be allowed to stop the recording at any time and request your words be deleted or revised. The information we collect will be kept on password protected USB devices and as password protected documents on NHS computers. Only the researchers will have access to this data. We allocate unique identification numbers to all of our research data so that no one would be able to identify who you are from any of the information we have collected. Anonymised direct quotations will be used in the write up of the study.

There are some cases where the researcher would discuss the information shared in your research interview with members of your care team, for example, if they were concerned about your physical or psychological health and felt you needed more support. In some cases, your care team might choose to share this information with other services, such as your general practitioner, or the local safeguarding team. This would only happen if they had concerns that you, or somebody else, may be at risk of harm.

In accordance with its current Records Retention Scale, research data are retained by UCL as a sponsor for 20 years after the research has ended. The UCL records office provides a service to UCL staff and maintains archived records in a safe and secure off site location. Access to stored records is strictly controlled.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [contact details given]. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Amanda C de C Williams, who is overseeing the research [contact details given].

You can also contact the Patient Advice and Liaison Service if needed [contact details given].

What will happen to the results of this study?

The results of this study will be submitted as a doctoral thesis. We also hope that the results of this study will be published in scientific journals and presented at conferences and teaching events for other professionals to learn from. No identifiable information would be contained in any report or publication of the results. As a participant, you will be asked to give your contact details should you wish to be provided a summary of the research results.

Who is organising and funding this study?

The study is being conducted as part of a Clinical Psychology Doctorate at University College London (UCL).

How have patients and the public been involved in this study?

Service users have helped to design the interview questions you will be asked, and have helped design this information sheet.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the North West - Preston Research Ethics Committee.

Thank you for reading this information sheet and for considering taking part in this research.

If you find it easier to contact us by post to express your interest, please write to:
[contact details given]

Appendix D: Copy of consent form

[UCL DEPARTMENTAL LOGO]

CONSENT FORM

Title of Project: The experience of having COPD in working-age adults: A framework analysis

1. I confirm that I have read the 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 my research interview is being audio recorded. I am aware that I can ask the interviewer to stop, delete, or edit the recording at any point.
4. I consent to the use of anonymised direct quotations of my comments in the dissemination of this research.
5. I understand that there are some cases where the researcher would discuss the information shared in this interview with members of my care team, for example, if they were concerned about my physical or psychological health and felt I needed more support. I am aware that the researcher would always let me know if they were going to do this.
6. I understand that there are some cases where my care team might share this information with other services, such as with my general practitioner, or the local safeguarding team. This would only happen if there were concerns that I, or somebody else, may be at risk of harm. I am aware that the researcher would always let me know if this was going to happen.
7. I understand that data collected during the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this study. I agree to these persons having access to this information.
8. I would like to receive feedback on the findings of the study to the following email address
9. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

Appendix E: Copy of interview schedule

A. Introduction

I am interested in understanding your experiences of COPD. I will start with general questions about COPD and then move on to how COPD affects you.

B. COPD

- In your own words, how would you describe COPD?
- What symptoms cause you problems?

Prompts: Are these consistent/predictable or do they vary day to day? What do you do to cope with them?

C. Stage of life

As we age, our values and priorities change.

- What would you say your values and priorities are at the moment?

Prompts: family, work, friendships, relationships, activities, interests, health, religion

- Has COPD affected how able you are to live your life according to these values and priorities?
- Has COPD meant that your values and priorities have changed?

D. Specific areas of impact of COPD

I will now ask you about specific areas of your life and how COPD has affected you. Before I do this, I want to ask you two more questions about COPD.

- What do you think causes COPD?
- Where do you/did you get information from about COPD?
- Has COPD affected your mood?

Prompts: frustration, anger, low mood?

- What is it about COPD that has led you to feel this way?
- What goes through your mind when you are breathless?
- Can you give me an example of a time you were breathless recently?

Prompts: Where were you? What was happening in your body? What went through your mind? What did you do?

- COPD symptoms can be very worrying. Do you feel anxious about your symptoms?
- What changes do you notice in your body when your COPD is worse?

Prompts: Do you know why that happens? - COPD alone or anxiety?

- What makes your worry/anxiety worse?
- What helps your worry/anxiety?

Prompts: Times? Specific places, activities, people?

- Do your COPD symptoms affect what you can do day to day?

Prompts: Is there anything you avoid?

- If you didn't have COPD, what would you be doing now, in terms of work or main occupation?

Prompts: including carer, parent, training, self-employment, etc.

- What is it about COPD that stops you doing that?

Prompts: How did this come about? - travel, hours, sick leave?

- Has your COPD changed your relationships with people who are important to you and, if so, how?

Prompts: family routines, roles in family, workplace relationships, friendship groups

- What impact does COPD have on other day to day activities that matter to you?

Prompts: vocational/leisure activities, interests, household responsibilities

- Are there any other important areas of your life that COPD has changed that we haven't yet discussed? - What are these?

E. Close and debrief

- Is there anything else that you feel is important that you would like to comment on?
- Do you have any questions?
- Could I please take a brief employment history?

I would also like to find out some specific details about your COPD.

- When were you first diagnosed?
- How long have you been receiving support from COPD services for?

Thank you for taking part.

Appendix F: Example section of transcript, coded as per analysis stage 2

Motivation?
 Can't sustain?

- 1 P01: Yeah, well, I'd say yes because if you say you can't do it, and you, that's it, you're gonna, but the
easy to give up
- 2 thing is you can only do what you can do, you haven't got to do it, a lot of people think look at him
knowing own limits.
- 3 he's walking up there quick but I'm out of breath and so are they and they haven't done as much as
- 4 me but, the thing is that I push myself to, well knowing I'm in a safe place, I'm in a gym in a London
pushing oneself PR feels safe
- 5 hospital so if something happens I don't have to worry too much about it
- 6 I: Yeah very true, so it sounds like you're saying there's lots of areas of your life that are important
- 7 for you at the moment and that you value so a big one for you at the moment is your family and
- 8 your mum's health and making sure she's ok. There's also being active and being busy, but also not
- 9 being stuck in the same routine so also something about having different things every day to do, and
- 10 then also your health is something you particularly value.

Taking responsibility.

- 11 P01: Well yeah but also that's a different thing that, it's nothing to do with COPD, that's in there, you
- 12 know what I mean, it's up to me, if I wanna do the same things every day but if I wanna change it,
taking control/responsibility.
- 13 you know, COPD is not telling me to do that, I meant telling me not to climb a mountain but it ain't
knowing limits.
- 14 telling me to change my routine but that's a different problem from the chest but it all affect me, its
everything in combination
- 15 affected me all different way.
- 16 I: And these don't have to be things to do with COPD. They can just be things that you think, actually
- 17 that's really important to me at the moment.

Feeling able
 Having choice, having skills.

- 18 P01: That's basically, the most important things is the COPD but I know that's there it isn't going to
COPD most important
- 19 go away so anything else from that really is up to me so don't push myself so I'm gonna fall over and
uncurable taking responsibility
- 20 I'm exhausted but you know, gonna do it, it's a personal thing. If I wanna go out there and walk
knowing limits
- 21 home, I could walk home probably but it'd take me about 4 hours, whereas if I wanna get a bus and,
- 22 you know it's up to yourself. If you feel you wanna push yourself and walk for an hour, keep stopping
Having choice Pacing
- 23 but, as I say it's seasons different. In the winter I don't really wanna spend too much time outside
unpredictability with seasons.
- 24 but in the summer it's different, pair of shoes and off you go.

Appendix G: Copy of coding framework used in analysis

- 1.0 Employment
 - 1.1 Loss of
 - 1.1.1 Changing routine
 - 1.2 Adaptations made by employer
 - 1.3 Work as something I value
 - 1.4 Manual work
 - 1.5 Other
- 2.0 Experience of services
 - 2.1 Accessibility
 - 2.2 Relevance to my needs
 - 2.3 Hospitalisations with infections / experience of a really bad infection
 - 2.3.1 Experiences with emergency services
 - 2.4 Meeting others with COPD
 - 2.5 Medication
 - 2.5.1 Rescue packs
 - 2.5.2 Inhalers
 - 2.6 Other
- 3.0 Low mood
 - 3.1 Hopelessness
 - 3.2 Lack of motivation
 - 3.3 Withdrawing from others
 - 3.4 Downward comparisons
 - 3.4.1 With others
 - 3.4.2 With my past self
 - 3.5 I should thoughts
 - 3.6 Letting people down
 - 3.7 Suicidal thoughts
 - 3.8 Frustration
 - 3.9 Other
- 4.0 Context
 - 4.1 Working class context
 - 4.2 Faith
 - 4.3 Aging
 - 4.4 Smoking culture
 - 4.5 Other
- 5.0 Anxiety
 - 5.1 Avoidance
 - 5.2 Future thinking
 - 5.2.1 Fear of dying
 - 5.3 Panic
 - 5.3.1 Panic linked to COPD breathlessness
 - 5.4 Stress
 - 5.4.1 Impact of stress on immune system
 - 5.5 Memorable infection experience that I come back to when I'm anxious
 - 5.6 Ways I manage my anxiety
 - 5.7 Other
- 6.0 Shame
 - 6.1 About symptoms
 - 6.2 About medication use
 - 6.3 About smoking
 - 6.3.1 Beliefs that this is my fault
 - 6.4 About my changing abilities
 - 6.5 About needing to be cared for by others

- 6.5.1 Feeling a burden
- 6.6 Other
- 7.0 Adjustment/acceptance
 - 7.1 Coming to terms with diagnosis
 - 7.1.1 Realising seriousness
 - 7.1.2 Disease progression
 - 7.2 Experience receiving diagnosis
 - 7.3 Sharing diagnosis with others
 - 7.4 Taking responsibility
 - 7.5 Sense of unfairness / why me thinking
 - 7.6 Feeling unable to cope
 - 7.7 Other
- 8.0 Comorbid health conditions
 - 8.1 Mental health
 - 8.2 Pain
 - 8.3 Heart conditions
 - 8.4 Multiple comorbidities
 - 8.5 Other
- 9.0 Changing abilities
 - 9.1 Day to day tasks
 - 9.2 Self-care
 - 9.3 Hobbies/enjoyment
 - 9.4 Taking time/ being slowed down
 - 9.5 Other
- 10.0 Relationships
 - 10.1 Distance in relationships/loss of relationships
 - 10.2 Closeness in relationships
 - 10.3 Being cared for
 - 10.4 Caring for others
 - 10.4.1 Experiences caring for others with COPD
 - 10.5 Importance of others
 - 10.6 Social isolation
 - 10.7 Role in family
 - 10.8 Other
- 11.0 Ways of coping
 - 11.1 Push it away
 - 11.2 Think positively / make positive comparisons
 - 11.3 Practical ways of coping
 - 11.4 Asking for help
 - 11.5 Sometimes the practical techniques don't work
 - 11.6 Making the most of things
 - 11.7 Smoking (as a way to manage/cope)
 - 11.8 Put a face on, pretend I'm ok
 - 11.9 Setting manageable goals
 - 11.10 Other
- 12.0 Physiology
 - 12.1 Knowing own body
 - 12.2 Constant symptom burden
 - 12.3 Breathlessness
 - 12.3.1 Experiences of breathlessness before COPD diagnosis e.g. asthma
 - 12.4 Fatigue
 - 12.5 Incontinence
 - 12.6 Concentration
 - 12.7 Sleep

- 12.8 Appetite/weight loss
- 12.9 Pain
- 12.10 Other
- 13.0 Loss of control
 - 13.1 Importance of independence
 - 13.2 Unable to plan
 - 13.3 Unpredictability of COPD
 - 13.4 Other
- 14.0 Practical changes
 - 14.1 Pacing
 - 14.2 Smoking
 - 14.2.1 Stopping smoking
 - 14.2.2 Difficulties stopping smoking
 - 14.2.3 Benefits of smoking
 - 14.3 Lifestyle changes to look after health
 - 14.4 Self-efficacy
 - 14.5 Using medication
 - 14.6 Breathing techniques
 - 14.7 Prioritising
 - 14.8 Other
- 15.0 Other

**Appendix H: Example section of transcript, charted using coding framework,
as per analysis stage 4**

1 P01: Yeah, well, I'd say yes because if you say you can't do it, and you, that's it, you're gonna, but the
 2 thing is you can only do what you can do, you haven't got to do it, a lot of people think look at him
 3 he's walking up there quick but I'm out of breath and so are they and they haven't done as much as
 4 me but, the thing is that I push myself to, well knowing I'm in a safe place, I'm in a gym in a London

5 hospital so if something happens I don't have to worry too much about it
 6 I: Yeah very true, so it sounds like you're saying there's lots of areas of your life that are important
 7 for you at the moment and that you value so a big one for you at the moment is your family and
 8 your mum's health and making sure she's ok. There's also being active and being busy, but also not
 9 being stuck in the same routine so also something about having different things every day to do, and
 10 then also your health is something you particularly value.

11 P01: Well yeah but also that's a different thing that, it's nothing to do with COPD, that's in there, you
 12 know what I mean, it's up to me, if I wanna do the same things every day but if I wanna change it,
 13 you know, COPD is not telling me to do that, I meant telling me not to climb a mountain but it ain't
 14 telling me to change my routine but that's a different problem from the chest but it all affect me, its
 15 affected me all different way.

16 I: And these don't have to be things to do with COPD. They can just be things that you think, actually
 17 that's really important to me at the moment.

18 P01: That's basically, the most important things is the COPD but I know that's there it isn't going to
 19 go away so anything else from that really is up to me so don't push myself so I'm gonna fall over and
 20 I'm exhausted but you know, gonna do it, it's a personal thing. If I wanna go out there and walk

21 home, I could walk home probably but it'd take me about 4 hours, whereas if I wanna get a bus and,
 22 you know it's up to yourself. If you feel you wanna push yourself and walk for an hour, keep stopping
 23 but, as I say it's seasons different. In the winter I don't really wanna spend too much time outside
 24 but in the summer it's different, pair of shoes and off you go.

Appendix I: Example section of framework matrix, developed in stage 5 of the analysis

	A	B	C	D	E
1	Participant	Experience of services	Context	Comorbidities	Physiology
2	P06	PR as being a new experience, opportunity to meet others. Depression and panic mean that it took a lot to get there: Page 7, lines 4-9 <i>'with my depression and that, I was sort of more at home, I never really went out, done things, so going to a pulmonary rehab was sort of like a big thing for me'</i>	History of having experienced traumas and coping alone: Page 18, lines 24-26 <i>'now, most of the time I just feel worn out'</i>	Complex picture, having an anxiety diagnosis, experiencing panic attacks, having depression, and having COPD. Symptoms can get confusing. Can be overwhelming and frustrating: Page 8, lines 11-15 <i>'with me it's like a four combination things. It's your breathing, your depression, your anxiety and your panic attacks all at once'</i>	Struggle to pick apart anxiety and COPD breathlessness having frequent panic attacks: Page 11, lines 24-26 <i>'breathe through the COPD, that's when the panic attacks because I'm panicking about me not being able to'</i>
3	P07	PR as very helpful experience. Meeting others with COPD was found to be useful: Page 2, lines 26-33. <i>'it's recognising different peoples level and how they deal with it basically and their symptoms has been yeah, very helpful'</i>	Faith background, but not practicing in religion. Supportive family network: Page 5, lines 6-13. <i>'I come from a Christian background, I'm not a practicing Christian but as far as I'm concerned it's how I live my life'</i>		Experiencing breathlessness, sometimes managing self, sometimes needing hospitalisation. Having a judgement call. Fatigue as a sign of serious infection: Page 10, lines 6-8 & page 10, lines 33-36. <i>'I'll feel listless and the breathing aspect will become quite debilitating'</i>
		Struggled at PR as found exercising in public difficult: Page 5, lines 23-35. <i>'I'd rather do it in my own house on my own'</i> Feeling judged by healthcare professionals, care lacks compassion, they think it's my fault as a smoker: Page 20, lines 34-41.	Grew up in a context of smoking being the norm: Page 5, lines 10-11. <i>'I started smoking what I was 11 years old, my first day at secondary school it was'</i>	Comorbid osteoporosis from repeat steroid use: Page 1, lines 30-36. <i>'you end up you've got osteoporosis because of all the steroid use you've had'</i>	Breathlessness all consuming. Symptom burden: Page 2, lines 31-42. <i>'I wanna breathe, that was it me breathe',</i>

Appendix J: Copy of Research Ethics Committee acknowledgement of compliance

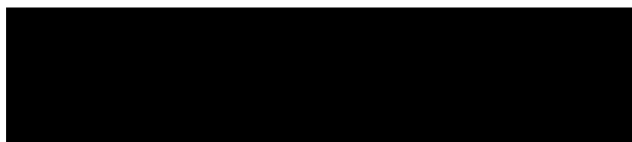
North West - Preston Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 August 2017



Dear Dr 

Study title: The experience of Chronic Obstructive Pulmonary Disease in working age adults: A framework analysis
REC reference: 17/NW/0454
IRAS project ID: 221004

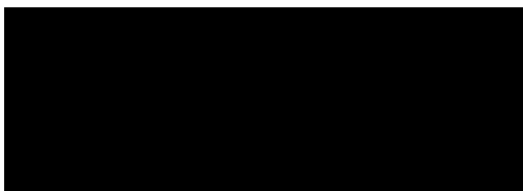
Thank you for your response. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 03 August 2017

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant consent form [consent form]	2	09 August 2017
Participant information sheet (PIS) [PIS]	2	09 August 2017

Appendix K: Copy of Health Research Authority ethical approval



11 August 2017

Dear Dr 

Letter of HRA Approval

Study title: The experience of Chronic Obstructive Pulmonary Disease in working age adults: A framework analysis
IRAS project ID: 221004
REC reference: 17/NW/0454
Sponsor University College London

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.