A narrative ethnographic exploration of the presence, absence, and impact of meaningfulness in day-to-day life when living with palliative care needs arising from Chronic Obstructive Pulmonary Disease (COPD)

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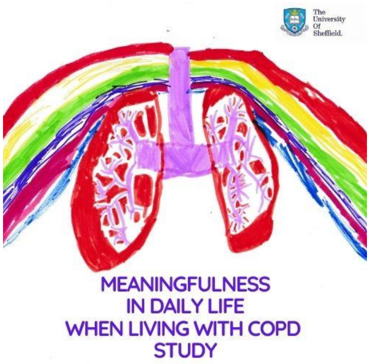

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Abstract

Chronic Obstructive Pulmonary Disease (COPD) is a progressive respiratory disorder characterised by persistent airflow limitations within the lungs. The condition is currently the third leading cause of death worldwide. Living with COPD involves navigating day-to-day life with a relentless and overwhelming symptom burden of breathlessness, chronic cough and sputum production, fatigue and anxiety and depression. This symptom burden inevitably leads to the need for palliative care alongside active treatment for those living with COPD.

The true philosophy of palliative care extends beyond conventional medical interventions and physical symptom management, requiring holistic consideration of the physical, emotional, social, and existential elements of suffering. For those living with COPD, the impact of the condition upon individual's existential situation is evidenced, with the presence of life meaning being of importance to those living with the condition. The presence of meaningfulness within day-to-day life is of significance within the context of palliative care, through its ability to enable coping with changing life circumstances, and the facilitation of inner peace for an individual. Understanding how meaningfulness is manifest within the day-to-day lives of those living with palliative care needs arising from COPD, alongside the impact of the absence of life meaning is necessary to gain a novel insight into the palliative care needs of this population. By understanding how individuals identify meaning in day-to-day life, this can inform the support required to be delivered by health professionals to maintain this, or for those experiencing an absence of life meaning, to be supported to identify its presence.

The aim of this doctoral study was to explore, through a narrative ethnographic approach, the presence, absence, and impact of meaningfulness within the day-to-day lives of those living with palliative care needs arising from COPD. A narrative ethnographic methodology was used to facilitate a multi-dimensional and deep insight into the existential situations of participants. A set of six specifically designed objects, cultural probes, were used by participants for a two-month period. These included a disposable camera, a journal, and a set of thought-provoking postcards. Each participant then gave a narrative interview within which the completed cultural probes were used to scaffold the discussion. Six individuals from England (United Kingdom) participated within this study. Data was analysed using a structural narrative analysis approach. Data interpretation was facilitated using the triangulation protocol to integrate multiple data sources.

A conceptual framework was developed to illustrate the study's findings, incorporating both the presence of and interruption to meaningfulness within day-to-day life for those living with palliative care needs arising from COPD. The study findings are presented in three themes: meaningfulness through personal value congruence, meaningfulness through taking control of personal dignity and barriers to identifying meaning through personal value incongruence. The use of cultural probes as a research method with palliative care populations was found to reveal unique insights into the day-to-day lives of the study population. Recommendations are made suggesting possible content to develop an intervention to support those living with COPD to identify meaning within day-to-day life. The study findings will inform healthcare professionals, educators, and policy developers.

Abbreviations

BLF	British Lung Foundation
COPD	Chronic Obstructive Pulmonary Disease
PPI	Patient and Public involvement

Glossary of Key Terms

Existentialism

Existentialism is a philosophical perspective that focuses on individual existence, freedom, and choice. It emphasises that humans are responsible for creating meaning in their own lives, often in the face of adversity. Existentialists argue that life has no inherent purpose or value, and it is up to each person to find their own path.

Meaningfulness

Meaningfulness refers to the quality of having purpose, significance, or value, particularly in relation to a person's life, actions, or experiences. Something is considered meaningful if it contributes to a sense of fulfilment, aligns with one’s values, or provides a sense of connection to a broader narrative. Meaningfulness often involves a feeling that an experience is of importance.

Chapter 1.0 – Introduction

1.1 – Introduction

This doctoral research study explores how people with palliative care needs arising from chronic obstructive pulmonary disease (COPD) experience meaningfulness in day-to-day life, and the impact of its presence and absence. The main determinants for undertaking this study were the absence of an understanding within the wider literature of the impact of life meaning upon the quality of life for individuals living with palliative care needs arising from COPD, informing future palliative care planning and delivery for this population. The authors previous clinical nursing experience of caring for, and observing those living with COPD accessing acute healthcare services due to existential distress further motivated the need for this research.

COPD is a complex and progressive respiratory condition, characterised by persistent and irreversible airflow limitation (World Health Organisation, 2019a). COPD encompasses a spectrum of conditions, primarily including chronic bronchitis and emphysema, and is often caused by prolonged exposure to irritating gases or particulate matter, such as those found in cigarette smoke, air pollution, or occupational exposures (Viegi *et al.*, 2007). COPD is the third most common cause of mortality worldwide, causing 3.29 million deaths throughout 2019 (World Health Organisation, 2023).

Individuals living with COPD experience a substantial and multifaceted symptom burden that significantly affects their quality of life (Johansson *et al.*, 2019). Physical symptoms of COPD include chronic breathlessness, persistent cough, and sputum production (World Health Organisation, 2023). Furthermore, the associated impact of these symptoms often extend beyond the physical, resulting in social isolation, and associated depression and anxiety (Elkington *et al.*, 2004).

The disease trajectory associated with COPD is characterised by notable intervals of health deterioration, interrupted by sudden and severe exacerbations, any of which could culminate in death (Landers *et al.*, 2017). As a result, difficulties are present in predicting the pre-death phase of COPD, and as such, a holistic, timely and consistent approach to planning and accessing palliative care (Elkington *et al.*, 2005; Vermylen, Szmuilowicz and Kalhan, 2015). Furthermore, there is an identified need for the provision of palliative care to commence alongside active treatment given the associated relentless symptom burden of COPD (Carlucci, Guerrieri and Nava, 2012; Iyer *et al.*, 2022).

Interventions and global healthcare policy aimed to address the palliative care needs of those living with COPD largely focus upon the management of associated physical symptoms, alongside associated anxiety and depression (Gold Standard Framework, 2011; Global Initiative for Chronic Obstructive Lung Disease, 2019a; NICE, 2020). Whilst this is of importance, less prevalent within the wider literature and healthcare policy is the evaluation of the existential experiences and perceptions of individuals living with COPD, and how such experiences influence and determine their palliative care needs.

A systematic integrative review was undertaken using an integrated convergent synthesis of included study findings to develop themes related to existential suffering in the day-to-day lives of those living with palliative care needs arising from COPD. The literature review identified four themes underpinning the presence of existential isolation; liminality, loss of personal liberty, lamented life, and life meaning. Furthermore, the review indicated that there has been limited exploration into the presence of meaningfulness and the experience of meaninglessness, along with associated impacts in the context of COPD.

This study was undertaken with participants living in their own homes in Nottingham, Ilkeston, Sheffield and London. Participants were invited to take part within this study during their attendance at a British Lung Foundation (BLF) Breathe Easy support group. They were asked to self-certify they met the study inclusion criteria of; being over sixty-five years of age, under the care of a specialist COPD team, and identified that living with COPD impacts their ability to undertake daily activities.

A narrative ethnographic methodology was used to underpin this study, to gain rich, in-depth and meaningful data. Data collection encompassed the use of cultural probes, and narrative interviews with each participant to explore the presence and absence of meaningfulness in day-to-day life. Cultural probes are a collection of objects specifically designed for the population under study, to reveal fragments of information upon thoughts and emotions within everyday lives of typically hard to reach and unfamiliar groups (Gaver, Dunne and Pacenti, 1999; Gaver *et al.*, 2004). Each participant took part within a narrative interview, to build upon the ethnographic cultural probe data collected, to reveal a privileged and detailed understanding of participants day-to-day life experiences (Gubrium and Holstein, 2008). A Patient and Public Involvement group (PPI) was developed by the author and were involved within the study design phase, the development of the recruitment strategy and the design and review of the cultural probe objects used.

Data analysis commenced with the creation of an ethnographic description of each participant to give context to the meanings generated within the study findings developed by the researcher and each participant (Spradley, 1980). A structural narrative analysis was then undertaken of the narrative interview transcriptions (Labov, 1972), followed by the adoption of the data triangulation protocol to integrate both data types and integrate the study findings (O'Cathain, Murphy and Nicholl, 2010).

The findings from this study are presented through three key themes: ‘meaningfulness through personal value congruence’, ‘meaningfulness through taking control of personal dignity’ and ‘interrupted life meaning through personal value incongruence’. Furthermore, the study findings present the use of cultural probes as a novel and effective data collection method within palliative care research.

The findings from this study relating to the presence of, interruption to, and impact of meaningfulness in the day-to-day lives of those living with palliative care needs arising from COPD will inform future practice, policy, education and research to inform the provision of patient focused and holistic palliative care for this patient population.

1.2 – Aims and Objectives

The aim of this study was to explore, through a narrative ethnographic approach, the presence, absence, and impact of meaningfulness in the day- to- day lives of people living with palliative care needs arising from COPD.

The objectives were:

- To determine how people with palliative care needs arising from COPD derive meaning in their lives.
- To develop an understanding of how individuals living with such a physically and mentally impactful condition experience interruption to the identification of meaningfulness, to give a new insight into the palliative care needs of this patient population.
- Where meaninglessness is manifest, to explore its impact upon the lives of those with palliative care needs arising from COPD.

1.3 – Thesis Overview

This first chapter has presented the underpinning rationale for undertaking this study and has stated the aim and associated objectives. Chapter two presents the background to COPD, alongside it's incidence, prevalence and socioeconomic impact. The COPD symptom burden is explored within a palliative care context. Chapter three provides a systematic integrative review of the literature upon existential suffering in the day-to-day lives of those living with palliative care needs arising from COPD. The review findings present four themes: liminality, loss of personal liberty, lamented life, and life meaning, with each contributing towards the presence of existential suffering. Interpretation of the review findings identified that the impact of the presence and absence of meaningfulness has been little explored in populations living with palliative care needs arising from COPD. Chapter four presents the research philosophy of this study, with discussion of the epistemological and ontological approaches. The research methods employed to fulfil the research aims and objectives are then presented. The study findings commence with an ethnographic description of each participant within chapter five, alongside key definitions of concepts used throughout the subsequent chapters. Chapters six, seven and eight present the three themes developed from data analysis. Chapter six (meaningfulness through personal value congruence) presents how meaningfulness within daily life is present when an individual’s personal values remain aligned with their personal goals. Chapter seven (meaningfulness through taking control personal dignity) focuses upon how participants were able to take control of their own dignity through asserting and maintaining control over life choices and the acceptance of limitations. Chapter eight (interrupted life meaning through personal value incongruence) considers how the presence of future worries and feelings of a loss of control interrupt the presence of meaningfulness within day-to-day life. Chapter nine presents the usability and acceptability of cultural probes as a research method by the participants within this study and offers reflection on this method from the researcher. Chapter ten (the discussion) explores how this study's findings contribute to existing knowledge in the context of previous literature. Furthermore, the study's strengths and weaknesses are presented, alongside the implications for clinical practice, education, policy, and research.

1.4 – Chapter Summary

This chapter has provided an overview of the motivations behind conducting this research study. From the authors clinical nursing experience, the presence of existential suffering for those living with palliative care needs arising from COPD was evident, however the wider literature to support this is limited. Understanding how the presence and absence of life meaning impacts this population is necessary to inform future patient-centred and holistic palliative care. The background and further context to this study is now presented within chapter two.

Chapter 2.0 – Background

2.1 – Introduction

The aim of this narrative ethnographic study was to explore the presence, absence and impact of meaningfulness within the day-to-day lives of those living with palliative care needs arising from COPD.

This chapter presents a background to COPD and its causes, alongside it's prevalence and the socio-economic burden in a global context. The symptom burden of COPD is then presented, followed by a critical discussion upon the current policy and guidelines underpinning palliative care provision for this patient population. The concept of existential suffering is then introduced and discussed to give content to the integrative literature review within Chapter three.

2.2 – Chronic Obstructive Pulmonary Disease (COPD)

COPD is a progressive respiratory disorder characterised by persistent limitations in airflow within the lungs, typically due to a combination of airway inflammation and structural changes (NICE, 2018; World Health Organisation, 2023). It encompasses a group of chronic lung disorders, primarily including chronic bronchitis and emphysema, which often coexist and contribute to the disease's complex pathophysiology (NICE, 2018). Initial presentation of COPD often encompasses symptoms of: a persistent cough, frequent production of sputum, and progressive dyspnoea (characterised by difficulty in breathing), and a history of recurrent lower respiratory tract infections, each of which are variable in severity from day-to-day (Viegi *et al.*, 2007; Kessler *et al.*, 2011; Global Initiative for Chronic Obstructive Lung Disease, 2023). For individuals exhibiting such symptoms, alongside exposure to risk factors associated with COPD, the consideration of a COPD diagnosis is warranted. The most significant risk factor in the development of COPD is tobacco smoking, however it is documented that only twenty percent of smokers actually develop COPD (Terzikhan *et al.*, 2016). Air pollution presents a further risk to the development of COPD (Park *et al.*, 2021), with some suggesting that a pre-existing genetic disposition alongside unfavourable lifestyle choices increase this risk (Wang *et al.*, 2022). Low birth weight and prematurity are also evidenced to increase an individual's development of the condition, alongside recurrent childhood respiratory infections and genetic factors (Bolton *et al.*, 2012; Global Initiative for Chronic Obstructive Lung Disease, 2023).

Diagnosis of COPD through forced spirometry demonstrating a post-bronchodilator FEV1/FVC ratio less than 0.7 is imperative to establish the degree of airflow limitation (Global Initiative for Chronic Obstructive Lung Disease, 2023). The FEV1/FVC ratio is a measure used in pulmonary function tests to assess lung function. It represents the ratio of the forced expiratory volume in one second (FEV1) to the forced vital capacity (FVC), calculating the proportion of air a person can forcibly exhale in the first second of a forced expiration relative to the total volume of air they can exhale forcefully (Torén *et al.*, 2021). A decreased FEV1/FVC ratio is indicative of airflow limitation, and values below 70% in adults suggests the presence of obstructive lung disease (NICE, 2018; Global Initiative for Chronic Obstructive Lung Disease, 2023). Where spirometry results indicate the FEV1/FVC ratio is less than 0.7, classification of the severity of COPD is required (Table 1.0). The classification allows healthcare professionals and patients to understand the level of airflow limitation, guiding treatment decisions. The severity assessment may also involve considering additional factors such as: symptom presentation, exacerbation history, and quality of life impact. Assessment of symptom impact, particularly breathlessness, is guided through the use of two validated tools (Global Initiative for Chronic Obstructive Lung Disease, 2023). The mMRC Scale is a validated self-assessment tool to capture the impact of breathlessness related to activity in daily life (Rajala *et al.*, 2017). Whilst this tool is recommended for use within current COPD management policy and guidelines (NICE, 2018; Global Initiative for Chronic Obstructive Lung Disease, 2019b), a wider understanding of the symptomatic impact of COPD is necessary to formulate a holistic assessment. Therefore, the use of the COPD assessment test (CAT) is recommended to concurrently capture the burden of symptoms.

Table 1.0 - COPD Severity Classifications

STAGE	SPIROMETRY READING
Stage 1	FEV1 80% of predicted value or higher
Stage 2	FEV1 50–79% of predicted value
Stage 3	FEV1 30–49% of predicted value
Stage 4	FEV1 less than 30% of predicted value

The physiological impact of COPD often extends to the presence of systemic co-morbidities including: cardiac disease, diabetes mellitus, hypertension, osteoporosis and psychological disorders (World Health Organisation, 2023). The COPD disease trajectory is characterised by significant periods of decline in health status, interrupted by acute exacerbations, any of which may result in death (Landers *et al.*, 2017). COPD is a major global health concern, with a significant impact on both individuals and healthcare systems (Quaderi and Hurst, 2018).

2.3 – Prevalence of COPD

The prevalence data available in the wider literature upon COPD presents variations due to differing underpinning research methodologies, application of diagnostic criteria and approaches to data analysis (Mathers and Loncar, 2006; Global Initiative for Chronic Obstructive Lung Disease, 2023). The global prevalence of COPD in 2019 was a reported 212.3 million diagnosed cases, with 323 million deaths attributed to the condition throughout the year, making the condition the third most prevalent cause of death worldwide (Safiri *et al.*, 2022; World Health Organisation, 2023). Underdiagnosis is acknowledged due to the reported underuse of spirometry testing (Global Initiative for Chronic Obstructive Lung Disease, 2023), suggesting these figures are a global underestimate of the prevalence of the condition. The disease prevalence presents challenges to healthcare providers worldwide upon the significant need for provision of care and treatment for this patient population from diagnosis through to the end of life. Furthermore, a recent systematic review of 162 papers encompassing 260 global sites from 65 countries identified an increased prevalence of COPD through advancing age (Adeloye *et al.*, 2022) . Given the global ageing population, the demand for care and treatment has the potential to continue to increase. The global distribution of COPD diagnosis presents variation, with the largest proportion of individuals diagnosed with COPD living in low to middle income countries, requiring guidelines to manage the condition throughout all stages of disease progression to be reflective of regional risk factors and available healthcare resources (Tabyshova *et al.*, 2021; Adeloye *et al.*, 2022). Furthermore, the requirement for culturally sensitive interventions to assist with the management of COPD are necessary.

2.3.2 – Socioeconomic Burden of COPD

The cost of care and treatment for COPD holds a significant global socio-economic burden, with a predicted demand of INT$ 4.326 trillion from the world economy between 2020 and 2050 (Chen *et al.*, 2023). The cost of palliative care provision, alongside the cost of informal carers needing to cease paid employment for someone with COPD is absent from this prediction, suggesting a significant underestimate. Within the United Kingdom, the economic impact of COPD has been assessed at £1.9 billion per annum upon society (British Lung Foundation, 2017). To develop informed policy and guidelines to meet the holistic needs of those living with COPD, an accurate understanding of the socioeconomic burden is necessary, given the symptom severity of the condition and associated cost of treatment and care.

2.4 – Symptom burden of COPD

Symptom burden refers to the personalised experience encompassing the physical and psychological manifestations of a condition, taking into account factors including the intensity, frequency, and emotional distress associated with these symptoms (Farrell and Savage, 2012). Variability of the impact of COPD symptoms on day-to-day life is often present, but not always dependent upon the severity of the disease (Kessler, Partridge and Miravitlles, 2011; Miravitlles and Ribera, 2017). The wider literature identifies changeability in the impact of symptom burden across annual seasons, alongside weekly and daily variations (Kessler, Partridge and Miravitlles, 2011; Tsiligianni *et al.*, 2011), presenting challenges in the development of interventions to address the impact upon non-static goals. The symptom burden of COPD when compared to those living with lung cancer has been found to be comparable at the point of referral to palliative care services (Wysham *et al.*, 2015), with the need for concurrent active treatment, alongside palliative management of symptoms to facilitate a holistic approach at the time of need (Carlucci, Guerrieri and Nava, 2012).

Breathlessness is the most commonly featured symptom of COPD, with evidence suggesting its impact beyond the physical, negatively influencing the individual's quality of life and their ability to undertake activities of daily living (Partridge, Karlsson and Small, 2009; Espinosa de los Monteros *et al.*, 2012). Breathlessness often leads to decreased exercise tolerance and physical activity in COPD patients, resulting in a sedentary lifestyle contributing to muscle weakness and deconditioning (O'Donnell *et al.*, 2020). The fear of breathlessness during activities can lead to avoidance behaviour, further limiting the individual's engagement in daily life and an associated increase in anxiety and depression (Bestal *et al.*, 1999; Miravitlles and Ribera, 2017). Breathlessness is a common reason for accessing healthcare services and hospitalisation amongst COPD patients, with exacerbations of the condition being the prominent cause (Chen *et al.*, 2023). Whilst medicinal treatments such as bronchodilator therapy and interventions including pulmonary rehabilitation are evidenced to offer some symptomatic improvement of chronic breathlessness in COPD, it often becomes more impactful throughout disease progression (Miravitlles, Worth and Soler Cataluña, 2014; Hutchinson *et al.*, 2018).

The impact of cough and sputum production in COPD is complex and plays a crucial role in the overall clinical picture of the condition. Persistent cough and increased sputum production are hallmark features of COPD, contributing significantly to the morbidity and quality of life of affected individuals due to the association with increased risk of exacerbation (Miravitlles, 2011). Persistent coughing can result in physical and social limitations, while the chronic production of sputum can lead to feelings of embarrassment and isolation (Cook *et al.*, 2019). Furthermore, such symptoms are reported to result in interruptions to sleep patterns for over

70% of those living with COPD, resulting in a lesser quality of life (Nunes *et al.*, 2009; Miravitlles, 2011; Valipour *et al.*, 2011).

Individuals with COPD encounter more significant challenges in psychological functioning such as symptoms of anxiety and depression compared to those with other chronic medical conditions, with a particularly high prevalence amongst those receiving palliative care (Solano, Gomes and Higginson, 2006; Pumar *et al.*, 2014; Miravitlles and Ribera, 2017). The presentation of anxiety and depression when living with COPD is thought to be 'bidirectional', with the use of cigarette smoking as a coping mechanism for anxiety and depression leading to an increase in COPD severity (Atlantis *et al.*, 2013; Yohannes and Alexopoulos, 2014). Symptoms of anxiety and depression can result in: feelings of fear, a lack of hope, reduced self-esteem and an increased dependence upon others, facilitating a cycle that then increases the desire to smoke and further exacerbates physical symptoms of the condition (Yohannes and Alexopoulos, 2014).

Living with the associated symptoms of COPD such as breathlessness, chronic cough and sputum production can significantly impact quality of life, with a prospective multicentre study of 791 participants demonstrating this (Monteagudo *et al.*, 2013). Quality of life is evidenced within some studies to deteriorate throughout disease progression (Zamzam *et al.*, 2012; Rafaela *et al.*, 2019). Contrastingly, the relationship between lung function impairment in COPD and quality of life is also described as weak, with some individuals describing a good quality of life despite poor lung function, and others with lesser lung function impairment reporting a disproportionate decline in quality of life (Brien, Lewith and Thomas, 2016). The relentless symptom burden of living with COPD, at whatever stage in disease progression is able to impact an individuals quality of life, and as such palliative treatment of symptoms alongside active management of the condition is required to provide holistic care to individuals (Carlucci, Guerrieri and Nava, 2012).

2.5 – Philosophy of Palliative Care

The philosophy of palliative care, rooted in a humanistic and patient-centred approach, encompasses a profound understanding of the complexities inherent in serious, life-limiting illnesses. Central to this philosophy is the acknowledgment that optimal care extends beyond conventional medical interventions, necessitating a holistic consideration of the physical, emotional, social, and spiritual dimensions of suffering (Saunders, 2001; World Health Organisation, 2019). Emphasising the enhancement of the overall quality of life for patients and families facing these challenges, compassionate and dignified care provision is required (Boston, Bruce and Schreiber, 2011). Palliative care emphasises open communication, shared decision-making and a holistic approach to managing symptoms and alleviating distress at any stage throughout illness progression and is not exclusively reserved for end-of-life situations (Carlucci, Guerrieri and Nava, 2012; Sorenson, 2013).

The philosophy of palliative care combines two traditional approaches to medicine, the Hippocratic and the Asklepian, to allow for the care and consideration of an individual as a whole (Lucas, 2018). The Hippocratic approach focusses upon the external interventions to treat commonly presenting symptoms of a condition (Lucas, 2018), whilst the Asklepian component is an approach to medical management and care focussed upon the facilitation of healing of an individual, beyond the physical symptoms of illness (Egnew, 2005). The term 'healing' within the context of palliative care philosophy refers to the process of moving an individual away from suffering, towards a sense of completeness that does not rely on achieving a cure (Kearney, 1996). Whist alleviation from suffering is presented as the overarching goal of palliative care, some suggest this needs to be approached with some realism, as in some situations this may not be possible in its entirety (Hartogh, 2017). This appears relevant when exploring the provision of palliative care for those living with COPD given the significant symptom burden affecting some both physically and existentially. Evaluation of the Hippocratic medical model for those living with advanced COPD is well evidenced, resulting in global healthcare policy largely focused upon the relief of physical disease progression symptoms (Gold Standard Framework, 2011; NICE, 2018; Global Initiative for Chronic Obstructive Lung Disease, 2023), including quality of care standards, the use of opiates and therapeutic oxygen to alleviate breathlessness. Less prevalent within the literature is the evaluation of perceptions and interventions linked to meeting the existential situation of those living with COPD and associated palliative care needs. Yet for individuals suffering from COPD, the associated symptoms and hardships are both physically and mentally exhausting and often occupy their whole life (Giacomini *et al.*, 2012).

2.6 – Palliative Care Provision in COPD

People living with COPD often receive more life-prolonging treatments and are less likely to receive palliative care when compared to those living with lung cancer, despite them living with a symptom burden estimated to be more impactful (Brophy, Greenstone and Gore, 2000; Carlucci, Guerrieri and Nava, 2012; Hyasat and Sriram, 2016). The palliative care needs for individuals living with COPD are present at varying stages within the disease trajectory, with early intervention in meeting these needs evidenced to improve quality of life (Iyer *et al.*, 2022).Furthermore, to address the holistic needs of those living with the unrelenting symptoms of COPD, active treatment and palliative care are required concurrently (Carlucci, Guerrieri and Nava, 2012; Janssen *et al.*, 2023), commencing at a point within disease progression defined by patient need (Farquhar, 2016; Iyer *et al.*, 2022).

Current healthcare policy and guidelines give significant focus to the palliative management of the physical COPD symptom burden, with pharmacological and intervention based recommendations made (NICE, 2018; Global Initiative for Chronic Obstructive Lung Disease, 2023; Janssen *et al.*, 2023). Whilst such policies acknowledge the need to meet a person's existential needs, little guidance is offered upon how to address this, despite evidence suggesting the need for healthcare professionals to be responsive to the signs of those experiencing such suffering (Elofsson and Ohlen, 2004). Wider palliative care policy advocates the use of tools to enable those living with life-limiting conditions to identify their own support needs (NHS National End of Life Care Programme, 2010; NICE, 2016). Such tools however, are largely focussed upon the burden of disease and offer limited guidance upon how to support individuals to manage within day-to-day life (Gardener, Ewing and Farquhar, 2019). The wider literature upon the palliative care needs for those living with COPD largely mirrors the guidance given through relevant policy, with study findings identifying the presence of symptoms and their impact upon individuals both physically and existentially (Elkington *et al.*, 2004; Gardiner *et al.*, 2010; White *et al.*, 2011). The absence of an understanding of the COPD disease trajectory for each individual, and how symptoms will progress throughout life is an identified support need for those living with the condition (Gardiner *et al.*, 2009, 2010; Gardener *et al.*, 2018). Furthermore, an identified need for emotional adaptation to the impact of living with COPD is recognised (Gardener *et al.*, 2018). Limitations are present within the wider literature upon the success of interventions aiming to explore exactly what a person requires when living with palliative care needs arising from COPD to meet their existential needs, and address elements of existential suffering. A recent contribution towards addressing this gap has been made through the development of the Support Needs Approach for Patients (SNAP) tool (Gardener *et al.*, 2019; Gardener, Ewing and Farquhar, 2019). The tool, co-created with individuals living with advanced COPD, facilitates individuals identifying what is of importance to them in daily life, and which elements they require support with, to enable person-centred discussions upon any unmet needs (Gardener *et al.*, 2019). Elements of the tool address potential areas of existential concern for those living with advanced COPD, such as understanding their illness to manage expectations alongside addressing future worries. This is a valuable contribution towards enabling the alleviation of potential existential suffering for those living with palliative care needs arising from COPD, and has potential to positively influence their psychological, emotional, and physical well-being (Yalom, 1980).

2.7 – Existential Suffering

Existential suffering encompasses the deep distress arising from profound questions about the nature of existence, the meaning of life, and the human experience (Yalom, 1980). It often emerges in moments of existential crisis, where individuals grapple with the uncertainties of their existence, the inevitability of mortality, and the search for life meaning and purpose (Frankl, 1968; Yalom, 1980; Tan and Wong, 2012). Existential suffering often leads to psychological distress via a sense of hopelessness, and a significant reduction in overall quality of life, impacting the ability to derive satisfaction and fulfilment from daily experiences (Frankl, 1963; Fagerström, Eriksson and Engberg, 1998). This impact is particularly pronounced in the context of chronic illness and palliative care (Chochinov *et al.*, 2005, 2016), necessitating the need for understanding and addressing of existential suffering to enable holistic and compassionate care delivery (Boston, Bruce and Schreiber, 2011).

The concept of existential suffering remains under researched for those living with COPD, especially the development of tools and interventions to assess, plan care for and identify the support needs of individuals to facilitate the alleviation of symptoms. Existential suffering is an individualised experience, and the absence of generalised resolutions explain the absence of routine care planning about this dimension (Bolmsjö, Hermerén and Ingvar, 2002). There is a need to explore the impact of existential suffering through integration of a collective body of evidence exploring the experiences of those living with palliative care needs arising from COPD to better understand the existential elements of importance to them and identify ways to support this patient population. This work has been undertaken and is presented within the integrative literature review within chapter three of this thesis.

2.8 – Chapter Summary

This chapter has given a background to the key elements under exploration within this doctoral study. COPD has been defined, and its causes and the process of diagnosis explained. The epidemiology of COPD has been explored, highlighting the significant prevalence, cause of mortality and socio-economic burden of the condition. The philosophy of palliative care is explored with a subsequent critical discussion upon the current guidance and provision of palliative care in COPD. This highlighted the need for further research upon the existential elements of palliative care for those living with COPD to allow identification of their support needs. The concept of existential suffering is then discussed within a palliative care context, highlighting the need for a review of available evidence of its impact for those living with palliative care needs arising from COPD. This review of the literature is presented within the next chapter (chapter three).

Chapter 3.0 – Integrative Literature Review

3.1 – Introduction

The aim of this integrative review was to synthesise the available evidence related to existential suffering within the lives of those living with palliative care needs arising from COPD and examine its importance in, alongside its influence upon day-to-day-life. Within this chapter, the methods of the integrative review are described, providing an overview of the search strategy and study selection processes. An integrative convergent synthesis approach was used to develop the review findings. This review was published within the Palliative Medicine journal on 19th February 2021:

Bolton, L. E., Seymour, J. and Gardiner, C. (2022) ‘Existential suffering in the day to day lives of those living with palliative care needs arising from chronic obstructive pulmonary disease (COPD): A systematic integrative literature review’, *Palliative Medicine*. SAGE Publications Ltd, pp. 567–580.

3.2 – Integrative Review Methods

An integrative approach was chosen to address the aims of this literature review to facilitate the integration of evidence from diverse research methodologies to develop a holistic understanding of existential suffering (Broome, 1993; Whittemore and Knafl, 2005). Integrative literature reviews assist in shaping future research studies, through highlighting gaps within the existing literature, contributing to the formation of research aims and objectives (Russell, 2005; Aveyard and Bradbury-Jones, 2019). The findings from this integrative review shaped the aim and objectives of this doctoral research study.

This review was guided by a checklist developed following the critical review of seventeen integrative review methodological publications (Soares *et al.*, 2014), to ensure methodological rigor and transparency of the review findings. Alongside this, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was utilised to structure the review search strategy and study selection phases (Page *et al.*, 2021).

3.3 – Search Strategy

Table 2.0 presents the pre-defined search terms collaboratively developed with a specialist health studies librarian, focussing upon two key themes to answer the review aim; COPD and existential suffering. To ensure a comprehensive literature search, a combination of subject headings and key text words were utilised.

Table 2.0 - Integrative Review Search Terms

COPD Terms (To search with 'OR')	**Existential Suffering Terms (To search with 'OR')**
Chronic Obstructive Pulmonary Disease COPD Emphysema Respiratory Disease Respiratory Conditions COPD Management COPD Treatment COPD Interventions COPD Exacerbation Pulmonary Disease Chronic Obstructive Airway Disease COAD Chronic bronchitis	Existential suffering Existential distress Meaninglessness Life-meaning Hopelessness Absence of hope Purposefulness Existential Existentialism Anxiety Anxiety management Depression Depressive Low mood Resilience Emotional Emotion Suffering Loneliness Hopelessness Meaning Meaning-making Worthlessness Existential therapy Existential anxiety Existential crisis Existential counselling Existential psychology Existential therapy Spirituality

From April 2019 to December 2019, nine databases were searched for relevant literature: Web of Science core collection, Cumulative Index of Nursing and Allied Health Literature, Cochrane Systematic Review database, Ethos – Thesis database, PsychINFO, SCOPUS, PROSPERO – Registration of Systematic Reviews, ASSIA and Google Scholar. A subsequent database search was undertaken in January 2021 to identify any further publications meeting the review inclusion criteria.

The search process involved an individual search of each term, followed by combining all terms using the Boolean operator 'OR' within each theme. Subsequently, the search results from both themes were then combined using the Boolean operator 'AND' to generate the final search results for each database. This process was completed for each of the nine databases searched. The reference lists of papers relevant to the review aim were subsequently studied to identify any further papers potentially meeting the review inclusion criteria. This did not generate any further papers for inclusion. No restrictions were placed upon publication dates; however, inclusion was limited to papers published in the English language.

3.4 – Study Selection

Study inclusion was determined through a methodical three-stage sifting process, which encompassed the evaluation of title, abstract, and full text. Pre-defined inclusion and exclusion criteria (Table 3.0), were applied at the full-text screening phase of study selection, as shown within figure 1.0.

Table 3.0 - Integrative Review Inclusion and Exclusion criteria

	Inclusion Criteria	Exclusion Criteria
Population	• Adults aged > 18years • Studies where the researcher has defined the participants as having advanced COPD by the use of one or more of the following descriptive indicators: • Advanced COPD • Severe COPD • Very severe COPD • End stage COPD • Palliative COPD • Palliative care needs • End of life needs • Studies where the palliative care needs of participants with advanced COPD have been acknowledged or their status is described as requiring a palliative approach to care. • Studies including participants with advanced COPD and associated palliative care needs within a study where another chronic disease population has been included and the results are able to be identified to each chronic disease group.	• Studies exploring existential suffering when living with advanced COPD where associated palliative care needs are not identifiable within the study

Thirty-five studies were included in the review: nineteen qualitative studies, four qualitative systematic reviews, nine quantitative studies, one mixed method study and two integrative reviews. Appendix A presents the study characteristics for each included paper.

Assessing the quality and risk of bias in integrative reviews poses a complex challenge with limited clear guidance available (Conn and Rantz, 2003; Whittemore and Knafl, 2005). To ensure a meaningful evaluation, a specific data evaluation tool was chosen for each type of included study (Conn and Rantz, 2003). The critical appraisal of each paper was undertaken using the following appraisal tools:

- Qualitative Studies: Critical Skills Appraisal Programme Checklist for Qualitative Research (2018)
- Quantitative Studies: Checklist for Quasi-Experimental Studies – The Joanna Briggs Institute (2017)
- Mixed Method Studies: Both above checklists were used for each component.

The quality assessment (Appendix B) appraised the methodological rigor and risk of bias for each included study. Each of the thirty-five studies included in the review demonstrated high methodological rigor and displayed minimal risk of bias.

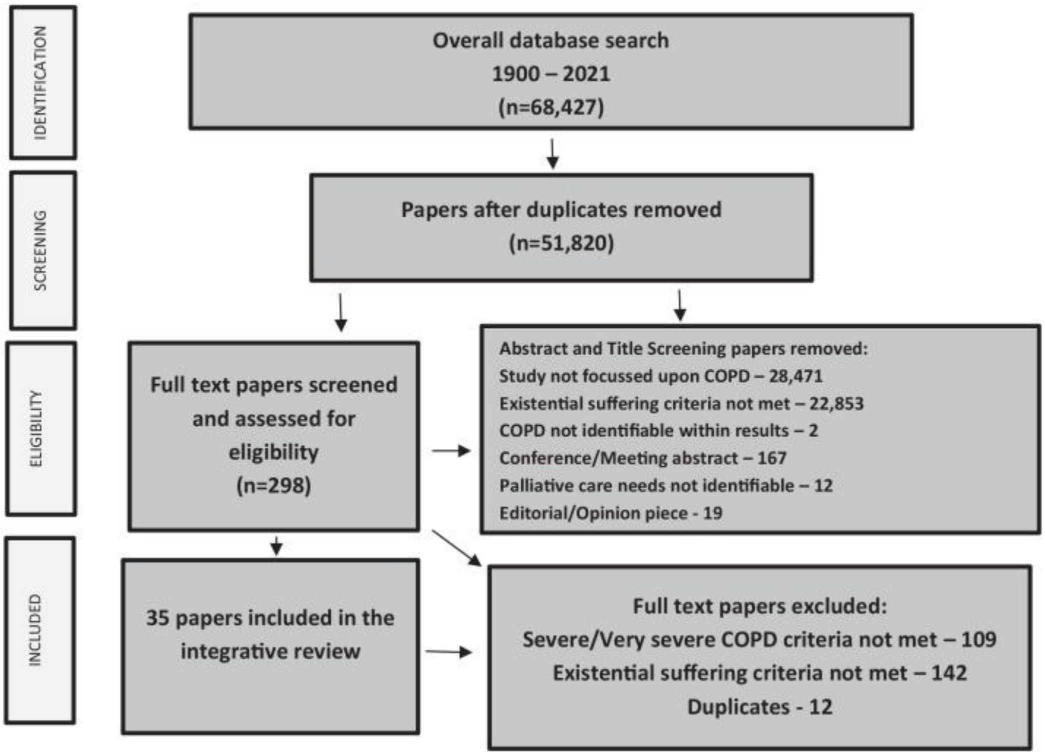


Figure 1.0 - PRISMA Flowchart

3.5 – Data Extraction and Synthesis

Data extraction from each study determined study characteristics and assessed study quality. A specifically designed data extraction tool, tailored for this integrative review, facilitated the organisation of study information, encompassing study aims, design, sample selection, data collection, analysis, and findings.

An integrated convergent synthesis approach to data analysis was employed to derive themes aligned with the review aims, as demonstrated within Figure 2.0. This process entailed identifying themes separately from the qualitative and quantitative studies, followed by recognizing meta-themes across all study types. This method minimised the emphasis on the methodological nuances of each paper, enabling the integration and synthesis of study findings based on their shared focus on the same concept (Noyes *et al.*, 2019). The qualitative data analysis software, QUIRKOS, was utilised for storing and organising the data into themes.

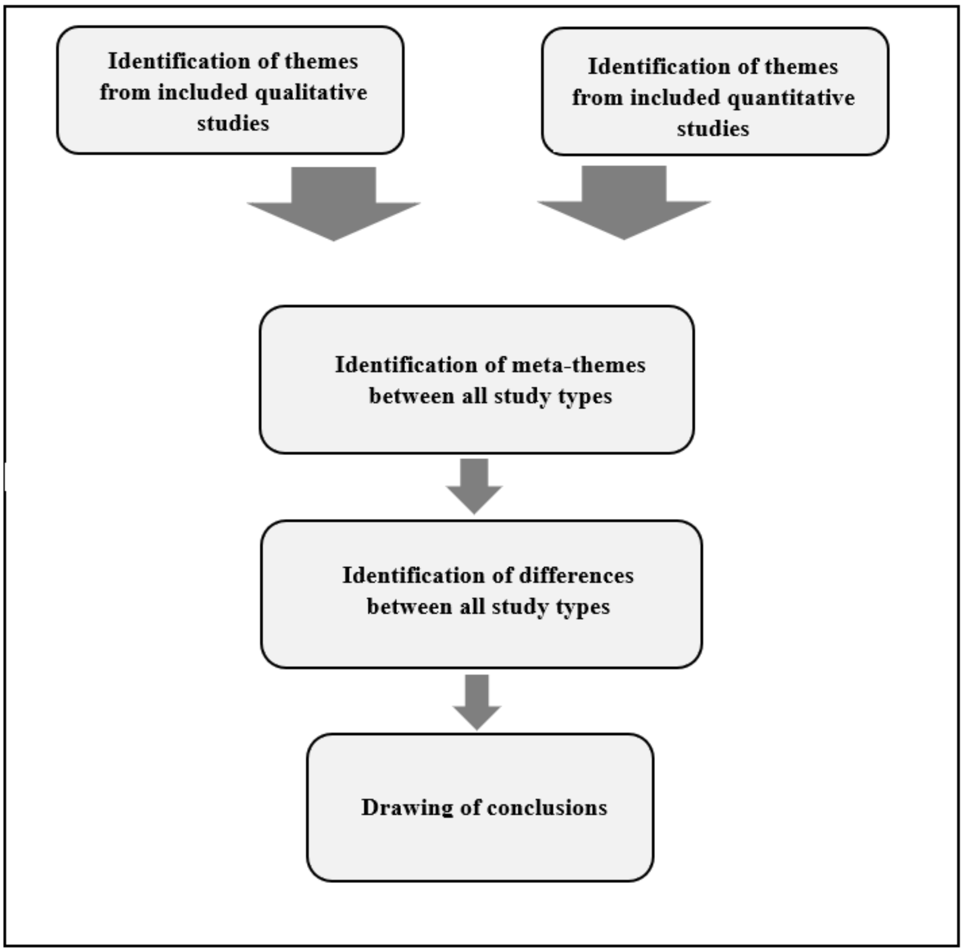


Figure 2.0 - Integrative Review Data Synthesis Process

3.6 – Integrative Review Findings

The review included thirty-five papers, from which the collective participant pool across these studies comprised of 1453 individuals, with 1090 having severe or very severe COPD. Identifiable data from participants at earlier stages of COPD progression or those without palliative care needs were deliberately excluded from this review. There were six systematic reviews (four qualitative reviews and two integrative reviews) addressing 215 studies (Disler *et al.*, 2014; Dunger *et al.*, 2015; Cruz, Marques and Figueiredo, 2017; Rosa *et al.*, 2017;

Gardener *et al.*, 2018; Russell *et al.*, 2018; Lovell *et al.*, 2019). Explorations of the disease experience and its meaning to those with COPD was the focus of fifteen studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Sheridan et al., 2011; Cooney et al., 2013; Low et al., 2013; Hayle et al., 2013; Disler et al., 2014; Gabriel et al., 2014; Stridsman et al., 2015; Dunger et al., 2015; Brien, Lewith and Thomas, 2016; Marx et al., 2016a; Harb, Foster and Dobler, 2017; Keil et al., 2017; Quaderi and Hurst, 2018). Three studies focussed upon elements of existential suffering when living with COPD (Chochinov et al., 2005; Olsman et al., 2015; Reijnders et al., 2018). Disease related anxiety and emotions were explored in four studies (Strang, Ekberg-Jansson and Henoch, 2013; Harrison et al., 2017; Rosa et al., 2017; Ivziku et al., 2019), with generalised patient concerns related to living with COPD in two further studies (Lindqvist and Hallberg, 2010; Lovell et al., 2019). One study explicitly explored end of life fears in COPD (Stenzel et al., 2015). Two studies identified the support needs of those living with COPD (Gardener et al., 2018; Gardener, Ewing and Farquhar, 2019) with two further studies exploring the impact of advanced COPD upon carers and family members (May et al., 2016; Cruz, Marques and Figueiredo, 2017).Established coping strategies used by those living with COPD were identified within two studies (Stenzel et al., 2015; Brien, Lewith and Thomas, 2016), and a further four studies evaluated the impact of interventions to assist coping when living with COPD (Doyle, 1992; Gale and Sultan, 2013; Russell et al., 2018; Vitacca et al., 2019). The integrated convergent synthesis of included studies revealed the presence of existential suffering within day-to-day life when living with palliative care needs arising from COPD.

Five distinct themes emerged (as shown within figure 3.0): Liminality, Loss of Personal Liberty, Lamented Life, Life Meaning, and Existential Isolation. The impact of each theme is multi-directional, with each component of existential suffering influencing the development of another.

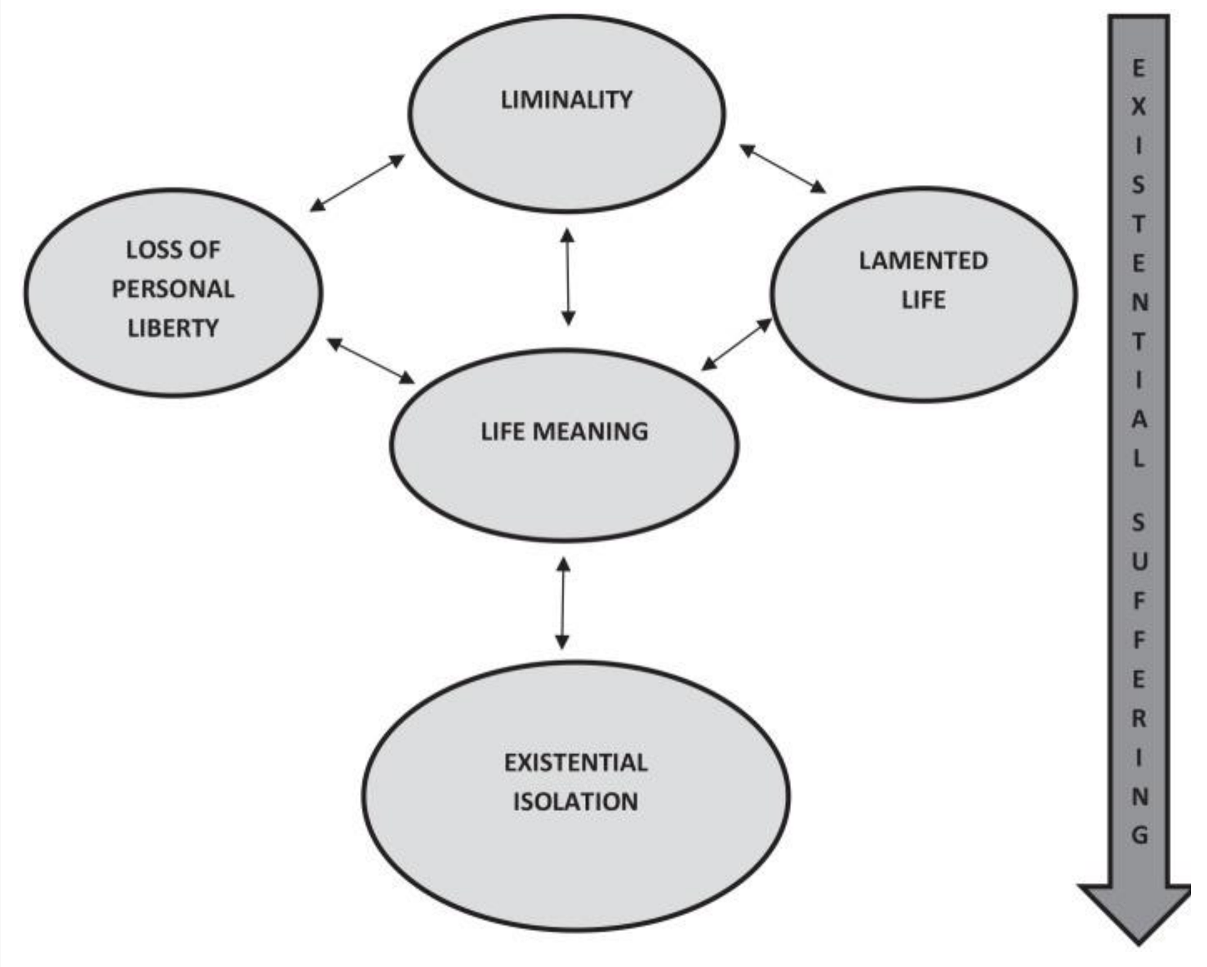


Figure 3.0 - Conceptual diagram of existential suffering for those living with palliative care needs arising from COPD

3.6.1 - Liminality

For individuals living with advanced COPD and associated palliative care needs, a prevalent sense of residing in a liminal space was identified from fifteen studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Ek et al., 2011; Cooney et al., 2013; Gale and Sultan, 2013; Disler et al., 2014; Gabriel et al., 2014; Dunger et al., 2015; Brien, Lewith and Thomas, 2016; Marx et al., 2016; Harrison et al., 2017; Rosa et al., 2017; Harb, Foster and Dobler, 2017; Lee et al., 2018). This experience involved grappling with an overwhelming sense of uncertainty, coupled with an ongoing effort to navigate the realities of their transformed lives through reflections on the past and considerations of the future.

Participants found themselves in a state where they no longer identified with their former selves yet found difficulty in defining their current identity. The emotions of loss and grief for their previous lives contributed to an uncertain outlook on their future selves, complicated further by the anticipation of how the progression of COPD would unfold.

Underpinning this theme of liminality, contributing to feelings of living between two lives, were four sub-themes: '*Disease non-acceptance'*, '*Attack on personal identity'*, '*Acceptance of a new you'* and '*Redefining own life role'*.

Disease non-acceptance

The denial of having COPD was evident in three of the included studies (Lindqvist and Hallberg, 2010; Disler et al., 2014; Dunger et al., 2015), contributing to a prolonged sense of living in this liminal space and hindering adaptation to new life circumstances. For those who had to some extent acknowledged the impact of the disease, this acceptance often felt compelled by the overwhelming burden of symptoms (Lindqvist and Hallberg, 2010; Marx et al., 2016). One participant, facing very severe COPD, expressed "*It won't become worse, at least that's what I imagine*" (Dunger et al., 2015) . Table 4.0 presents quotations from included studies to demonstrate this sub-theme. This denial stemmed from participants refusing to acknowledge their new limitations and adopting a *'just carry on*' attitude toward life (Brien, Lewith and Thomas, 2016; Rosa *et al.*, 2017). Despite being in a late stage of disease progression with a considerable symptom burden, there was a desire among participants for healthcare professionals to assist in accepting the reality of the disease (Brien, Lewith and Thomas, 2016). One participant articulated a wish for healthcare professionals to '*do something about it and get back to normal,*' indicating a persistent longing for a cure (Brien, Lewith and Thomas, 2016).

Table 4.0 - Disease non-acceptance quotations from included studies

Disease non-acceptance quotations from included studies	Source
'I still don't accept it…it's accepting, and accepting and moving on from it'	(Brien, Lewith and Thomas, 2016)
'Because that's what causes, it's the main factor in the depression. It is accepting and knowing my limitations'	(Brien, Lewith and Thomas, 2016)
'Helping somebody to help me to accept that that's what's happening... I know the cough's there I know I've got COPD, but that doesn't mean to say I'm going to accept it'	(Brien, Lewith and Thomas, 2016)
'I just want them to find something, do something about it and get me back to normal'	(Brien, Lewith and Thomas, 2016)
'It won't become worse; at least this is what I imagine'	(Dunger *et al.*, 2015)
'He continues to do things, but his behaviour has changed. I think he is more aggressive, because he cannot deal with the situation'	(Gabriel *et al.*, 2014)
'There's certain information that I don't want. The doctors, the nurses, especially Dr [name], he'd have an idea how long I'm going to last, but I don't want to know, not bothered'	(Disler *et al.*, 2014)
'I have learnt the disease and learnt to live with it, but that I haven't accepted it is another matter'	(Lindqvist and Hallberg, 2010)
'I felt very frustrated when I was feeling so ill, I couldn't accept this disease. It was impossible, but in the end I had to'	(Lindqvist and Hallberg, 2010)
'At first I didn't take any of it all that seriously ((sniffle)) (3) until last year, when nothing more was possible…'	(Marx *et al.*, 2016)

For those who had partially accepted the impact of the disease on their lives, the overpowering symptom burden played a significant role in this acceptance (Lindqvist and Hallberg, 2010; Marx *et al.*, 2016). One participant reflected on this, stating '*I didn't take any of it all that seriously ((sniffle)) until last year when nothing more was possible*' (Marx *et al.*, 2016). The absence of disease-specific information, either due to healthcare professionals not providing it, or patients choosing to remain uninformed, further influenced acceptance of the impact of living with COPD (Disler *et al.*, 2014; Brien, Lewith and Thomas, 2016). This reluctance to accept the reality of a life-limiting condition was further rooted in its impact on individuals' personal identity.

Attack on Personal Identity

The impact of living with advanced COPD and associated palliative care needs on an individual's self-perception and a longing for their former existence emerged in eleven of the included studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Ek *et al.*, 2011; Gale and Sultan, 2013; Disler *et al.*, 2014; Gabriel *et al.*, 2014; Brien, Lewith and Thomas, 2016; Marx *et al.*, 2016; Harrison *et al.*, 2017; Lee *et al.*, 2018). As shown within Table 5.0, a sense of embarrassment about their new personal identity was voiced from participants within included studies. This embarrassment was underpinned by anticipated perceptions of family members, friends, the general public, and healthcare professionals by the individual living with the condition (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Disler *et al.*, 2014; Lee *et al.*, 2018). This emphasised the influential role of an individual's social relationships and experiences upon them accepting their new personal identity.

Feelings of worthlessness and inadequacy in daily life underpinned feelings of shame and embarrassment (Ek and Ternestedt, 2008; Disler et al., 2014; Marx et al., 2016), continuing to present an attack upon individuals' personal identity. Participants were conscious of and influenced by how others perceived them, with one participant expressing concerns about the presence of oxygen therapy, *'then the oxygen keeps hissing and everyone asks: what is that? So you avoid going anywhere with it'* (Elofsson and Ohlen, 2004). Others felt the impact of no longer being able to carry out tasks they once did, which threatened their identity as individuals: '*Yeah, change of lifestyle completely from a doer to a non-doer*' (Disler et al., 2014).

Table 5.0 - Attack on Personal Identity Quotations from included studies

Attack on Personal Identity Quotations from included studies	Source
'And then you feel awful and at that point you just want to get away from everything, even commit suicide, you feel like there's just no point'	(Ek and Ternestedt, 2008)
'She grieved over her lack of stamina and felt unsuccessful because she did not even have the strength to walk short distances without taking a break'	(Ek and Ternestedt, 2008)
'I have one of those tubes in my stomach, and once it leaked and there was food all over the bed and on the floor. And I sat there in my bed in my sticky nightgown and they (the staff) came…it was so embarrassing'	(Ek and Ternestedt, 2008)
'but then you feel small…you feel really small…'	(Ek and Ternestedt, 2008)
'I can't talk when I'm short of breath, and then it sounds as if I'm angry when I try to get out what I want to say, and you think I'm angry [turns to her husband], but that's not the case, it's just that I don't have enough breath'	(Ek *et al.*, 2011)
'Some of them felt rather uncomfortable with this technology and used terms such as being 'bound to it' or 'captured by it'	(Elofsson and Ohlen, 2004)
'Then the oxygen keeps hissing and everyone asks: what is that? So you avoid going anywhere with it'	(Elofsson and Ohlen, 2004)
'I'm not the person I used to be (…) my family feels sad to see me this way'	(Gabriel *et al.*, 2014)
she felt like a 'dog on a lead'	(Gale and Sultan, 2013)
'distressed by the visibility of her breathing to others'	(Disler *et al.*, 2014)
'What she really wanted was to be inconspicuous in her breathing and for it to be automatic and invisible'	(Disler *et al.*, 2014)
'It's hard to explain because you can't see any difference, I still look the same'	(Disler *et al.*, 2014)
'yeah change of lifestyle completely from a doer to a non-doer'	(Disler *et al.*, 2014)
'I've gotten to the point where I can hardly function in my home anymore'	(Disler *et al.*, 2014)
I'm not a spectator, I like to be doing'	(Disler *et al.*, 2014)
'I watch them go out and potter. And then I feel bad, worthless'	(Disler *et al.*, 2014)
'She has to help me up the stairs. She has got to shower me. Help me get dressed. Basically, the stupid things that I should be able to do myself'	(Disler *et al.*, 2014)
'I've adapted to it now. I don't do anything full stop..'	(Brien, Lewith and Thomas, 2016)
'I'm just a piece of skin on bones that doesn't do a hell of a lot anymore because of my pain'	(Lee *et al.*, 2018)
'I don't want to realize that I've got this, I want to be the person I was'	(Lindqvist and Hallberg, 2010)
'At first I didn't take any of it all that seriously ((sniffles)) (3) until last year, when nothing more was possible…'	(Marx *et al.*, 2016)
'I mean the only thing that bothers me as far as other people go [cough] is my coughing. That can sort of embarrass me. Other than that . . . It's gross.'	(Harrison *et al.*, 2017)
'We [her partner] don't go out … Even the course that I'm doing at the moment I always sit two seats away from the next person… I'm very self-conscious…'	(Cooney *et al.*, 2013)
'Nobody wants to be near me in the mornings believe me … I get into the bathroom I know it's horrendously bad. I like to go away on my own because I know that I'd embarrass everybody …'	(Cooney *et al.*, 2013)
Participants talked about 'breathing problems', 'colds' and 'bad chests'. It is not clear whether this is because their doctor had not used the term 'COPD' or if this was a conscious decision not to take on the stigma of the disease	(Cooney *et al.*, 2013)
'... and then suddenly become a frail old man'	(Lindqvist and Hallberg, 2010)

The profound breathlessness experienced by individuals living with COPD led to some feeling misunderstood and frustrated, as effective communication without judgment became challenging*: 'I can't talk when I'm short of breath, and then it sounds as if I'm angry when I try* *to get out what I want to say, and you think I'm angry [turns to her husband], but that's not the case, it's just that I don't have enough breath'* (Ek *et al.*, 2011). The threat to personal identity forced one participant to become unable to identify meaning and purpose within life, to the extent of contemplating ending their own life: *'and then you feel awful and at that point you just want to get away from everything, even commit suicide, you feel like there's just no point'* (Ek and Ternestedt, 2008).

The stigma associated with accepting a COPD diagnosis was rooted in feelings of guilt, as the illness was often seen as self-inflicted, particularly due to its association with smoking. Accepting the impact of COPD meant accepting personal responsibility for these identity changes, which was a challenging process for individuals. Certain participants acknowledged the impact of advanced COPD on their identity without fully accepting the diagnosis, perceiving these changes as sudden (Lindqvist and Hallberg, 2010; Cooney *et al.*, 2013).

For some participants within included studies however, acceptance of changes to personal identity was evident.

Acceptance of a 'new you'

Seven studies presented findings indicating that participants had initiated the process of accepting their new identity as a coping mechanism for dealing with declining health and diminished quality of life (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Disler et al., 2014; Gabriel et al., 2014; Dunger et al., 2015; Brien, Lewith and Thomas, 2016; Rosa et al., 2017). Table 6.0 illustrates these participant perceptions.

Table 6.0 - Acceptance of a 'new you' Quotations from included studies

Acceptance of a 'new you' Quotations from included studies	Source
'It's not anything, it's accepting'	(Brien, Lewith and Thomas, 2016)
'I must adapt to the situation'	(Dunger *et al.*, 2015)
'There is no turning back. You can't puzzle your head with what it would have been like otherwise. You have to take life as it comes'	(Elofsson and Ohlen, 2004)
'Interviewer: Do you feel joy when thinking of past times? Mrs Eriksson: Yes, I do, because I've had a good life'	(Elofsson and Ohlen, 2004)
'We have to think about our day-to-day lives and think that there is always someone else that is worse than us'	(Gabriel *et al.*, 2014)
'Yes, in the beginning I would have liked a little bit more information. At least it prepares you for the general decline in health'	(Disler *et al.*, 2014)
'I don't know. I don't like fuss. I don't like being fussed about. I get embarrassed. I just don't like attention on me'	(Harb, Foster and Dobler, 2017)
'COPD patients' perspective was to 'just carry on' as best they could despite troublesome symptoms and limitations in functioning'	(Rosa *et al.*, 2017)

Expressing gratitude for past experiences and opportunities, as well as gaining perspective by comparing their lives with others, emerged as a strategy for adjusting to new life limitations (Elofsson and Ohlen, 2004; Gabriel *et al.*, 2014). This approach was underpinned by a strong sense of positivity; for instance, one participant allowed herself to experience joy when reminiscing: *'Interviewer: Do you feel joy when thinking of past times? Mrs. Eriksson: Yes, I do, because I have had a good life'* - (Elofsson and Ohlen, 2004). Through acceptance of a new personal identity because of COPD disease progression, some participants were able to begin to understand its influence on their new life role.

Redefining own life role

Alterations in an individual's role within both family units and society were observed in three studies (Elofsson and Ohlen, 2004; Gabriel *et al.*, 2014; Dunger *et al.*, 2015), as shown within Table 7.0. The redefinition of their life role was made possible through a combination of contentment with the limited functions they still had, and acceptance of the changes in their life role and the ability to accept help within day-to-day life.

Table 7.0 - Redefining of own life role Quotations from included studies

Redefining of own life role Quotations from included studies	Source
'I have to be satisfied with what I have'	(Elofsson and Ohlen, 2004)
'I must adapt to the situation'	(Dunger *et al.*, 2015)
'Now I can't do a thing for them [family], my wife is the leader and she is responsible for everything'	(Gabriel *et al.*, 2014)

3.6.2 – Lamented Life

The overarching theme of a lamented life, whereby participants described a lack of hope, a perceived absence of a future, and profound sadness about their current situation was evident within twenty-two studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Sheridan et al., 2011; Ek et al., 2011; Strang, Ekberg-Jansson and Henoch, 2013; Gale and Sultan, 2013; Disler et al., 2014; Gabriel et al., 2014; Olsman et al., 2015; Stenzel et al., 2015; Dunger et al., 2015; Brien, Lewith and Thomas, 2016; Chochinov et al., 2016; May et al., 2016; Harb, Foster and Dobler, 2017; Harrison et al., 2017; Lee et al., 2018; Reijnders et al., 2018; Russell et al., 2018; Ivziku et al., 2019; Vitacca et al., 2019; Gardener, Ewing and Farquhar, 2019).

Living with palliative care needs arising from COPD was portrayed as an ongoing series of losses. The liminal state in which participants found themselves influenced feelings of hopelessness and emptiness, underpinned by an inability to predict their future. Thoughts of grief regarding the loss of their former life translated into a perceived lack of life purpose (Ek and Ternestedt, 2008; Disler *et al.*, 2014), exacerbated by the inability to plan for a fulfilling future (Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Disler *et al.*, 2014; Dunger *et al.*, 2015; Brien, Lewith and Thomas, 2016; Lee *et al.*, 2018).

Four sub-themes underpinning the experienced lamented life were identified: hopelessness, worthlessness, fear and desolation.

Hopelessness

Thirteen studies (as illustrated in Table 8.0), revealed feelings of hopelessness in everyday life, highlighting participant's perceptions of having no future and deep sadness about their current circumstances (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Sheridan et al., 2011; Disler et al., 2014; Dunger et al., 2015; Olsman et al., 2015; Brien, Lewith and Thomas, 2016; Harb, Foster and Dobler, 2017; Lee et al., 2018; Vitacca et al., 2019; Ivziku et al., 2019). Thoughts and feelings of loneliness leading to immense sadness for those living with COPD are supported by emotions of grief and loss of their former life and abilities. (Ek and Ternestedt, 2008; Hotston and Keeley, 2013; Disler et al., 2014), with one participant describing: '*if you feel hopeless, you're not up to anything at all. You don't do anything. You just remain seated, and then you easily sink down*' (Olsman et al., 2015).

Feelings of hopelessness facilitated an absence of purpose in life (Ek and Ternestedt, 2008; Disler et al., 2014), impacting their emotional quality of life, as presented within two quantitative papers through the use of validated mental quality of life and anxiety and depression tools (Ivziku et al., 2019; Vitacca et al., 2019).

The absence of being able to plan a fulfilling future life was also a contributory factor to feelings of hopelessness (Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Disler et al., 2014; Dunger et al., 2015; Olsman et al., 2015; Lee et al., 2018).

Table 8.0 - Hopelessness Quotations from included studies

Hopelessness Quotations from included studies	Source
feeling of ‘*waiting for death’*	(Dunger *et al.*, 2015)
‘I cry when I’m alone, of course I do’	(Ek and Ternestedt, 2008)
‘Times like this are awful…you know how they talk about those black holes that people fall into and are supposed to climb out of again…that’s a pretty good comparison’	(Ek and Ternestedt, 2008)
‘First you don’t want to recognize that you’re repressing everything unpleasant…like sweeping it under the rug…but sometimes it all comes out anyway’	(Ek and Ternestedt, 2008)
‘At times like this I feel…I only want to cry…and then I think…no, God, ugh!!…this is no fun and I don’t want to live any more’	(Ek and Ternestedt, 2008)
‘I have nothing to look forward to…I’ve had these thoughts many times’	(Ek and Ternestedt, 2008)
‘So essentially my day consists of nothing more than resting and reading a little; no, this isn’t living, it’s just existing…I just am’	(Ek and Ternestedt, 2008)
‘So there’s a lot you have to give up, a great deal’	(Disler *et al.*, 2014)
‘We had a lot of ideas, but you know, ill health messed it all up’	(Disler *et al.*, 2014)
‘A spectator in life’	(Disler *et al.*, 2014)
‘The only problem is loneliness. but I can only blame myself. I could go out, but I usually just sit here’	(Disler *et al.*, 2014)
‘I have nothing to look forward to’	(Disler *et al.*, 2014)
‘I don’t believe in just living for the sake of living’	(Disler *et al.*, 2014)
‘I feel downhearted at times because everybody’s rushing after you and doing this and doing that’	(Harb, Foster and Dobler, 2017)
‘Right now it’s hurting me. It lasts for hours, maybe all day each day. It’s just not to the point where I am going to cry tears’	(Lee *et al.*, 2018)
‘I have given up, I can’t do nothing’	(Lee *et al.*, 2018)
‘Well, you feel a bit like—to put it in a nutshell—that it is rather pointless continuing’	(Lindqvist and Hallberg, 2010)
‘If she dies tomorrow, my wife, then I’ll die too. This is absolutely certain, because I can’t manage alone’	(Lindqvist and Hallberg, 2010)
‘These included psychological responses to limitations on everyday activities and relationships that led to social isolation, loss of hope and fear of death’	(May *et al.*, 2016)
‘So the hospital has already written me off as well’	(Olsman *et al.*, 2015)
‘If you feel hopeless, you’re not up to anything at all. You don’t do anything. You just remain seated, and then you easily sink down’	(Olsman *et al.*, 2015)
‘Now I just have to put up with it, now that I’ve got it um never gets any better’	(Sheridan *et al.*, 2011)
Patients depressive symptoms negatively influencing their MCS - MCS = Patients mental quality of life	(Ivziku *et al.*, 2019)
As shown in the figures the NT observed that patient’s problems were almost the same (overall bad days of life, negative emotions, and perception of disease deterioration), but became more marked as the health status got worse.	(Vitacca *et al.*, 2019)

Being unable to plan and carry out life events and activities in the future led to participants believing they had a pointless existence as a ‘*spectator in life’* (Disler et al., 2014), resigning themselves to the idea of a restricted and unfulfilling life being their only option with advanced COPD, generating feelings of worthlessness.

Worthlessness

Eight of the included studies presented perspectives relating to feelings of worthlessness within current life situations (Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Disler et al., 2014; Gabriel et al., 2014; Brien, Lewith and Thomas, 2016; May et al., 2016; Lee et al., 2018; Russell et al., 2018). The demise or absence of feeling useful within their daily lives fuelled feelings of being unable to accomplish tasks that had been once taken for granted, resulting in low self-esteem (Ek and Ternestedt, 2008; Disler et al., 2014; Gabriel et al., 2014; Lee et al., 2018), as demonstrated within Table 9.0. One participant perceived their life to be so worthless, they voiced '*If you were a dog, the RSPCA would have you up for keeping me alive'* (Disler et al., 2014). Observing others undertaking tasks previously able to have been completed independently led to feelings of immense sadness and worthlessness (Ek and Ternestedt, 2008; Gabriel et al., 2014). Furthermore, the inability to formulate any life ambition led to emotions of giving up on daily life, particularly with associated feelings of being a burden to others (May et al., 2016; Lee et al., 2018).

Overarching feelings of sadness and hopelessness due to the loss of their former identity and life was articulately expressed by one participant: *'Everything has changed; my whole life has changed. You begin to feel so worthless, and as if you should go to the guillotine'* (Lindqvist and Hallberg, 2010).

Table 9.0 - Worthlessness Quotations from included studies

Worthlessness Quotations from included studies	Source
'It's at the stage where they can do nothing for me now. The last appointment I had with the specialist they wrote me off. … they won't contact me anymore because there's nothing else they can do'	(Brien, Lewith and Thomas, 2016)
S described not even having the strength to walk short distances without having to stop to breathe all the time. This made her feel sad	(Ek and Ternestedt, 2008)
'I watch them go out and potter…and then I feel bad, worthless. I sit here and feel that I can't accomplish anything'	(Ek and Ternestedt, 2008)
'I used to do everything and now I can't do any of those things, I'm reduced to nothing'	(Gabriel *et al.*, 2014)
'I tell you, my house is my prison'	(Gabriel *et al.*, 2014)
'Everything changes, our lives turned upside down in all aspects, all! In terms of emotional states (…) our lives stopped!'	(Gabriel *et al.*, 2014)
'I hate housework now. I've got to get somebody, it's driving me crazy, I swear to God I've never had such a messy house'	(Disler *et al.*, 2014)
' I sit here and feel that I can't accomplish anything'	(Disler *et al.*, 2014)
'If you were a dog, the RSPCA would have you up for keeping me alive'	(Disler *et al.*, 2014)
'It stopped everything in its tracks (had to stop work), yeah change of lifestyle completely from a doer to a non-doer'	(Disler *et al.*, 2014)
'It really, really stops your flow of motion and when I have no flow of motion then I have no ambition. It takes away from what you can do, then it takes away from what you want to do	(Lee *et al.*, 2018)
'Everything has changed; my whole life has changed. You begin to be so worthless, and as if you should go to the guillotine'	(Lindqvist and Hallberg, 2010)
Feelings of worthlessness and burdensomeness were commonly experienced. Some reviews suggested that they were experienced more acutely by women	(May *et al.*, 2016)
'you can exercise all you want, but if your heart is aching, you're feeling depressed, you'll give up'	(Russell *et al.*, 2018)

Fear

Symptoms of extreme breathlessness influenced significant feelings of fear about dying for those within included studies (Ek *et al.*, 2011; Strang, Ekberg-Jansson and Henoch, 2013; Disler *et al.*, 2014; Brien, Lewith and Thomas, 2016). Fear resulted in participants further isolating themselves from meaningful socialisation opportunities due to the risk of becoming breathless (Strang, Ekberg-Jansson and Henoch, 2013), and anxieties about being away from medications, such as their nebuliser, known to facilitate a feeling of security (Brien, Lewith and Thomas, 2016). One quantitative study presented findings showing that the presence of anxiety and depression, alongside decreased walking ability were statistically significant predictors of fear of dying (Stenzel *et al.*, 2015).

Table 10 - Fear Quotations from included studies

Fear Quotations from included studies	Source
'it put me in [a] fear state really because I didn't want to leave my nebuliser'	(Brien, Lewith and Thomas, 2016)
'Maybe the worst thing is not knowing whether I'll be able to cope'	(Ek *et al.*, 2011)
'I thought oh God! This isn't terminal! Not me'	(Disler *et al.*, 2014)
'That's why I was curious, but at the same time afraid of knowing what was left'	(Disler *et al.*, 2014)
'which I do get and really terribly out of breath as a result, then it's very frightening'	(Disler *et al.*, 2014)
'It's scary, the more you try to calm yourself down and regulate your breathing to get the deep breaths in, it's like trying to choke yourself at the same timed I wouldn't wish it on anyone'	(Disler *et al.*, 2014)
'But it is the most frightening thing that I have ever experienced'	(Disler *et al.*, 2014)
'It felt just like I was about to die. It's that damned fear when you can't get enough air. It's so hard to imagine. Not being able to get enough air. It feels like I'm suffocating'	(Strang, Ekberg-Jansson and Henoch, 2013)
I'm afraid to go out. The last time I went out I thought, oh my God, is this it?'	(Strang, Ekberg-Jansson and Henoch, 2013)
'Well, I don't know how to put it; I'm afraid of dying'	(Strang, Ekberg-Jansson and Henoch, 2013)
'I've lived my life. But I don't want to die yet'	(Strang, Ekberg-Jansson and Henoch, 2013)

Desolation

The feeling that participants did not have a meaningful life existence led to feelings of desolation as reported in seven studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Ek *et al.*, 2011; Sheridan *et al.*, 2011; Gale and Sultan, 2013; Disler *et al.*, 2014; Reijnders *et al.*, 2018). This sub-theme differs from that of loneliness, as participants described as sense of abandonment and desertion as opposed to describing the unhappiness felt through loneliness. Descriptions of life being empty with little reward (Table 11) resulted in participants feeling abandoned and deserted (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Disler *et al.*, 2014), with participants believing friends no longer chose to socialise with them due to their medical condition; '*It's been lonely since my friends disappeared… I think they were scared…they didn't know how to deal with this, after all, it's a fatal disease …they didn't know how they should treat me'* (Ek and Ternestedt, 2008). Feelings of loneliness were further described due to the loss of socialising and becoming housebound; '*and if you lose the social aspect, when everyone else comes home from work, I have nothing new to share'* (Ek and Ternestedt, 2008).

Input from healthcare professionals was identified as a required area for development within two studies (Ek and Ternestedt, 2008; Ek *et al.*, 2011), who revealed more emphasis should be given upon addressing social situations of those living with advanced COPD; *'the healthcare staff never ask about this……but it's the social aspect that's important'* (Ek and Ternestedt, 2008), suggesting they would welcome the facilitation of meaningful interventions to fulfil their desire to have meaning within their daily lives.

Table 11 – Desolation Quotations from included studies

Desolation Quotations from included studies	Source
'It's been lonely since my friends disappeared…I think they were scared…they didn't know how to deal with this, after all, it's a fatal disease…they didn't know how they should treat me'	(Ek and Ternestedt, 2008)
'S described that when these friends could no longer handle seeing her condition worsen, they withdrew'	(Ek and Ternestedt, 2008)
'The only problem is loneliness…but I can only blame myself…I could go out, but I usually just sit here'	(Ek and Ternestedt, 2008)
'And if you lose the social aspect, when everyone else comes home from work, I have nothing new to share'	(Ek and Ternestedt, 2008)
'the healthcare staff never ask about this…but it's the social aspect that's important'	(Ek and Ternestedt, 2008)
'I cry when I'm alone, of course I do'	(Ek and Ternestedt, 2008)
'No, no one has asked about me. Sometimes I wish someone would ask how we're doing here at home'	(Ek *et al.*, 2011)
'So I live as long as I live. Life isn't very rewarding, certainly not'	(Elofsson and Ohlen, 2004)
'I mean, you know, it's the old syndrome, isn't it, you're on your own, I mean, the best thing that's happened to me is having them windows there, you can see what's going on outside'	(Gale and Sultan, 2013)
'It just goes so slowly'	(Disler *et al.*, 2014)
'I am not as happy as I used to be. I don't go to see my friends anymore'	(Sheridan *et al.*, 2011)
About 46% of patients experienced moderate-to-very severe loneliness	(Reijnders *et al.*, 2018)

3.6.3 – Loss of Personal Liberty

Twenty studies reported how living with advanced COPD removed choice in life, and the associated impact upon life meaning (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Apps *et al.*, 2013; Low *et al.*, 2013; Strang, Ekberg-Jansson and Henoch, 2013; Cooney *et al.*, 2013; Gale and Sultan, 2013; Disler *et al.*, 2014; Gabriel *et al.*, 2014; Stridsman *et al.*, 2015; Dunger *et al.*, 2015; Brien, Lewith and Thomas, 2016; Marx *et al.*, 2016; Rosa *et al.*, 2017; Russell *et al.*, 2018; Lovell *et al.*, 2019; Ivziku *et al.*, 2019).

Feelings of frustration were presented (Table 12), through participants no longer being able to undertake pleasurable life activities and hobbies; *'I used to love to dance. I can't any more……Anything physical is gone now as I haven't got the breath'* (Cooney *et al.*, 2013).

Further frustrations were voiced through participant's inability to undertake the activities of daily living they previously could, such as meeting their personal hygiene needs, mobilising and going shopping (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Cooney *et al.*, 2013; Disler *et al.*, 2014; Brien, Lewith and Thomas, 2016). In turn, this loss of ability caused one participant to grieve their former life: *'there's a lot you can't do…a great deal, and much you have to give up….'* (Ek and Ternestedt, 2008), leaving them in a life absent from meaning and purpose.

Table 12 – Loss of Personal Liberty Quotations from included studies

Loss of Personal Liberty Quotations from included studies	Source
'I'm quite sedentary'	(Brien, Lewith and Thomas, 2016)
'It's silly…because I can't breathe I can't do the exercise and I can't do nothing'	(Brien, Lewith and Thomas, 2016)
'I have to think what I'm going to do and how much breath I'm going to need to do it, so I'm permanently thinking about it….'	(Brien, Lewith and Thomas, 2016)
'It stops me gardening and it bothers me that way. I get frustrated with not being able to do things..... I've adapted to it now..'	(Brien, Lewith and Thomas, 2016)
'I used to go down fishing on the rocks … fairly regularly, but now there's always a bit of a walk and a climb attached to it … I would still, I think, enjoy it just as much but I'm just not inclined to do it'	(Cooney *et al.*, 2013)
'I don't walk much now because I know that it would [make me breathless] I avoid anything that would … I do the usual housework only to do it at my own pace. If I feel like doing it I do it. If I feel like not doing it I sit down, and that's it'	(Cooney *et al.*, 2013)
'There's a lot you can't do…a great deal, and much you have to give up…for example, do I have the strength to go out now?'	(Ek and Ternestedt, 2008)
'I don't do much now...as I can't do anything, I can just as well lie where I am.. .There hasn't been any work done lately'	(Elofsson and Ohlen, 2004)
'I would like to be able to go to the shopping mall, but that takes so much energy, so much energy, that it would have to be really necessary'	(Disler *et al.*, 2014)
'Sometimes I can't walk from here into the back kitchen, I'm that short of breath, I get breathless even going to the toilet'	(Disler *et al.*, 2014)
'It takes me so long to just get dressed'	(Disler *et al.*, 2014)
'now I'm refined to just doing a couple of things a day'	(Disler *et al.*, 2014)
'And the simplest tasks now are a big effort'	(Disler *et al.*, 2014)
'I've gotten to the point where I can hardly function in my home anymore'	(Disler *et al.*, 2014)
'Just from putting my shoes on in the morning, even that can make me breathless'	(Brien, Lewith and Thomas, 2016)

Meaninglessness in a Shrinking World

The absence of meaning in participants daily lives was present within seven studies, as displayed within Table 13 (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Ek *et al.*, 2011; Gale and Sultan, 2013; Disler *et al.*, 2014; Gabriel *et al.*, 2014; Lovell *et al.*, 2019). Feelings of life being '*just an existence'* were evident, with one participant describing their meaningless day: *'So essentially my day consists of nothing more than resting and reading a little; no, this isn't living, it's just existing…..I just am'* (Ek and Ternestedt, 2008). Further descriptions of meaninglessness within their lives portrayed a sentiment of the absence of joy (Table 13), due to being physically and socially restricted from any meaningful activities or interactions; *'it's like you are on a leash, tied to a regimen'* (Disler *et al.*, 2014). Study findings showed that as

COPD progressed, individuals experienced a range of gradually increasing restrictions to participation in activities outside of home (Elofsson and Ohlen, 2004; Disler *et al.*, 2014). The impact of existing in a life without meaning caused some participants to wish they were no longer living (Ek and Ternestedt, 2008), with one participant discussing feelings of suicide, *'and then you feel awful and at that point you just want to get away from everything, even commit suicide, you feel like there's just no point'* (Ek and Ternestedt, 2008). An overwhelming sub-theme underpinning a lack of life meaning was that of a restricted life, the main contributor to their shrinking world.

Table 13 – Meaninglessness in a Shrinking World Quotations from included studies

Meaninglessness in a Shrinking World Quotations from included studies	**Source**
'And then you feel awful and at that point you just want to get away from everything, even commit suicide, you feel like there's just no point'	(Ek and Ternestedt, 2008)
'life seemed meaningless and then she thought about committing suicide'	(Ek and Ternestedt, 2008)
'S described that life sometimes felt so meaningless that she wanted to die'	(Ek and Ternestedt, 2008)
'I have nothing to look forward to…I've had these thoughts many times'	(Ek and Ternestedt, 2008)
'So essentially my day consists of nothing more than resting and reading a little; no, this isn't living, it's just existing…I just am'	(Ek and Ternestedt, 2008)
'...time goes by, but it's not very inspiring'	(Elofsson and Ohlen, 2004)
'I don't think I have my home here...this is not a real home'	(Elofsson and Ohlen, 2004)
'The risk of losing control over your life was also part of the experience of homelessness'	(Elofsson and Ohlen, 2004)
'There are some days that I prefer to be alone, in those days, I have no joy to go out'	(Gabriel *et al.*, 2014)
'the technologies required to manage their COPD remained highly visible'	(Gale and Sultan, 2013)
'If I'm honest, I have to say that I live in that chair for 99% of the time'	(Disler *et al.*, 2014)
'like you are on a leash, tied to a regimen'	(Disler *et al.*, 2014)
'I haven't done anything I like to do'	(Disler *et al.*, 2014)
'Last winter, I didn't go out at all'	(Disler *et al.*, 2014)
'A spectator in life'	(Disler *et al.*, 2014)

<u>*Restricted Life*</u>

The inevitable life restrictions when living with advanced COPD resulted in a lack of life freedom to undertake tasks and hobbies, as presented within table 14 (Cooney *et al.*, 2013; Gabriel *et al.*, 2014; Dunger *et al.*, 2015; Marx *et al.*, 2016; Harrison *et al.*, 2017). Restrictions on the ability to leave home were found to have the greatest impact, with some reporting abstinence from physical or social activities due to the experienced symptom burden (Low *et al.*, 2013; Gabriel *et al.*, 2014; Rosa *et al.*, 2017). This negatively perceived change in lifestyle, with associated feelings of loneliness and meaninglessness, contributed to the feeling of living in a shrinking world.

Table 14 – Restricted Life Quotations from included studies

Restricted Life Quotations from included studies	Source
'I think the breathlessness without a doubt reduces the freedom and the randomness with which you would live your life'	(Cooney *et al.*, 2013)
'To be able to do your own thing [is limited]'	(Cooney *et al.*, 2013)
'It depends on my pace if I go too fast, if I'm stressed out'	(Cooney *et al.*, 2013)
'You have to slow down. You can't go like other, normal people can'	(Cooney *et al.*, 2013)
'It does restrict me 'cause I can't go anywhere'	(Cooney *et al.*, 2013)
'The whole life has completely changed. (. . .) I love traveling, and I love life. In the past, I was out every day; this is not possible anymore. I can't do it anymore'	(Dunger *et al.*, 2015)
'I wish I could do more things, I wish I could go to work but I know that this [disease] will end up with me'	(Gabriel *et al.*, 2014)
'I'm restricted to my home'	(Gabriel *et al.*, 2014)
'I gave up things that could make me happy outside the home'	(Gabriel *et al.*, 2014)
'I stay at home instead of going out with my sisters. Now we talk more on the phone, I'm living a very isolated life'	(Gabriel *et al.*, 2014)
'We don't go for a walk, on vacations, family reunions have ended. We are very isolated'	(Gabriel *et al.*, 2014)
'unless I've got an hospital appointment I don't go out for weeks'	(Gale and Sultan, 2013)
'I can't even get in the garden now. No, because it's sloped and I can get down a bit but when it comes to coming back, it's Everest, to be honest, it's terrible, like, you know, a slight slope it's absolutely terrible'	(Gale and Sultan, 2013)
'It is my breathlessness; I can't walk far, so I am very handicapped'	(Lindqvist and Hallberg, 2010)
The model presented one statistically significant actor effect with patients' depressive symptoms negatively influencing their PCS - PCS = Patients physical quality of life	(Ivziku *et al.*, 2019)
The data indicated participants perceived the psychosocial impact of COPD to be their least and activity limitations as their most onerous health limitation	(Low *et al.*, 2013)
However, for many, coping simply meant limiting those factors that sometimes led to a total cessation of an activity	(Rosa *et al.*, 2017)

3.6.4 - Existential Isolation

Isolation in social, personal and family relationships was evident for participants within fifteen included studies (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Sheridan *et al.*, 2011; Ek *et al.*, 2011; Cooney *et al.*, 2013; Disler *et al.*, 2014; Gabriel *et al.*, 2014; Stenzel *et al.*, 2015; Cruz, Marques and Figueiredo, 2017; Harb, Foster and Dobler, 2017; Reijnders *et al.*, 2018; Russell *et al.*, 2018; Gardener *et al.*, 2018; Lovell *et al.*, 2019; Gardener, Ewing and Farquhar, 2019).

Social Relationships

Ten studies presented the greatest challenge for those living with advanced COPD to be maintaining social relationships (Elofsson and Ohlen, 2004; Sheridan *et al.*, 2011; Cooney *et al.*, 2013; Disler *et al.*, 2014; Gabriel *et al.*, 2014; Harb, Foster and Dobler, 2017; Keil *et al.*, 2017; Gardener *et al.*, 2018; Reijnders *et al.*, 2018; Gardener, Ewing and Farquhar, 2019; Lovell *et al.*, 2019). As demonstrated within Table 15, opportunities to meet with friends and socialise within local communities were limited, and in some cases impossible (Elofsson and Ohlen, 2004; Sheridan *et al.*, 2011; Disler *et al.*, 2014). This fuelled feelings of loneliness and meaninglessness within their lives, and was coupled with a lack of emotional support from social networks (Gardener *et al.*, 2018). Alongside this, some believed their friends were unable to understand and accept how the disease had changed them, and had therefore distanced themselves from a supportive friendship (Ek and Ternestedt, 2008).

Table 15 – Social Relationship Quotations from included studies

Social Relationship Quotations from included studies	Source
'I used to go up to a cousin of mine for maybe a week or whatever. I can't go there anymore'	(Cooney *et al.*, 2013)
'I have no opportunity to meet with old friends. That's a disadvantage'	(Elofsson and Ohlen, 2004)
'I don't go to my relatives' house, I don't go'	(Gabriel *et al.*, 2014)
I'm restricted to my home'	(Gabriel *et al.*, 2014)
'I stay at home instead of going out with my sisters. Now we talk more on the phone, I'm living a very isolated life'	(Gabriel *et al.*, 2014)
'I haven't seen many people this past month'	(Disler *et al.*, 2014)
'Last winter, I didn't go out at all'	(Disler *et al.*, 2014)
'if you lose the social aspect, when everyone else comes home from work, I have nothing new to share'	(Disler *et al.*, 2014)
'I have no opportunity to meet with old friends'	(Disler *et al.*, 2014)
Emotional support was also described in relation to the networks that patients build with their families, peers, and health care professionals	(Gardener *et al.*, 2018)
'Because I don't look as though I'm ill, the upsetting thing is that people don't believe you, they think you're putting it on, sometimes even friends and family'	(Russell *et al.*, 2018)
'I am not as happy as I used to be. I don't go to see my friends anymore'	(Sheridan *et al.*, 2011)
About 46% of patients experienced moderate-to-very severe loneliness	(Reijnders *et al.*, 2018)
In step 3, time since initial diagnosis, illness perceptions, problem-focused coping, depressive coping, and looking for social inclusion were significant predictors of mental HRQoL	(Stenzel *et al.*, 2015)
'S described that friends could no longer handle seeing her condition worsen, they withdrew'	(Ek and Ternestedt, 2008)

Included quantitative studies identified the significant loneliness experienced by those living with advanced COPD, with searching for social inclusion opportunities being identified as a significant predictor of mental health related quality of life (Stenzel *et al.*, 2015; Reijnders *et al.*, 2018). The overwhelming feeling of loneliness extended the presence of meaninglessness in life and were deepened by the changes and required adaptations to intimate and family relationships.

Personal and Family Relationships

The changes to intimate and close family relationships for those living with advanced COPD and associated palliative care needs were explored across six of the included studies (Ek and Ternestedt, 2008; Ek *et al.*, 2011; Cooney *et al.*, 2013; Disler *et al.*, 2014; Cruz, Marques and Figueiredo, 2017; Lovell *et al.*, 2019).Participants felt increasingly lonely and frustrated due to a sense of being misunderstood by their spouse or partner (Table 16). Perceptions of how the disease has impacted upon intimate relationships, forced a reshaping of personal relationship dynamics in order to cope (Ek *et al.*, 2011; Gabriel *et al.*, 2014). Frustrations were more pertinent if a spouse had taken on the role of carer, with one participant voicing how they felt misunderstood when communicating through severe breathlessness; *'I feel that sometimes I am a little bit aggressive in my answers, but she [wife] needs to understand my problems. She doesn't understand me'* (Gabriel *et al.*, 2014). Furthermore, feelings of embarrassment from accepting help from a spouse or partner affected the dynamic of their relationship resulting in reluctance to ask for assistance; *'She [wife] helps me with everything, but most of the times I do not ask for help because I feel embarrassed'* (Gabriel *et al.*, 2014).

The absence of intimate sexual relations between couples was identified as a contributory factor to existential isolation within their personal relationship across five studies (Ek *et al.*, 2011; Cooney *et al.*, 2013; Disler *et al.*, 2014; Cruz, Marques and Figueiredo, 2017; Lovell *et al.*, 2019). As a result of the unrelenting symptom of breathlessness, undertaking sexual activity became in most cases impossible, leading to feelings of disconnection with their partner. Within one study, a participant voiced they would still *'like to cuddle and that sort of thing'* (Ek *et al.*, 2011), suggesting that the desire to remain in a close intimate relationship remained present despite their current health status.

Dynamic changes to close family relationships were also evident, through the lack of ability to participate in activities with their loved ones. One participant with young children voiced her sadness of having to decline playing with them due to her severe breathlessness and exhaustion (Cooney *et al.*, 2013).

Table 16 – Personal and Family Relationship Quotations from included studies

Personal and Family Relationship Quotations from included studies	Source
'Making love, I can't make love very often because I can't breathe'	*(Cooney et al., 2013)coon*
'I can't walk. [I can't] go running with the kids or play with them because I'm out of breath after 5 minutes. They're only young and they keep saying 'Will you play table tennis with me mammy?' 'I'm not able to, honey'. I'm drained all the time.'	*(Cooney et al., 2013)*
Patients' negative attitudes/behaviours (e.g. resistance in participating in daily activities or treatment regimens) were profoundly distressing and contributed to a loss	*(Cruz, Marques and Figueiredo, 2017)*
Spouses also reported changes in sex	*(Cruz, Marques and Figueiredo, 2017)*
Due to the disease, they had shifted from an active to a slower rhythm of life	*(Ek et al., 2011)*
The couples had to reshape their relationships to cope with their new circumstances	*(Ek et al., 2011)*
The physical intimacy of the relationship had changed over time and now involved different forms of expression	*(Ek et al., 2011)*
'Maybe the hardest thing is that I'm just not up to having sex anymore [pauses for breath], I'm too sick and that's really hard [cries].'	*(Ek et al., 2011)*
'You just have to accept things as they are. In the long run it's not 100 percent important either. Now we are thankful as long as we still have each other.'	*(Ek et al., 2011)*
'But I'd like to cuddle and be close and that sort of thing. [silence]'	*(Ek et al., 2011)*
'The care and concern are excessive; she [wife] is extremely concerned with me'	*(Gabriel et al., 2014)*
'She [wife] helps me with everything, but most of the times I do not ask for help because I feel embarrassed'	*(Gabriel et al., 2014)*
'I feel that sometimes I am a little bit aggressive in my answers, but she [wife] needs to understand my problems. She doesn't understand me!'	*(Gabriel et al., 2014)*
'From totally personal things, like intercourse. out of the question!'	*(Disler et al., 2014)*
'She [my wife] sometimes doesn't under- stand'	*(Disler et al., 2014)*
'It has an awful effect on my life. Making love, I can't make love very often because I can't breathe'	*(Lovell et al., 2019)*
'But I'd like to cuddle and be close and that sort of thing [silence]'	*(Ek et al., 2011)*

3.6.5 – Life Meaning

Within 15 included studies, participants described elements within their daily lives that facilitate a sense of meaning and purpose, through the limited activities they can carry out. This allowed for distraction from their illness and current health state (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Sheridan *et al.*, 2011; Strang, Ekberg-Jansson and Henoch, 2013; Hayle *et al.*, 2013; Disler *et al.*, 2014; Stridsman *et al.*, 2015; Dunger *et al.*, 2015; Brien, Lewith and Thomas, 2016; Doyle *et al.*, 2017; Keil *et al.*, 2017; Reijnders *et al.*, 2018; Gardener *et al.*, 2018; Vitacca *et al.*, 2019). Furthermore, attitudes towards their illness influenced how they adapted to life limitations and were still able to identify contributions to society giving them a sense of purpose; *'I have so much to give – I'm great with teenagers, I'm a good grandmother, I'm a good wife, that's what I believe'* (Ek and Ternestedt, 2008). Feelings of inner peace and acknowledgement of contributions to society created a sense of life meaning: *'I am at peace with myself because I did nothing purposely in harming others and I did not owe anybody anything that I did not return in my life'* (Disler *et al.*, 2014).

Activities

Maintaining or discovering new activities within daily life enabled participants to identify meaning and a sense of purpose (Table 17). Undertaking hobbies within their physical limitations provided participants with a focus for their time, and allowed them to identify a sense of achievement (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Brien, Lewith and Thomas, 2016). Activities such as reading, playing the piano and '*pottering round the house'*, were identified as resulting in pleasure. Assisted trips outside of the home, and feeling connected to society by looking out of the window further enhanced feelings of pleasure and meaning (Ek and Ternestedt, 2008; Strang, Ekberg-Jansson and Henoch, 2013). Caring for and interacting with pets underpinned feelings of meaningfulness, with one study reporting many participants had described *'their dog as being the most meaningful creature in their life'* (Strang, Ekberg-Jansson and Henoch, 2013).

Table 17 – Activities Quotations from included studies

Activities Quotations from included studies	Source
'It was great to have that feeling again, that you could get out and enjoy nature, just like in the old days'	*(Ek and Ternestedt, 2008)*
'And then I try to do my morning chores, my husband makes the beds and things…and then I potter about as usual and pick a few flowers'	*(Ek and Ternestedt, 2008)*
'I sat there and drank coffee and read…and occasionally they came over to touch base…it was great…but they could hardly reach the handles to steer and people didn't get out of the way…so I had to call out beep beep (laughter)…it probably looked pretty funny…but we had an outing anyhow, and that was the main thing'	*(Ek and Ternestedt, 2008)*
'Belongingness and social interaction with others, especially with children and grandchildren, were important'	*(Ek and Ternestedt, 2008)*
'I have a wonderful grand piano ...when I feel like being in that mood; I sit down and play for a while. And if I'm not in that mood, I might ease my mind by playing'	*(Elofsson and Ohlen, 2004)*
'I just try and take my mind off it by reading. I might watch some telly. listening to my music. Just things to try and take my mind of it... Yes, that's my way of coping with it really'	*(Brien, Lewith and Thomas, 2016)*
The telephone was an essential means of keeping in touch when they did not have the energy to meet people	*(Strang, Ekberg-Jansson and Henoch, 2013)*
Many mentioned their dog as being the most meaningful creature in their life	*(Strang, Ekberg-Jansson and Henoch, 2013)*
'I cannot do as much anymore; I can no longer go for a walk. But I sit by the window and look out at times. And I watch a lot of television, which I enjoy'	*(Strang, Ekberg-Jansson and Henoch, 2013)*

Social interactions with family and friends, even if solely through the use of the telephone were linked to feelings of belongingness (Ek and Ternestedt, 2008; Strang, Ekberg-Jansson and Henoch, 2013). Whilst participants voiced maintaining these activities gave them a sense of belonging and purpose, they also provided a coping mechanism of distraction from their poor health status.

Distraction

As demonstrated within table 18, distraction as a result of activities and interactions was an evident coping mechanism for participants within three included studies (Ek and Ternestedt, 2008; Disler *et al.*, 2014; Brien, Lewith and Thomas, 2016). The development of controls enabled distraction from symptoms and feelings of anxiety, maintaining a good sense of humour, the application of positive thinking and abstaining from worrying through '*taking life as it comes'* (Disler *et al.*, 2014; Brien, Lewith and Thomas, 2016). Despite these mechanisms being expressed by a minority of people within included studies, their perceptions demonstrate the ability of such distraction methods to have a positive impact upon coping with such a challenging health related situation.

Table 18 – Distraction Quotations from included studies

Distraction Quotations from included studies	Source
'I just try and take my mind off it by reading. I might watch some telly. …. listening to my music. Just things to try and take my mind of it'	*(Brien, Lewith and Thomas, 2016)*
'Dialogue with others was important in daily life, and opportunities to chat and share experiences with others in a similar situation also gave them strength to continue'	*(Ek and Ternestedt, 2008)*
'Whenever I get an infection, a bacterium, then I'm ill. But like now, I'm not ill because I can eat properly, I can still laugh, I still have fun in my life'	*(Disler et al., 2014)*
'I try to keep myself in good humour'	*(Disler et al., 2014)*
'[I] always reckon, if you worry about it, the worry will kill you before the other does'	*(Disler et al., 2014)*
'I guess I just take a day at a time'	*(Disler et al., 2014)*
'I learn how to live one day at one time because I do not know whether I can live two days later'	*(Disler et al., 2014)*
'I already have got my own controls with it and I never get anxious'	*(Brien, Lewith and Thomas, 2016)*
'It is accepting and knowing my limitations'	*(Brien, Lewith and Thomas, 2016)*
Positive thinking	*(Gardener, Ewing and Farquhar, 2019)*
'Today, I'm proud that I have got as far as I have done, and that I can handle this'	*(Lindqvist and Hallberg, 2010)*

Healthcare Professional & Intervention Input

The value and impact of interactions with healthcare professionals and access to supportive interventions was identified as a sub-theme influencing life meaning across seven of the included studies within this review (Gale and Sultan, 2013; Hayle *et al.*, 2013; Stridsman *et al.*, 2015; Doyle *et al.*, 2017; Gardener *et al.*, 2018; Reijnders *et al.*, 2018; Vitacca *et al.*, 2019).

An overwhelming sense of social connection through attendance at intervention based sessions gave participants increased confidence and peace of mind when living with such unrelenting symptom burden, as demonstrated within Table 19 (Gale and Sultan, 2013; Doyle *et al.*, 2017; Gardener, Ewing and Farquhar, 2019; Vitacca *et al.*, 2019).

Table 19 – Healthcare Professional & Intervention Input Quotations from included studies

Healthcare Professional & Intervention Input Quotations from included studies	Source
'peace of mind'	*(Gale and Sultan, 2013)*
'It settles your mind more than anything peace of mind I've got to be honest with you on that. It does save me a lot of aggro [colloquial: aggravation] don't it?'	*(Gale and Sultan, 2013)*
'Before I never knew whether I needed them, you know, and it was get up to A&E and admitted to hospital y Well now I've got that [telehealth] I can get in touch with them'	*(Gale and Sultan, 2013)*
'puts you aware of what's happening'	*(Gale and Sultan, 2013)*
'I felt it was, I felt I was being monitored, I felt like a connection, to be honest, like you know, to the [CRS] team'	*(Gale and Sultan, 2013)*
'I know there's someone at the other end of that line that can help me'	*(Gale and Sultan, 2013)*
Two studies highlighted the need to address the emotions surrounding end of life: patients noted, in particular, the value in observing and talking to other patients	*(Gardener et al., 2018)*
Proactive contact from health care professionals to provide monitoring and reassurance	*(Gardener, Ewing and Farquhar, 2019)*
'they've just given me a bit more confidence in myself. It's good surroundings. You know, good nurses, and doctors … they sit and listen to you and ask you questions. … It makes you feel as though they're taking notice of you'	*(Hayle et al., 2013)*
'Like I said, that thing where you're sliding downhill and you're feeling less important – in fact you feel that you're a waste of time, waste of space, but they're bringing you up again and they make you feel as though you're important and you're someone worthwhile'	*(Hayle et al., 2013)*
T-tests showed a significant difference in the mean score on the Cognitive Therapy Rating Scale between the cognitive behaviour therapists and befriending	*(Doyle et al., 2017)*

Feelings of social isolation were overcome through healthcare professional and intervention input (Doyle *et al.*, 2017; Vitacca *et al.*, 2019). Furthermore, a feeling of importance via healthcare professionals giving participants reassurance and advice enabled them to believe they were someone worthwhile and deserving (Gale and Sultan, 2013; Hayle *et al.*, 2013).

The value of discussions with other people living with COPD was also evident, particularly when exploring end of life care issues. One included systematic review paper (Gardener *et al.*, 2018), identified the need to address the emotions surrounding end of life care for those with COPD and highlighted the benefit of peer support in facilitating this.

3.7 – Discussion of Integrative Review Findings

This integrative review provides a synthesis of international evidence exploring the presence of existential suffering and associated palliative care needs in advanced COPD. The evidence suggests existential suffering significantly impacts upon the daily lives of those living with COPD. Living in a state of liminality, originating in patient's loss of identity and own life role resulted in feelings of loneliness, worthlessness and a desolated life. The absence of life meaning and purpose as a result of the physical and emotional restrictions when living with advanced COPD enforce existential isolation. For some, life meaning had some presence in daily life. Activities such as hobbies and their associated ability to distract from the impact of living with COPD gave some individuals meaning and purpose. Input from healthcare professionals and participation within interventions further facilitated this.

This integrative review shows that despite living with advanced COPD and its associated overwhelming symptom burden, patients do not always accept having the condition. As suggested within the wider literature, this is due to the disease being acquired through smoking leading to a denial of symptoms to ease feelings of guilt (Lindqvist and Hallberg, 2010; Nguyen et al., 2013).

Resonance with wider research

As suggested within the wider literature, poor disease acceptance amongst this population is identified to be as a result of the unpredictable increase in symptom burden, and its impact upon quality of life throughout disease progression, hindering adaptation to living with the condition (Uchmanowicz *et al.*, 2016). Furthermore, the association between knowledge of the disease and an increase in fear of future symptoms and impact upon quality of life diverts individuals away from accepting they have the condition (Stenzel *et al.*, 2015). Contrastingly, alternative literature suggests an increase in disease knowledge is able to facilitate disease acceptance (Jones, 2007; Gardener *et al.*, 2018). This integrative review challenges such evidence when understanding the relationship between existential suffering and disease acceptance. This review identified through the acceptance of having a life limiting condition, associated feelings of meaninglessness and hopelessness became prevalent. Furthermore, embarrassment around their new personal identity and the need to re-define their own life role was underpinned by accepting they had to live with COPD. This led to experiences of living within a liminal space, unsure of their new personal identity.

Liminality is conceptualised as a lived experience whereby individuals are in an ambiguous state of being '*neither one thing or another'* (Turner, 1967 p:96). Literature upon late-stage cancer identifies a state of liminality occurring when living and dying occur concurrently (Adorno, 2005), a notion transferable to the COPD disease trajectory. Living within a liminal space develops experiences of ambiguous life direction and social separation (McKechnie, Jaye and MacLeod, 2010), influencing existential suffering through the generation of loneliness, hopelessness and meaninglessness in daily life. Further work argues that on arriving at a liminal state, through suffering from an incurable illness, the individual is unable to return to a pre-liminal state (McKechnie, Jaye and MacLeod, 2010). Contrastingly, this integrative review challenges this viewpoint, identifying that existential suffering and associated liminality is able to be addressed through specifically designed interventions (Hirai, Morita and Kashwagi, 2003). This review found support and guidance from healthcare professionals themselves, and healthcare professional led interventions positively influenced individual's life meaning, through a sense of social connection and societal purpose. Findings presented from intervention studies within COPD demonstrate relief from symptoms of existential suffering (Monninkhoff *et al.*, 2003; Williams *et al.*, 2014; Bove *et al.*, 2017). Within Williams' (2014) study, 23 participants received a healthcare intervention aimed to improve quality of life in patients with COPD. The study findings highlighted the emotional and social support delivered through the intervention, leading to feelings of success, improvement in low mood and a sense of being looked after, contributing to individuals' existential wellbeing. These findings are echoed in the work of Bove et al. (2017), yet what remains unknown is the most impactful intervention elements and style of delivery upon existential suffering.

An element of existential suffering for those living with advanced COPD and associated palliative care needs is the difficulty in identifying, or absence of, life meaning. The absence of life meaning and it's physical and psychological effects is little explored within COPD, with studies aiming to discover this accessing the viewpoints of minimal participants, hindering generalisability of results (Elofsson and Ohlen, 2004; Lindqvist and Hallberg, 2010; Marx *et al.*, 2016). Exploring such a personal element within an individual's life requires a deep and rich understanding, hindering the recruitment of large participant numbers due to the necessary vast amount of data to be collected to explore this concept thoroughly. Explorations of the presence of meaninglessness in daily life within populations receiving palliative care across cancer and other long-term conditions is present within the wider literature, with an increase in its significance upon an individual's realisation they are facing death (Breitbart *et al.*, 2004). The process of rediscovering life meaning within such a significant life phase allows individuals to transfer feelings of hopelessness and guilt into an engaged and purposeful response to daily life (Breitbart et al., 2004), yet challenges to implementation into clinical practice are evident. The absence of literature upon how to address meaninglessness, alongside evidence of successful intervention content and delivery methods, results in existential suffering rarely being addressed in clinical care. A study aiming to determine the perceived effectiveness, required approach, and content of an intervention to address existential suffering in terminally ill cancer patients explored the views of 456 healthcare professionals (Hirai, Morita and

Kashwagi, 2003). Findings demonstrated a meaning-centred approach to an intervention, comprising of life-review interviews, cognitive restructuring and exploring life values was the most effective approach (Hirai et al. 2003). This integrative review aligns with these findings, with included studies suggesting the exploration of life values through interventions enhanced feelings of being worthwhile alongside developing a sense of life control (Hayle *et al.*, 2013; Vitacca *et al.*, 2019).

Interestingly, the concept of spirituality was absent from this review's findings yet is often encompassed in the wider literature as an element of an individual's existential wellbeing. Whilst a spiritual following, for some individuals may contribute to feelings of purpose, life meaning and offer explanations upon significant life events and situations, for others it holds less or no importance. Literature upon the required content of palliative care suggests the spiritual needs of individuals are to be met, however for some this may be wholly inappropriate, suggesting an approach to existential suffering may offer generalisability across all in need.

3.8 – Strengths and limitations of the review

The limitations of an integrative review methodology are acknowledged due to the complexity of integrating empirical and theoretical evidence from various methodologies (Whittemore and Knafl, 2005). As a result, reduced rigor and potential bias were considered throughout the review. For the one included mixed-method study, separate critical appraisal tools were used to assess the methodological rigor of the quantitative and qualitative elements separately. This approach may have overlooked the integration between the two elements of this study and may have opened the appraisal to bias via one component being scrutinised more than the other. A critical appraisal tool specifically designed to methodologically assess integrative reviews was not used, and as such this may subject this review to scrutiny in relation to its trustworthiness. Although a comprehensive database search was conducted, it was restricted to English and American English languages, and grey literature was not included, which may have led to the omission of relevant papers. This review is necessarily limited by the data provided by the original authors of the included studies. Database searches were conducted between April 2019 and January 2021, therefore, any studies published after this period were not included but may be relevant. Additionally, the review was completed before the Covid-19 pandemic, and it is recognized that individuals living with COPD have likely experienced significant changes in their daily lives. It is speculated that existential suffering may have worsened during this time.

3.9 – Chapter Summary

This chapter has presented an integrative literature review upon the presence of existential suffering within the daily lives of those living with palliative care needs arising from COPD. The review has identified that this experience is personal to each individual, with each element of existential suffering holding differing degrees of significance. Among the diversity of elements, the importance of finding meaning in life stands out as the most substantial aspect of existential suffering for those facing COPD. The rediscovery of life meaning, underpinned by a reduction in feelings of worthlessness and hopelessness is identified evident for some. However, for individuals contending with the relentless burden of symptoms, achieving this without intervention is challenging. Further research is required to explore the impact of meaninglessness, both physically and psychologically, in the daily lives of those with palliative care needs arising from COPD to underpin future interventions aiming to address this.

This integrative review of the wider literature has influenced the development of this study's aims and objectives. The review findings will be re-visited within chapter ten, the discussion.

Chapter 4.0 – Methodology and Methods

4.1 - Introduction

This study explores how people with palliative care needs arising from COPD experience meaningfulness and the impact of the presence or absence of meaning on their daily lives. This chapter describes firstly , the research design, aim and objectives. The underpinning philosophy is then described, followed by an explanation of its qualitative and narrative ethnographic methodology. The philosophical underpinning of this study, methodological foundation and methods used are presented within Figure 4.0. The research methods used, cultural probes and narrative interviews, are then presented.

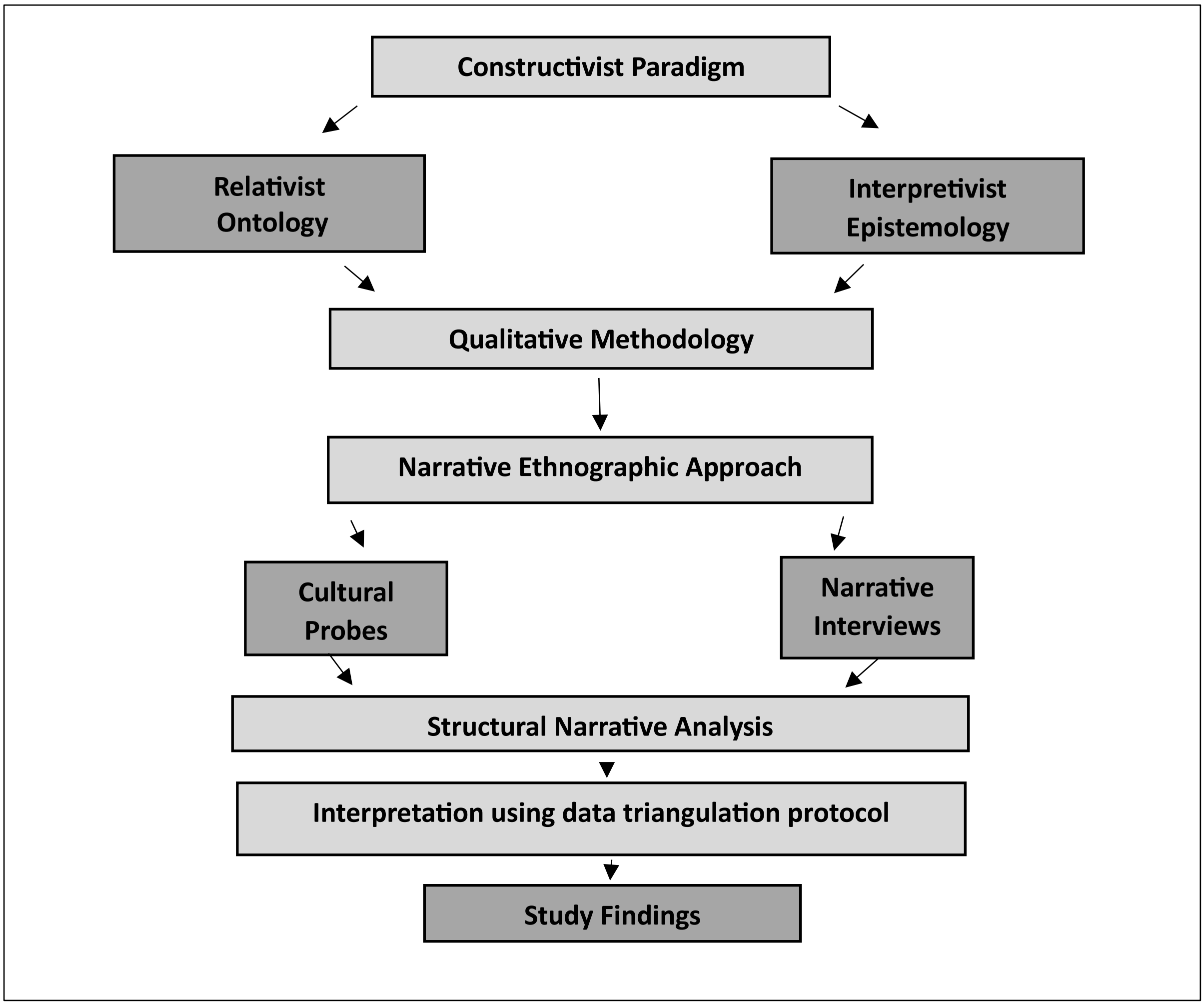


Figure 4.0 - Study Overview

4.1.1 – Research Design summary

This study used an ethnographic data collection method of cultural probes (Gaver, Dunne and Pacenti, 1999), followed by a narrative interview. Six participants, each living with palliative care needs arising from COPD used a specifically designed collection of artefacts (cultural probes) for a two-month period, to capture the constructs within their day to day lives contributing to the presence and absence of meaningfulness. Each participant then took part in a narrative interview via videocall or telephone, using the completed cultural probes to underpin the conversation. The study was set in the United Kingdom. Participants were recruited via their attendance at a British Lung Foundation (BLF) Respiratory Support Groups from Nottingham, Ilkeston, Sheffield, and London.

Data analysis and interpretation were approached via an ethnographic description of each participant within their cultural context, with interview transcriptions and cultural probe data subjected to structural narrative analysis. Data interpretation to combine both the narrative interview and cultural probe data was achieved using a triangulation protocol.

4.1.2 – Aim and Objectives

The aim of this study was to explore, through the narratives of people living with palliative care needs arising from COPD, the presence, absence, and impact of meaningfulness in their day to day lives.

The objectives were;

- To determine how people with palliative care needs arising from COPD derive meaning in their lives.
- To develop an understanding of how individuals living with such a physically and mentally impactful condition experience interruption to the identification of

meaningfulness, to give a new insight into the palliative care needs of this patient population.

- Where meaninglessness is manifest, to explore its impact upon the lives of those with palliative care needs arising from COPD.

4.1.3 - Justification for participant population

As defined within the aim of this study, the participant population under exploration is people living with palliative care needs arising from COPD. As previously explored within section 2.4, the impact of the significant COPD physical symptom burden and the associated impact upon quality of life does not always correlate with the severity of disease progression (Kessler *et al.*, 2011; Miravitlles, 2011; Miravitlles and Ribera, 2017). Furthermore, the need for concurrent active treatment, alongside palliative management of symptoms to facilitate a holistic approach at the time of need is required (Carlucci, Guerrieri and Nava, 2012). For some living with the condition, the significant symptom presentation occurs within the early stages of disease progression, with these symptoms requiring palliative management. Therefore, should this study have recruited only those with a classification of COPD defined as '*advanced*' or '*severe*', a population of people would have been excluded from eligibility to participate, despite living with a significant symptom burden requiring palliative intervention. Therefore, it was decided by the researcher that the term '*with palliative care needs'* would enable the inclusion of participants throughout all stages of COPD disease progression to best reflect the population under exploration.

4.2 – Underpinning Research Philosophy

This section presents the constructivist paradigm, relativist ontological and interpretivist epistemological positions underpinning this study. In turn, this provides a rationale for application of a narrative ethnographic methodology. The researchers' personal beliefs about how individuals' personal experiences are understood, and gain meaning within the world will influence this work and are reflected throughout.

4.2.1 – Constructivist Paradigm

Existential experiences such as meaningfulness in day-to-day life, when living with palliative care needs arising from COPD are unique to everyone. To facilitate the exploration and understanding of individuals 'internal experiences' from their own perspective, the constructivist paradigm was employed as a framework to guide this study (Guba and Lincoln, 1989; Denicolo, Long and Bradley-Cole, 2016). The aim of this study does not lend itself to providing an objective and factual account of reality through the researcher and the researched being separate entities (Pring, 2000; Ritchie and Lewis, 2003). Adoption of a positivist viewpoint would not allow for exploration of how meaning is derived by individuals within their daily lives, as viewing the world through this lens would assume life meaning is already in existence, awaiting discovery by an individual (Crotty, 1998; Scotland, 2012).

The constructivist philosophical view point allows for the exploration of how people view the world and their existence, and how personal views have impact upon choices and actions, leading to profound and subjective insights and understandings of individuals' personal experiences (Denicolo, Long and Bradley-Cole, 2016). Furthermore, constructivism embraces the continuum of change throughout an individual's life course, acknowledging how an individual's constructs of reality continually adapt because of life experiences. This is of significance when exploring the meaning given to life experiences when living with palliative care needs arising from COPD, and has allowed me to view each participant as an exclusive and efficient meaning maker (Raskin, 2011). Furthermore, constructivism recognises the possibility of many personally constructed experiential realities (Alvesson and Deetz, 2000) and embraces not only how that meaning is created, but also why (Denicolo, Long and Bradley-Cole, 2016).

Interactions between the researcher and participant within this study have been prominent within the development of an understanding of life meaning (Crotty, 1998). This enabled an understanding of why a particular meaning was given to an experience, after revealing underpinning personal attitudes (Denicolo, Long and Bradley-Cole, 2016).

The following principles of the constructivist paradigm have underpinned this study (Guba and Lincoln, 1982, 1985):

- *Acknowledgement of multiple realities*

  Each participant's individual reality and meaning has been developed and adapted through the experience of living with palliative care needs arising from COPD (Alvesson and Deetz, 2000). These present multiple constructs offering differing interpretations (Appleton and King, 2002), each being of equal value. Whilst presenting a consolidated view of how meaningfulness presents and is absent within the day to day lives of those living with palliative care needs arising from COPD, the multiple constructs of discovered meaning have been acknowledged and detailed. (Appleton and King, 2002).

- *Unique Constructions*

  This study is underpinned by the view of '*mutual simultaneous shaping'* where by all '*causes and effects (are) inextricably intertwined'* (Guba and Lincoln, 1982 p242). Furthermore, participant's perspectives of reality have been interpreted and contextualised, revealing diversity amongst constructions of their life meaning (Lub, 2015).

- *Absence of generalisations*

  The aim of this study does not lend itself to determining a generalised explanation of how meaningfulness is constructed within the daily lives of those living with palliative care needs arising from COPD, each experience is unique (Guba and Lincoln, 1985). In exploring the existential concept of meaningfulness, generalisations are beyond reach, and it is impossible '*to imagine that all human activity is completely determined by one universal set of relationships'* (Guba and Lincoln, 1989 p94). Further, the unique contexts and circumstances of each person are an essential element of the study.

- *Researcher participant relationship*

  The concept of objectivity is absent within constructivist approach research. The significance of the researcher participant relationship within this study has been embraced, acknowledging the mutual influence on the emergence of findings (Guba, 1990 p27). Reflexivity is further discussed within section 4.7 of this thesis.

- *All beliefs represented*

  Individual beliefs and values of the researcher and participants are acknowledged as necessary to develop new knowledge within this study (Appleton and King, 2002), and have carried equal weight within the development of the study findings (Guba and Lincoln, 1994). The author's personal world views and values have influenced this research and are presented within the following two sections outlining ontological and epistemological positions.

The constructivists paradigm aligns with the overarching philosophical concept being explored within this study. Existentialism, as previously discussed within chapter two, presents the notion that essential elements of an individual's existence, including freedom, choice, responsibility and meaning, have influence upon their choices and actions within daily life (Yalom, 1980). To explore this concept in relation to meaningfulness within the daily life, the personal experience of each participant through captured reflections and interpretation of their subjective viewpoint upon significant life experiences is necessary. Furthermore, the experience and impact of existential components such as the presence of meaningfulness when facing significant life events (Bugental, 1999), is fundamental to meeting aims of this study.

4.2.2 – Relativist Ontological Position

This reflection is written in the first person to convey a rich reflective insight into the researchers experiences.

As the author of this thesis, my personal nursing experience of caring for individuals with COPD has shaped the methodological approaches of this research (Grix, 2002). Acknowledgment is given to the vast differences in the impact of the disease upon individuals existential situation, supporting the relativist ontological position.

Professional Reflections

Having been a registered nurse since 2005 and specialising in the care of respiratory patients since 2007, I have noted significant variation in how COPD affects each person beyond their physical symptom presentation.

I have cared for many patients who are repeatedly admitted into acute hospital settings labelled as requiring 'a social sort out' or 'not coping at home'. Assessment often revealed no acute medical need for hospital admission, with minor changes to the impact of physical symptoms that were able to have been managed within their usual community setting. I noticed patterns of recurrent hospital admissions for individuals over a number of years, often when relatives or carers were away on holiday. This influenced me engaging in professional reflective conversations with patients upon how they felt living with COPD. Often, patients described feeling useless because of their limited ability to function with the condition. Some had been forced to give up work due to the severity of COPD, and we discussed the impact of this and how that made them feel in relation to their life purpose.

As a registered nurse, I found it challenging within the limits of the existing healthcare infrastructure, alongside an absence of a robust evidence base to know how to address this. This experience has shaped my own viewpoint upon life meaning and influenced methodological approaches to use within this study.

My experience has acknowledged the multiple lived realities at individuals living with palliative care needs arising from COPD, influencing me to reflect these within the findings from this study to ensure realistic recommendations for future research, education and clinical practice are made. This conscious choice has enabled me to give voice to this patient population in hope to highlight the need to address existential elements of care with the same importance as physical symptoms.

Social ontology is related to how an individual determines the nature of reality (Creswell, 2013; Bryman, 2016). The philosophical debate of ontology presents differences in how individuals experience reality, faced with and without the influence of life events. For those living with palliative care needs arising from COPD, physical symptom burden is often comparable, yet the experience and impact of meaningfulness is different for each person (Easterby-Smith, Thorpe and Lowe, 2002).

Application of a relativist lens upon the aim of this study, to explore through the narratives of people living with palliative care needs arising from COPD, the presence absence and impact of meaningfulness in their day-to-day lives, facilitates the presentation subjective accounts and interpretations of each individuals reality (Levers, 2013).

The impact of participation within this study related to each individual's acquisition of knowledge upon how they identify meaning in day-to-day life is reflected within the interpretivist epistemological lens through which this research has been undertaken.

4.2.3 – Interpretivist Epistemology

Epistemology relates to how individuals acquire knowledge (Crotty, 1998 p3; Grix, 2002). Interpretive epistemology recognises that knowledge is dependent upon individual interpretations (Crotty, 1998). Utilising this viewpoint when exploring meaningfulness within the daily lives of those living with palliative care needs arising from COPD allowed for participants to construct a personal understanding of life meaning throughout the study process (Crotty, 1998), revealing the personal meaning attached to life experiences. The creation of a reciprocal relationship between the author and each participant allowed for differences in interpretations to be embraced (Carson *et al.*, 2001; Rolfe, 2006), with an emergence of new knowledge as an effect (Avis, 1995). An open approach to multiple presentations of life meaning from each participant removed the risk of generalisations (Hudson and Ozanne, 1988), allowing the co creation of this new knowledge.

The constructivist framework, together with the experiential ontological and epistemological lenses were applied to this study through a qualitative research methodology, namely narrative ethnography. The use of cultural probes and narrative interviews as data collection methods were adopted to explore meaningfulness within the day-to-day lives of participants.

4.3 - Qualitative Research Methodology

The subjectivity of perspectives in the understanding of life meaning co-constructed within this study was facilitated by a qualitative research methodology, using a narrative ethnographic approach. It is acknowledged that by considering the underpinning of a range of research approaches and methods, research practice and quality is improved (Ritchie and Lewis, 2003). The consideration given to other qualitative methodologies is summarised within table 20. Whilst each of these qualitative methodological approaches presented offered some potential for addressing the aims of this study, the individual experience of meaningfulness in day-to-day life would have remained hidden without the use of both an observational approach alongside capturing participants' own voices. The subjective concept of meaningfulness is often difficult to identify and recollect, therefore the use of a narrative ethnographic approach, using observational data to prompt each participant's own narrative, has allowed for the identification of meaningfulness to be co-constructed between each participant and the researcher.

Table 20 - Suitability of different qualitative methodologies

Methodological Approach	Suitability within this study	Limitations within this study
Phenomenology	Focus upon how individuals attach meaning to an experience through exploring the alliance of an individual and situation (Laverty, 2003; Rodriguez and Smith, 2018). Has been used to explore existential themes when living with illness (Ashworth, 2003).	Absence of Co constructed meanings between researcher and participant, alongside the potential influence of researcher believes upon findings (Rodriguez and Smith, 2018). This may prevent the true insights of meaningfulness in daily life being revealed.
Grounded Theory	Unsuitable as it aims to generate theory from data collected (Glaser and Strauss, 1967).	Identifying individual's multiple truths upon what holds meaning within their lives is not identifiable through theory generation.
Case Studies	Offer an understanding of complex phenomenon through holistic accounts from participants (Hodkinson and Hodkinson, 2001).	Direct observation as a component of the case study design was deemed too burdensome for the population under study.
Ethnography	The use of a purely ethnographic methodology would allow for immersion within the culture and social practices of participants (Spradley, 1980; Hammersely and Atkinson, 2019), giving relevant context to the revelation of how meaningfulness is identified within participants daily lives.	Direct observation of participants within their daily lives would be required, which would have been too burdensome for the study participants. Elements of an ethnographic approach were however used within the narrative ethnographic design of this study which is further explained within section 3.4 of this thesis.
Narrative Inquiry	Places emphasis upon the co-construction of meaning within life experience, harmoniously exploring how elements of an individual story interlink (Clandinin and Connelly, 2000).	A person's narrative is their own story, and as such relies upon their recollection of memories and feelings after an event. Meaningfulness in day-to-day life may have been a difficult to identify and recollect, therefore this method alone may have left gaps within participants stories. Narratives have however been used in conjunction with an ethnographic approach within this study and is further presented within section 4.3.4 of this thesis.

4.3.1 – Narrative Ethnography

Narrative ethnography expands an individual's narrative , through positioning it alongside an ethnographic insight, to reveal an understanding of day-to-day life experience (Gubrium and Holstein, 1995, 2008). This methodology was applied as the most appropriate to explore the aims of this study, given its ability to facilitate a multi-dimensional insight into the presence, absence and impact of meaningfulness within the day-to-day lives of those living with palliative care needs arising from COPD. Through the adoption of this methodology, combining the ethnographic data collected from the use of cultural probes (further explained within section 4.3.2 of this thesis), with each participant's narrative story, emotions were highlighted to give depth to participants descriptions of experiences, revealing the character within the person (Beatty, 2010; Goffman, 2014). Consequently, this revealed their existential position related to meaningfulness within day-to-day life.

This methodology asked the researcher to undertake inclusive thinking around the type of data needed to address this studies aim (Gubrium and Holstein, 1995). As suggested by Squire *et al.* (2014), researchers need to look beyond simplistic ideas which position narratives as the gold standard method to understand the lives of individuals. Adopting the narrative ethnographic methodology has allowed for a unique, deep, and rich insight into the existential situation of each person who participated.

From the production of both ethnographic and narrative data as previously described, perspectives were captured from both the spoken word alongside internal thoughts and non-verbal language. Whilst exploring an individual's narrative story begins to reveal an account of the phenomenon of interest (Connelly and Clandinin, 1990), it is known that some emotions attached to such phenomenon are only revealed through '*ethnographic examination'*

(Gubrium and Holstein, 1995 p:51). As a result, identifying instances of meaningfulness in the daily lives of participants, alongside instances whereby life meaning can be challenging. Discussions held within the narrative interviews, using cultural probes as prompts, allowed for a deeper understanding of the context and meaning of an experience, revealing the deeper presentation of the presence of meaningfulness (Gubrium and Holstein, 1995).

To date there is no evidence of the application of a narrative ethnographic methodology to underpin a research study exploring life experiences when living with palliative care needs arising from COPD, meaning this study holds a novel application of cultural probe and narrative interview methods. This may be attributed to the well documented potential burden to a participant due to the nature of ethnographic research in its direct observational form (Reigada, Sapeta and Centeno, 2019), particularly for those in the palliative phase of disease progression. Palliative care research itself presents its own challenges, due to the necessity to encompass a holistic assessment of an individual (Higginson, 2016).

The wider literature presents examples of both narrative and ethnographic research across populations of people living with palliative care needs arising from COPD. A narrative inquiry approach was used to explore the experiences of people living with dying with advanced COPD (Molzahn *et al.*, 2021). Two narrative interviews were undertaken with sixteen participants living with COPD at the end of life. Findings related to their experience of dying were presented including descriptions of it being a '*scary process*' and *'the need to prepare'* (Molzahn *et al.*, 2021). An ethnographic study exploring an in-depth understanding of the attitudes and needs of those living with COPD throughout differing phases of the disease undertook video conference interviews with twenty-eight people living with moderate to severe COPD (Martinez-Guiu, Arroyo-Fernandez and Rubio, 2021). Alongside this, each participant completed a video home tour of the spaces within their homes, and an introductory video recording about themselves. This facilitated an insight from each participant into the personal and cultural influences upon their lived experiences. Findings were comparable to those within the narrative study upon daily life when in the palliative phase of COPD disease progression, including life being overwhelming and the need to prepare for the next life phase. The ethnographic work of Martinez-Guiu, Arroyo-Fernandez and Rubio (2021) also allowed for the identification of differing personality traits influencing the experience of dying, through the exploration of cultural and personal circumstances. Whilst these findings provide a novel insight that may not have been identified using an alternative qualitative research method, this study did not reveal the impact of life experiences. Combining an ethnographic and narrative approach to data collection, via application of a narrative ethnographic methodology, enables an understanding of personal and cultural influences upon participants day to day lives is coupled with a deep narrative exploration of their life experience and its impact. Narrative ethnography takes the narrative story itself, positioned alongside the ethnographic insight, to explore the cultural context of its creation, through the development of an understanding of day to day life experience (Gubrium and Holstein, 2008). Culture underpins the actions of human individuals, through personal perceptions, tendencies and aspirations absorbed within (Williams, 1995), and arguably contributes to the construction of meaningfulness within the lives of individuals. Furthermore, this approach, by combining the ethnographic elements of data collection with each narrative highlighted emotions, revealed depth to descriptions of experience, and presented the character within each participant (Beatty, 2010), thus revealing their multi-dimensional existential position related to meaningfulness within day to day life.

The strengths and limitations of the narrative ethnographic methodology were continually considered throughout to strengthen its application to address the study aims. The absence of objectivity present within this methodology was embraced throughout this study, through the development of trust between the researcher and participant, delivering a transparent and original insight into their day to day lives. This relationship is further discussed within section 4.7 of this thesis upon reflexivity. The methodology has allowed for submersion into the social settings of participants, allowing for observation through the use of cultural probe artefacts (further explained in section 4.3.2), to gain natural insights upon day to day life (Goffman, 2014). This has then been further embellished through the narratives given by participants, assisting to infuse and organise cultural factors within the study findings (Ricoeur, 1984). The use of cultural probe artefacts and narrative interviews as data collection methods within this narrative ethnographic study are now presented within sections 4.3.2 and 4.3.3.

4.3.2 – Cultural Probes

The creative and visual ethnographic method of cultural probes was adopted within this study to identify and explore elements from within participants lives contributing to the presence, absence and impact of meaningfulness. Participants used a collection of objects, for a set time period, specifically designed for the population under exploration. A participatory design model influenced the creation of the cultural probes (Hemmings *et al*., 2002), through the presentation of ideas to the study PPI group, including the style, colour and the potential insights to be gained from participants lives to meet the aims of the study. This is further presented within section 4.3.3.

The use of cultural probes originated as a data collection method in the field of art and design by Gaver *et al*. (1999), who intended this approach to facilitate participants exploring beyond immediate situations to explore personal ‘*beliefs, desires and cultural preferences*’ (Burrows, Mitchell and Nicolle, 2015 p:920). Consequently, the probes capture personal insights to trigger the imagination of researchers to open possibilities for interpretation (Gaver, Dunne and Pacenti, 1999). Each probe is designed and produced to uncover fragments of information upon thoughts and emotions within day to day life of usually difficult to reach and unfamiliar groups (Gaver, Dunne and Pacenti, 1999; Hemmings *et al.*, 2002; Gaver *et al.*, 2004), arguably a suitable approach when wanting to explore the presence and absence of meaningfulness within day to day life. They have the ability to capture elements of, and document lives in context (Mattelmäki and Battarbee, 2002). Cultural probes are not designed to capture a comprehensive insight into participants lives, therefore this study's narrative ethnographic methodological underpinning allows for data collected from the probes to be contextualised and built upon through a narrative interview to generate further insight. Uncertainty in the data captured through the cultural probes is to be expected and embraced (Gaver, Dunne and Pacenti, 1999), as this is reflective of the diversity within each participant's daily life. Furthermore, uncertainty will lie within which probes each person may like or dislike, or if they will use any of the probes at all.

The use of cultural probes when exploring the daily lives of those living with palliative care needs arising from COPD is a novel approach. There is no published evidence using this research method within this context. This method has however succeeded in gaining this insight within several research studies in other areas of healthcare research. A study to support the design of assisted living technology (Wherton *et al.*, 2012), created and used a set of cultural probes to explore how particular technology would work within a specific home setting. The probes used included a camera, a home and life scrapbook and a body map to identify symptoms and impairments. Data gathered from 31 participants developed an understanding of how assisted living technology may be of benefit within the home.

Furthermore, the probes facilitated participant and researcher interaction, with the open ended intention behind the probe design facilitating broad discussion (Wherton *et al.*, 2012). Indirect yet valid insights were evoked that would have remained hidden or not be acknowledged via an interview method. The study conclusions alluded to the use of cultural probes being valuable in exploring meanings and social constructs within this study population.

An exploration of personhood in those living with dementia used cultural probes to 'engage deeply with the participant and inquire around her sense of what is personally meaningful' (Wallace *et al.*, 2013 p:2). The cultural probes used within this study included a camera, a first prize rosette, a dressmaking pattern and a model home. Despite this study including only one participant, the elicitation of insights into life meaning gave the author of this thesis confidence in its ability to explore such a multi-dimensional existential experience.

Burrows et al (2015) identified within a study of nine participants exploring the independence of older adults, that the variation in responses is to be expected as participants choose which of the individual items within the set of cultural probes they are most comfortable to use. The use of cultural probes within this study remains true to its initial philosophy as a research method that is not designed to capture a comprehensive answer to a hypothesis, but to lead towards capturing unexpected ideas without domination or influence (Gaver, Dunne and Pacenti, 1999). Therefore, a variation in responses through differing probes used is welcomed, to facilitate comfortable participation for each individual and elicit truthful insights.

Despite these studies having captured unique personal insights, the potential challenges, limitations and invitation for criticism when using a novel research method applied to a new patient population remained a concern for the researcher throughout this study. The recruitment of participants receiving palliative care into research studies is unsurprisingly challenging (Jordhoy *et al.*, 1999; Hanson *et al.*, 2014), given the overwhelming symptom burden experienced alongside limited time. Interestingly, within one study using a cultural probe method, the concept of '*cognitive offloading'* was presented as a therapeutic benefit of participation (Wherton *et al.*, 2012). Whilst this would require further exploration to determine its relevance within the patient population explored within this study, the cathartic experiences of participation are further discussed within Chapter nine of this thesis. The requirement for participants to use the cultural probes within their own space and time presents another dimension to this challenge (Graham *et al.*, 2007), therefore design of the probes to specifically reflect the culture in which they are to be used is paramount to their success. The design process and associated patient and public involvement will now be discussed within section 4.3.3.

4.3.3 – Cultural Probe Design

The underpinning design and aesthetic appearance of a set of probes is paramount to enable usability and facilitate the capture of unplanned observations through a '*playful and subjective'* approach (Gaver, Dunne and Pacenti, 1999; Gaver *et al.*, 2004). Allowing the probes to evoke personal and spontaneous feelings is achieved through informal and aesthetically simple designs (Gaver, Dunne and Pacenti, 1999). Within this study, significant consideration was given to the design of each probe, ensuring each was culturally appropriate, and appealing to the participant. The author of this thesis holds no experience in product design, therefore advice was sought upon the appropriateness of the use of cultural probes through meeting with the creator, William Gavers at Goldsmiths University, London in February 2019. A discussion exploring the use of the cultural probe method to answer the aim and objectives of this study led to advice upon considering the questions needing to be answered, and consequently allowing this to influence probe creation. Furthermore, probes are to be designed to reveal a privileged insight into the lives of individuals without researcher influence upon responses, and as such require confidence in their design to achieve exploration of the required concepts. The probes used within previous healthcare related research studies were also considered in relation to the data they captured, and the insights reported within the study findings. Design of the cultural probes included consideration of colour psychology, and patient and public involvement to shape acceptability and usability considerations. .

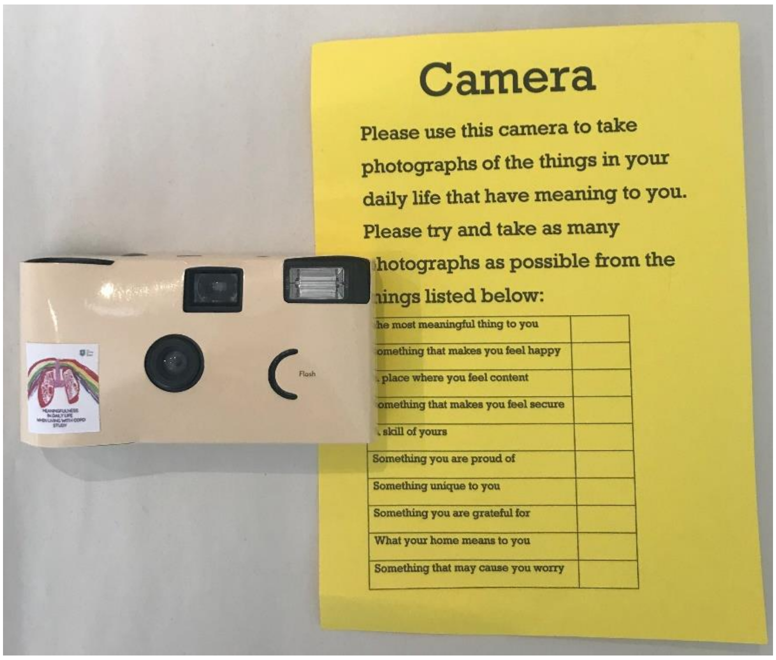
The meanings of colour have been debated over decades, in relation to understandings of evoked feelings, and thoughts (Zammitto, 2005). It is presented that the use of colours may emphasise or diminish some personal emotions (Taylor, 1962; Riley, 1995; Kwon, 2002), enabling objects such as cultural probes to become aids to communication and reflectors of meaning (Demirbilek and Sener, 2003). Drawing upon evidence from the field of product design and marketing to better understand colour choice for each probe and associated user instruction cards, its influence has limitations. Whilst some psychologists disregard evidence linking certain colours to specific human responses (Kaiser, 1984), colour testing to determine personality traits is a widely used practice within psychiatry (Singh, 2006). The link between colours of objects and associated emotions has been explored by (Cimbalo, Beck and Sendziak, 1977) presenting how certain colours linked to either happy or sad emotions. Alternative studies contest this and bring the psychology of colour and associated emotions into debate (Singh, 2006). Generalisations around the impact of object colour upon emotions is not supported from the wider literature, and as such has been a consideration as opposed to an essential component of cultural probe design within this study. The author of this thesis concluded that justified colour choices, based upon colour psychology evidence, would be made to influence each probes design. However, acknowledging that certain emotions may be evoked for some but not all included participants.

4.3.4 – Patient and public involvement in cultural probe design

Patient and public involvement (PPI) has been of significance when designing cultural probes for use within this study. The characteristics of each probe including their appearance, usability and purpose were discussed and collectively created with the group, of whom some individuals living with palliative care needs arising from COPD. When using ethnographic methods of data collection, a rich understanding of context is required (Spradley, 1980). Developing the cultural probes for use by the patient population within this study, in collaboration with people living with COPD allowed them to give insight upon their contextualised usability. An initial discussion upon the use of cultural probes by people living with COPD was held with the PPI group members who voiced their belief this would be an acceptable request to make of people who wished to participate. Some of the group members voiced the need to make it very clear to participants that they did not have to use all of the probes, just the ones they were comfortable with, as having to use them all would have been too burdensome. Following an exploration of the use of cultural probes used within other healthcare related studies, alongside research upon the use of colour psychology to influence probe design, six potential cultural probes were shown to fourteen PPI group members for discussion. This was undertaken via Zoom in October 2020. Group members consisted of a previous respiratory nurse who now runs a support group for people living with lung conditions alongside thirteen people living with COPD at various stages of disease progression.

A total of 6 culturally specific probes were designed and produced by the author of this thesis for use within this study. The probes and their underpinning design and rationale are now presented.

Disposable camera



Camera

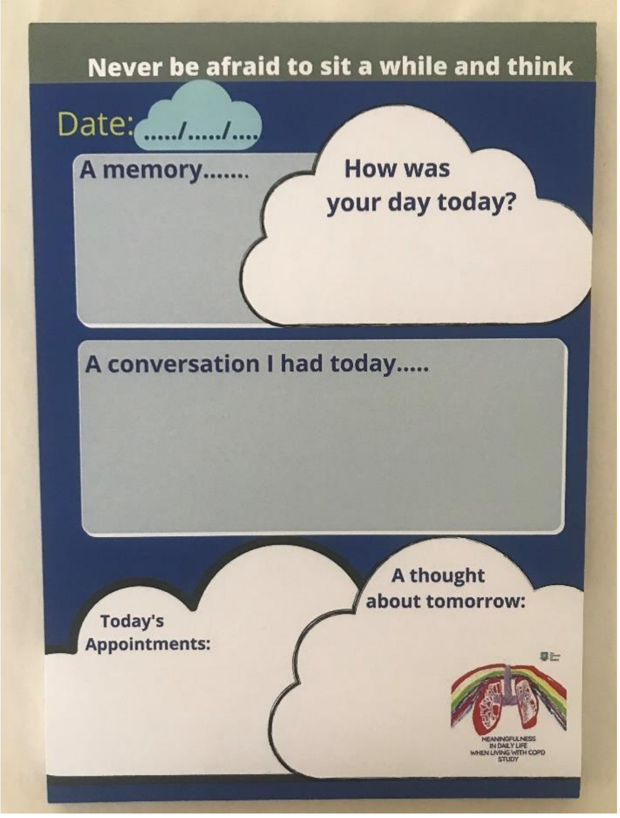
Please use this camera to take photographs of the things in your daily life that have meaning to you. Please try and take as many hotographs as possible from the ings listed below:

he most meaningful thing to you	
omething that makes you feel happy	
place where you feel content	
omething that makes you feel secure	
skill of yours	
Something you are proud of	
Something unique to you	
Something you are grateful for	
What your home means to you	
Something that may cause you worry	

A disposable camera was included within the set of probes, repackaged and accompanied with an instruction card to suggest ideas of particular images that may give insight into elements of meaningfulness and meaninglessness within participants day to day lives. The requests were purposefully open ended, to allow unplanned images to be taken informing the researcher of representations that may not have otherwise been captured (Gaver *et al.*, 2004), or spoken upon within an interview.

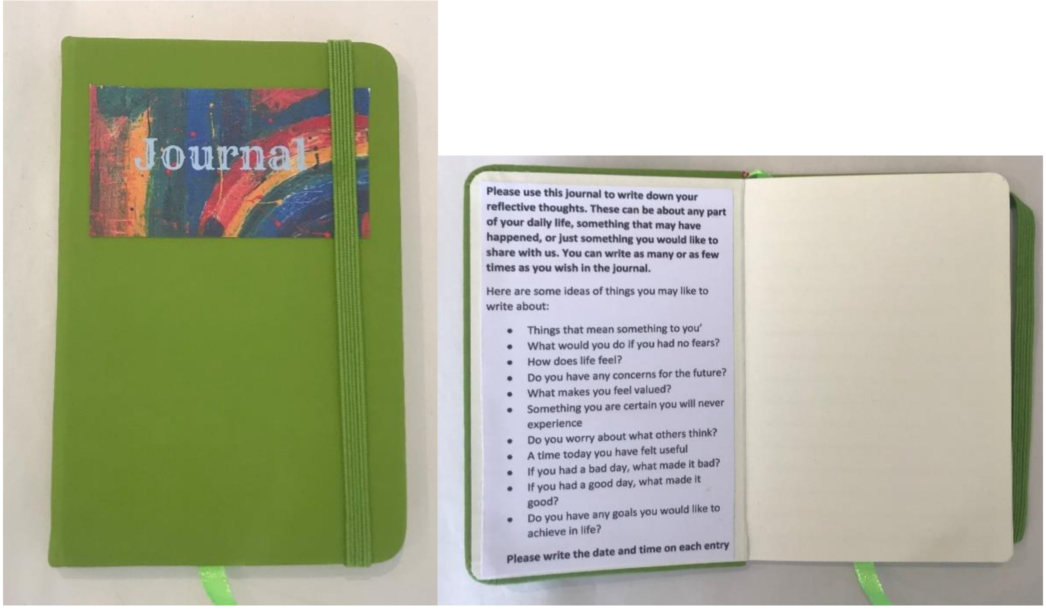
The aesthetic appearance of both the camera and accompanying instruction card was designed and produced with consideration, underpinned by the evidence base upon colour psychology. It is evidenced that the colour yellow stimulates mental activity, captures individuals attention and promotes logical thinking (Arnheim, 1962; Birren, 1978). As participants were expected to use the probes within their own time and home/outside environments, potentially bringing limitations to the motivation to use them, probes designed to catch attention and potentially keep interest in participation were produced. The PPI group provided a positive opinion of the usability for the disposable camera and commented upon the nostalgic emotions it evoked given most images are now taken through digital devices. These nostalgic emotions were voiced to transport individuals to times gone by, as such facilitating the opportunity for reflection upon life and its meaning. The open-ended suggestions for photographs were developed based upon the findings from the integrative literature review underpinning the aims and objectives of this study, alongside discussions with the study PPI group around their acceptability within the study population. In particular, the connection to the components of meaningfulness, including elements of life that evoked feelings of happiness, security, and contentment were complimented with suggestions around elements causing worry in day-to-day life, so as not to potentially exclude identification of elements of meaninglessness. Upon explaining the use of the cultural probes to each participant, the researcher made clear that this was not an exhaustive list, and as such each participant was encouraged to photograph anything they chose, to reflect the presence or absence of life meaning.

Think Pad



The ThinkPad aims to capture thoughts, feelings and emotions at various intervals throughout the time each participant used the cultural probes to underpin further discussion within the narrative interview. The informal design and use of the ThinkPad, whereby each participant could make brief reflective notes at any time of the day aligned with the playful philosophy of cultural probe design. The use of the colour blue was an intentional choice by the researcher as it is known to evoke relaxing emotions to facilitate contemplation and reflection (Arnheim, 1962; Taylor, 1962; Birren, 1978; Riley, 1995). The prompts presented upon the ThinkPad were consciously developed to trigger thoughts upon elements of meaningfulness and meaninglessness within day to day life. By asking participants to recall a memory, or consider thoughts about tomorrow may have led them to identify constructs within life related to meaning. Guiding participants to reflect upon a conversation had was drawn from existing literature upon social interaction, and the possibility of it’s influence on meaning within day to day life (Steger *et al.*, 2006; Pedersen *et al.*, 2018). Upon presenting this probe to the PPI group, they felt it's informal appearance and its ability to not be too time consuming to use would facilitate its success in capturing brief reflective thoughts, whilst respecting and considering the potential participation burden. The PPI group unanimously stated this probe was the most acceptable to them.

Journal



Please use this journal to write down your reflective thoughts. These can be about any part of your daily life, something that may have happened, or just something you would like to share with us. You can write as many or as few times as you wish in the journal.

Here are some ideas of things you may like to write about:

- Things that mean something to you’
- What would you do if you had no fears?
- How does life feel?
- Do you have any concerns for the future?
- What makes you feel valued?
- Something you are certain you will never experience
- Do you worry about what others think?
- A time today you have felt useful
- If you had a bad day, what made it bad?
- If you had a good day, what made it good?
- Do you have any goals you would like to achieve in life?

Please write the date and time on each entry

The journal provides a place for participants to record daily activities alongside reflections upon personal thoughts and feelings. A list of suggestions upon ideas for reflective writing within the journal are included on the inside cover, underpinned by findings from the study integrative literature review. The ideas and questions are related to thoughts upon fear and worry alongside reflecting upon good days, feeling valued and future goals. The inclusion of a journal was considered to give participants autonomy of the content they share, alongside the time of day they choose to write an entry (Bolger, Davis and Rafaeli, 2003). The burden upon a participant when completing a daily journal is highlighted within the wider literature, however was overcome within this study through instructing participants that they could make an entry as frequently as they wished (Bolger, Davis and Rafaeli, 2003). As the journal made up one of the six probes given to participants, reliance on daily completion to gain an insight into their daily lives was not a requirement. The colour green was chosen for the front cover of the journal to potentially evoke feelings of tranquillity, balance, safety and healing (Wright and Rainwater, 1962), with such emotions potentially encouraging reflection upon day-to-day life.

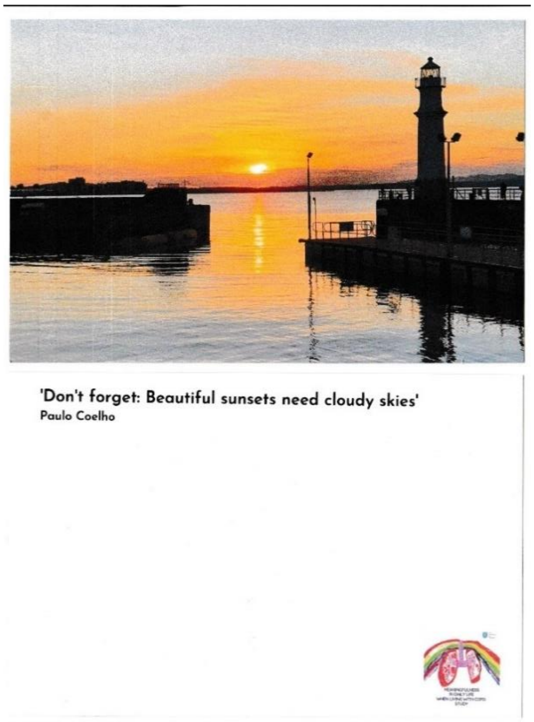
Photographic Postcards

Postcards

Take a postcard. Look at the image.
Write your thoughts and memories.
What does it mean to you?

A selection of seven postcards were produced and included within the set of cultural probes given to each participant. Postcards, a probe, used by Gaver (1999) within his initial study using this method, stated their presence is to evoke familiar informal feelings of sending postcards throughout life. Furthermore, they guide participants to offer limited insight into their reflection, given the small space upon which to write. This was not deemed as a limitation to data collection, as the content written upon each postcard was further discussed within each participant's narrative interview. Again, this probe is designed to limit participant burden when using, as each participant had choice around only using the postcards they felt comfortable to. The use of quotations on each postcard to guide reflective thoughts related to meaningful life experiences was an intentional element of their design. The inclusion of quotations may have influenced responses given by each participant, as some may have considered them as being motivational. This had potential to influence participants in choosing to record positive thoughts, as they may have been motivated to do so. As is presented within the findings chapters of this thesis, the participants within this study recorded reflections on both positive and challenging experiences.

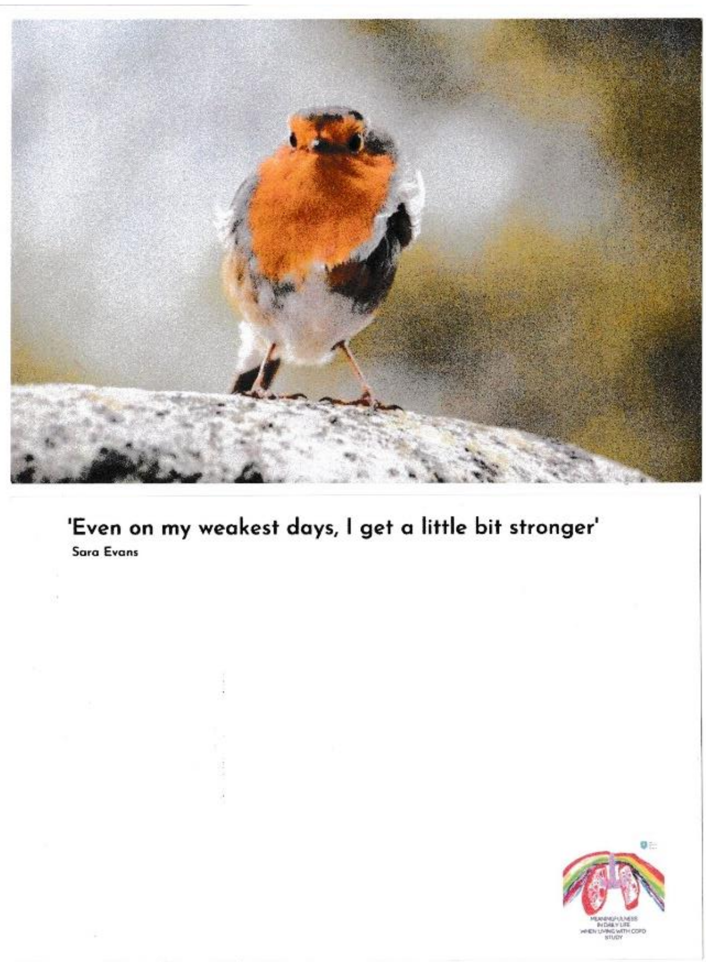
1. *Sunset*



'Don't forget: Beautiful sunsets need cloudy skies'
Paulo Coelho

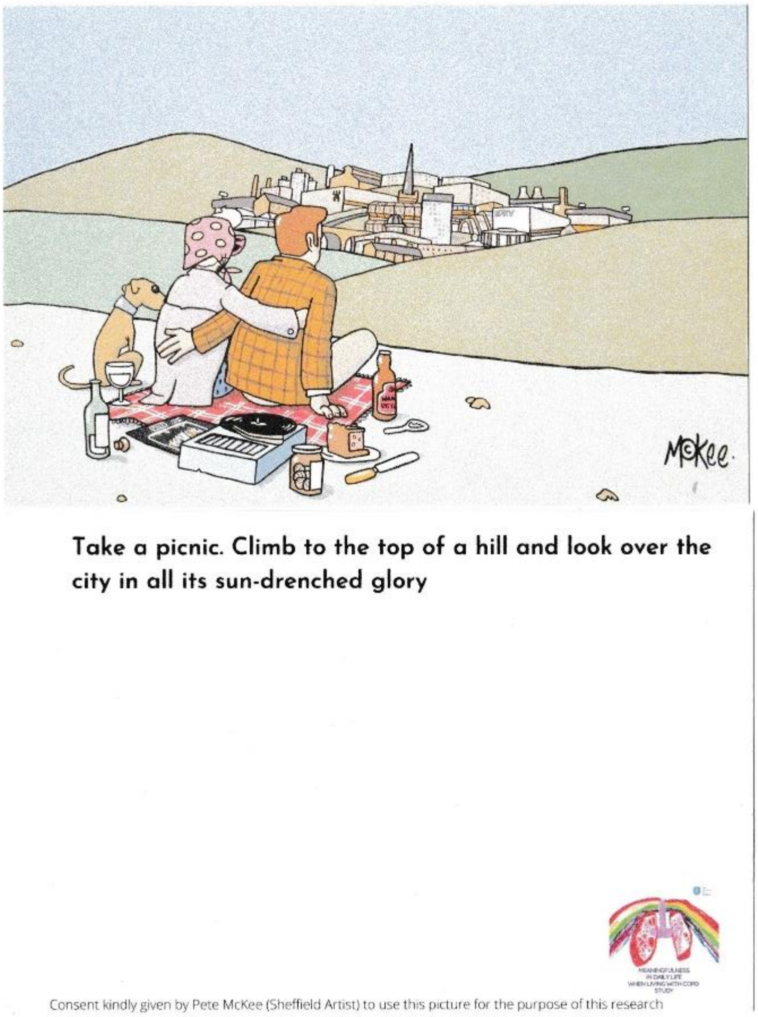
This image of a sunset and associated quotation was selected to facilitate thoughts around progressing through difficult times during life.

2. Robin



The image of a robin signifies for some the presence of something lost. This image aimed to provoke reflective thoughts and feelings around loss throughout their journey when living with COPD.

3. A Perfect Day

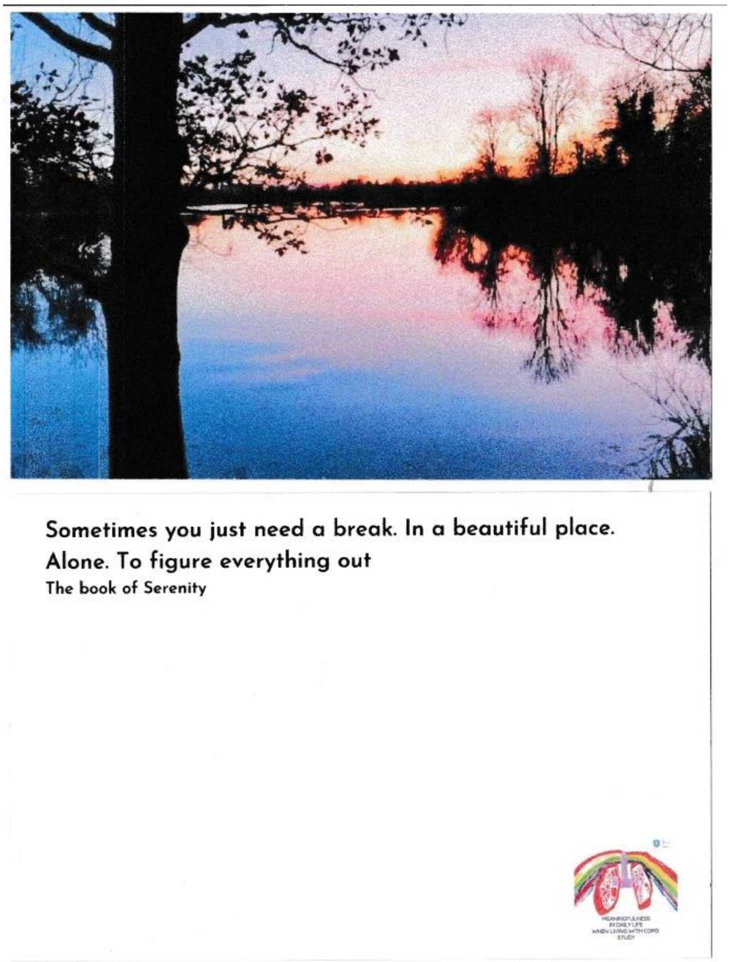


Take a picnic. Climb to the top of a hill and look over the city in all its sun-drenched glory

Consent kindly given by Pete McKee (Sheffield Artist) to use this picture for the purpose of this research

The selection of this artwork and quotation hoped to guide thoughts and reflections upon family and social relationships of significance. Acknowledgement must be given to the local artist who produced this work, Pete McKee, who gave consent for it to be used as a part of this research study.

4. *Reflection on a lake*



Sometimes you just need a break. In a beautiful place.
Alone. To figure everything out
The book of Serenity

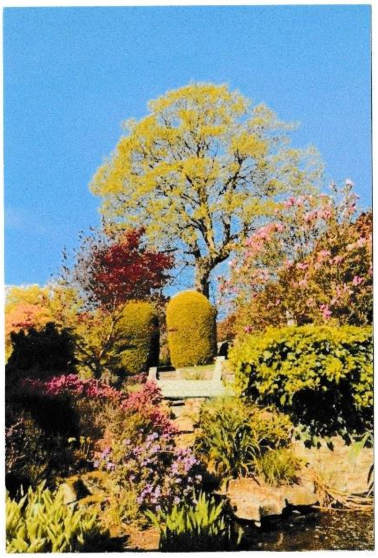
MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

This reflective image of the trees in a lake and associated quotation upon ‘figuring out’ a situation was used to facilitate participants thinking about how the future will look.

5. *Garden*

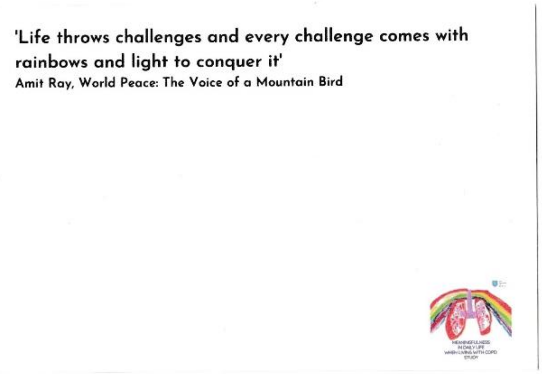
We grow through what we go through
Tyrese Gibson

MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY



The use of an image of a garden encouraged participants to consider personal growth through difficult situations when adapting to life with COPD.

6. *Rainbow*

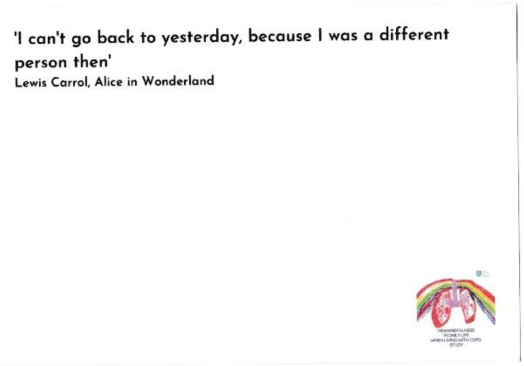


'Life throws challenges and every challenge comes with rainbows and light to conquer it'
Amit Ray, World Peace: The Voice of a Mountain Bird

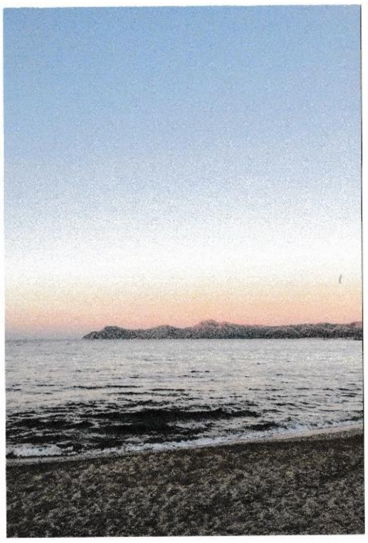
MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

This image and associated quotation stimulated participant thoughts and emotions upon overcoming challenge when living with a chronic condition with such significant symptom burden.

7. *Beach*



'I can't go back to yesterday, because I was a different person then'
Lewis Carrol, Alice in Wonderland



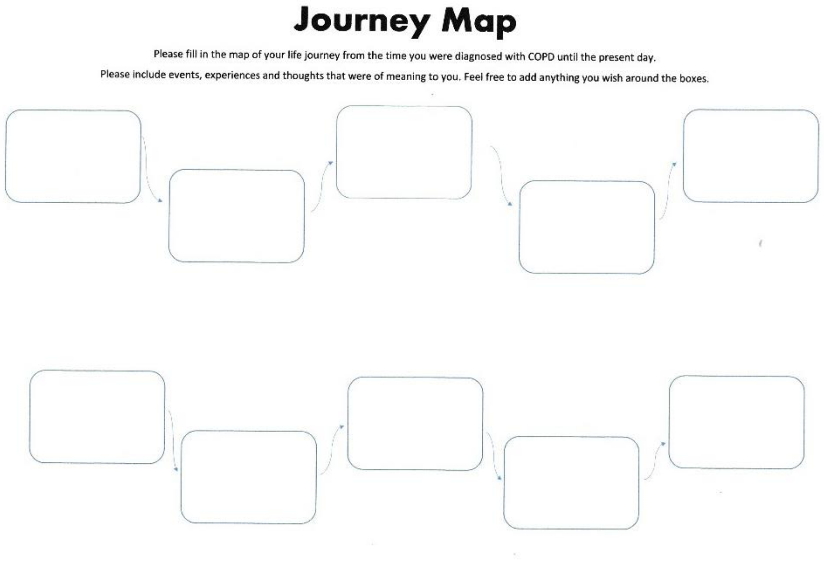
The image of a beach and the sea was used to evoke reflections upon times gone by. Particularly memories of holidays and visits to places of significance, in order to stimulate thoughts upon changes to day-to-day life when living with COPD.

Rosette

What do you think when you look at the
1st prize rosette?
A current life goal?
Something you have already achieved?
Please do tell us about it:

The use of a first prize rosette and associated reflection card was underpinned by the work of Wallace (2013) who explored personhood in the life of a person living with dementia. The rosette symbolises something the participant wishes to be acknowledged for, that they are proud of achieving or a current life goal. This probe aimed to capture an element of life holding meaning, or identifying the absence of meaning, facilitating further discussion within the narrative interview. From discussion with the study PPI group, this cultural probe was felt to evoke positive emotions upon meaningful life events.

Journey Map


Journey Map

Please fill in the map of your life journey from the time you were diagnosed with COPD until the present day.
Please include events, experiences and thoughts that were of meaning to you. Feel free to add anything you wish around the boxes.

The use of a life journey map to present significant illness related experiences from COPD diagnosis to the present day facilitated an opportunity for reflection for each participant. The journey map supported each participant’s narrative interview through discussing the presented recordings upon temporality. The study PPI group complemented the usability of this probe, and the freedom participants had whilst using. In particular, the absence of guidance within each box on the page, allowing participants to record life events meaningful to them.

Each participant within this study used the cultural probes for a period of two months. The probes were returned to the researcher and used to scaffold the narrative interview phase of this study.

4.3.4 – Narrative Interviews

Narrative interviews were used as a data collection method within this study, to build upon the ethnographic data collected from the cultural probes, to develop an understanding of participants day to day life experience (Gubrium and Holsten, 2008). This method facilitated contextualisation of the cultural probe data, allowing the researcher and participant to collectively identify emotions experienced in day-to-day life. Furthermore, this approach gave depth to descriptions of life circumstances, through revealing the character within each individual (Beatty, 2010).

Differences when compared to alternative interview approaches are striking when exploring the construction of narratives for inquiry, with the most significant being the focus of the researcher not aiming to just discover narratives, but to be an active part of their creation (Neander and Scott, 2016). Participants are situated at the centre of a study using a narrative approach, through the recording of their story up on life experiences and associated meaning (Anderson and Kirkpatrick, 2016). The absence of a pre-determined agenda for the interview encourages the use of broad questions upon life experiences, and when exploring a broad concept such as meaningfulness, a narrative interview approach is both suitable and effective. Alternative interview approaches were considered throughout the study design phase of this work, with the strengths and limitations of each approach critiqued when aligned to the study aims, again to enhance research practice and quality (Ritchie *et al.*, 2014).

- Structured interviews utilise predetermined questions posed to each participant which are closely aligned to the research aims (Bryman, 2016). Whilst structured interviews may present less variation in responses making generalizability of findings a simpler process, this is contradicted within the wider literature due to the imposed structure inhibiting the richness and depth of data collected . As such, this was dismissed as a suitable data collection method for this study as participants in depth discussion around such a personal existential concept of meaningfulness in life is required.

- The semi-structured interview offers less restriction than that of a structured approach, with the presence of some pre-planned questioning alongside the opportunity for further discussion upon the encouraged topics (Polit and Beck, 2021). Whilst this may have begun to answer the aim of this research, a true insight into the underpinning of meaningfulness within the daily life of participants is required, and this method may have restricted participants responses through direct questioning.
- Focus groups, when used in qualitative research offer the opportunity to observe interactions and relationships between participants through the sharing of experiences and opinions (Morgan, 1997). Whilst acknowledged as a research method that is useful when exploring sensitive topics (Carey, 1994), the researcher felt this approach would be inappropriate when asking participants to freely and comfortably reveal personal elements of life relating to the presence and absence of meaningfulness.

Narrative interviews were undertaken within this study to allow for an in-depth focus on the phenomenon of meaningfulness in day-to-day life, through the words of each participant.

4.4 – Methods

4.4.1 – Overview of Methods

The aim of this study was to explore the presence, absence, and impact of meaningfulness upon day-to-day life for those living with palliative care needs arising from COPD. This was achieved through the collection of data using cultural probes that were subsequently used to inform prompts for conversation within narrative interviews with each participant. Observational field notes were recorded throughout all interactions with participants. Narrative interviews were undertaken and transcribed verbatim. Data was analysed using an ethnographic case description of each participant and structural narrative analysis of each participants narrative interview. Data interpretation was undertaken using a data triangulation protocol approach, to identify where there are agreements, complimentary similarities or disagreements. Themes were then generated from this triangulation.

This section presents the study setting, research methods used and the data analysis approaches adopted. Furthermore, the ethical implications of this research are presented.

4.4.2 – Setting

Understanding the situational context of a study and its participants is necessary within qualitative research to allow for understanding of its multi-dimensional influences upon personal experiences, such as the societal, cultural, economic, and environmental influences that require acknowledgement when developing the study findings.

The environment surrounding study participants is structured within individuals' narratives, each holding their own set of circumstances contributing to individual understandings of life experiences (Gubrium and Holstein, 2008). This study was undertaken with participants living in their own homes in Nottingham, Ilkeston, Sheffield and London. Each participant attended a British Lung Foundation (BLF) Breathe Easy support group. As a result of the Covid-19 pandemic, the study setting and the recruitment strategy for this study required adaptation. This is further explained within section 4.4.7. Accessing the patient population required for this study through attendance at NHS healthcare settings proved challenging because of the pandemic. Following a discussion with the PPI group for this study, they supported the identification of potential participants through attendance at BLF Breathe Easy support groups as a suitable alternative. BLF Breathe Easy support groups are forums of peer support for individuals living with lung disease, alongside their families and carers. Meetings are held monthly and are accessible via self-referral or via a healthcare professional. Session content is variable, with some sessions being focused on a particular topic delivered by an external speaker, and others being around peer support and socialisation with people living with similar conditions. A recent change in the rebranding of the British Lung Foundation results in the organisation now being identified as Asthma and Lung UK. However, as the organisation at the time of recruitment and data collection within this study was named the British Lung Foundation, this name will be utilised throughout this thesis.

The incidence and prevalence of COPD is of significance within these geographical areas:

Nottingham

It is predicted that almost 11,400 people living in Nottingham have a diagnosis of COPD (Public Health England, 2015). Current evidence suggests that residents of Nottingham a 42% more likely than the national average to die of COPD (Nottingham Insight, 2016), lending its population to meet the inclusion criteria of this study when exploring the day to day lives of those living with palliative care needs arising as a result of the condition.

Ilkeston

The population of those living with COPD in Derbyshire (whereby Ilkeston is situated), is 23,103, providing a potentially significant study population meeting the inclusion criteria (Derbyshire County Council, 2014).

Sheffield

The prevalence of COPD in the historically industrialised city of Sheffield is 9981. The link between industry exposure and COPD development is long established (Waterhouse *et al.*, 2008) and as such, a pool of potential participants who meet the inclusion criteria of this study were available to be invited to take part.

London

In 2021, there were an estimated 115,000 individuals with a diagnosis of COPD living in London (Office for Health Improvement and Disparities, 2023). It is well documented that London suffers from poor air quality, and as such those living with COPD are presented with further factors contributing to potential exacerbations of their condition, with an average of two London residents hospitalised daily as a consequence (London Assembly, 2019). Evidently, London presents a pool of potential participants eligible to take part in this study.

Participants

A total of eight people were recruited to participate within this study: five female and three males. One participant withdrew from the study prior to using the cultural probes and another participant sadly died during enrolment within the study. An overview of each participant is presented within Table 21 to further contextualise the study setting and each individual person. Each participant was assigned a pseudonym to be described as throughout this thesis. The researcher believed referring to them as a name as opposed to a numerical identifier aligned with the philosophy of the study, exploring the day to day lives of *people*, with the participants at the centre of the study.

Table 21 - Social demographics of study participants

Participant	Sex	Age	Ethnic origin	Employment status/ Former career	Housing situation
1. Stephen	Male	89	White British	Retired administrator	Lives alone 4 bedroomed house
2. Patricia	Female	80	White British	Retired school support worker	Lives alone 3 bedroomed house
3. Sally	Female	80	White British	Retired Nurse	Lives with husband 3 bedroomed house
4. Craig	Male	74	White British	Retired	Lives with wife 2 bedroomed house
5. Geraldine	Female	79	White British	Retired Social Worker	Lives with husband 3 bedroomed house
6. Karen	Female	69	White British	Retired Lecturer	Lives with husband 2nd floor flat

An understanding of the social context surrounding each participant gives depth to the insight, with similarities and differences being identified, to understand the cultural influence of meaningfulness within day-to-day life when living with COPD. Each participant lived in their own home. All had previously worked, however were now retired for differing reasons. Two participants were still able to drive. Each participant attended a British Lung Foundation (BLF) Breathe Easy support group. An ethnographic description of each participant, revealing their unique cultural context, is presented within chapter five.

The most significant contextual pressures surrounding the day to day lives of each participant at the time of this study was the COVID-19 pandemic, which is now presented in section 4.4.3.

4.4.3 - Contextual pressure – COVID-19 Pandemic

The unprecedented times throughout the COVID-19 pandemic influenced the day to day lives and psychological well-being of those living with COPD (Yohannes, 2020). Many of those living with COPD were advised to shield throughout periods of the pandemic, at a time that evidence suggests may have exacerbated symptoms of anxiety, fear and depression (Yohannes, 2020). Participant recruitment to this study ran from July 2021 until January 2022. Individuals had been socially isolated and shielding for over a 12-month period upon enrolment. Whilst none of the participants voiced a particular increase in symptoms of psychological deterioration, acknowledgement and consideration is given to this throughout this study.

4.4.4 – Sampling

This study adopted homogenous purposive sampling approach (Holloway and Wheeler, 2010), to identify potential participants, allowing for the detection of information-rich participants aligned to the study aims (Patton, 2002; Palinkas *et al.*, 2015). The study inclusion and exclusion criteria are presented within tables 22 and 23, alongside an underpinning rationale for each component. Limitations of this sampling method are acknowledged, due to small sample sizes and associated implied lack of generalisability. However, this non-probability approach to sampling allowed for representation of the individual meaning from the accounts given from participants to remain, and not be generalised across the wider population (Denicolo, Long and Bradley-Cole, 2016). Furthermore, a small sample can explore a particular context or setting in depth (Silverman, 2013). The selection of participants within this study have differing socio-economic backgrounds and employment histories, allowing for some diversity in representation of those living with COPD (Ritchie *et al.*, 2014). Participant diversity related to a particular population is required within a study sample, to reveal a more comprehensive picture with deep insight into the phenomenon being explored (Ritchie *et al.*, 2014). Achieved through the adoption of this sampling method, the revelation of meaning and multiple truth constructs from within participants day to day lives has addressed the aim of this study (Polit and Beck, 2021).

Table 22 - Study Inclusion Criteria

Criteria	Rationale
Over 65 years of age	Data relating to COPD being the cause of death in the UK population states in 2012, 2719 people aged 15-64 died of COPD with 27,056 aged over 65 years (British Lung Foundation, 2016). This suggests those aged over 65 years will have begun developing associated care needs requiring a palliative approach.
Under the care of a specialist COPD team	To ensure each participant had a confirmed diagnosis of COPD.
Attends a British Lung Foundation Breathe Easy Support Group	This was related to the recruitment strategy and is further explained within the background section of this thesis.
Identifies that living with COPD impacts their ability to undertake daily activities	Determining if a participant was living with palliative care needs through other means may have posed significant ethical challenges. The participant may not have been informed by a healthcare professional that they are living within the palliative stage of disease progression. Allowing participants to self-identify that living with COPD impacts their day-to-day life indicates they do have palliative care needs.
Of any gender identity	To ensure a broad sample population.
Of any ethnic origin	To ensure a broad sample population
Fluent in speaking any language	To ensure a board sample population. Interpreter services were to be used should any participant show interest in participation and would have continued throughout their enrolment in the study.
No diagnosis of cognitive impairment	Using the cultural probes would have posed challenges for an individual living with cognitive impairment, particularly their ability to understand their purpose and use. Furthermore, participation within this study was deemed too burdensome for this population.

Table 23 - Study Exclusion Criteria

Criteria	Rationale
Under 65 years of age	For those under 65 years of age, their COPD disease progression would be less advanced, and their associated palliative care needs less easy to identify.
Are unable to give informed consent to participate themselves	Due to the complex nature of the data collection methods within this study, it was not deemed appropriate for those who were unable to give informed consent to participate. The use of the cultural probes would be too burdensome for the participant.
Are imminently dying	This study would be too burdensome and pose significant ethical challenges for someone in the last phase of life.

Alternative sampling strategies were considered throughout the design phase of this study. Whilst convenience sampling may have resulted in a larger sample, limitations due to the inability to obtain such in-depth data (Ritchie *et al.*, 2014), may have led to limitations in the meaning revealed. Theoretical sampling (Glaser and Strauss, 1967), would have been an inappropriate choice to approach sampling for this study, given it is not focused upon emerging theoretical constructs (Ritchie *et al.*, 2014). Requirements of a study sample such as geographical coverage and scale were not considered when designing this study's sampling strategy, as that process would contradict the interpretivist paradigm in which this research sits (Ritchie *et al.*, 2014).

4.4.5 - Sample Size

Determining an adequate sample size in qualitative research is a well debated topic within existing literature, and it is important to consider a suitable sample size within the initial study design (Sim *et al.*, 2018). Qualitative researchers often face criticism for the absence of justification of sample sizes used within studies (Marshall *et al.*, 2013). Whilst ensuring as a researcher, a study collects adequate data to allow for satisfactory analysis and presentation of findings (Marshall *et al.*, 2013), there is no single approach to determining this. Recent research has explored the notion of determining a qualitative study sample size using theoretically based knowledge. However, critics argue that this is contradictory to philosophical and methodological components underpinning qualitative research (Baker and Edwards, 2012), where the notion of 'saturation' of themes derived from data drives sampling decisions. This challenges the ethos of qualitative research whereby all truths all valid and reflect reality. Fugard and Potts (2015) extend this notion, proposing statistical calculation of a qualitative study's sample size. Their work presents in tabulated form, calculated from a binomial distribution, a minimum number of required participants to give confidence to an identified theme allowing assumptions to be made across the study population (Sim *et al.*, 2018). Further studies, such as the work of Galvin (2015) and Tran *et al.* (2017) again use statistical calculations to identify saturation of a theme related to the required number of participants. This approach would challenge the constructivist underpinning of this study, through its hypothesis of themes already defined prior to analysis. This study explores a range of accounts from individuals and welcomes the diverse presentations of meaningfulness and meaninglessness within the participants day-to-day lives. Furthermore, this statistical approach does not allow for themes to remain fluid throughout analysis, with this interchangeability facilitating the generation of meaning. Utilising sample sizes from within existing similar research studies is an alternative approach considered by qualitative researchers. The latter approach is broad and offers limited and often contradictory guidance, for example 30-60 participants are suggested for ethnographic studies by Bernard (2000), yet it is suggested in alternative work that between 10-20 participants would be sufficient to reveal lived experience (Bernard, 2013).

The concept of data saturation is frequently debated within qualitative research sample size calculation. Historically applied within grounded theory research, data saturation is now applied across many types of qualitative research design (Michelle O'Reilly and Parker, 2013), with inconsistencies of its application evident (Malterud, Siersma and Guassora, 2016). As an approach often used to benchmark the quality of a qualitative study, data saturation is achieved when there is sufficient information from the data to replicate a study and no further new information is emerging via coding (O'Reilly and Parker, 2013; Braun and Clarke, 2021). Within this study, the unique day-to-day life reality of each participant is presented, with each individual offering insights of new discovery (Wray, Markovic and Manderson, 2007). A data saturation approach was not used within this study to determine sample size, as the findings of this study are presented to reflect each individual's own accounts as both truth and reality. Given the limitations of the presented approaches to sample size calculation for this study, a pragmatic approach based upon the work of Malterud, Siersma and Guassora (2016) and their concept of 'information power' was adopted. Information power presents that the greater the amount of information held within the study sample, directly relevant to the study aims, the last number of participants are required (Malterud, Siersma and Guassora, 2016). Determining the sufficiency of information power within a sample is dependent upon five items as presented within table 24.

Table 24 - Information Power Items to enable sample size calculation.

Item	Explanation
1. The aim of the study	A broad study aim dictates the need for a larger sample than that of a narrow study aim, due to the phenomenon under study being of greater scope.
2. Sample Specificity	Information power is related to the experiences and knowledge upon the study aim amongst participants. Less participants are required when holding the characteristics specific to the study aim.
3. Use of established theory	The theoretical background of the study influences information power. A study with a strong theoretical background would require fewer participants.
4. Quality of dialogue	The quality of interview dialogue/data collection between the researcher and participant influences information power. Clear and well-founded dialogue requires fewer participants to reach information power.
5. Analysis strategy	A study exploring in-depth analysis of narratives requires fewer participants to reach information power than that of a cross-case analysis approach.

A conceptual model (Figure 5.0), developed by Malterud, Siersma and Guassora (2016) compliments the content presented in Table 24, and demonstrates how the items are applied to calculate an appropriate study sample size. The application of this model to guide sample size calculation for this research study is presented with in Table 25.

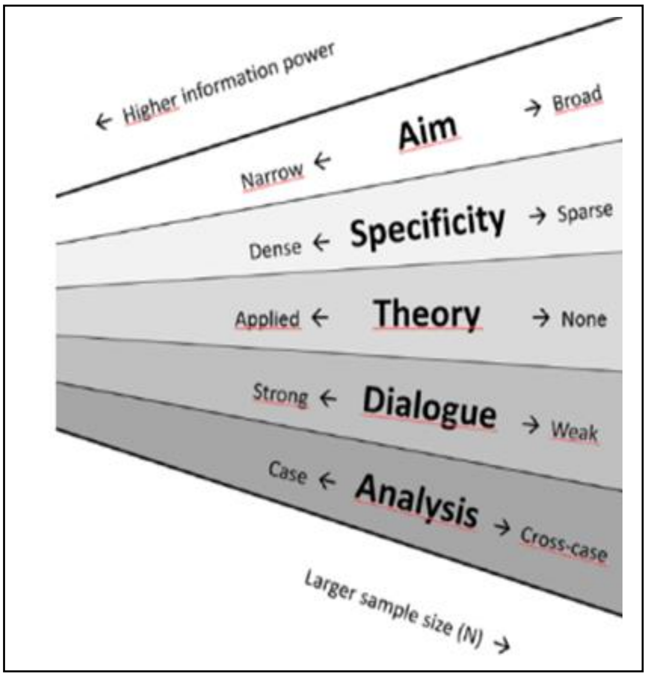


Figure 5.0 - Items and dimensions of Information Power – Conceptual Model

Literature suggests that transparency of the underpinning rationale related to sample size is low (Carlsen and Glenton, 2011), despite the need for qualitative researchers to adopt methods that are vigorous and valid, presenting transparent reflections upon how and why study design decisions are made (Mason, 2010; Malterud, Siersma and Guassora, 2016).

Table 25 - Application of Information Power Items to determine study sample size.

Item	Explanation to determine information power
1. The aim of the study	The aim of this study focuses upon the presence and absence of meaningfulness. This aim is narrow, focusing upon one element of day-to-day life experience, and as such could be answered with a small sample size.
2. Sample Specificity	the experiences and knowledge of each participant upon the study aim is extensive. Only they have the knowledge of knowing how living with palliative care needs arising from COPD impacts upon their day-to-day lives. A small sample is able to explore this.
3. Use of established theory	The theoretical background to this study is existentialism, a well-established philosophical viewpoint. Therefore, a small sample size is able to be used with findings based upon the studies underpinning theory.
4. Quality of dialogue	the collection of both the cultural probe data and dialogue within narrative interviews offer data of high quality. Participants used the cultural probes thoroughly and spoke openly and at length within the narrative interviews. Information power was reached through a small sample.
5. Analysis strategy	This study has explored in depth the narratives of individual participants and as such information power has been achieved by the small sample size

Alongside using the guidance given within the five items to determine information power (Malterud, Siersma and Guassora, 2016), a pragmatic approach to sample size calculation was also applied, given external factors upon the study at the time of its initial design and subsequent redesign due to the COVID-19 pandemic.

This research study is part of a doctoral award with available research resources being the researcher (doctoral student) and two academic supervisors. Therefore, the amount of data collected had to be manageable for the researcher to both collect and analyse independently with supervisory support. Furthermore, two sets of qualitative data were collected from each participant; a completed set of cultural probes (with potential use of up to six objects), and a narrative interview, giving a vast amount of in-depth data from which to generate meaning.

A sample size of between six and ten participants was decided upon to ensure adequate representation of the concept under exploration to meet the needs of this study. A total of six participants were recruited to this study, for which the recruitment methods are now presented in Section 4. 4. 6.

4.4.6 - Recruitment

Six participants were recruited via British Lung Foundation (BLF) breathe easy support groups to take part in this study. The recruitment strategy required amendment throughout the duration of this study due to the COVID-19 pandemic. This section will present the studies initial recruitment strategy (section 4.4.7), followed by the amended recruitment strategy (section 4.4.8) used to recruit all six participants to this study.

4.4.7 - Initial Recruitment Strategy

Ethical approval to undertake this today was granted by favourable opinion in October 2020 (Appendix C). Recruitment to the study, as presented in figure 6.0 commenced in February 2021 following the required study setup procedures with each of the respective research and innovation departments at each of the three included sites; Sheffield Teaching Hospitals NHS Trust (STH), The Rotherham NHS Foundation Trust (RFT) and the University Hospitals of Derby and Burton NHS Foundation Trust (UHDB). Appropriate research site contracts were obtained as per their local policy.

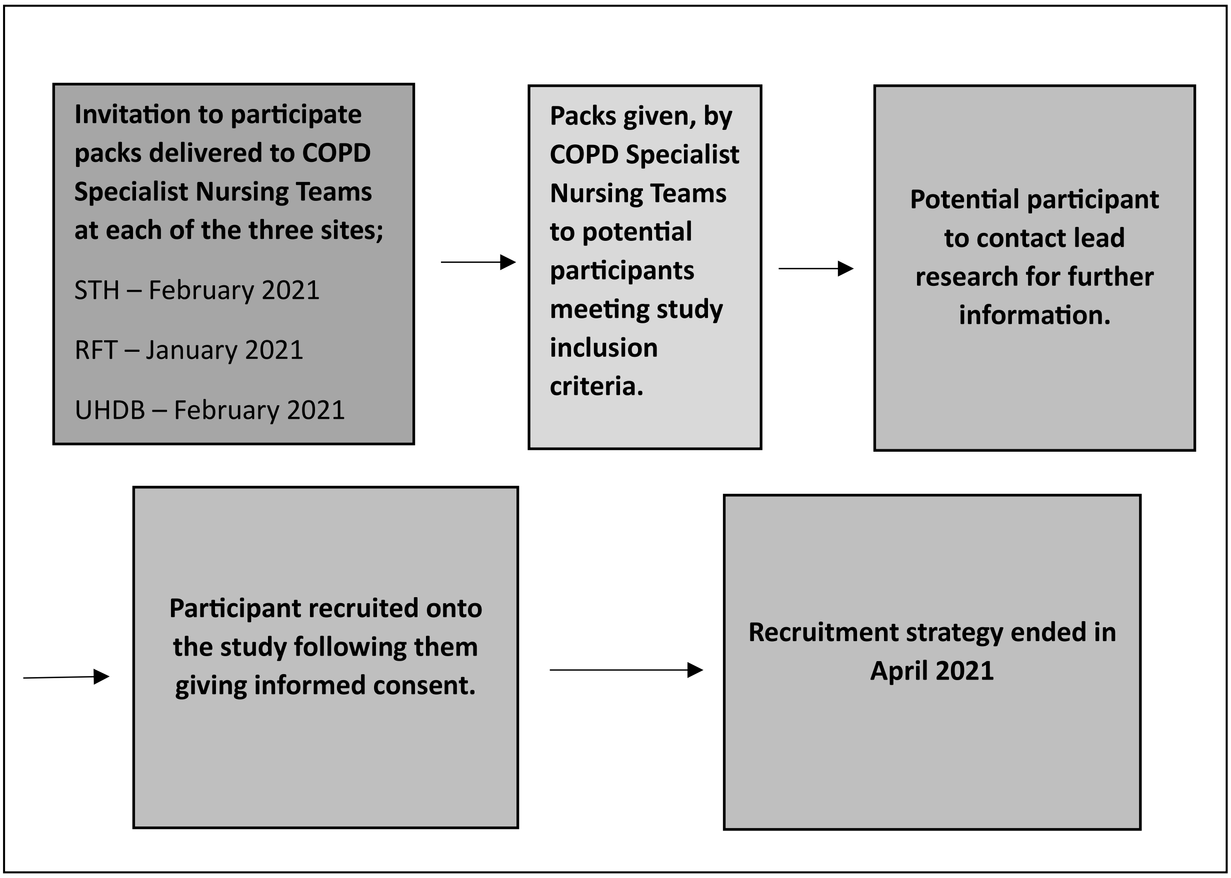


Figure 6.0 - Initial Recruitment Strategy

The initial recruitment strategy, as presented within figure 6.0 involved distributing invitation to participate letters and participant information sheets to individuals living with a diagnosis of COPD attending outpatient clinics at the three previously identified acute hospitals.

Invitations were distributed by respiratory clinical nurse specialists who identified potential participants using the study inclusion and exclusion criteria. A face-to-face teaching session was delivered by the researcher to each team of respiratory nurses to ensure consistency in interpretation of this criteria. No potential participants contacted the researcher from January 2021 to the end of April 2021 to express an interest in participation within this study. Due to ethical restrictions, I was unable to collect any information about patients who chose not to participate, however this was thought to be due to the following reasons;

- Limited COPD Face to face clinics were running at this time due to the COVID-19 pandemic meaning the opportunity for COPD specialist nurses to explain the study to potential participants was limited.
- COPD specialist nursing teams had been redeployed across other clinical settings to assist with patient demand due to the increased number of COVID-19 related hospital admissions. Therefore, their available time spent with COPD patients was significantly reduced, and understandably, recruitment to this study became less of a priority.
- People living with COPD were advised to shield at this time, and did not access hospital services as they usually would. Telephone consultations took precedence as their means of accessing COPD specialist nursing input, making it difficult for the COPD nurse specialists to give any potential participant a recruitment pack.

It was decided at the end of April 2021 that recruitment using this strategy should cease given no participants were enrolled at that point. Consideration was given to an amended recruitment strategy which was designed throughout May 2021, and an application made to the Newcastle and North Tyneside Research Ethics Committee (REC) on the 24th May 2021.

4.4.8 – Amended Recruitment Strategy

A favourable opinion from the Newcastle and North Tyneside REC was obtained for this amended recruitment strategy on the 11th June 2021 (Appendix C). Figure 7.0 presents the implementation of the amended recruitment strategy for this study.

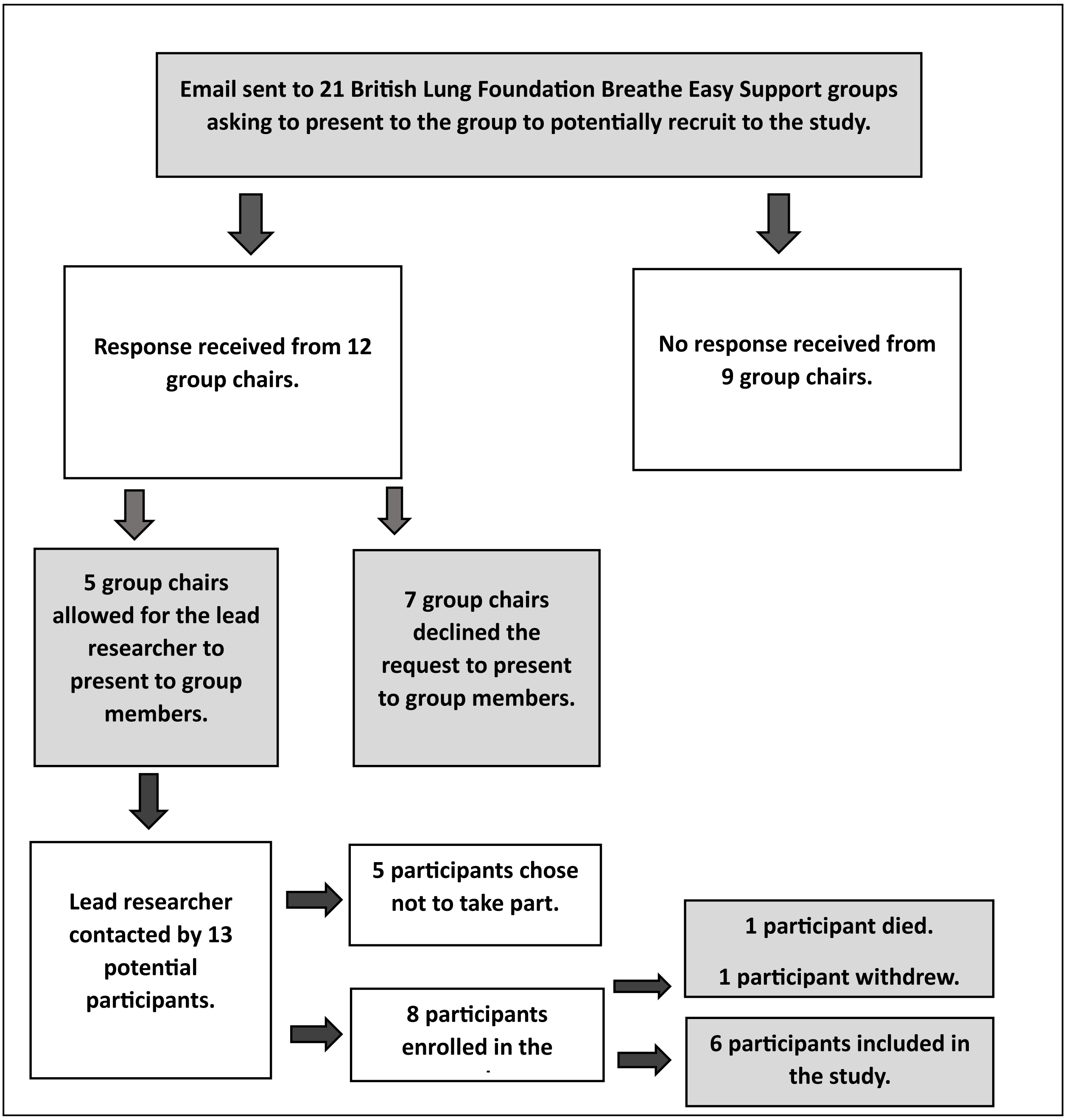


Figure 7.0 - Implementation of amended recruitment strategy

Participants were recruited to this study through attendance at a BLF breathe easy support group. Consent to contact the chair of each selected group was obtained from the BLF on 30th June 2021. The researcher sent an e-mail to the chair of 21 BLF support groups across England informing them of this study, and requesting an opportunity to present to the group, to potentially recruit participants to the study. Table 26 presents the groups contacted, the groups from whom a response was received, and the outcome of the request.

Table 26 - BLF Breathe Easy Support Groups approached to present this study

Group contacted by email	Response received	Presented at group/Reason request declined
Nottingham Edwalton	No	No reply
Nottingham West	Yes	Presented to group
Sheffield	Yes	Presented to group
Sefton, North Liverpool	No	No reply
Ilkeston	Yes	Presented to group
Darlington	No	No reply
Bury St Edmunds	Yes	Presented to group
Redditch and Bromsgrove	Yes	No group held since February 2020
Telford	Yes	No COPD attendees at this group
Trafford, Manchester	Yes	No COPD attendees at this group
Leeds	No	No reply
Paisley	Yes	No COPD attendees at this group
South East Kent	Yes	No meetings at this time
Chesterfield	Yes	No meetings at this time
Norwich Hospital	Yes	No current group attendees
Westminster	Yes	Presented to group
Lewisham	Yes	No meetings at this time
Colchester	No	No reply
Norwich	No	No reply
Stoke	No	No reply
Dover	No	No reply

Out of the 21 groups contacted, 12 responses were received. Five group chairs facilitated the researcher to attend an online meeting to present the research study. Reasons for the chairs rejecting the researchers request included no members had a COPD diagnosis and groups were not running at the time due to the COVID-19 pandemic. A total of 52 people attending five BLF breathe easy support groups were presented to. The number of attendees with a diagnosis of COPD is unknown, as ethical restrictions prevented the lead researcher from asking them of their diagnosis at the meeting. This was particularly relevant given the meetings were all held online via Zoom, offering no opportunity for confidential conversations alongside group members not wishing to disclose such personal information to a stranger. The presentation delivered to each group can be found in appendix D. The presentation outlined the aims of the study and the requirements of taking part including a detailed explanation of the use of the cultural probes. The study inclusion criteria were then explained, followed by ways to contact the lead researcher for further information.

A total of 13 potential participants contacted the researcher, all via e-mail, requesting further information upon participation in the study. A telephone conversation was held explaining the study and allowing the potential participant to ask any questions. Following on from this, an invitation to participate pack was then posted to each potential participant via Royal Mail. This pack contained an invitation to participate letter (Appendix E) alongside a participant information sheet (Appendix F). Each potential participant, if they chose, contacted the researcher to express their wish to participate or not. Of the 13 individuals who initially expressed an interest, eight went on to take part in the study.

The reasons given from the remaining five participants not wishing to participate included:

- diagnosis of a further life limiting condition
- relocating for the summer months with family
- 3 participants chose not to contact the lead researcher following receipt of the invitation to participate pack.

The first participant was enrolled onto the study on the 6th of July 2021 and the last participant enrolled on the 27th of September 2021. The researcher continued to present at BLF breathe easy support groups until January 2022 whereby recruitment for this study ended on the 31st of January 2022.

Eight participants initially enrolled on this study, two of whom were husband and wife. In October 2021 the researcher was informed by the husband within this couple that his wife had sadly died. He chose to withdraw from the study at that time. This was facilitated immediately by the researcher to avoid any unnecessary burden to him. He wished to keep the cultural probe data completed by his wife up to that point, therefore data from both the husband and wife is not included within this study. The remaining six participants remained enrolled in the study until the 31st of January 2022 whereby an e-mail was sent to inform them of this and thanking them for their participation. Table 27 presents each participant's enrolment journey. Each participant offered informed consent upon the day of enrolment to the study. This is further explained within section 4.7.2. Data collection commenced that day with the cultural probes box being posted to them via Royal Mail.

4.4.9 – Reflection upon study population

The recruitment of participants solely via BLF breathe easy support groups presented some limitations to the study population, given the motivation and engagement required to access such support. This resulted in all six participants within this study being physically able, within the limitations of living with COPD, to still engage in activities of importance to them. This is not reflective of the wider COPD population, as identified within the integrative literature review underpinning this study, highlighting the impact of existential suffering in day-to-day life. Upon reflection, continuing to recruit participants via NHS settings, through an amended recruitment strategy of the invitation to participate packs being posted to patients meeting the study inclusion criteria, may have enabled the recruitment of a study population more representative of the significant existential impact of living with COPD. This may have resulted in an alternative insight into how the presence of meaningfulness is generated. The insight gained from the population within this study remains of value, as they have contributed to an understanding of strategies used within day-to-day life to generate meaning, explored within the findings of this study. Whilst the study inclusion criteria enabled the recruitment of participants from any ethnicity, the six people who chose to participate within this study identiifed as white British. The associated limitations of this is discussed within section 10.9.

As previously presented within section 4.4.5, the researcher aimed to recruit between 10-20 participants to this study. Further limitations in relation to this small sample size are also acknowledged within section 10.9.

Table 27 - Study participants enrolment journey

Participant name (pseudonym)	Date sent PIS	Date gave informed consent	Date cultural probe sent	Date cultural probes collected	Interview date	Time enrolled in the study
Stephen	06/7/21	06/07/21	06/7/21	27/9 /21	01/10/21	13 weeks
Craig	06/7/21	07/7/21	07/7/21	27/09/21	04/10/21	14 weeks
Patricia	06/7/21	12/07/21	12/07/21	27/09/21	08/10/21	13 weeks
Sally	21/7/21	30/7/21	30/7/21	11/10/21	24/11/21	17 weeks
Geraldine	21/7/21	20/7/21	20/7/21	24/11/21	11/02/22	29 weeks (illness)
Karen	29/7/21	30/7/21	30/7/21	10/11/21	19/11/21	18 weeks
Cheryl	30/7/21	27/9/21	27/9/21	Withdrawn 30th October 2021	-	13 weeks
Richard	30/7/21	27/9/21	27/9/21	Withdrawn 30th October 2021	-	13 weeks

4.4.10 - Data Collection

The total duration of data collection for this study was eight months, from July 2021 until February 2022. Data collection ended at this point as all enrolled participants had completed using the cultural probes and had participated within a narrative interview. As demonstrated within table 27, participants were enrolled within the study between 13 and 29 weeks. Geraldine, the participant who was enrolled within the study for 29 weeks used the cultural probes for the required 2-month period.

4.4.11 - Cultural Probe Data Collection

Each participant was sent a box of cultural probes to use for a period of two months. One participant, Geraldine, had her box of probes for a four-month period. This was due to her being unwell with an injury upon receipt of the probes so began to use them two months later when she had recovered. Each cultural probe box contained a set of six probes and instructions for use, with each participant able to select as many or as few as they wished to use. Table 33 displays the probes each participant selected to use. Every participant used at least two probes, with one participant using all six over the two-month period. The journal was the most popular probe used, and the rosette and associated life achievement reflection card being the least popular amongst those participating within the study. An exploration of the reasons behind the choice of probes used is explored within chapter nine of this thesis, presenting a discussion of its suitability as a research method within palliative care research.

Throughout the two-month period that each participant used the probes, they were able to contact the researcher via email or telephone as many times as they wished to gain further clarification upon how to use them. Only one participant contacted the researcher, and this was for instructions upon how to physically use the disposable camera. No participant contacted the researcher to discuss the content to include when using each of the probes.

The probes were collected by secure courier from each participant’s home address and returned to the researcher. An e-mail was sent to each participant to inform them of the safe receipt of the probes and how to arrange their narrative interview. The interview date and time were agreed at a suitable time for each participant.

4.4.12 - Narrative Interview Data Collection

A narrative interview was undertaken with each participant. Interviews were scheduled at a time suitable for each participant and took place either via the telephone (five participants) or via the online video conferencing platform Zoom (1 participant). They lasted between 30 and 65 minutes. Each interview was recorded using a Dictaphone and transcribed verbatim by the researcher. The self-transcription of the narrative interviews is considered a strength within this study, the process of transcription is regarded as a crucial element in ensuring the quality of interview-based qualitative research (Bell, Bryman and Harley, 2018), and is favoured as a key element within data analysis (Point and Baruch, 2023). The process of transcription by the researcher deeper familiarity with the data, such as the nuances of the conversation, including tone, pauses and emphasis, providing a deeper insight that may have been missed if a transcription service had been employed (Bird, 2018). Furthermore, a detailed understanding of the emotional dynamics revealed within each narrative interview enabled the researcher to interpret meanings and intentions behind the spoken word more accurately (Brandenburg and Davidson, 2011). Emersion within the data from the point of transcription facilitated accurate coding and categorisation alongside subsequent theme development. Self-transcription also enabled the researcher to reflect on their own role within each narrative interview, identifying any biases or influences they may have had. A basic interview structure, underpinned by wider literature informed each narrative interview. In addition, each participant was encouraged and enabled to freely give their narrative on living with COPD to gain a rich insight into the presence and absence of meaningfulness within their day to day lives. This approach was presented to the study PPI group who agreed it was an appropriate approach to discussing a potentially sensitive topic with participants.

The interview structure was as follows:

1. *Introduction* - The researcher approached each narrative interview with the aim of creating a productive relationship with each participant (Drabble *et al.*, 2016). The researcher adopted a friendly and personable manner to build a rapport and put the participant at ease. This aimed to allow participants to feel equal to the researcher, facilitating a comfortable environment in which to describe the experiences shaping meaningfulness within their daily lives (Ritchie *et al.*, 2014; Holloway and Jefferson, 2021).
2. *Review of the research project* - The introduction to each interview was of significance, giving context to the participant upon the origin of questions to be asked and facilitating the development of a collaborative research relationship (Holloway and Jefferson, 2021). Prior to commencing the questions upon the experience of daily life when living with COPD, the researcher reminded the participant of the cultural probes they had used and of the aim of the study. This allowed for participants to develop a mental framework in which to place their narrative (Holloway and Jefferson, 2021). Each participant was reminded of the confidentiality processes in place throughout their participation, and each participant confirmed they were happy to continue.
3. *Opening interview question* - Each participant's interview began with a question based upon 'when you were diagnosed with COPD, how did that make you feel?' the wording within the question was a conscious choice to orientate them towards the beginning of their narrative story upon their experience of living with COPD (Josselson, 2010).
4. *The interview and use of interview prompts* - The interview prompts schedule was adapted for each participant following the researcher reviewing their cultural probes prior to the narrative interview. To undertake this process, principles of photo

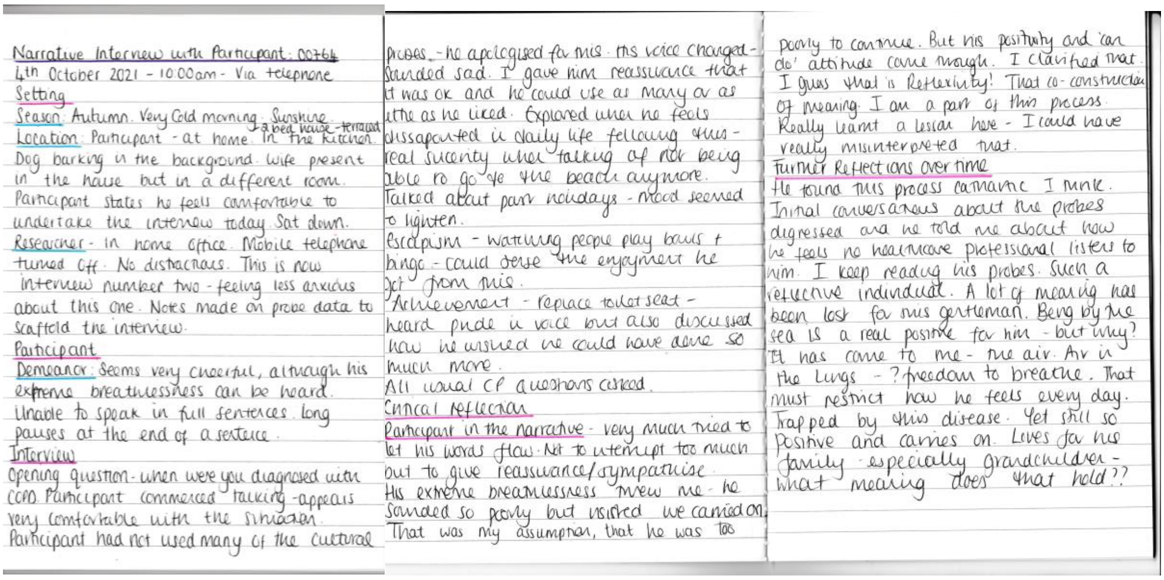
elicitation research were adopted, with adaptations made to account for the differing types of data collected from the cultural probes. This approach has been used within existing healthcare research, using data collected in differing forms such as photos and journals to underpin discussion in interviews. Glaw *et al.* (2017) adopted the method of photo elicitation interviewing to identify and explore sources of meaning within the lives of adults living with or without depression. This study used the interview with each participant to reveal the meaning and importance of each image, eliminating the variability of interpretation between the researcher and participant (Bryman, 2016). The interview prompt questions, as shown in the example within figure 8.0, were intentionally brief. This allowed the participant to given their own story, whilst co-constructing their own narrative with the researcher, adhering to the methodological principles of narrative inquiry (Clandinin and Connelly, 2000). Through this approach, member checking of the participants intended meaning behind their recorded life events and feelings within the cultural probes occurred, therefore ensuring the trustworthiness of this process and the data collected alongside subsiding ambiguity (Birt *et al.*, 2016; Glaw *et al.*, 2017).

Cultural Probes with similar content around feeling exhausted, tired and low in mood:	**Question relating to these probes**:
Journal entries – multiple entries relating to feeling 'tired' or 'fed up'. **Think-Pads-** reference to feeling exhausted and tired when describing the day on multiple days **Photos** – reference to undertaking more sedentary activities in the evenings	In some of the journal entries and in other probes, you have referred to feeling tired and not really feeling motivated. Does that happen often for you?
Cultural Probes with similar content around the importance of family:	**Question relating to these probes:**
Journal entries – multiple entries related to conversations, days out and interactions with family. **Think-pads** – family frequently feature within the people Sally converses with **Photos** – Multiple photos of family, days out with family **Rosette** – reflections upon family being proudest achievement.	You family have featured a lot within what you have included in the probes. Can you tell me about that please?

Figure 8.0 - Interview Prompt Schedule example: Sally

5. *Natural end* – No set time limit was given for each narrative interview. Participants were not informed of how long they had been within the interview at any point. Each interview came to a natural end once each participant believed they had spoken of all they wished to.
6. *Closing remarks* – Once the interview had ended and recording stopped, each participant was thanked for their time and efforts in participation. They were reminded they could contact the lead researcher should they have any questions following the interview up until the end of their participation in the study.

Field notes were taken throughout each narrative interview. Field notes are required when undertaking qualitative research to give context to the data to be analysed (Patton, 2002; Creswell, 2013), through placing the study data within a worldly context around a certain participant population (Phillippi and Lauderdale, 2018). Furthermore, rigour and trustworthiness of qualitative study may be increased through the use of field notes as a researcher critically reflects throughout data collection, acknowledging potential or actual bias (Phillippi and Lauderdale, 2018). A structured approach was taken to documenting field notes throughout data collection within this study. An excerpt from one set of field notes from a narrative interview with one participant, Craig, is presented in figure 9.0.



Narrative Interview with Participant: 00764
4th October 2021 - 10:00am - Via telephone

Setting

Season: Autumn. Very Cold morning. Sunshine.
Location: Participant - at home. 2 bed house - terraced In the kitchen. Dog barking in the background. Wife present in the house but in a different room. Participant states he feels comfortable to undertake the interview today. Sat down.
Researcher - in home office. Mobile telephone turned off. No distractions. This is now interview number two - feeling less anxious about this one. Notes made on probe data to scaffold the interview.

Participant

Demeanor: Seems very cheerful, although his extreme breathlessness can be heard. Unable to speak in full sentences. long pauses at the end of a sentence.

Interview

Opening question - when were you diagnosed with COPD. Participant commenced talking - appears very comfortable with the situation. Participant had not used many of the cultural probes. - he apologised for this. His voice changed - sounded sad. I gave him reassurance that it was ok and he could use as many or as little as he liked. Explored when he feels dissapointed in daily life following this - real sincerity when talking of not being able to go to the beach anymore. Talked about past holidays - mood seemed to lighten.
Escapism - watching people play bowls + bingo - could sense the enjoyment he got from this.
Achievement - replace toilet seat - heard pride in voice but also discussed how he wished he could have done so much more.
All usual CP questions asked.

Critical Reflection

Participant in the narrative - very much tried to let his words flow. Not to interrupt too much but to give reassurance/sympathise. His extreme breathlessness threw me - he sounded so poorly but insisted we carried on. That was my assumption, that he was too poorly to continue. But his positivity and 'can do' attitude came through. I clarified that. I guess that is Reflexivity! That co-construction of meaning. I am a part of this process. Really learnt a lesson here - I could have really misinterpreted that.

Further Reflections over time

He found this process cathartic I think. Initial conversations about the probes digressed and he told me about how he feels no healthcare professional listens to him. I keep reading his probes. Such a reflective individual. A lot of meaning has been lost for this gentleman. Being by the sea is a real positive for him - but why? It has come to me - the air. Air in the Lungs - ? freedom to breathe. That must restrict how he feels every day. Trapped by this disease. Yet still so positive and carries on. Lives for his family - especially grandchildren - what meaning does that hold??

Figure 9.0 - Field Note Excerpt

As displayed, the following components were documented within the field notes taken throughout each narrative interview:

- Setting – participant - location of interview. Room interview took place/season/time of year. Any other people present. Any distractions .

  Researcher - location of interview. Any distractions. Feelings prior to interview commencing.
- Participant demeanour
- Notes throughout the interview - the opening question used. How does the participant seem - happy, sad, quiet. How certain topics effect tone of voice. Is the participant willing to talk.
- Critical reflection immediately after interview - researcher as a participant in the narrative.
- Any further reflections on the situation over time.

4.4.13 - Summary of Data Collection

Data collection for this study took place over an eight-month period from July 2021 until February 2022, when each participant had completed using the cultural probes and had given a narrative interview. Table 28 summarises the data types collected.

Table 28 - Summary of Data collected

Total Number of Probes completed	25						
Narrative Interviews	**Length of Interview**	**Postcards**	**Journal**	**Journey Map**	**Rosette**	**Camera**	**Think-pad**
Stephen	47:24	0	1	0	0	0	1
Craig	39:50	1	1	1	0	0	0
Patricia	31:18	1	1	0	1	1	1
Sally	1:02:42	1	1	0	1	1	1
Geraldine	50:37	1	1	1	0	1	1
Karen	28:30	1	1	1	0	1	1
Total length of interview data	5:00:21						

The data collected included 25 completed cultural probes and five hours and twenty-one seconds of interview data. The use and reasons underpinning participants choice of cultural probe use is further explored and presented within the findings chapter of this thesis.

4.4.14 - Data Analysis

An ethnographic description of each participant, followed by a structural narrative analysis of the interview and cultural probe data was used to interpret the data collected and develop the findings within this study. Figure 10 presents a diagrammatic representation of the data analysis and interpretation process.

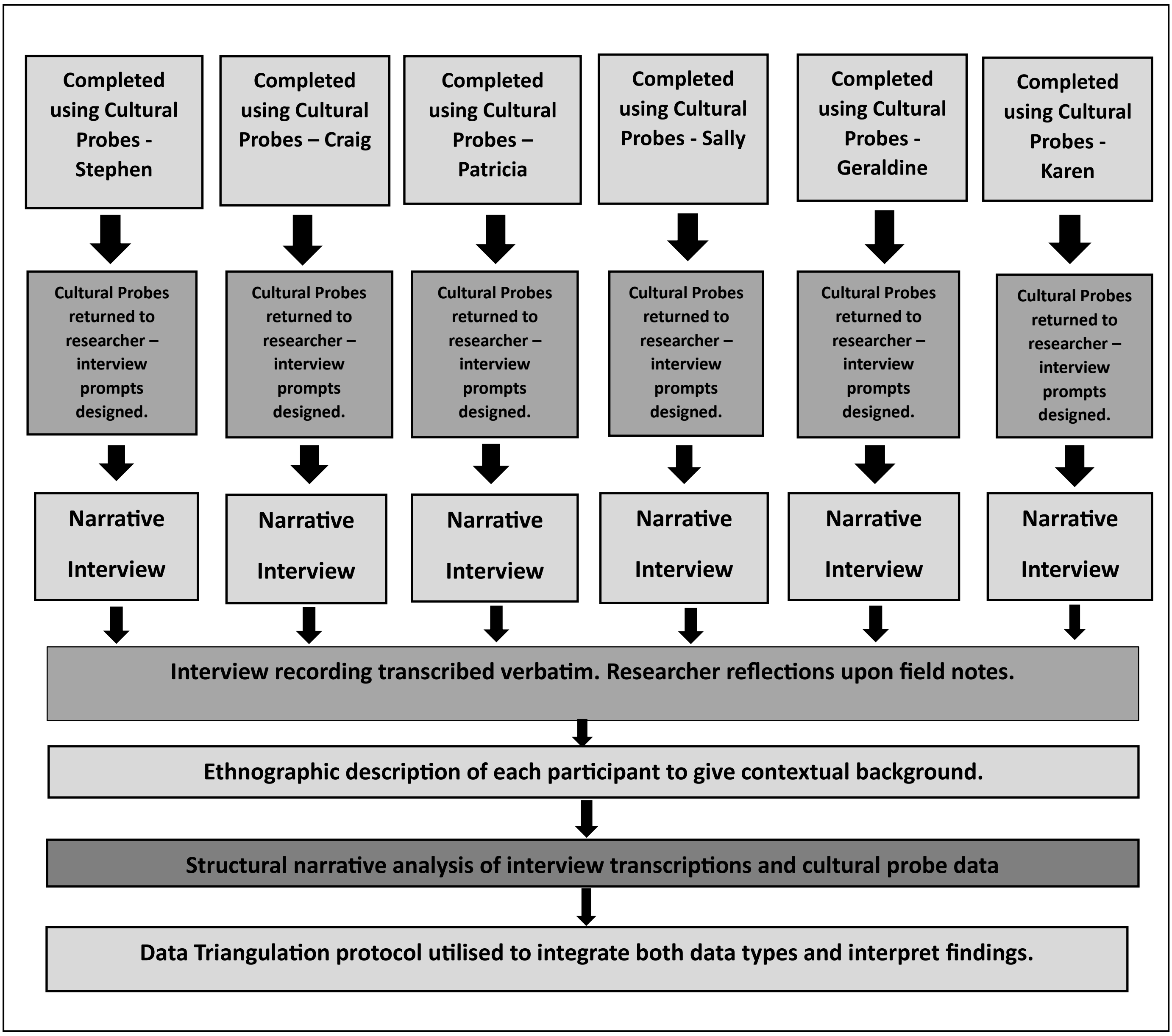


Figure 10 - Data analysis and interpretation process

This approach was given considerable thought, to enable an accurate presentation of each story in an orderly and understandable way, whilst maintaining the multi-dimensional depth of each account (Ritchie *et al.*, 2014). As demonstrated within figure 10, each layer of data analysis and consequential interpretation builds upon the previous layer, to answer the research aim. The following four sections present the process adopted within each layer of data analysis and interpretation in detail.

4.4.15 - Ethnographic description of each participant

A description of each participant, their social context and live circumstances has been written by the researcher as an element of the data analysis and interpretation process within this study. Termed within the literature as '*thick description'*, presenting this information provides not only a rich understanding of the social context of this study, but gives cultural context to meanings generated collectively by the researcher and each participant (Geertz, 1973; Spradley, 1980). Presenting this description of each participant has enabled a holistic understanding of each person, allowing profound contextualisation of their narratives, utilising their individual world view. The development and presentation of a thick description of the cultural context surrounding each participant facilitates understanding upon why they behave as they do, and the meanings they are trying to express (Geertz, 1973). This also enables the study findings to be presented within the true context as intended by this study's participants (Brewer, 2000).

Each ethnographic description has been constructed using the following components of cultural context to structure the text:

- Participant referred to by the pseudonym they chose.
- Age
- Marital status
- Family situation
- Housing situation
- Geographical location
- Employment status/former employment
- Date of COPD diagnosis
- Cause of development of COPD

4.4.16 - Structural Analysis of Cultural Probe and Narrative Interview Data

Narrative analysis encompasses a number of approaches to varied types of texts, all of which represent stories (Reissman, 2005). This umbrella term directs researchers to take the constructed texts, apply some organisation, alongside the use of contemporaneous fieldnotes, and closely inspect identify connections (Reissman, 2005). Unlike alternative qualitative methodologies, narrative inquiry explores much more than the analysis of short phrases, which can be easily taken out of context. Narrative inquiry encompasses participants discourse upon reality alongside their expressions used to convey this (Polkinghorne, 1995). In turn, participants' life experiences are presented in the form of a story, co- constructed between the participant and researcher with a distinguished plot facilitating context and meaning (Ricoeur, 1984; Polkinghorne, 1995). When exploring the presence and absence of meaningfulness in the day-to-day lives of those living with palliative care needs arising from COPD, it is necessary to explore the connection between life events and consequential life choices (Carr and Kemmis, 1986) as each individual's narrative plot. Narrative plots are disconnected and do present in a linear pattern through past, present and future, with links between a former life choice to a later consequence being created by analysis through reflective realisation when exploring a life episode and its meaning (Polkinghorne, 1991). Narrative plots are created by analysis, to link a former life choice to a later consequence, through reflective realisation when exploring a complete life episode (Freeman, 1984). Often only revealing their meaning from this process (Polkinghorne, 1995).

The multi-dimensional elements of plots within individual stories, when combined through analysis, present a cohesive story featuring incidental contributory episodes (Polkinghorne, 1995), which is of particular relevance when exploring life meaning and its impact. The development and consequential structure of an individual story an associated plot, is influenced by the analytical approach used. Narrative analysis defines how a researcher organises the collective data into a structured intelligible account (Polkinghorne, 1991), providing new knowledge upon a subject area. Narrative structural analysis explores the a story not only focusing upon its content, but also an exploration of the meaning behind symbolic expressions (Burke, 1952). The linguistic components (structures) have a narrative allowing for interpretation of the valuable differences between participants construction of meaning upon life events (Reissman, 1989).

This study explores how meaningfulness and meaninglessness is manifest within the day-to-day lives of those living with palliative care needs arising from COPD, therefore variations in the construction of life meaning is of paramount significance. Through analysing the structural components of each individual's narrative, variations in personal meaning upon significant life events and associated choices are revealed, giving deep and rich insights into participants day-to-day lives and the meaning attached to it.

4.4.17 - Structural Analysis – The Process

Following verbatim transcription of each narrative interview by the researcher using Microsoft word, Labov's analytical model of structural elements (Labov, 1972), was applied to the text. This model of structural coding facilitated the understanding of each clause within the narrative text (Reissman, 2008). Table 29 presents the six categories of the structural analysis model, explaining the interpretive function of each.

Table 29 - Labov's Narrative Structural Analysis Model (Simpson, 2005)

Narrative Code	Narrative Question	Narrative Function
ABSTRACT (AB)	What was this about?	Indicates a story is about to commence. Commands attention from the listener
ORIENTATION (O)	Whom or what is a part of the story? Time and location of it taking place	Assists the listener to contextualise the story
COMPLICATING ACTION (CA)	Then what happened?	The core narrative of the story
RESOLUTION (R)	What finally happened?	A final significant event of the story
EVALUATION (E)	So what?	Language used functionally to give clarity to the main point of the story
CODA (C)	How does it end?	A signal that the story has now ended, directing the listener back to the point in which the narrative began

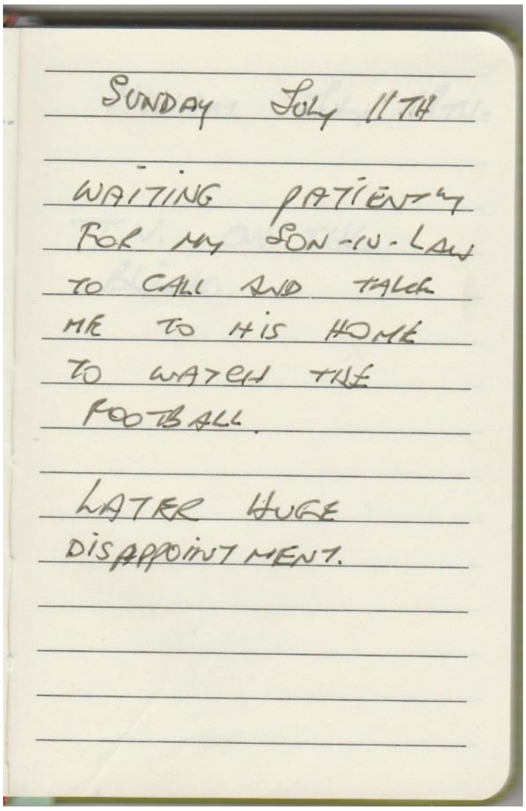
Each narrative interview transcription was broken down into structural elements (small stories), that were subsequently coded separately as individual units. A worked example of the coding of a structural element within Stephen's narrative interview transcription is presented within Table 30. Within this example, Stephen's narrative presents a story through time, with this inductive analytical method representing the individual meaning their story has for them, keeping the context of the spoken word intact. Whilst objective events are presented to the reader, the intertwined narrative structures around the circumstances leading up to a diagnosis of COPD and its meaningful impact is revealed.

Table 30 - Stephen – Narrative Structure 1

What started it all for me Louise (.) I went on a, a supposed to be a pleasure trip on the Settle to Carlisle Railway	A
That entailed getting the train in Notting- [Nottingham] er I'd been invited by a couple of friends of mine (.hh) We got the train in Nottingham to Leeds (.1) and then (.2) the hotel where we stayed (.2) to get to the station was uphill	O
and right out of the blue (.hh) halfway up the hill (.hh)I had to suddenly stop to catch my breath	CA
This was a completely new sensation for me	EV
(.hh) and by the time I got on the train, erm, I was then relaxed so that was ok(.2) so that was ok (.h). When we got to Carlisle, I had to decline the invitation of my colleagues to walk round because I knew I'd be out of breath=, so I just sat and whatever	CA
(.h) and that was the very first manifestation so I couldn't wait to get back home (.h) and get to the surgery and have a word with my doctor	EV
And the doctor, Dr Turnstone who is no longer with us, er with at the practice (.h) but he more or less immediately diagnosed COPD	R
[So I'd] never heard of this COPD you know before you know .h and then (2) thereafter I went through a whole routine of tests and all the rest of it (.h) including the CT scan. (.h)	CA
I then had a meeting with the consultant who showed me the state of my lungs with all these tiny little holes which if if memory serves he explained that was the problem (.h) because these little holes were letting the oxygen that I was breathing escape	CA
and therefore causing me a problem breathing	R
This was about five years ago	O
Well its its different to how it was before obviously but (.)	CA
having accepted the situation, the condition that I'm in (.h) I've regulated my life accordingly (.)	EV
I know there are certain things I Can and can't do	C

Stephen chose to organise this narrative structure around acceptance of living with a life-limiting condition (COPD), with this linguistic presentation demonstrating the personal importance of regulation of life activities being a realistic and positive approach to carrying on. Stephen orientates us to the plot (OR), presenting to the reader a vivid example of a train trip with friends as background information surrounding the recognition of deterioration in his health. Evaluations (EV) within this structure present his personal methods to rationalise the impact of COPD. Stephen has a remarkably positive attitude to life, and this is reflected within his attitude towards the significant life event of being diagnosed with COPD. The complicating actions (core narrative of the story) are presented through Stephen discussing the process of diagnosis and how life had now become different to before. His narrative within this structure presents how meaningfulness is present within his day-to-day life, despite the regulations he has imposed upon the activities he is able to undertake.

This narrative is framed with an abstract statement (AB), describing how Stephen's journey with COPD began, and his current situation living with COPD (Coda), knowing he is unable to undertake certain activities. Although this narrative structure alone gives limited insight into how meaningfulness is present or absent within day-to-day life, the plot further develops throughout the whole narrative. Each narrative structure was then given a code related to the theme underpinning its content. Coded narrative structures were then grouped thematically for each individual participant's narrative story. Each participant's cultural probe data was then interwoven within this coding process. Each piece of cultural probe data was considered, and a code applied relevant to its content. As shown within Figure 11, a journal entry from Stephen describes how he is waiting for his son-in-law to collect him to watch a football match at his house.



SUNDAY JULY 11TH

WAITING PATIENTLY
FOR MY SON-IN-LAW
TO CALL AND TAKE
ME TO HIS HOME
TO WATCH THE
FOOTBALL.

LATER HUGE
DISAPPOINTMENT.

Figure 11 - Stephen – Journal Entry – 11th July 2021

This cultural probe entry was given the code of ‘relationships and connections’. Themes generated from the codes given to the cultural probe data were then integrated with the themed narrative structures. This process of integration and interpretation was undertaken using the triangulation protocol, and is further discussed within section 4.4.17 of this thesis.

The process of constant comparison was applied across all themed groups of narrative structures across all participants narrative interview transcriptions, to identify commonalities in both content and meaning to organise multiple structures relating to each theme (Braun and Clarke, 2006). This presented the multiple examples within each theme as a valuable finding of this study. The importance of a theme was not determined by its frequency of presentation within the narrative structures (Braun and Clarke, 2006), however through repeated reading of the identified structures within the narratives and re-visiting field notes and audio files, assurance was developed that participants had shared similar meanings

(Spradley, 1980). The final themes were labelled ensuring a clear difference between each. The interpretation of findings developed further throughout the writing up process of this thesis, and discussions between the researcher and supervisor throughout supervisory sessions.

Using the ethnographic approach of cultural probes alongside narrative interviews has augmented the findings from this study. The cultural probe data enabled truthful and novel insights into the presence and absence of meaningfulness in day-to-day life for those living with palliative care needs arising from COPD. The narrative interviews provided profound explorations, in participants own words, to give further depth to the study findings.

4.4.18 – Data Interpretation – Triangulation Protocol

The use of cultural probes alongside narrative interviews is a novel multi-method qualitative research approach that has not been published within the wider literature. As such, an interpretation method to account for multiple data types, and the facilitation of data integration has been adopted to generate the findings within this study. The seminal work of Denzin (1978) presented the concept of data triangulation as involving multiple sources of data to generate research findings. Data triangulation is often applied to mixed-method studies within the wider literature, as a means of integrating both qualitative and quantitative data. The triangulation protocol however, due to its function being to integrate multiple sources of qualitative data (O'Cathain, Murphy and Nicholl, 2010), was identified as being a suitable approach to data interpretation. Figure 12 displays the application of the triangulation protocol within this study.

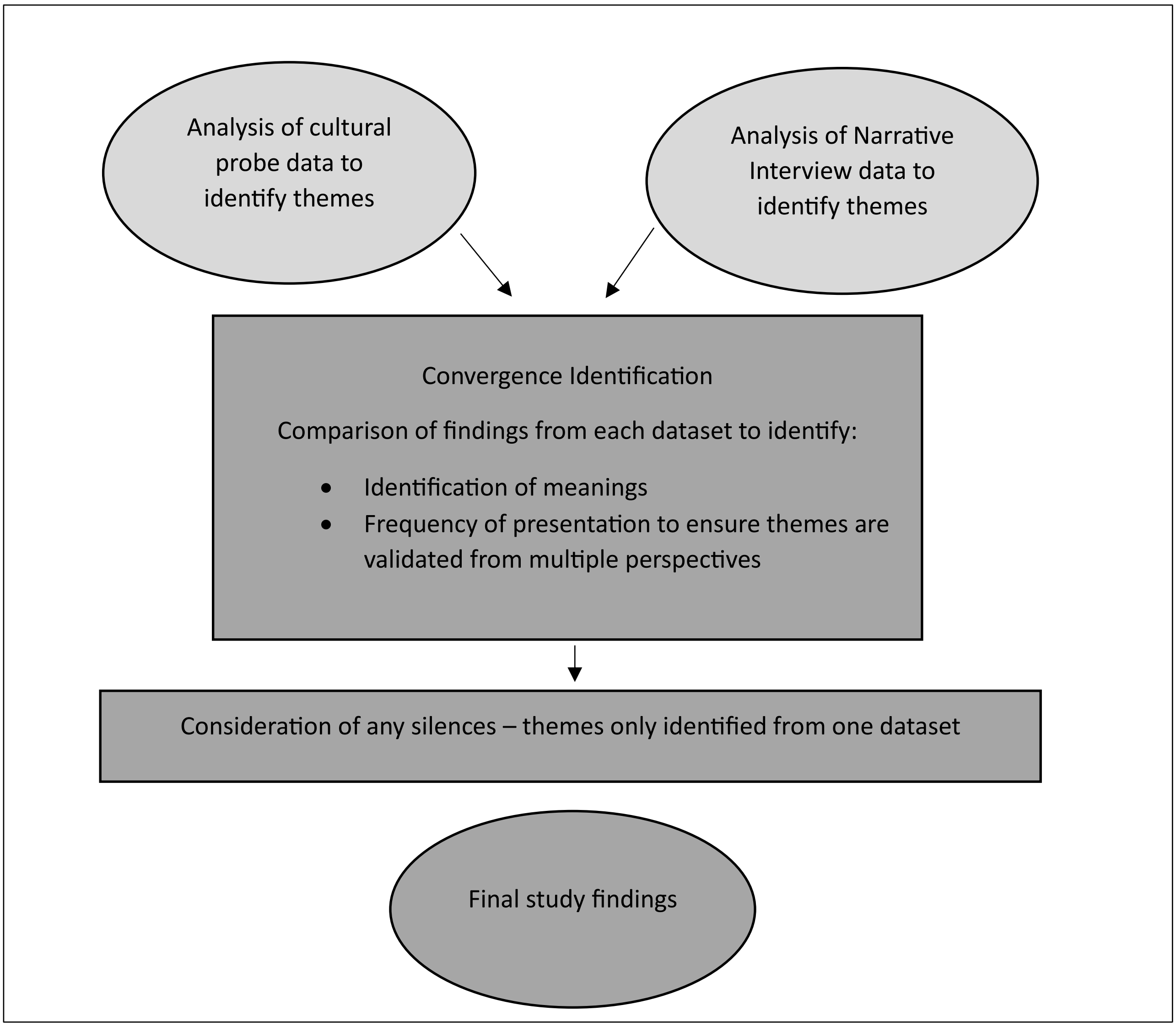


Figure 12 - Application of the triangulation protocol

The underpinning principle of this approach is to confirm the presence of single constructs across differing datasets to identify ‘convergent validity’ (Campbell and Fiske, 1959; Erzerberger and Prein, 1997). This approach allows researchers to move away from interpretation of findings from each single method, towards meta-themes present across differing methods (O’Cathain, Murphy and Nicholl, 2010), integrating the two sets of findings to generate a robust multi-dimensional understanding of intricate health matters, validated from multiple perspectives (Farmer *et al.*, 2006). When using a triangulation protocol to integrate and interpret study findings, a ‘convergence coding matrix’ is developed to identify themes from both data-sets that agree, partially agree, or disagree (Farmer *et al.*, 2006). Furthermore, ‘silences’ are identified, where one theme is evident within only one of the two data-sets, which is an expected situation as some research methods will most likely capture differing elements of the phenomenon under exploration (O’Cathain, Murphy and Nicholl, 2010). Unexpected silences may also be revealed through the use of this process, facilitating a deeper understanding of the phenomenon and identifying the need for further exploration (O’Cathain, Murphy and Nicholl, 2010).

The triangulation protocol method of data integration was applied within this study using the methodological principles presented by Farmer *et al.* (2006:p380), to triangulate findings from their published study examining ‘*contextual factors affecting Health Promotion dissemination, capacity building, and related research processes*’. This work is one of very few published worked examples of the triangulation protocol within qualitative research (O’Cathain, Murphy and Nicholl, 2010).

The following steps were undertaken to integrate the findings from the narrative interviews and cultural probe data within this study;

Sorting

The findings related to answering the aim of this research were sorted into two lists; narrative structures and cultural probes. Each list was reviewed separately to generate themes related to the research aim. They were then compared to identify frequency of presence across both data-sets, alongside the identification of variance amongst themes.

Convergence Identification

A comparison of each data sets findings, focusing upon their meanings, alongside their frequency and importance was then undertaken, as demonstrated within Table 31.

As shown, the frequency of themes is presented alongside supporting quotations and cultural probe data examples to illustrate each theme. For example, the number of times a particular theme was present within all data types, across narrative interviews and the cultural probes, to give an essence of its importance. As shown within Table 30, the data captured from the narrative interviews and cultural probes has allowed for the presentation of multiple perspectives upon the concept of meaningfulness within the day to day lives of those living with palliative care needs arising from COPD, facilitating a holistic picture of its impact (Farmer *et al.*, 2006). Furthermore, the process of data triangulation facilitates increased credibility of this study's findings, given the themes and associated sub-themes are present across data sets (Farmer *et al.*, 2006).

Table 31 - Theme Frequencies and Examples

	Number of Interview Respondents or Documents Mentioning Each Theme		**Sample Data**
Theme	**Narrative Interview Structures**	**Cultural Probes**	
1.Uninterrupted Personal Value Congruence	19	Thinkpad entries -19 Journal entries – 22 Photographs -14 Postcards – 8 Rosette Reflection -1	‘my greatest achievement was having my family and being able to support them’ Photograph at breathing exercise class ‘I’m so pleased I made a two minute radio piece for a sound festival’ ‘yesterday I was pleased that I went to a screening of student films where I used to work. I was greeted warmly and it made me feel valued’ ‘or I pop in, might just as well get on the bus and nip into Nottingham for no particular reason other than I can do it (.h).
Sub-Themes:			
Physical Ability to meet personal values	9	Thinkpad entries - 3 Journal entries – 7 Photographs -3 Postcards – 1	‘working hard on keeping exercising has improved my strength and stamina’ Photograph reflecting a walk in Regents Park ‘walked down to a friends with birthday present for her….felt good that I’d managed it’ ‘and then there’s the singing for breathing….it has these good breathing exercises’ ‘a virtual exercise class today’ A thought about tomorrow: ‘looking forward to seated dancing’
Relationships and connections	9	Thinkpad entries - 11 Journal entries – 8 Photographs - 6 Postcards – 3	‘long conversation planning to see a friend in a nursing home. Both friends have lost their husbands’ Speaking of attending a Breathe Easy group: ‘but the ones that did turn up we all get on well together, and it means a lot to me ‘ ‘incidentally having been in touch with these people its really good for me’ Photograph of family photographs on the wall in a participants home Photograph of participant with grown-up children

	Number of Interview Respondents or Documents Mentioning Each Theme		**Sample Data**
1.Uninterrupted Personal Value Congruence	**Narrative Interview Structures**	**Cultural Probes**	
Sub-Themes:			
Fulfilment and Purpose	6	Thinkpad entries -1 Journal entries – 8 Postcards – 1	‘today I marked a game of bowls, the first time in months, I was a little nervous at first, not wanting to let anyone down…very enjoyable’ ‘everyone was so pleased to meet up. Face to face. Three new members. All the effort worthwhile’ ‘its terribly important to keep busy…and feel valued’
Overcoming Challenges	5	Postcards -2	‘going through difficulties can make one far more understanding of other people’s suffering’ ‘yes, you can’t have the rainbow without the rain’ ‘its tough and this weather makes it worse, but I know it won’t get better so I make the most of life’ ‘life with COPD is a series of little wins’

	Number of Interview Respondents or Documents Mentioning Each Theme		**Sample Data**
Theme	**Narrative Interview Structures**	**Cultural Probes**	
2. Meaningfulness through taking control of personal dignity	33	Thinkpad entries - 3 Journal entries – 7 Photographs -1 Postcards – 1	‘a rest day. Some regret not going on planned outing but wise decision’ ‘I really don’t want to be defeated by this illness – or limited by it – and yet I do have to accept my limitations’ ‘I was determined to get out every single day. That might sound boring, but to me it was an achievement to get out of the house and do a bit of shopping that I didn’t really need’ ‘you know I’ve got the scooter…. It gives me a feeling of satisfaction and sense of achievement’
Sub-Themes:			
Asserting and maintaining control over life choices	15	Thinkpad entries -3 Journal entries – 3 Postcards – 2	‘I just don’t see any other way to do it t:to survive (.h) I I mean er I I should imagine for some people it would be quite easy (.h) to descend into a slower despondency but (.h) I I I’ve never been like that for me’ ’ And lets them know that it’s not the end of the world. There are things available. Um. And it’s a get together. It’s a social atmosphere’
Acceptance of New Limitations	14	Thinkpad entries -2 Journal entries – 4 Photographs -1	‘well I mean I’m eighty eight, I’ve not got that many years. I’m determined to enjoy what I’ve got’ Well its it’s different to how it was before obviously but (.) having accepted the situation, the condition that I’m in (.h) I’ve regulated my life accordingly (.) I know there are certain things I can and can’t do. Erm, for example Louise (.h) just just to get back to the scooter deal (.h) Which I do (laughing) if that’s alright, you know you’re the vector for that if you like (.h) erm so it works both ways Louise that’s the thing (.h) that’s what I said to the patients as woman initially (.h) that erm you know that the students they mustn’t think it was all one way that erm we do get do feel useful as a result of taking part

	Number of Interview Respondents or Documents Mentioning Each Theme		Sample Data
Theme	Narrative Interview Structures	Cultural Probes	
3.Interuptted life meaning through Personal Value Incongruence	7	Thinkpad entries -19 Journal entries – 16 Photographs -1 Postcards – 2 Journey Map - 3	‘what silver linings have I found? Some companionship, some spurs to greater physical activity, but the gathering darkness is not always pierced by sunbeams’ ‘apart from that general feeling of inadequacy, because of the inability to do things like tying shoe laces for example’ ‘I do not want to be defined by my condition so it is important that I find other meaningful activities to do’
Sub-Themes:			
Future Worries	5	Journal entries – 4 Photographs -1 Journey Map -1	Um. Again - Again, it’s the fear of the unknown because you get all these, uh, people saying, “Well, this will happen, that u’ll happen.” Who knows? They don’t, they don’t, they don’t, do they. Yes well it’s all tied up with trying so much to live and how to make that work
Loss of Control	3	Journal entries - 2	(.h) Yes duck (.h) like today, its muggy (.h) this is the worst for COPD muggy weather (.h) you can’t do owt at all because you are fighting all the time (.h)

4.5 – Ethical Considerations

Ensuring the ethical principles of non-maleficence, beneficence, autonomy and justice has been of paramount importance throughout this study (Murphy and Dingwall, 2001). Such strategies have included gaining informed consent from participants, strict maintenance of confidentiality and anonymity, the minimisation of potential participant harm and research dissemination.

4.5.1 – Ethical Approval

Ethical approval for this study was obtained from the North-East, Newcastle and Tyneside 2 Research Ethics Committee. Approval of the study to include the initial recruitment strategy (as described within section 4.4.7 of this thesis), alongside undertaking face to face narrative interviews was granted in November 2020 (Appendix C). A substantial amendment was then submitted following the enforced Covid-19 restrictions and associated changes to the study recruitment strategy in May 2021. Ethical approval was granted from the same Research Ethics Committee on 28th June 2021 (Appendix C) – Reference 20/NE/0246 – Protocol No: 169078.

4.5.2 – Informed Consent, Confidentiality and Anonymity

As presented within section 4.4.8 of this thesis, the researcher visited five British Lung Foundation Breathe Easy support groups to deliver a recruitment presentation. Potential participants were asked to email or telephone the researcher to express their interest in participation. Upon contacting the researcher, each participant gave their consent to be sent an invitation to participate letter (Appendix E) and a Participant Information Sheet (Appendix F). The Participant Information Sheet gave accurate and thorough details about participation within the study, using non-technical language to facilitate understanding (Silverman, 2014). Each participant had this information for a minimum of a week, and they contacted the researcher to arrange a telephone call to ask and receive answers to any questions they had. Once each participant expressed they wished to participate, verbal informed consent was taken via the telephone and recorded by the researcher. At this point each participant was allocated a unique identification number, used to label the informed consent audio files. Each component of the consent form was read out to the participant, and verbal consent obtained for each element individually. The researcher documented this upon the study consent form (Appendix G). The completed consent forms contained no personably identifiable data, only the unique identification number. The audio files and completed consent forms were saved as digital files, within encrypted and password protected folders in the researcher's secure research data electronic storage space.

Appropriate data storage measures were taken to maintain confidentiality and anonymity. Upon receipt of the cultural probe data by the researcher, it was immediately reviewed and made only identifiable by each participants unique identification number. From the cultural probe data returned to the researcher, there were no identifiable elements of participant's personal data to reveal their identity, such as their real name or address. The cultural probe data were always stored in a locked filing cabinet. The narrative interviews were transcribed by the researcher who is the only person who holds copies of these documents. The interview audio files, and electronic interview transcriptions are stored within encrypted, and password protected folders in the researchers secure research data electronic storage space. The Dictaphone used to record each interview as a back up to the recording taken upon the researcher's computer was locked in a secure filing cabinet at all times until the interview had been transcribed. The Dictaphone audio file was then immediately deleted. Data and personal participant information was stored and used in accordance with the Data Protection Act (1988), and the University of Sheffield research data guidelines upon information security.

4.5.3 – Safeguarding

A risk assessment for participation within this study was completed and can be found within Appendix H. People who lacked mental capacity to make autonomous decisions were not included within this study. Consideration was given to the potential risk that each participant may find discussing the presence and absence of meaningfulness distressing. This risk was discussed with the study PPI group who voiced that the benefit of the research related to the generation of new knowledge to inform future care delivery outweighed this risk. A clear procedure was created for any participants who did become distressed throughout their time participating within this study. Each participants General Practitioner (GP) was informed via letter of their participation (Appendix I). As such, the GP was aware of their participation and what this included, should they contact them in relation to changes in their mood or emotions. Furthermore, the researcher included an information sheet within the Cultural Probe box sent to each participant informing them of how to contact their local mental health self-referral services. The researcher contacted each participant twice throughout the time they had the cultural probes to use. A part of this conversation was to ensure they were happy to continue with participation in the study, and to express any feelings of upset or distress. Should this have occurred, a discussion with the participant would have been held and if needed, withdrawal from the study facilitated. No participant voiced any changes to their emotional state whilst enrolled within this study.

The burden of giving up time to participate within this study was considered. No monetary reimbursement was offered for participation. Contact with participants throughout their enrolment was kept to a minimum to decrease this potential risk of burden as much as possible. The study PPI group voiced that as participants were fully informed of their commitments in participating through the invitation to participate letter and participant information sheet, alongside them voluntarily contacting the researcher to express an interest in participation, this risk was minimised as they had agreed to this commitment.

At the end of each interview, the researcher and participant had a conversation to ensure they remained comfortable with their participation, giving them the opportunity to ask any further questions.

4.5.4 – Dissemination of Findings and Impact

The findings from this study have and will be shared with researchers, academics and healthcare clinicians via conference presentations, journal publications and through teaching both in higher education settings and clinical practice settings. The researcher will also present the findings to the study PPI group who have been heavily involved throughout all stages of the study. As a result of this, an increased visibility of research outputs is facilitated (Marín-González *et al.*, 2017).

Whilst dissemination of findings is important, to facilitate research impact and change, the study findings will be communicated through methods relating to how people acquire new knowledge (National Institute for Health Research, 2023). Research impact and knowledge mobilisation has been considered throughout this research. As participants were recruited via attendance at British Lung Foundation breathe easy support groups, a summary report of findings will be sent to the British Lung Foundation research team.

The researcher has delivered teaching sessions to Respiratory Clinical specialist teams within a large local acute NHS Hospital upon the literature review underpinning this study alongside the study and findings. Furthermore, the researcher is a Senior Lecturer at a University in the

East-Midlands. The methodology and methods, alongside the findings from this study have been included within taught content to multiple cohorts of student nurses, allowing them to reflect upon its relevance within their own clinical practice.

4.6 – Trustworthiness

A number of strategies were implemented to enhance trustworthiness within this study, to demonstrate the findings are worthwhile of acknowledgement (Guba and Lincoln, 1985). Trustworthiness within qualitative research is often objected to by positivists, due to concepts such as validity and reliability being addressed in alternative ways, without the focus of seeking replicability (Shenton, 2004; Stahl and King, 2020). Whilst some state that terms such as validity and reliability remain relevant within qualitative research (Ritchie *et al.*, 2014), others present concepts including credibility and transferability when presenting the strengths of the study findings (Guba and Lincoln, 1985; Shenton, 2004).

The trustworthiness criteria developed by Lincoln and Guba (1985) have been used to scaffold descriptions of the techniques used within this study to address credibility, transferability and conformability of the study findings.

Credibility

Credibility within qualitative research refers to how accurately the perspectives and experiences are represented, alongside the study findings being well-founded through robust handling (Shenton, 2004). Within this study, credibility was initially addressed through the use of well-established research methods appropriate for the phenomenon being studied (Yin, 1994), alongside triangulation by the use of multiple data collection methods and sources of data. Member checking within the narrative interviews to ensure accurate interpretation of the meaning within the cultural probe data occurred (Silverman, 2013). A limitation to the credibility of this study is the absence of returning the narrative interview transcripts to participants for accuracy checking following transcription. The researcher transcribed the interviews verbatim, paying particular attention to each nuance to ensure accuracy. Furthermore, the application of a structural narrative analysis approach to the narrative interview data allowed for interpretation to be undertaken using whole structures of the narrative as opposed to utilising one singular sentence. This approach may have mitigated some elements of misinterpretation.

The provision of thick description, through the writing of ethnographic accounts upon each participant, presents real-life situations of each participant alongside the context surrounding them (Shenton, 2004), enabling interpretation to be undertaken within its contextual origin. Frequent de-briefing sessions were held throughout this study between the researcher and supervisors to develop trustworthy study findings (Cresswell, 2013).

Transferability

As the findings from qualitative research studies are reflective of a limited number of distinct settings and individuals, it becomes challenging to establish the generalisability of the findings and draw conclusions that are universally applicable two different contexts and populations (Shenton, 2004). A researcher does, however, hold the responsibility of demonstrating how a study's findings may be of relevance to similar contexts, patient populations and service providers. The use of thick description of the participant context will allow for the reader to determine if the circumstances presented within this study are able to be connected with their own roles or patient populations (Malterud, 2001).

Dependability

As a result of the dynamic and ever changing healthcare environment, the replication of identical study findings is not possible (Shenton, 2004). A detailed description is given within this study of the research design and data analysis and interpretation methods used, enabling a future researcher to replicate this work (Cresswell, 2013).

Confirmability

Confirmability explores the extent of which research findings are reflective of the perspectives and experiences of participants, as opposed to being influenced by the researchers biases or interests (Shenton, 2004). Through the adoption of triangulation of data types and the triangulation protocol to facilitate interpretation, confirmability has been enhanced within this study (Guba and Lincoln, 1985; Shenton, 2004). Reflexivity has further enhanced this, with the researchers beliefs and assumptions available for interpretation upon their influence. The limitations of this study are presented within section 10.8.5 of this thesis allowing awareness for the reader of identified methodological flaws (Shenton, 2004).

4.6.1 – Triangulation

This study employed a triangulation approach encompassing method triangulation, data source triangulation, and investigator triangulation (Shenton, 2004; Hammersley and Atkinson, 2007). Method triangulation entailed using two distinct data collection methods; cultural probes and narrative interviews. Multiple participants were recruited to this study to facilitate data source triangulation, allowing the comparison of data across different study participants (Hammersley and Atkinson, 2007). Whilst data collection was undertaken by one researcher, investigator triangulation was achieved through ongoing discussions upon the study findings within supervisory meetings to validate interpretation (Stake, 1995).

4.6.2 – Discussion of discrepancies

To further increase the credibility of this study 's findings, discrepancies and contradicting themes within narrative interview excerpts and cultural probe data are presented within the triangulation protocol (Cresswell, 2013). The process of data interpretation using the triangulation protocol method embraces the reporting and understanding of discrepancies, under such demonstrates trustworthy reporting of findings by the researcher (Guba and Lincoln, 1985).

4.7 – Reflexivity

Reflexivity involves recognising how the researcher’s role, prior experiences and personal attitudes can potentially influence the process of data collection, analysis and documentation (Dowling, 2019; Hammersely and Atkinson, 2019). It has been proposed that researchers may exhibit a level of sensitivity towards particular observations due to their past experiences (Schatzman and Strauss, 1973), therefore maintaining reflexivity is crucial during the analysis phase to distinguish between pre-existing knowledge and insights present within the data collected (Dowling, 2019). One effective approach to address this issue, is to explicitly incorporate reflection upon prior experiences as an integral part of the research methodology (Gabbay and Le May, 2011), presented within section 4.2.2 of this thesis.

Throughout data collection within this study, a reflective diary of notes was kept. The content included the researchers’ immediate thoughts and feelings upon the data captured, alongside initial ideas upon findings. The researcher’s pre-existing knowledge and experience has been considered throughout each stage of this study process, and as advised by Malterud (2001), acknowledged within the study’s strengths and limitations.

4.8 – Chapter Summary

Narrative ethnography was selected as the most appropriate methodology align to this study's aim, to explore the presence and absence of meaningfulness in the day-to-day lives of those living with palliative care needs arising from COPD. This methodological framework facilitates the opportunity to explore personal meanings in a cultural context. The underpinning rationale for the use of cultural probes and narrative interviews as appropriate data collection methods has been critically presented. The study setting, approach to sampling and the study recruitment strategy has been presented, alongside the approach to data analysis. Ethical considerations have been discussed. Particular attention has been given throughout this chapter to demonstrate adherence to the principles of trustworthiness, triangulation and reflexivity. The next chapter (five) presents an overview of the study findings and an ethnographic description of each participant.

Chapter 5.0 – Findings Overview and ethnographic participant accounts

This study intended to explore, through the narratives of people living with palliative care needs arising from COPD, the presence, absence, and impact of meaningfulness within their day to day lives. This introductory chapter presents an overview of the study findings, and an ethnographic presentation of each participant. Definitions of key terms used within the study findings are given.

5.1 – Overview of study findings

The three key themes emerging from this study's findings are: 'meaningfulness through personal value congruence', 'meaningfulness through taking control of personal dignity' and 'personal value incongruence'. The themes and associated sub-themes are presented over the subsequent three chapters (chapters six, seven and eight), and are displayed within table 32.

Chapter 6 presents an exploration of how when living with palliative care needs arising from COPD, meaningfulness within daily life is present when an individual's personal values remain aligned with their individual goals. This is facilitated through five sub-themes developed from the personal values held by participants: Physical ability to meet core values, relationships and connections, fulfilment and purpose, creativity and self-expression and overcoming challenges.

The theme upon meaningfulness through taking control of own dignity is presented in Chapter 7. This chapter presents how the participants within this study were able to take control of their personal dignity through asserting and maintaining control over life choices and the acceptance of new limitations.

Chapter 8 considers the theme of personal value incongruence, whereby when study participants are unable to meet personal values, this contributes to feelings of meaninglessness within day-to-day life. Furthermore, the presence of future worries and a loss of control in life facilitate the incongruence between individual's personal values and the imposed limitations when living with palliative care needs arising from COPD. Extracts from narrative interviews and cultural probe data are presented to illustrate key points within each theme.

Chapter nine gives a presentation of the use of cultural probes as a novel research method when exploring the lives of those living with palliative care needs. The findings are then contextualised within the existing literature, and their significance presented within the discussion chapter of this thesis (Chapter 10).

Table 32 - Overview of study findings

Chapter	Theme	Associated Sub-themes
Chapter 6	Meaningfulness through Personal Value Congruence	• Physical ability to meet core values • Relationships and connections • Fulfilment and purpose • Overcoming challenges
Chapter 7	Meaningfulness through taking control of personal dignity	• Asserting and maintaining control over life choices • Acceptance of new limitations
Chapter 8	Personal Value incongruence	• Unable to meet personal values • Future worries • Loss of control
Chapter 9	The use of Cultural Probes as a research method in palliative care research	• Acceptability • Usability • Unique insights

5.2 Key Definitions

Prior to the presentation of findings, definitions of key terms used are given to ensure clarity upon their meaning within the context of this research study.

5.2.1 – Personal Values

An individuals personal values give motivation to their behaviours, providing subjective guidance upon the importance of principles over both time and varied situations (Rokeach, 1973; Sagiv *et al.*, 2017). The absence of harmony between an individual's personal values and actual life experience mask clarity when identifying life meaning. (Rogers, 1959). Values are an individual, fixed philosophy upon personal and social actions within daily life (Rokeach, 1973; Suar and Khuntia, 2010), fundamental to an individual's psychological structure and personality (Pitts and Woodside, 1991). Values guide each characteristic of a humans conduct (Rokeach, 1973). The inherent features of values establish an individuals external behaviours, with people identifying these features when selecting activities in which to participate, possessions they obtain and the development of personal principles and importantly through lived experiences (Suar and Khuntia, 2010).

The Theory of Basic Human Values (Schwartz, 1992), focuses upon ten objectives holding great influence upon individuals lives (Russo *et al.*, 2002). This remains the most prominent, evidenced based theory upon personal values to date (Roccas *et al.*, 2014; Brosch and Sander, 2015). Figure 13 presents the ten human values defined by Schwartz (1992). Each value is underpinned by motivation from the individual.

Figure 13 - Theory of Basic Human Values (Schwartz , 1992)

Understanding each value, and its underpinning motivation is required to contextualise how the presence of personal value congruence within the daily lives of participants in this study contributes to life meaning. Personal value congruence is defined and further explored within section 5.2.2 of this thesis. Each of the personal values presented within Figure 13 are reported to be similarly structured throughout culturally varied populations, implying a general ordering of human motivation (Schwartz, 2012). A person holds several values, each ordered in a personal hierarchy of importance. When a value is influenced by a life circumstance, feeling is evoked (Schwartz, 2012). Using the value of independence to illustrate, when this becomes endangered, feelings of hopelessness and despair are activated. Feelings of happiness are however initiated when independence can be enjoyed, achieving personal value congruence.

5.2.2 - Personal Value Congruence

A concept founded by humanistic psychologist Carl Rogers, an individual's personal value congruence is founded upon how their personal values are aligned with how they are able to live their life (Burns, 1978; Shamir, House and Arthur, 1993). The process of value alignment is underpinned by a person reviewing their understanding of self, to include personal values, in coordination with their life experiences (Rogers, 1959). This coherence between personal values and personal surroundings contribute to feelings of life purpose and significance, conducive to the development of meaningfulness in daily life. This concept is further explored within Chapter 6.0 of this thesis, where the study findings related to personal value congruence are presented.

5.2.3 – Personal Value Incongruence

Personal value incongruence refers to a situation in which an individual's personal values or beliefs are in conflict or misalignment with one another, evoking a distortion of self (Rogers, 1959). This incongruence can manifest in various ways, such as conflicting moral values, contradictory goals, or inconsistent principles. The absence of harmony between someone’s personal values and actual life experience masks clarity when identifying life meaning, through the regulation of an individual’s behaviour (Rogers, 1959). When someone experiences personal value incongruence, they may feel inner turmoil, confusion, or a sense of being torn between different sets of values. This internal conflict can lead to stress, dissatisfaction, and difficulty in making decisions that align with their core beliefs (Bao *et al.*, 2012). Resolving personal value incongruence often involves self-reflection upon identifying their personal hierarchy of values, and potentially adjusting one's values or life choices to create a more harmonious and aligned value system (Hitlin and Piliavin, 2004). This can be a challenging process, however it can lead to greater clarity and a stronger sense of personal integrity. Furthermore, congruence of personal values is evidenced to improve well-being (Monteiro, Musten and Leth-Steensen, 2019).

5.2.4 – Personal Dignity

Personal dignity is an ethical concept associated with a personal sense of self-worth, respect and value (Oosterveld-Vlug *et al.*, 2013; Laranjeira and Dourado, 2022). Autonomy over life choices to meet individual needs, and develop a sense of agency is found to improve individuals quality of life and enable a dignified existence (Rodríguez-Prat *et al.*, 2016). For those living with chronic illness and associated palliative care needs, a person’s perception of dignity may alter as a result of the impact of unpredictable and fluctuating symptom burden (Chochinov *et al.*, 2002).

5.3 – Ethnographic Participant Descriptions

This section will now present a holistic account of each individual who participated within this study, to provide a rich understanding of each participant alongside the social and cultural context of the interpretations generated from the study findings (Spradley, 1980). Each account contains the following participant information to allow their presentation within their own cultural context:

- Participant referred to by a pseudonym.
- Age
- Marital status
- Family situation
- Housing situation
- Geographical location
- Employment status/former employment
- Date of COPD diagnosis
- Cause of development of COPD

5.3.1 – Stephen

'despite the COPD, life goes on'

Stephen was 79 years old when he gave consent to participate within this study. His strikingly positive attitude shone from the researchers first interaction with him, upon contact to express his interest in participation. He chose to participate in the study following listening to a recruitment presentation given by the researcher at his BLF breathe easy support group. Stephen's reasons for participation were underpinned by wanting to help others living with the same condition as him, demonstrating his considerate nature. This remained evident throughout each interaction with the researcher.

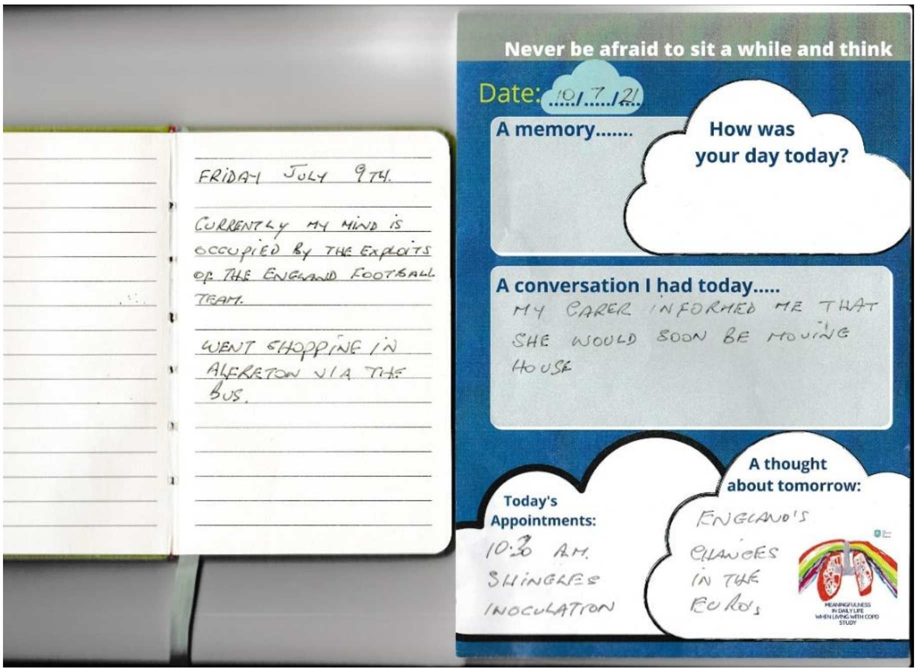
Originally born in Ireland, Stephen moved to England aged fifteen years. Following the death of his wife, he now lives alone in a three-bedroomed semi-detached house in Nottingham. His strong Irish accent remains. He has two daughters, who live in other cities. Stephen did not disclose if he had other children, as he only spoke of these two. He speaks fondly of his grandchildren and how he enjoys speaking with them over videocalls.

Diagnosed with COPD '*about five years ago*', due to a '*sudden realisation*' that he could '*no longer tie his shoelaces without becoming breathless*', Stephen's associated symptom burden has developed significantly throughout that time. Observed from researcher interactions with Stephen, he was unable to speak in full sentences, and his pause for breath between every few words was noticeable. Stephen uses oxygen at home to help alleviate his feelings of overwhelming breathlessness. He describes how minimal exertion leads him to '*breathe more* *heavily'*. At the time of his participation (October 2021), he had recently had a stairlift installed at home as previously he faced daily struggles going up and downstairs due to breathlessness. The underpinning cause of Stephen's COPD was not discussed.

Within the month prior to participation in the study, Stephen acquired a mobility scooter to aid him in leaving the house. Interactions with him revealed the joy, independence, and opportunity this has brought him. He talks with such happiness about the '*little trips'* he takes himself on every day for '*no apparent reason, just to get out of the house'*. He takes trips around Nottingham to visit different shops, to fill his days with adventure and enjoy interaction with the people he meets. Stephen's journal entries reflect this, through records of conversations he has had with people such as the bus driver, a restaurant waitress and the practice nurse.

Stephen is a regular attendee at his local Breathe Easy support group. Having visited this meeting to deliver the study recruitment presentation, the researcher observed his sincere contributions towards supporting other members. Offering advice to others with the same condition as him, and many words of positivity and encouragement.

Alongside this, Stephen has a great love of football, and from the interactions noted within his journal, thinkpad entries and from speaking with him, the sport plays an important role within his life, often evoking an emotional reaction within him:



FRIDAY JULY 9TH.

CURRENTLY MY MIND IS OCCUPIED BY THE EXPLOITS OF THE ENGLAND FOOTBALL TEAM.

WENT SHOPPING IN ALFRETON VIA THE BUS.

Never be afraid to sit a while and think

Date: 10.7.21

A memory.......

How was your day today?

A conversation I had today.....
MY CARER INFORMED ME THAT SHE WOULD SOON BE MOVING HOUSE

Today's Appointments:
10:30 A.M. SHINGLES INOCULATION

A thought about tomorrow:
ENGLAND'S CHANCES IN THE EURO'S

Stephen holds great fondness of his hobby of writing and delivering a general knowledge quiz to family and friends via social media each week. Something he began doing in the 2020 Covid-19 lockdown for '*something to do*', but he has continued since through the enjoyment of putting it together. He is also in the process of writing his own life story, with an international audience of friends and family eagerly awaiting the next chapters as he writes them. The sense of achievement this brings him is heard through the excited tone of voice, especially when speaking of how a friend has suggested he considers publishing these memoirs.

Despite living each day with the significant symptom burden associated with COPD, Stephen holds an immensely positive personal attitude. Each situation he describes is done so with focus upon the enjoyment he felt or his solution to the barriers faced, telling of how he has '*learnt to adapt*'. The restrictions imposed through his illness are seldom mentioned. Stephen describes how '*despite the COPD, life goes on*', an evident personal philosophy of a gentleman who '*takes each day as it comes*'.

5.3.2 – Sally

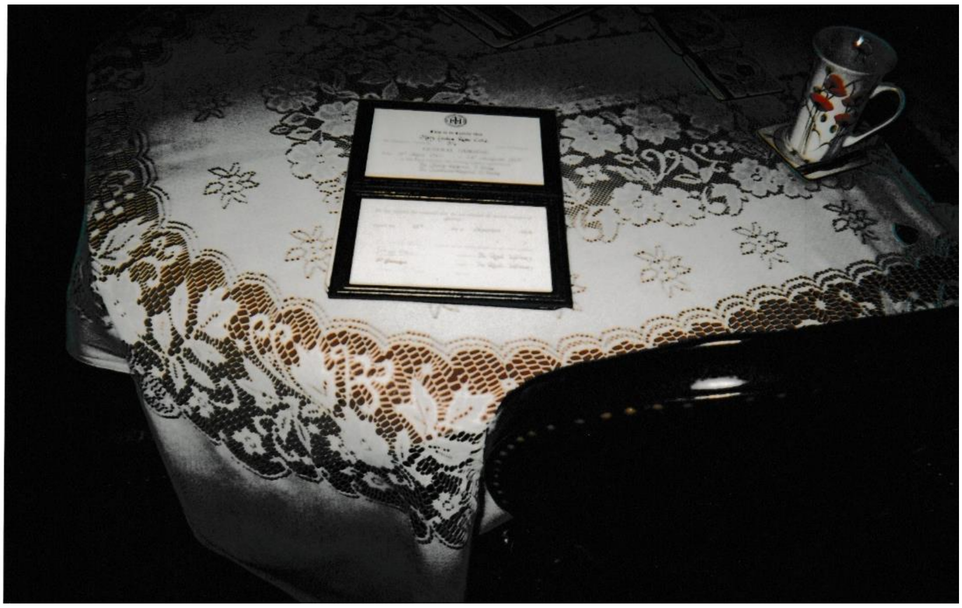
'It's not the end of the world'

As an active participant of her local Breathe Easy support group, Sally is well-positioned to offer support to others having been diagnosed with COPD in 2002. The enjoyment Sally gains from her involvement within this is evident, particularly when she describes the activities and events this has enabled her to participate in.

Sally was 79 years old at her time of participation in this study and lives with her husband in a semi-detached house. They have three children and grandchildren, who all live in different cities to Sally. Despite this geographical distance, it is evident they have a very close relationship. Sally speaks with pride and sincere fondness about each of them. The family spent time living abroad when the children were younger, namely Germany and Saudi Arabia due to Sally's husbands' employment. She recalls these experiences with detail, and an evident feeling of happiness and achievement from her time living there.

As a retired state registered nurse, Sally speaks proudly and fondly of her former career, and it is evident she holds an immense sense of pride. She describes how '*being a nurse never leaves you'* and throughout her narrative interview, spoke with clarity in her positive memories of her career.

One of the photographs she took as a part of this study, to reflect something she was proud of, was her nursing qualification certificate:



Sally's husband has significant health issues, and at the time of participation, Sally described a recent period where he had been unable to drive, limiting their ability to undertake hobbies and social activities. Sally spoke of how life is much improved as her husband is back driving, removing the need for them to use public transport and the added burden that brings. Sally had found this situation difficult due to the added physical exertion required to use public transport.

Sally experiences a significant symptom burden through living with COPD. She is breathless on exertion and describes how she routinely uses '*rescue breathing quite often during the day and when in bed too'*. Her husband does much of the '*heavy housework'* as she is no longer able. Despite this, Sally exudes a positive attitude and pushes herself to achieve her own personal goals. such as participating in seated dancing and other exercise for health classes.

5.3.3 – Karen

‘The gathering darkness is not always pierced by sunbeams’

Karen was aged 69 years when she participated within this study. Whilst taking part in a research project in 2008, Karen was diagnosed with COPD, much to her surprise given at the time, she had no symptoms. From then, until the time of her participation within this study, her symptom burden has worsened to such an extent she was forced to retire from work. Karen was a university lecturer and was no longer able to complete the required two-hour commute as she could ‘*no longer walk’* due to her breathlessness. Karen does still engage in some work-related activities at home such as ‘*external examining and tutoring’* and by her own explanation states ‘*I love to have work to do’*. Through speaking with Karen, it was evident her career was extremely enjoyable and important to her. She reflects fondly of her contribution to a ‘*Cultural Olympiad’* in 2010, organised by her then place of work. Pride is evident within Karen’s voice when she describes how she envisaged ‘*an image of the breath and blowing’* to underpin her idea to arrange glass blowing workshops for the local community as a part of this event.

Their work then formed part of a display, that when put together ‘*did look wonderful’*:

Karen lives in a flat in London, England with her husband. She has a son, who does not live with them. Access to the flat is via sixty-six stairs, a significant challenge and worry for Karen given her relentless shortness of breath. This situation is a continual worry for Karen, given her understanding that her COPD will most likely further deteriorate.

Virtual attendance at her local Breathe Easy support group allows Karen to speak fondly of the support his offers her. She believes ‘*it is very important to keep busy’* and such social activities, short walks in the park and reading help her to fulfil this belief.

The privileged insight into Karen’s life given to the researcher revealed times of difficulty and frustration were also observed through the reflections given. Karen describes how she ‘*feels a bit fearful when you have got this condition’* to make any future goals, expressing that life is ‘*all tied up with trying so much to live, and how to make that work*’.

5.3.4 – Geraldine

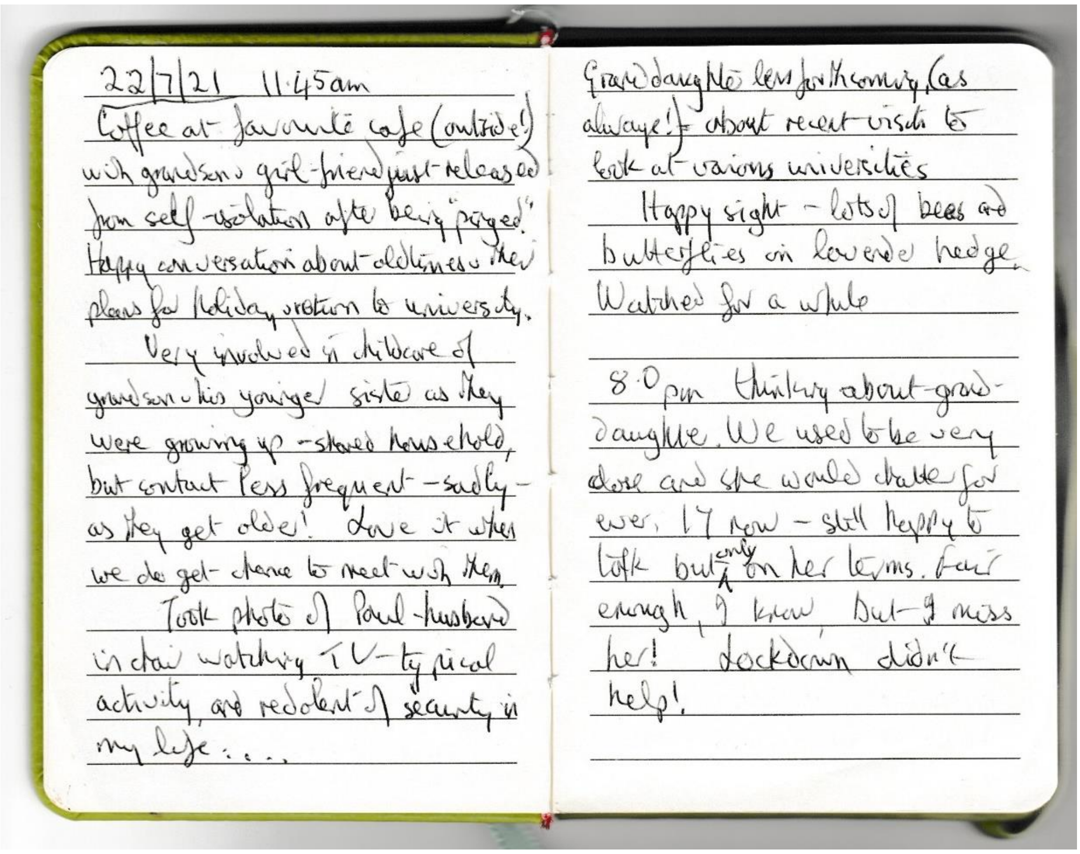
'you can't have a rainbow without rain –
You need the contrasts -
the not so good, to appreciate the special good things'

Receiving a diagnosis of COPD in 2013 came as quite a surprise for Geraldine, given she had never smoked, and she remains unaware of the cause of its development. Despite originally refusing to accept the diagnosis and subsequently declining the invitation to undertake pulmonary rehabilitation, Geraldine, aged 79 years at the time of participation, is now extremely compliant with all medications related to controlling her COPD. She also lives with a diagnosis of Myalgic Encephalomyelitis (ME). Furthermore, she received a hip replacement in 2020. Despite this, Geraldine has a very upbeat personality, identifying positive experiences from her daily life with ease.

She lives with her husband, daughter, son-in-law and grandchildren in Sheffield. Describing the top floor of the house in which they live as the '*penthouse*', Geraldine and her husband are somewhat *'self-contained'*. The attic comprises of a living room, bathroom, kitchen and bedroom, allowing them to live independently upon one floor, whilst having the support of family on hand. They cook an evening meal weekly for the whole family, something she very much looks forward to. The comfort and feelings of security this brings Geraldine is evident when she speaks of this situation, alongside the company and interaction.

Geraldine describes her husband as '*security*' in her life. She explained within her diary of how when they met, Geraldine was a widow with two children, and her now husband has '*taken* *them on'* and supported her ever since. Her appreciation of this is evident, especially when she is having a difficult day, and he supports and helps her.

Her fondness for her grandchildren, and the meaning of their relationship was evident throughout interactions with Geraldine. She spoke with excitement of times they spend together and has documented concern within her cultural probes upon situations they encounter causing them difficulty.



22/7/21 11.45am

Coffee at favourite cafe (outside!) with grandson's girl-friend just released from self-isolation after being "pinged". Happy conversation about old times & their plans for holiday, & return to university.

Very involved in childcare of grandson & his younger sister as they were growing up – shared household, but contact less frequent – sadly – as they get older! Love it when we do get chance to meet with them.

Took photo of Paul – husband in chair watching TV – typical activity, and redolent of security in my life . . .

Granddaughter less forthcoming (as always!) about recent visits to look at various universities

Happy sight – lots of bees and butterflies on lavender hedge. Watched for a while

8.0pm thinking about grand-daughter. We used to be very close and she would chatter for ever. 17 now – still happy to talk but only on her terms. Fair enough, I know, but I miss her! Lockdown didn't help!

As a retired Social Worker, Geraldine had a keen interest in helping others and managed to still do this through her voluntary work as a patient educator and participation within research studies. She attends her local breathe easy group supported by the British Lung Foundation, and values the friendships made through this.

Her self-defined ‘se*dentary lifestyle’* involved walks with her husband and hobbies such as embroidery, activities she can undertake within the limitations of her medical conditions. Geraldine did not speak of this lifestyle with negativity, but with fondness and a sense of feeling content.

5.3.5 – Patricia

' I manage you know'

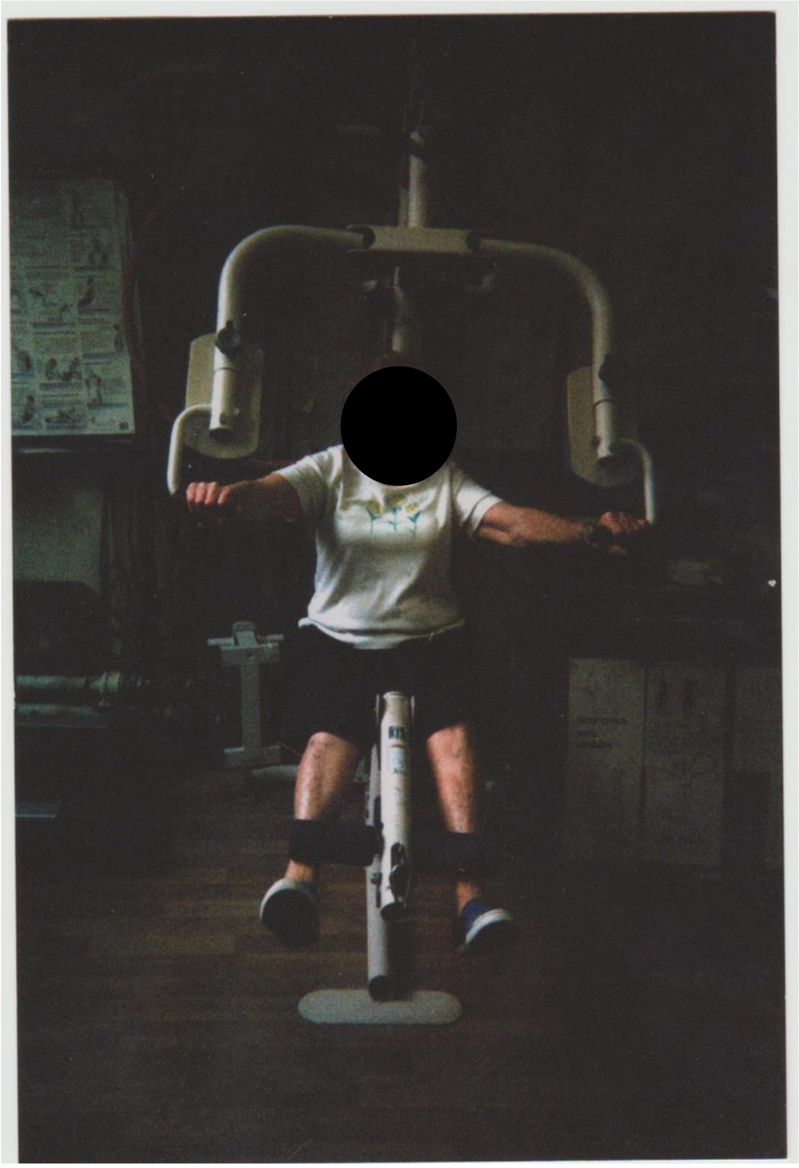
Patricia's diagnosis of COPD six years ago evokes strong emotions of anger for her, as the believed cause of development was passive smoking. She was aged 80 at her time of participation in this study. Her now deceased husband smoked heavily throughout the duration of their marriage, as Patricia explains, '*even in bed'*. She believes this is why she now lives with this condition, having never smoked herself. As reflected upon within her journal, this emotion of anger makes her feel '*guilty*', a privileged insight captured through her use of the cultural probes into the conflicting meaning this facilitates.

Patricia lives alone in a three bedroomed detached house in Ilkeston, Derbyshire. She has a downstairs existence, having made one of her reception rooms into a bedroom, as she was experiencing difficulties going up and downstairs. She lives in hope that by having this downstairs existence, she will not need to leave her home if her condition deteriorates.

Patricia is extremely close to her family, particularly her grandchildren and great-grandchildren who bring her such happiness. She has a grandchild who lives in Australia, who has children of her own. Patricia speaks of how she hopes to meet these grandchildren one day, '*before it's too late'*.

Her determination to remain as independent as possible is evident. She attempts to leave her home every day to undertake a walk, her shopping or to meet friends. Although this is somewhat difficult at times due to her relentless breathlessness, she speaks of how she paces herself, '*has a rest'* and often uses taxi's if this becomes too much of a challenge.

Patricia is a member of her local breathe easy support group and speaks fondly of the friendships she has made there. She also attends a local exercise for health class, demonstrating her determined character to continue to push herself.



Within the cultural probes Patricia completed, attendance at these sessions is something she very much enjoys and allows for feeling a sense of achievement.

Helping others is a significant part of Patricia's daily life, despite the symptoms she experiences from living with COPD. Patricia hosts a weekly knitting club at her home, with a group of friends to allow '*a bit of chatter and to help each other'*. She also speaks of when neighbours and friends give her help, such as taking her somewhere in the car, she enjoys '*paying them back'* by doing things for them.

Despite living with significant breathlessness and associated fatigue, Patricia lives her life as full as possible within these limitations. She does not speak of these in a negative way, quite the opposite with the researcher's interactions with her being heavily focussed upon overcoming the barriers of living with COPD brings.

5.3.6 – Craig

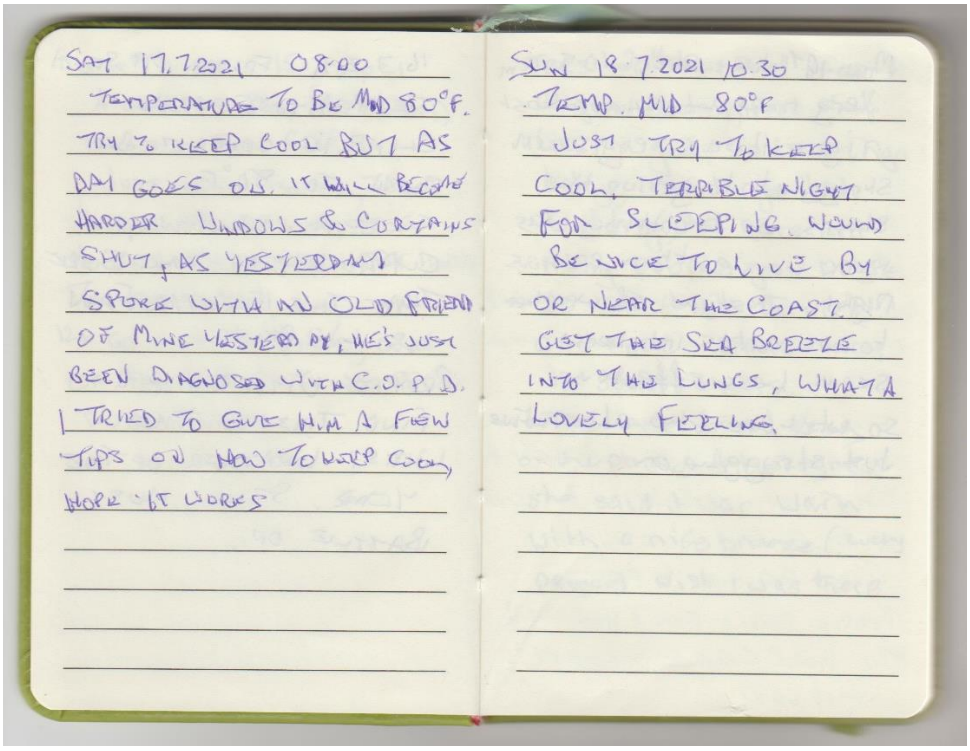
‘Still, must battle on’

Craig was diagnosed with COPD in 2006 as he had begun to feel breathless upon minimal exertion. As a result, he was forced to retire from work at the age of fifty-eight, something which he described ‘*hit me hard’*. He was 74 years old at the time of participation in this study. His health has deteriorated significantly since that time, with a diagnosis of spinal stenosis and prostate cancer, with the associated treatment causing further deterioration in his lung health. Craig is severely breathless at rest, evident when he speaks with a need to take a breath between every few words.

He lives in a two-bedroomed mid-terraced house in Ilkeston with his wife and spends much of his time at home. He writes about occasional trips to the bingo and to watch indoor bowls at a club nearby which he describes as ‘*enjoyable*’. He also speaks with friends and family often via the telephone, again something bringing enjoyment into his daily life.

Craig attends his local BLF breathe easy support group and has been a member since it was founded. He speaks very little of what this brings him, however, continues to regularly attend. The number of children Craig has was not explored, or his relationship with them. He did however speak with great fondness of a granddaughter, who visited him regularly.

Craig regularly reflects upon trips to the coast and how this is '*good for the breathing'*. A sense of relaxation and calm is given when he describes breathing in the sea air, something he only remembers and longs to do again.



SAT 17.7.2021 08.00
TEMPERATURE TO BE MID 80°F.
TRY TO KEEP COOL BUT AS
DAY GOES ON, IT WILL BECOME
HARDER WINDOWS & CURTAINS
SHUT, AS YESTERDAY
SPOKE WITH AN OLD FRIEND
OF MINE YESTERDAY, HE'S JUST
BEEN DIAGNOSED WITH C.O.P.D.
I TRIED TO GIVE HIM A FEW
TIPS ON HOW TO KEEP COOL,
HOPE IT WORKS

SUN 18.7.2021 10.30
TEMP. MID 80°F
JUST TRY TO KEEP
COOL, TERRIBLE NIGHT
FOR SLEEPING, WOULD
BE NICE TO LIVE BY
OR NEAR THE COAST.
GET THE SEA BREEZE
INTO THE LUNGS, WHAT A
LOVELY FEELING.

Many of Craig's journal entries are based upon the weather and how that impacts his symptoms of COPD, particularly breathlessness. He describes how in very hot weather, he keeps all windows and curtains closed to try and maintain a cooler environment, placing further restrictions upon his day-to-day life. Criag explains how he '*breathes better'* in cooler weather.

Out of the six participants within this study, the symptom burden experienced by Craig and associated limitations upon day-to-day life was the most significant. He presented to a life of feeling frustrated due to these limitations, and the absence of being able to undertake enjoyable activities.

5.3.7 – Chapter Summary

This chapter has introduced an overview of the three themes of: ‘meaningfulness through personal value congruence’, ‘meaningfulness through taking control of personal dignity’ and ‘personal value incongruence’, forming the findings of this study. Definitions of key terms have been presented. Furthermore, ethnographic descriptions of each participant have been given to allow understanding of the study findings within a cultural context. The following chapters (six, seven and eight), will detail each of these themes, integrated with extracts from narrative interview and cultural probe data.

Chapter 6.0 – Meaningfulness through Personal Value Congruence

This chapter presents how meaningfulness is present within the day-to-day lives of people living with palliative care needs arising from COPD, when they can meet their core personal values within the limitations of the condition and associated symptom burden.

Personal value congruence refers to the degree of harmony between an individual's personal values and the environment in which they exist (Burns, 1978; Shamir, House and Arthur, 1993). Personal values are not static and may evolve and change over time as a result of on-going life experiences and continual self-discovery. As individuals navigate through day-to-day life, they continuously shape and re-define their personal values, ultimately defining what is of importance to them. This is evident for those living with a chronic condition such as COPD, as participants within this study show that living with such a relentless symptom burden forces the re-evaluation and re-shaping of their personal values. The symptoms of COPD experienced daily for those within this study included chronic breathlessness, fatigue, and for some, reduced socialisation. Despite this, participants personal values were still able to be met within day-to-day life, leading to increased self-esteem and a remaining sense of identity, facilitating subsequent life meaning through a sense of fulfilment and purpose. Personal value congruence is presented by participants within this study as a subjective experience, as each individual's personal values are ordered in respect of their importance to them, dependent upon their cultural context and environment in which they live. Throughout the data interpretation process undertaken within this study, it was identified that each participant was striving to meet similar personal values. Figure 14 displays the five sub-themes within this chapter, of the personal values held by the six participants within this study. As illustrated, having the physical ability to meet their core values was necessary for participants to achieve personal value congruence, and identify meaningfulness within day-to-day life.

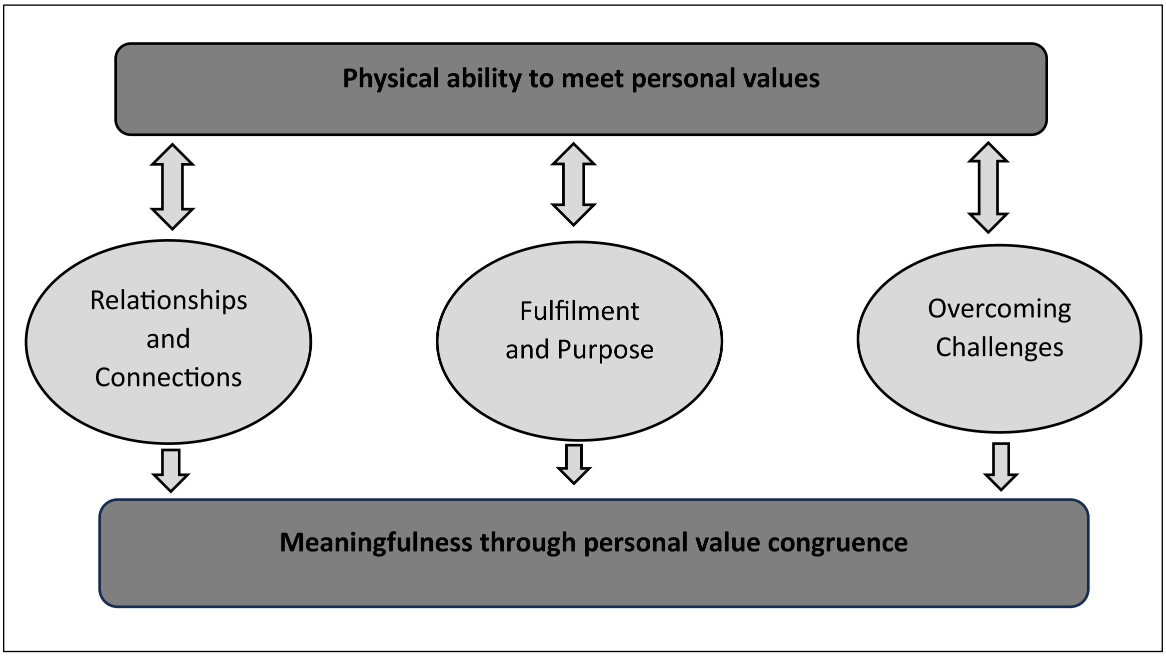


Figure 14 - Personal Values facilitating meaningfulness through personal value congruence.

The following five sub-sections of this chapter will present how participants were able to meet each of their personal values within the limitations of living with palliative care needs arising from COPD, to facilitate the presence of meaningfulness within day-to-day life.

6.1 – Physical ability to meet personal values

The participants within this study revealed that despite living with the significant symptom burden due to palliative care needs arising from COPD, they were still able to meet their core personal values. This was achieved if they had the physical ability to do so, or were able to adapt how values were met, generating meaningfulness within day-to-day life through personal value congruence. Undertaking activities of importance to them facilitated the presence of meaningfulness through associated feelings of accomplishment and purpose and remaining self-identity.

Stephen

Stephen gave insight into the meaning generated within his day-to-day life through having the physical ability to leave his home each day, following the recent acquisition of a mobility scooter. Prior to this, Stephen faced difficulty when trying to leave his home to go shopping or attend his breathe easy support group, due to how breathless he becomes on minimal exertion. As he now has a mobility scooter, to reduce the exertion needed to travel from one place to another, he is physically able to undertake trips around his local area and further afield with the use of public transport. As shown within an excerpt from Stephen's narrative interview (Narrative Structure 9), having the physical ability to leave the house, for '*no particular reason*' is of great importance to him, facilitating meaningfulness within his day-to-day life through a feeling of accomplishment.

Narrative Structure 9 – Stephen

***Stephen**: 'or I pop in, might just as well get on the bus and nip into Nottingham for no particular reason other than I can do it (.h).*

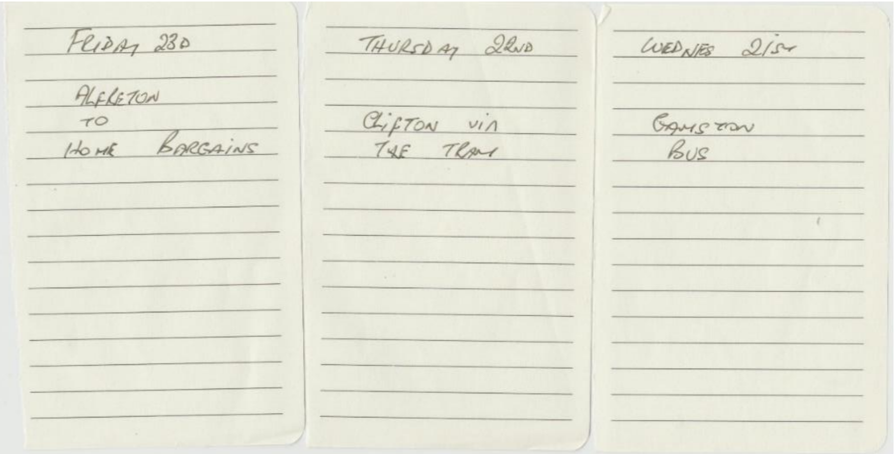
***LB**: Yeah, that's really interesting. So, thinking about that, there is no reason why but for you to go out because you can go and do it?*

***Stephen**: (.h) but yeah, and to get back to the lockdown deal once that finished and I could get outside (.h) I was determined to get out every single day. That might be that might sound boring but to me it was an achievement to get out of the house and get on the bus (.h) and go to either Derby (.h) Alfreton or Nottingham. I'd do a bit of shopping that I didn't really inessential items but (.h) enough to justify leaving the house shall we say you know.*

***LB**: I guess what that brings to your daily life is is really important isn't it, erm*

***Stephen**: It I, I'm I'm I'm constantly aware of the restrictions and limitations that having COPD places upon me (.h) but my way of combatting that (.h) is to do exactly what I have just been telling you.*

As shown within narrative structure two, Stephen speaks of how he is conscious to combat the limitations imposed upon him through living with COPD. Therefore, having the physical ability to leave the house daily holds great importance to him. Many of Stephen's journal entries (as shown within Figure 15), also reflected the significance of this, often with his daily outing being the only element of his day recorded.



FRIDAY 23D

ALFRETON
TO
HOME BARGAINS

THURSDAY 22ND

CLIFTON VIA
THE TRAM

WEDNES 21ST

GAMSTON
BUS

Figure 15 - Stephen – Journal Entries – 21st, 22nd and 23rd June 2021

Whilst Stephen spoke of other elements within his day-to-day life, such as his love of watching football on the television, writing a weekly quiz for friends and spending time with family, it was evident that being able to leave his home to undertake his shopping, attend his support group and meet friends facilitated significantly more meaning within his life. The acquisition of a mobility scooter has allowed Stephen's quality of life to improve, and this is evident from the excitement and joy in his voice when he speaks of the positive difference it has made to his daily life. He continued to return to the topic of the scooter throughout his narrative interview, each time highlighting the positive impact this has had upon day-to-day life for him.

Sally

Similarly, Sally is able to identify meaningfulness within her day-to-day life through having the physical ability to undertake activities of importance to her. She has been a very keen dancer since a young age, continuing to undertake this hobby in an adapted format in keeping with her COPD symptom burden. This allows Sally to meet her core personal values of self-expression and achievement. Sally regularly attends a virtual exercise class, '*seated dancing*'.

Narrative Structure 5 – Sally

Sally*: I - I love the - I love the seated dancing on Zoom.*

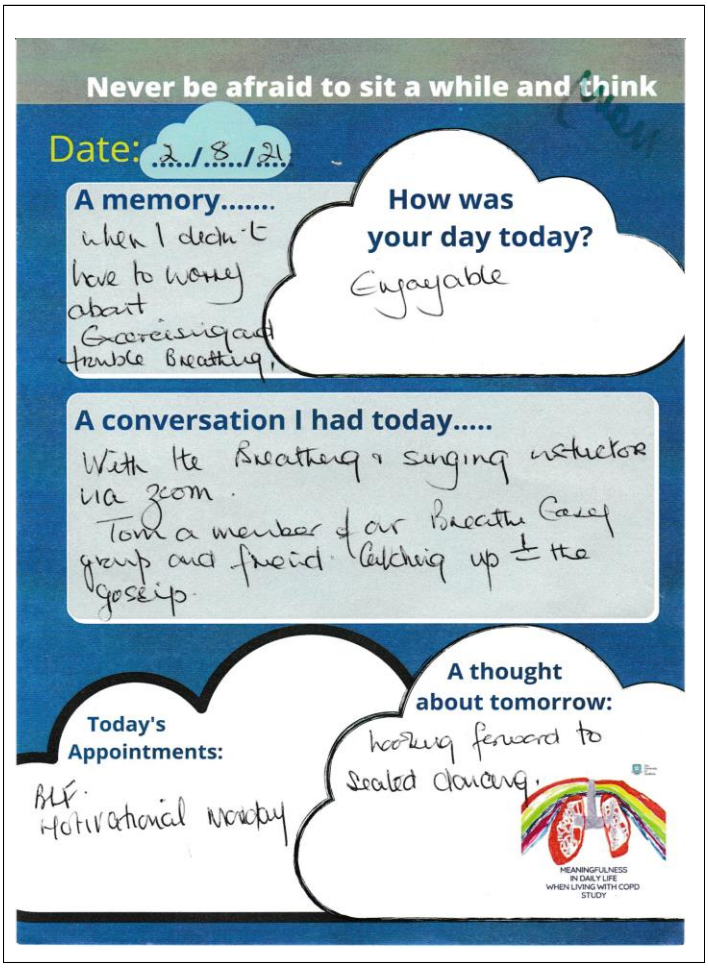
LB*: That really interested me, and it sounds fantastic.*

Sally*: It is, yeah. And we got the music, you see, coming over.*

LB: *Yeah.*

Sally*: As well. It's all to music. So, you've got a feel-good factor in the music, you know.*

As presented within narrative structure five, Sally experiences what she refers to as a '*feel good factor'* from attending these sessions, and this is further captured within her cultural probes, is something for her to look forward to in day-to-day life.



Never be afraid to sit a while and think

Date: 2./8./21

A memory.......

when I didn't have to worry about Exercising and trouble Breathing.

How was your day today?

Enjoyable

A conversation I had today.....

With the Breathing & singing instructor via zoom.
Tom a member of our Breathe Easy group and friend. Catching up with the gossip.

Today's Appointments:

BLF.
Motivational Monday

A thought about tomorrow:

Looking forward to Seated dancing.

MEANINGFULNESS IN DAILY LIFE WHEN LIVING WITH COPD STUDY

Figure 16 - Sally – Thinkpad Entry – 2nd August 2021

As show in figure 16, a memory documented upon this day was about a time in her life when she did not have to worry about breathlessness when exercising. This further emphasised the importance of Sally still having the physical ability to meet her personal values around a sense of achievement and purpose in day-to-day life, through an adapted way of attending dancing classes within her breathlessness limitations.

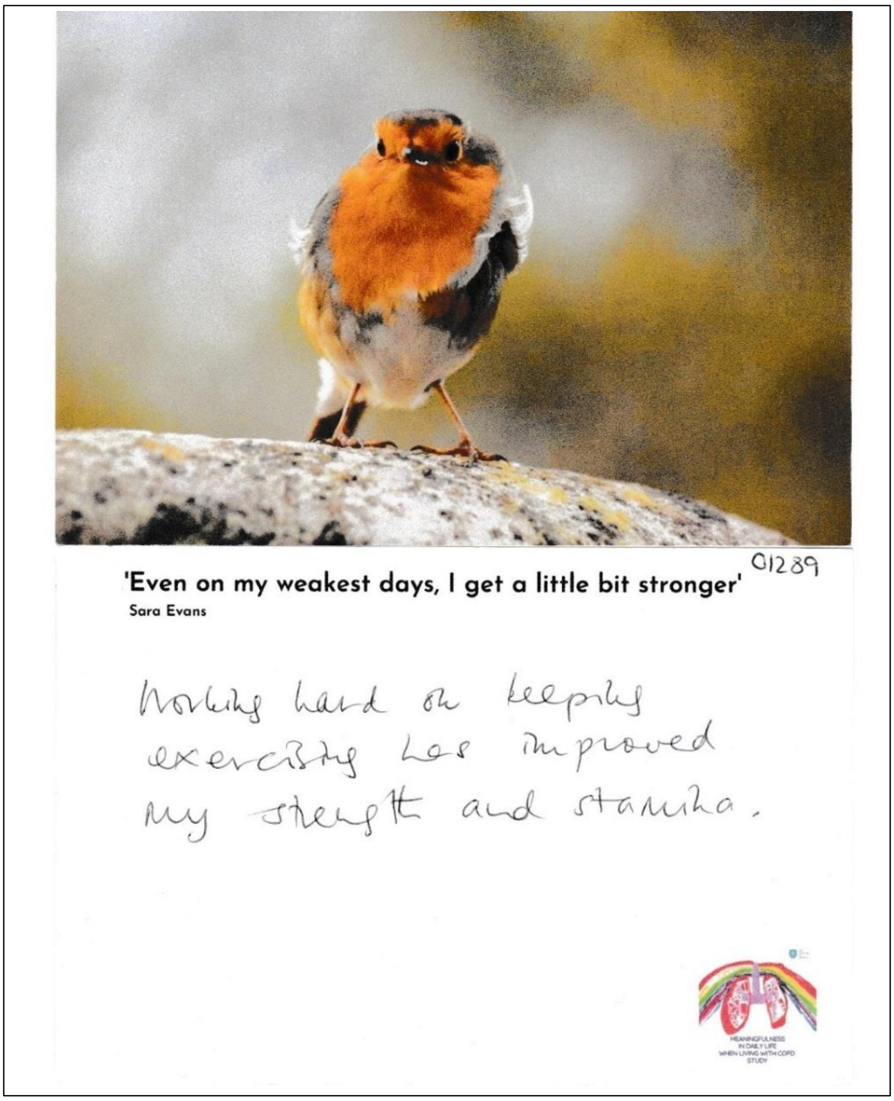
Despite her evident frustration of the physical impact of living with COPD, and how this causes her '*worry*', Sally also has the ability to visit family and friends, enjoying day trips to places of interest.

Figure 17 - Sally – Photograph

As shown within figure 17, Sally captured photographs within her cultural probes of day trips she had enjoyed with her family. She wrote within her journal of the enjoyment she experiences through spending time with her family, meeting her core personal values of relationships and connections. Having the physical ability to participate within these day trips and meet her personal core values facilitated meaningfulness within her day-to-day life.

Karen

The symptom burden experienced by Karen within her day-to-day life has increased significantly throughout her disease progression, forcing her to retire from work as her ability to travel the required distance to commute to and from work became too difficult for her. She has however, continued to push herself to undertake exercise within the physical limitations of her condition, bringing meaning to her daily life as she believes, as show in figure 18, this will improve her health.



01289

'Even on my weakest days, I get a little bit stronger'
Sara Evans

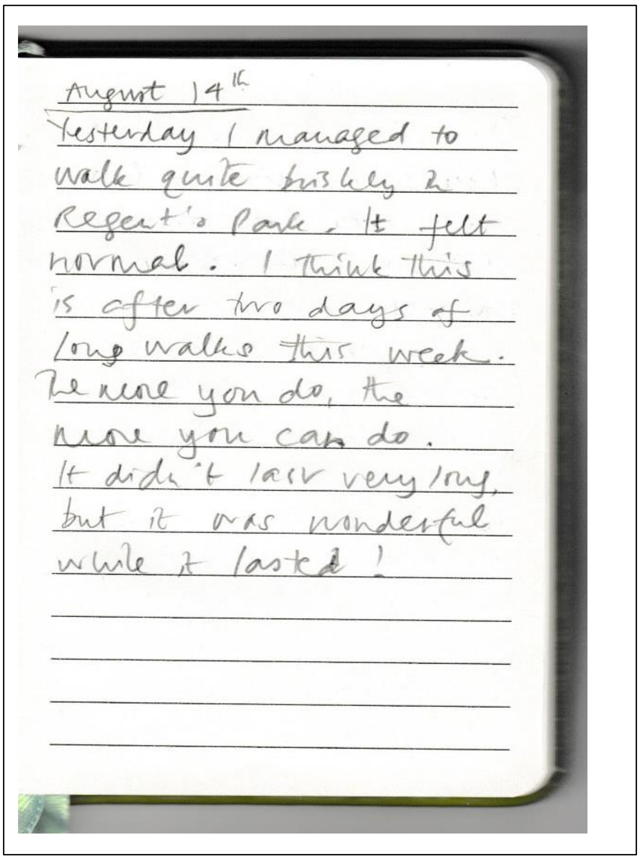
Working hard on keeping
exercising has improved
my strength and stamina.

MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

Figure 18 - Postcard – Karen

The meaning generated for Karen from her having the physical ability to undertake some exercise within the physical limitations of her health, meeting her personal core value of achievement, is shown within Figure 19.

Karen writes of her belief that '*the more you do, the more you can do'*, following a walk the previous day to Regent's Park, which she describes as '*wonderful*'. Through the adoption of an attitude of overcoming challenge to meet her core personal value of achievement, having the physical ability to do this generates meaning within Karen's day-to-day life.

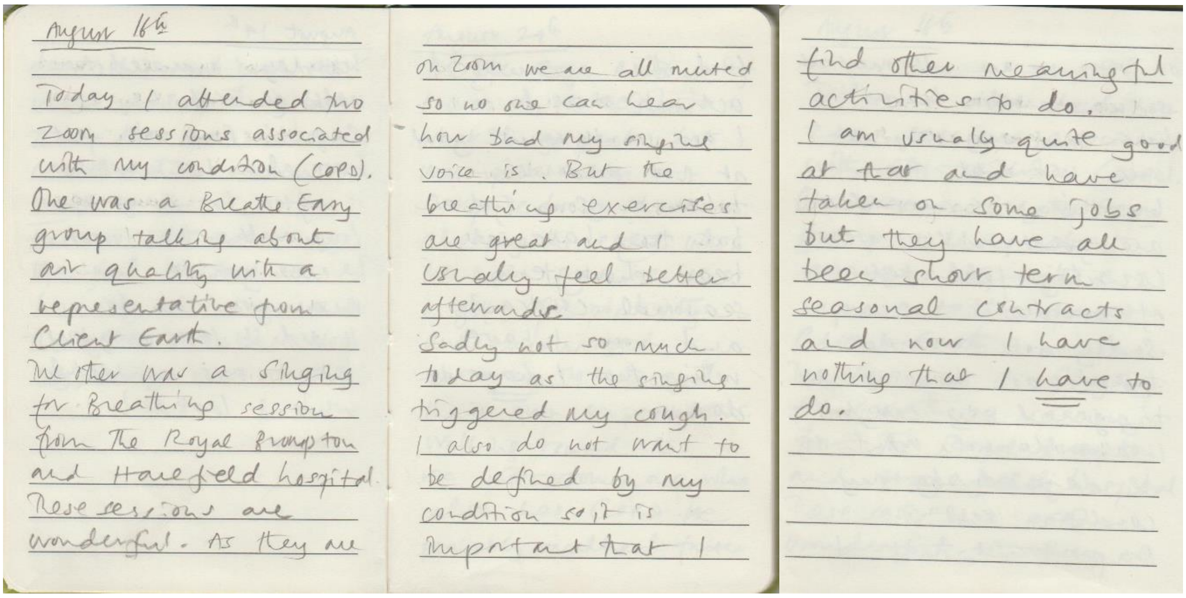


August 14th
Yesterday I managed to
walk quite briskly to
Regent's Park. It felt
normal. I think this
is after two days of
long walks this week.
The more you do, the
more you can do.
It didn't last very long,
but it was wonderful
while it lasted!

Figure 19 - Karen – Journal Entry - 14th August 2021

Having the physical ability to meet her core personal values to generate meaning in day-to-day life is further demonstrated within Karen's journal entries upon her attendance at online '*Singing for Breathing'* sessions.

She writes (figure 20), of how she is in search of more of these activities, writing '*and now I have nothing that I have to do'*. The need for Karen to have a purpose in day-to-day life is evident from this journal entry, and her ability to identify '*meaningful activities'* to achieve this, within the physical limitations of living with COPD facilitates personal value congruence.



August 16th
Today I attended two
Zoom sessions associated
with my condition (COPD).
One was a Breathe Easy
group talking about
air quality with a
representative from
Client Earth.
The other was a Singing
for Breathing session
from The Royal Brompton
and Harefield hospital.
These sessions are
wonderful. As they are

on Zoom we are all muted
so no one can hear
how bad my singing
voice is. But the
breathing exercises
are great and I
usually feel better
afterwards.
Sadly not so much
today as the singing
triggered my cough.
I also do not want to
be defined by my
condition so, it is
important that I

find other meaningful
activities to do.
I am usually quite good
at that and have
taken on some jobs
but they have all
been short term
seasonal contracts
and now I have
nothing that I have to
do.

Figure 20 - Karen – Journal Entry – 16th August 2021

Geraldine

Geraldine is able to identify meaningfulness within her day-to-day life through participation in daily tasks within the physical limitations of living with palliative care needs arising from COPD to meet her core personal values, remaining '*quite active in a sort of way'*. Geraldine lives with her husband in the attic of her daughters' home, referring to this as the '*penthouse*'. This allows her to be somewhat self-sufficient within her day-to-day life, as the attic has a kitchen area and bathroom. Knowing her family are downstairs however, offers security to Geraldine, should she require any physical help or support. This situation also allows the generation of meaningfulness within Geraldine's day-to-day life, as her and her family take in in turns to cook the whole family a meal.

Narrative Structure 3 - Geraldine

Geraldine *- 'which is the one family meal we have with the whole of the family which is lovely, its once a week you know. We take it in turns to do it'*

Having the physical ability to do this generates feelings of purposefulness for Geraldine, and as such is a meaningful element within her daily life. Geraldine has adapted her hobbies and daily activities to meet her physical capabilities within the limitations of living with COPD, enabling her to meet her core personal values. Geraldine's hobbies are physically sedentary in nature, facilitating security in knowing they will not impact upon her breathlessness.

Narrative Structure 6 - Geraldine

LB *- Erm since sort of since your diagnosis in 2013 I mean you've referred in some of your diary entries around sort of I've picked up hobbies that you like to do such as your cross stitch and embroidery.*

Geraldine *- Yes*

LB*: Erm and that watching the television and that sort of gives you security as an activity because you know that you know it's not physically exerting you is how I've interpreted that*

Geraldine*: Yes*

Through this adaptation of hobbies, Geraldine is able to meet her core personal values as a sense of achievement is gained, facilitating meaning within her day-to-day life. Within the physical limitations of living with COPD, Geraldine is able to go on short walks, and is aware of the need to adapt the intensity of the activity to alleviate her symptom of breathlessness.

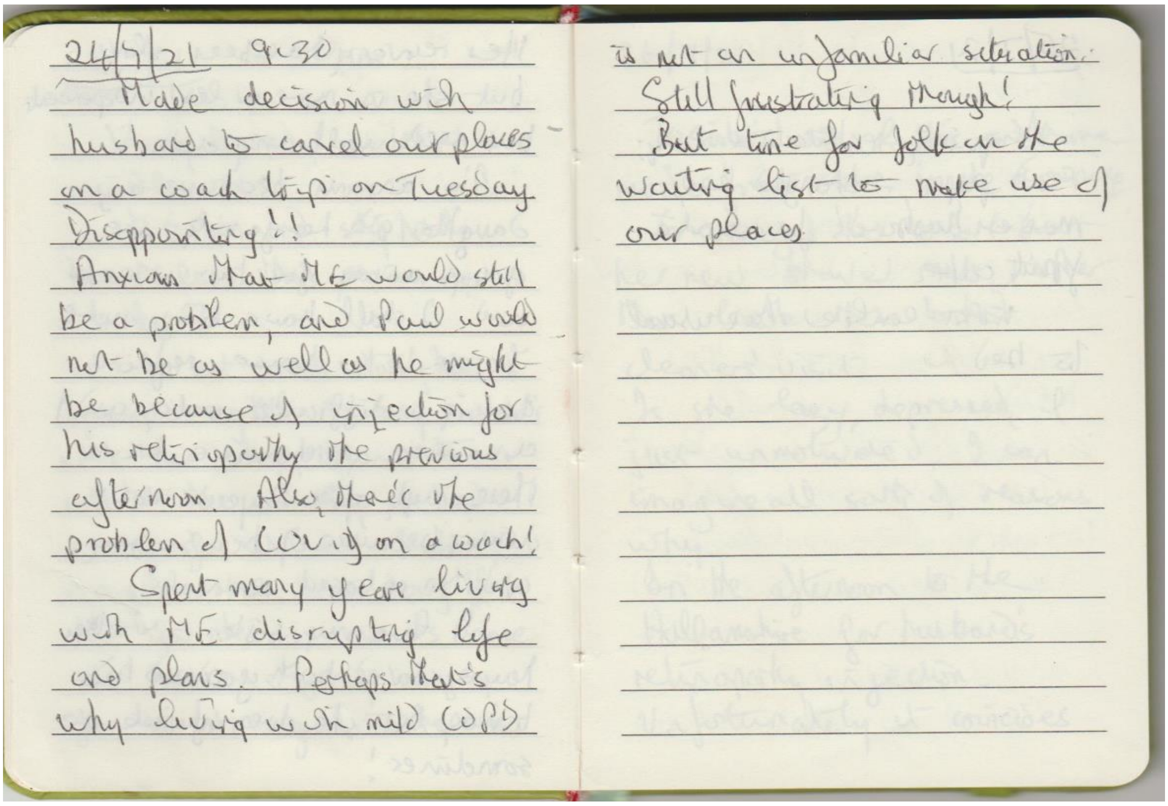
Narrative Structure 4 - Geraldine

Geraldine *- Erm (.h) but but if it (.h) what I do find sometimes now is (.h) erm its only five minutes from our house down to Abbeydale Road at the bottom (.h) and erm I mean walking down isn't usually a problem (.h) but some days erm (.h) if we've gone down to have a coffee or go to the Post Office or something (.h) you know I might have to stop momentarily (.h) for a moment or two coming back up the hill*

LB *- Yeah*

Geraldine *- So you know I do always have the Salbutamol with me but I don't often need it if I just stop and rest (.h) it was funny the other day, I was coming back on my own and erm one of our neighbours who's a retired GP (.h) I'd I'd sort of leaned up on his gate (laughing) on his wall and he came out and sort of said was I alright and I said 'yeah yeah, you know its just my COPD playing up' (laughing).*

Having the physical ability to go for a short walk allows Geraldine to meet her core personal value of purposefulness, facilitating personal value congruence and generating meaning within her day-to-day life. This was further identified within Geraldine's journal entry (figure 21), where she describes how she had to cancel a coach trip due to the potential of a flare up of her ME symptoms. She describes this as being '*disappointing*' and goes onto describe how when living with COPD this '*is not an unfamiliar situation'* as both long-term conditions inhibit her physical ability to undertake pleasurable activities at times. Feelings of frustration facilitate personal value incongruence for Geraldine, through the prevention of her meeting her core personal values.



24/7/21 9:30

Made decision with husband to cancel our places on a coach trip on Tuesday. Disappointing!!

Anxious that ME would still be a problem, and Paul would not be as well as he might be because of injection for his retinopathy the previous afternoon. Also, there's the problem of COVID on a coach!

Spent many years living with ME disrupting life and plans. Perhaps that's why living with mild COPD is not an unfamiliar situation.

Still frustrating though!

But time for folk on the waiting list to make use of our places

Figure 21 - Geraldine – Journal – 24th July 2021

Patricia

Patricia also identifies meaning within her day-to-day life through having the physical ability to meet her core personal values of purposefulness and achievement. This facilitation of personal value congruence is enabled by her determination to undertake some form of exercise or activity most days, as shown within narrative structure eight.

Narrative Structure 8 – Patricia

LB *- Do you, so do you try and plan to do something ev-every single day? Cause you sound very busy [laughing]*

Patricia *- Yes .h erm you know in fact I get so busy sometimes I am glad to have a day in with nothing to do*

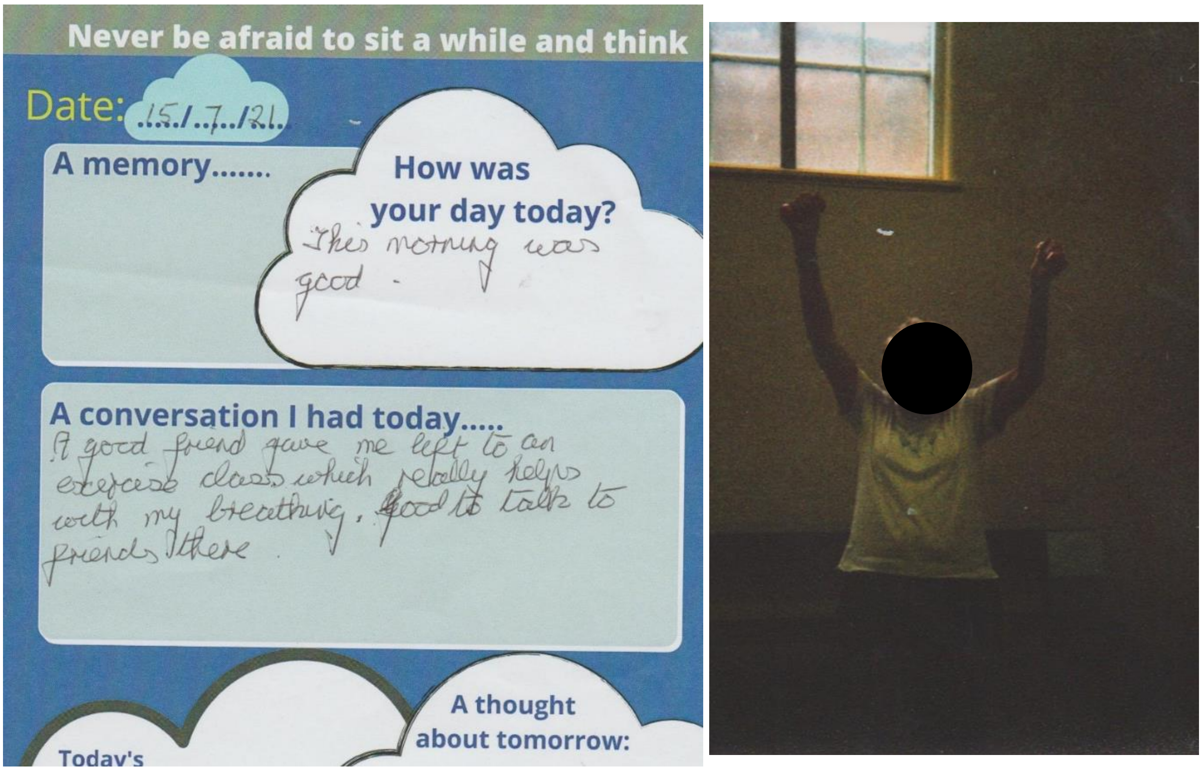
LB *- Yes. I'm sure*

Patricia *- Well I say nothing because I can do some knitting and erm catch up on what I've recorded that I want to watch you know .h but erm yeah*

LB *- Yes.*

Patricia *- Usually I go out at least for some part of the time .h erm I think of a rest when I get home but sometimes I'm thankful I don't have to .h go out .h because I go out so much*

By encouraging herself to engage in an activity either by leaving her home for a walk or to meet friends or participating within an online exercise for health class at home, Patricia gains a sense of achievement. This also allows her to socialise with people, creating meaning within her life from undertaking these activities. Patricia's physical ability to meet these core personal values has declined throughout her time living with COPD. The associated breathlessness she experiences often causes the need for her to rest throughout walks and pause within exercise classes. However, she has overcome this by adapting the activities she undertakes and has the occasional day at home as shown within narrative structure eight, to allow herself to recover. She sees the benefits of attending the exercise for health classes as shown within the Think-pad entry below, particularly an improvement in her symptoms of breathlessness. This demonstrates how participating in such classes is a meaningful activity for Patricia, which is evident from the photograph she had taken of herself at an exercise class to record something that makes her feel happy (Figure 22).



Never be afraid to sit a while and think

Date: 15/7/21

A memory.......

How was your day today?
This morning was good.

A conversation I had today.....
A good friend gave me lift to an exercise class which really helps with my breathing. Good to talk to friends there.

Today's

A thought about tomorrow:

Figure 22 - Patricia – Think-pad Entry – 15th July 2021 and Photograph

Patricia also enjoys some light gardening within the limitations of living with COPD, and chose to photograph her garden (Figure 23), as one of the most meaningful things to her within her day-to-day life.

Figure 23 – Patricia – Photograph

The meaning this created for Patricia was explored within her narrative interview, and as shown within narrative structure seven, her enjoyment for being able to '*do what I ca*n' is evident.

Narrative Structure 7 -Patricia

LB*: There's some of your beautiful garden.*

Patricia*: [laughing] yes yes .h although I want to get out to it again but the weathers .h not been I've got to pick my days because of my breathing and how I feel .h*

LB*: Yes*

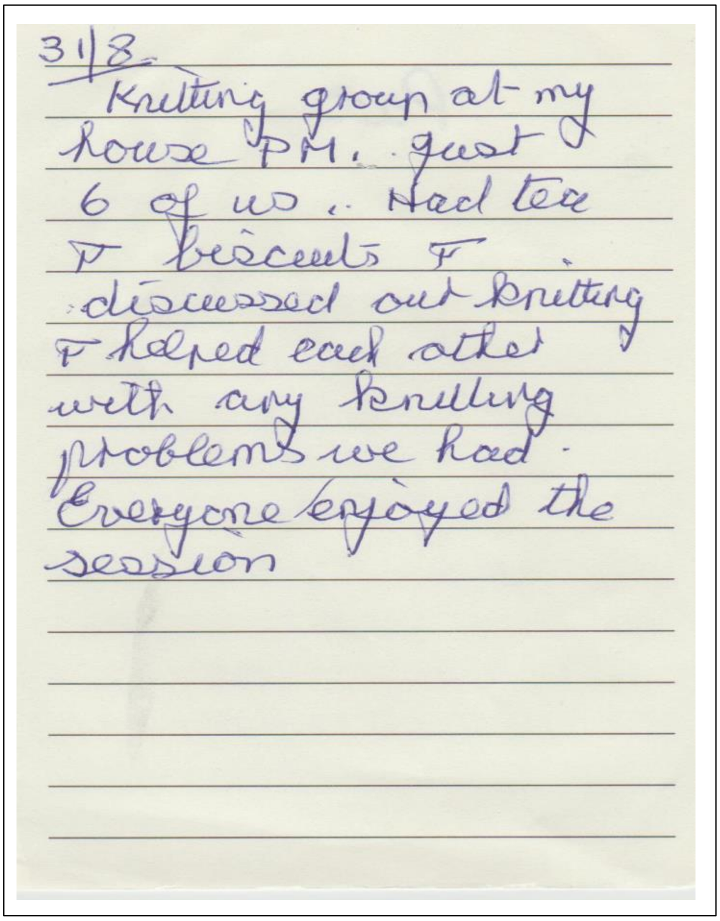
Patricia*: But I love to be in it and just do what I can. And I have a gardener for a couple of hours every fortnight .h but and he's been away so it's four weeks .h you know.*

LB*: Yes, Yeah*

Patricia*: But erm I shall (.) I shall manage it this week for the last time so .h erm I always say I'm very lucky when I look out of both windows .h back and front I've got like something nice to look at (1) especially the birds on the front in my thing .h well pigeons mostly [laughing].*

Through Patricia accepting that she requires the help of a gardener, whilst still undertaking the elements of gardening that she is able within her COPD limitations, she experiences a sense of achievement and purpose, leading to personal value congruence.

On days where Patricia's symptom burden prevents her from undertaking physically exerting activities, or she is spending time resting, she finds meaning in more sedentary hobbies such as knitting. As shown within Patricia's journal entry in figure 24, and frequently throughout her journal and think-pad entries, she hosts a knitting group at home with friends. This brings socialisation and a sense of achievement to her day-to-day life, creating meaning through personal value congruence.

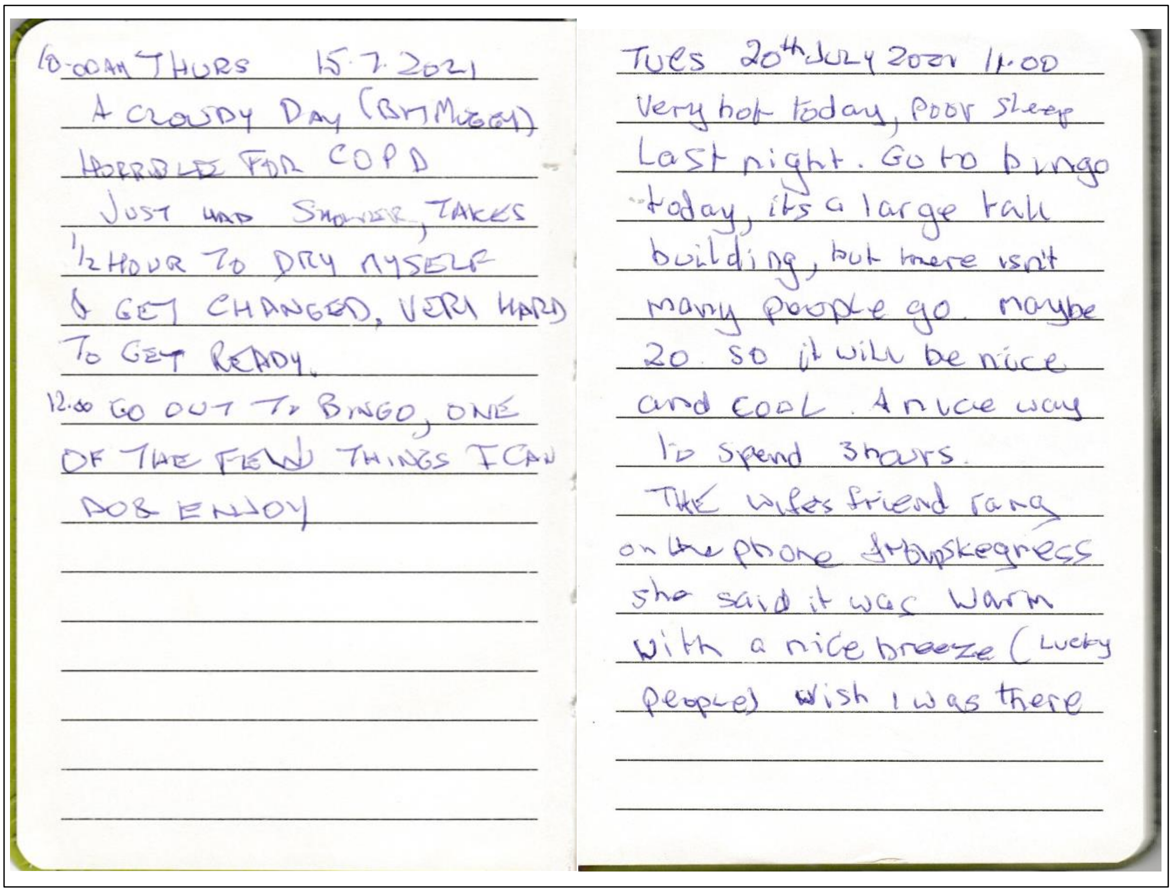


31/8.
Knitting group at my
house PM. just
6 of us. Had tea
& biscuits &
discussed our knitting
& helped each other
with any knitting
problems we had.
Everyone enjoyed the
session

Figure 24 - Patricia – Journal Entry - 31st August 2021

Craig

Craig also identified meaning within his day-to-day life through undertaking activities within the physical capabilities of living with palliative care needs arising from COPD. His chronic breathlessness is of significance, impacting on his ability to undertake tasks requiring minimal physical exertion. Despite this, Criag has identified hobbies he can undertake within day-to-day life such as playing Bingo.



10-00AM THURS 15.7.2021
A CLOUDY DAY (BIT MUGGY)
HORRIBLE FOR COPD
JUST HAD SHOWER, TAKES
1/2 HOUR TO DRY MYSELF
& GET CHANGED, VERY HARD
TO GET READY.
12.00 GO OUT TO BINGO, ONE
OF THE FEW THINGS I CAN
DO & ENJOY

Tues 20th July 2021 11.00
Very hot today, Poor Sleep
Last night. Go to bingo
today, its a large tall
building, but there isn't
many people go. maybe
20. so it will be nice
and cool. A nice way
to spend 3hours.
THE wifes friend rang
on the phone from Skegness
she said it was warm
with a nice breeze (Lucky
people) wish I was there

Figure 25 – Criag - Journal Entries – 15th July 2021 and 20th July 2021

As shown within his journal entries (Figure 25), Craig described playing Bingo as one of the few things he can do, and the enjoyment this activity holds facilitated meaning for him. This was further explored within his narrative interview (narrative structure four), as he described the value of this within his daily life through a sense of achievement, as he is physically able to visit the Bingo Hall and enjoy the activity.

Narrative Structure 4 – Craig

***LB**: So erm, within the journal you wrote in you have explained how you like to play Bingo. Is that something you do often?*

***Craig**: Yes duck (.h) 'bout the only thing I do do (.h) you see its not far so I can get a taxi and there is air conditioning you know (.h) so its cool for the breathing*

***LB**: Yes*

***Craig**: Not too many people go on an afternoon so its not crowded (.h) but a few I know so I sit with them (.h) someone from the lung group told me about it (.h) that's why I went and have carried on you see duck*

***LB**: It sounds like you erm really enjoy it*

***Craig**: Erm I do (.h) and its better when I win (laughing) (.h) but it's something to do isn't it? To fill up an afternoon out the house (.h) always feel good when I've been (.h) especially when I win*

Through having the physical ability to undertake this activity, Craig achieved personal value congruence to facilitate meaningfulness within his day-to-day life.

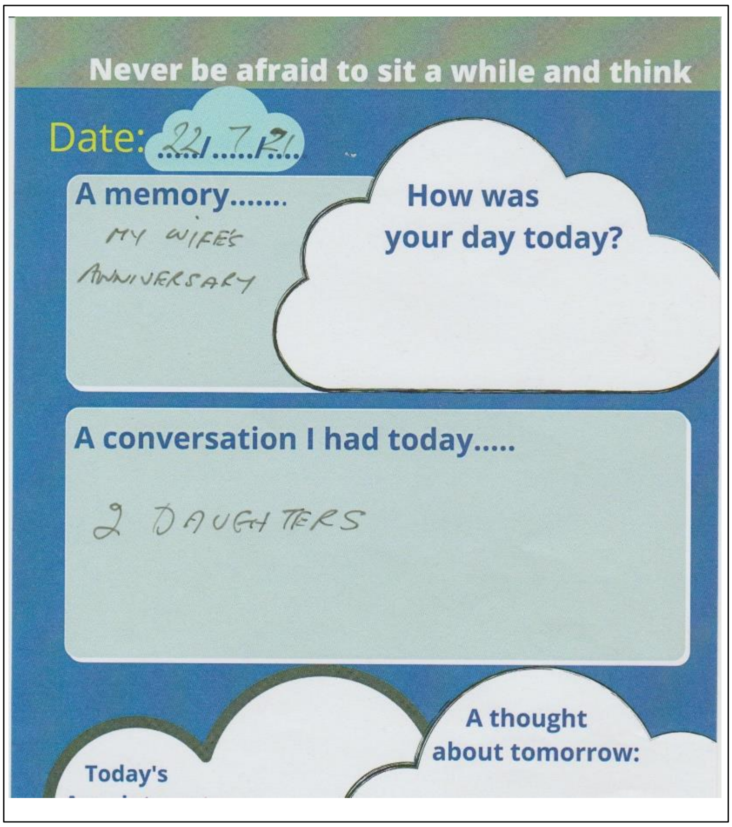
Each of the participants within this study identified meaningfulness within their day-to-day lives when they had the physical ability to meet their core personal values. The following three sub-sections of this chapter present participants personal values of relationships and connections, fulfilment and purpose, and overcoming challenges. Each person holds their own hierarchy of personal values, yet irrespective of their order, when they are met, personal value congruence and associated life meaning is generated.

6.2 – Relationships and Connections

Participants within this study were able to achieve personal value congruence and associated meaningfulness within day-to-day life through meeting their personal values of relationships and connections, as they identified these values to be important to them. The types of relationships and connections varied between participants, dependent upon the significance they assigned to them, alongside the availability of whom and what they were able to form a connection with.

Stephen

Stephen identified relationships and connections that generated meaningfulness within day-to-day life in many forms. He valued the relationship he has with his two daughters and their families. As shown within his Thinkpad entries (Figure 26), a conversation of significance with hid daughters is documented.



Never be afraid to sit a while and think

Date: 22/7/21

A memory.......

MY WIFE'S ANNIVERSARY

How was your day today?

A conversation I had today.....

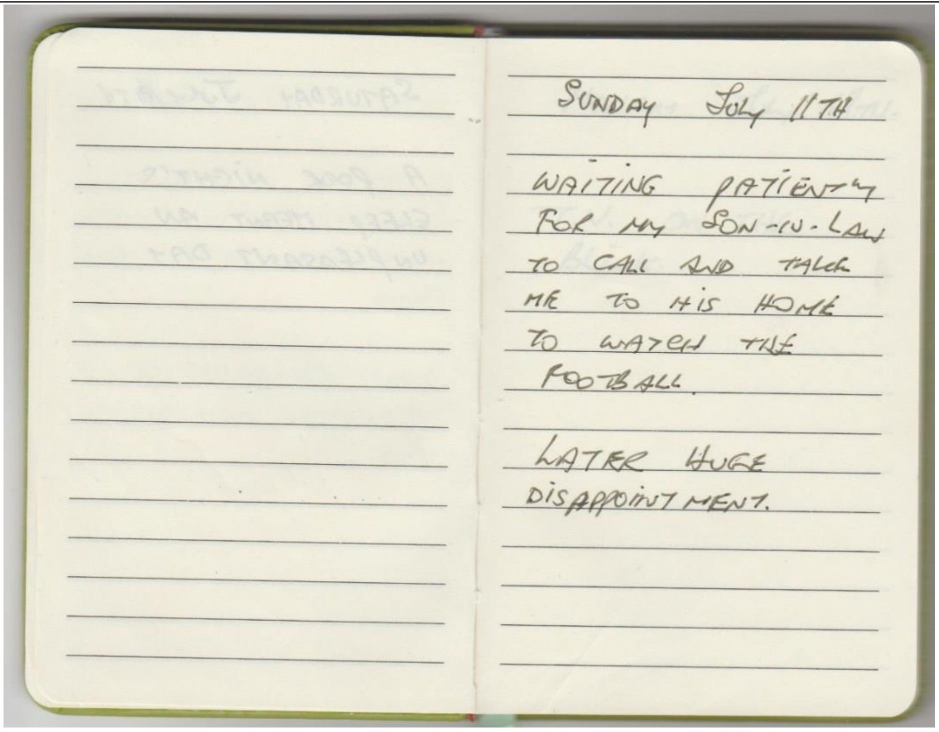
2 DAUGHTERS

A thought about tomorrow:

Today's

Figure 26 - Stephen – Thinkpad Entry – 22nd July 2021

Furthermore, a diary entry reflecting upon the day's events being centred around his son-in-law collecting him to watch the football further validates the meaning of these relationships.



SUNDAY JULY 11TH

WAITING PATIENTLY
FOR MY SON-IN-LAW
TO CALL AND TAKE
ME TO HIS HOME
TO WATCH THE
FOOTBALL.

LATER HUGE
DISAPPOINTMENT.

Figure 27 – Stephen – Journal Entry – 11th July 2021

Within his narrative interview, Stephen spoke with fondness about a recent trip to Weymouth with his sister and family, describing this as '*brilliant*'.

Narrative Structure 20 - Stephen

Stephen *-You see Louise a a month ago I was in Weymouth with my sister and her son and his wife and my daughter (.h) and her husband and my son grandson (.h) er and I was there for four-days and it was brilliant*

LB *- Yeah*

Stephen *- I hired a scooter while I was there (.h) [coughs] which gave me some much needed practice on it you know.*

LB *– Yeah*

These family relationships achieved personal value congruence within Stephen's day-to-day life, facilitating the presence of meaningfulness. He also has several friends across the world, whom he has not seen for a number of years, however he keeps in contact with them via the telephone or email. As shown within narrative structure twenty-two, he describes the meaning he has identified from maintaining these relationships, through stating '*that makes me feel good'*. Stephen acknowledges that these relationships are something of significance for him, describing them as '*one of the nice things'* in his life.

Narrative Structure 22 - Stephen

Stephen - *incidentally having being being in touch with these people it it it's really good for me (.h) because they're nice people we think along the same lines and and (.h) in the middle of the week one of them will email me on er (.h) something that's jogged their memory or something. Like that you know (.h) it's one of the nice things of my life at the minute is this (.h) contact I've been making with people (.h) er I be er it*

LB *-Yeah*

Stephen - *This is sounding (.) this is going to sound very conceited Louise but there are people in California and Toronto (.h) who await my Friday Friday chapter (.h) you know they they they They like what I =write*

LB - *Yeah=*

Stephen - *and all the rest of it you know (.h) so that makes me feel good*

A life journey of continual self-discovery is evident within Stephen's day-to-day life, through developing new ways to meet his personal values of relationships and connections. This is evident through his documentation of the impact of attending his local BLF breathe easy support group, as an opportunity to form new connections through living with COPD, as shown within narrative structure eighteen. The relationships and connections made not only by attending the group, but also with the people he meets on his journey to and from have generated positive feelings for Stephen, evident as he describes such interactions as '*bloody brilliant'*.

Stephen – Narrative Structure 18

Stephen *– now the Breathe Easy group (.) it's a whole new scene for me*

LB *- Yes*

Stephen *- And {name of group leader} who's the main mover she's (.h) she's absolutely brilliant that woman. She she can't do enough (.h) for those of us who suffer from COPD*

LB *- Yeah*

Stephen *- (.h) But now I'm in touch with a whole new set of different people*

LB *- Yeah*

Stephen *- Either either because we meet physically which is once a month which we re-started (.h) er Monday night's we have a virtual Zoom meeting (.h) and then in between I bump into these people out out of the house to have a chat so (.h) that's the sort of thing that erm (.) I like*

LB *- Yeah and you wouldn't have had that experience otherwise would you*

Stephen *- Well no I mean let me just put this another way (.) the very first day that I got on the scooter (.h) I went to down to Eastwood (.h) and the number of people [coughs] who* *acknowledged me and I acknowledged as I was going by I thought (.h) I've not seen these people for years*

LB *- Yeah*

Stephen *- You know (.h) I went to Morrisons the supermarket in Eastwood and (.h) I couldn't get round the shop I was bumping into people it was bloody brilliant*

Sally

Similarly, Sally was able to meet her personal values of relationships and connections, generating meaningfulness within her day-to-day life. She has also continued to shape and redefine her personal values throughout her COPD disease progression, to identify new ways to meet them. As demonstrated upon Sally's rosette reflection (Figure 28), she describes her biggest life achievement to be having and supporting her family.

What do you think when you look at the 1st prize rosette?
A current life goal?
Something you have already achieved?
Please do tell us about it:

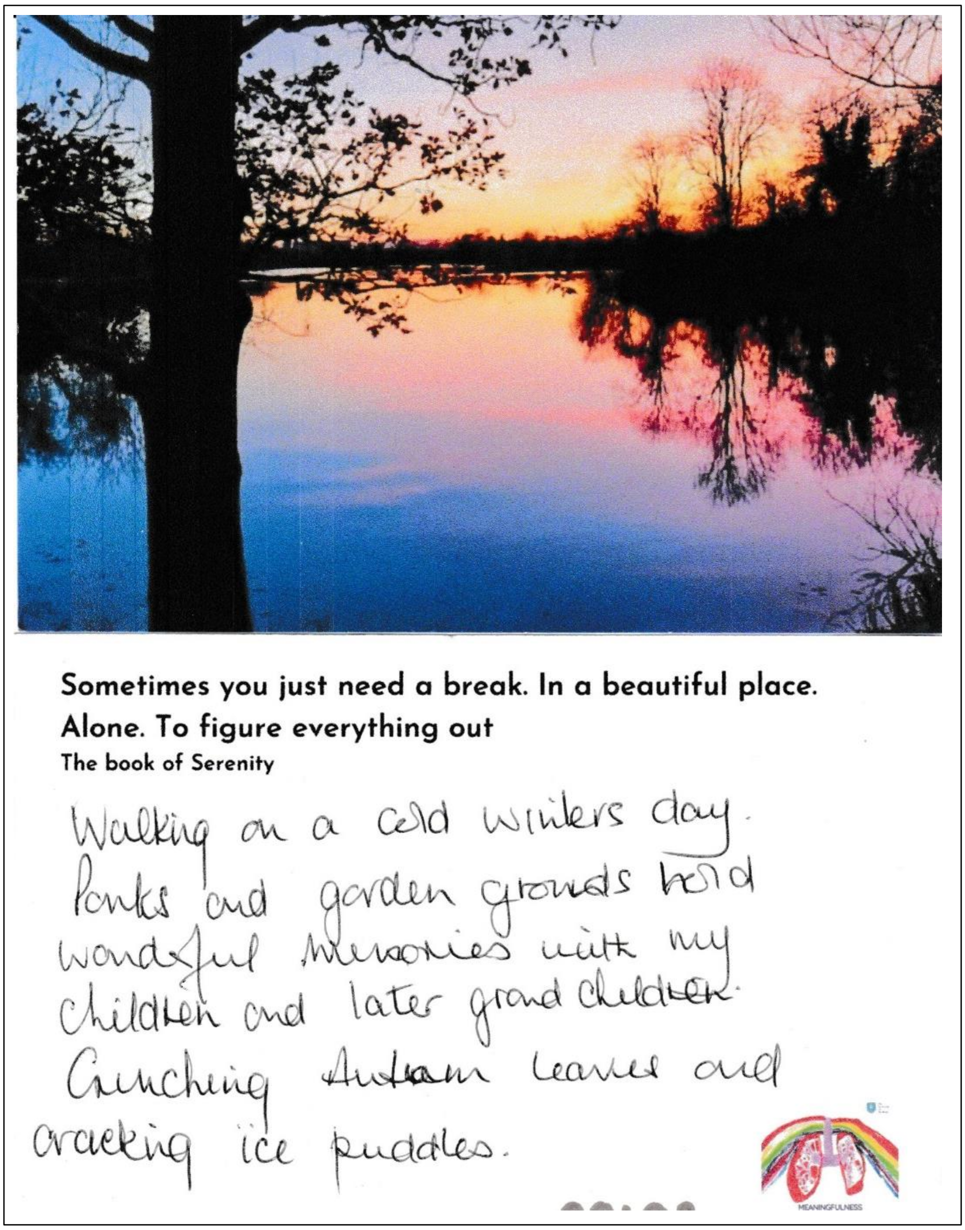
My greatest achievement was having my
family and being able to support them
results are photographs. The girls attended
state school. One had the good fortune to attend
a private school for a ~~fee~~ four years ~~attending~~ attaining
10 - O level results. My ~~eldest~~ girl attained
2 university degrees (1) Micro-biology-science
and (2) Teaching degree at Sheffield.
The eldest has attend law, history & politics degree-
at Nottingham. You will see the photos which.
The two boys have taken other routes but are
happy. Eldest in Sheffield Youngest in London
I attained SRN certificate in Sheffield at
Royal Infirmary 1963.
Later D 32/33 assessors certificate to teach
and assess.

Figure 28 - Sally – Rosette Reflection

She proudly wrote of her children's academic achievements, using this as a way of demonstrating her pride for them, but also identifying the importance of their strong relationship which is of great significance within her daily life. Sally also photographed a graduation picture of her daughter hung on her dining room wall (Figure 29), to further document this.

Figure 29 - Sally – Photograph

Sally's relationship with her children and grandchildren generates meaning within her day-to-day life, which is evident throughout many of her cultural probe entries. Sally further reflected on these meaningful relationships on her reflection postcard (Figure 30). Sally described days spent with her daughter as '*really good'* and '*enjoyable*'. From these cultural probe entries, it was evident Sally holds a relationship with her close family that met her personal values of relationships and connections, facilitating personal value congruence and subsequently meaningfulness within daily life.



Sometimes you just need a break. In a beautiful place.
Alone. To figure everything out
The book of Serenity

Walking on a cold winters day.
Parks and garden grounds hold
wonderful memories with my
children and later grand children.
Crunching Autumn leaves and
cracking ice puddles.

Figure 30 - Sally – Postcard

The significance and associated meaning of Sally's family relationships was further illustrated within her narrative structure ten. As shown, Sally spoke of the impact when she feels disconnected from her children, such as when one of her children stated they would telephone her at a certain time and then do not, resulting in her feeling less motivated.

Sally – Narrative Structure 10

LB *- And then on some of the entries, you've - you've kind of referred to feeling tired, not really feeling motivated. Does that happen often for you? Is that when - Or is that when you've done something significant the day before?*

Sally *- I think (overlapping conversation) Yeah. Uh, oh, um. If the - If one of the kids is (Laughter) - I know it shouldn't. If one of the kids say right, ill ring up on the weekend and they haven't, you know.*

LB *- Yeah.*

Sally *- Uh. And it's that disconnection.*

LB *- Yes.*

Sally *- I'd - I'd still need that connection with them. Yeah.*

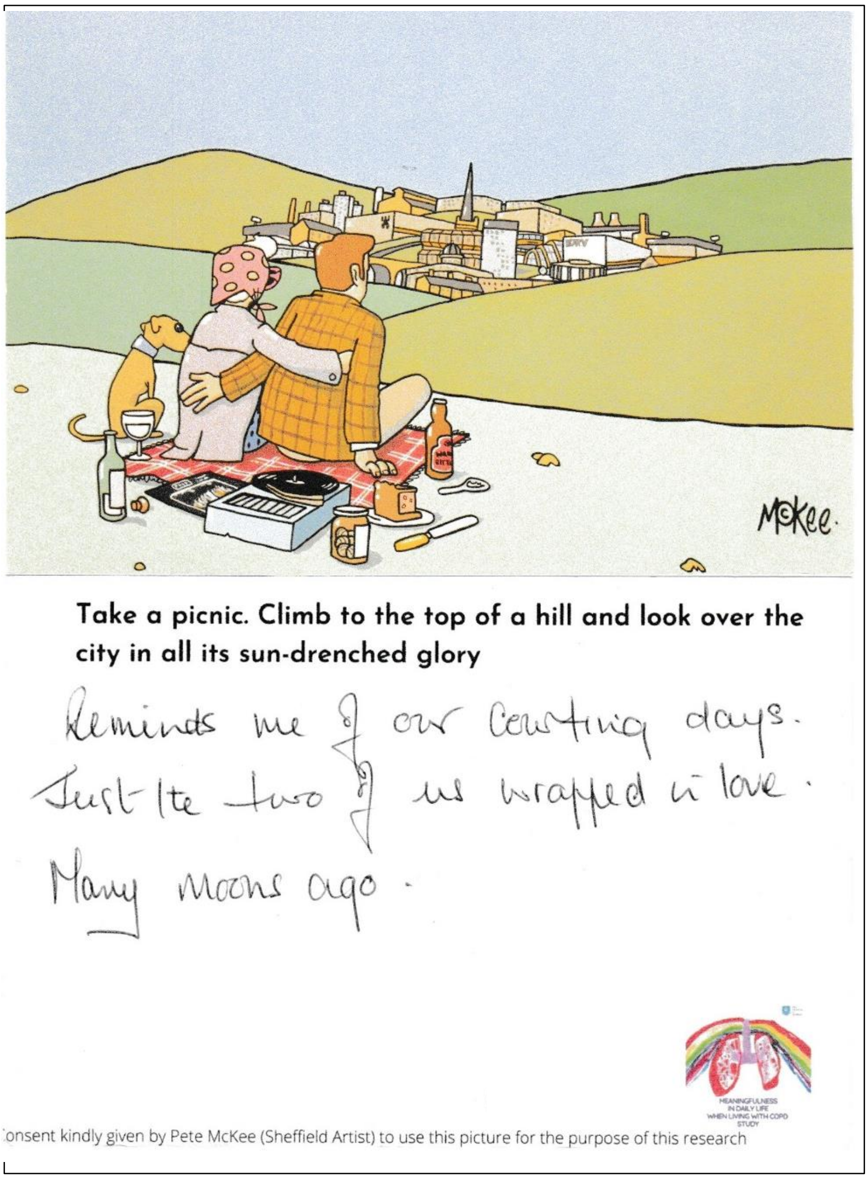
LB *- Yeah. Because they don't live locally any more, do they?*

Sally *- No. They don't, no.*

LB *- No. No, and that's…*

Sally *- I mean they've got their own families and what have you. Um. But they - You're still their mum choose how old they get, aren't you?*

Sally's relationship with her husband facilitates personal value congruence, and associated life meaning, evident upon one of her reflective postcards (Figure 30).



Take a picnic. Climb to the top of a hill and look over the city in all its sun-drenched glory

Reminds me of our Courting days.
Just the two of us wrapped in love.
Many moons ago.

onsent kindly given by Pete McKee (Sheffield Artist) to use this picture for the purpose of this research

Figure 31 - Sally – Postcard

As shown in Figure 31, Sally reflects of when her and her husband were in there '*courting days'* describing their relationship as being '*wrapped in love'*. The significance of this relationship to her is evident, facilitating meaning within her day-to-day life throughout their forty-seven-year marriage. Sally also spoke with in her narrative interview of how meaningful her husband is to her.

Sally – Narrative Structure 1

LB *- And that really comes across in - in what you've written about how much meaning and purpose your family give you, particularly your children. But then I think in one of your - I've just made some notes, but in of your entries on the little think pads, the notepads with clouds on it you filled in, um, you referred to Bob and said you don't know what you'd do, um, if you lost your husband. Um.*

Sally *- That's true. Oh, yeah.*

LB *- It is. That just gave me a real sense that he's so meaningful to you.*

Sally *- Yeah. Yeah.*

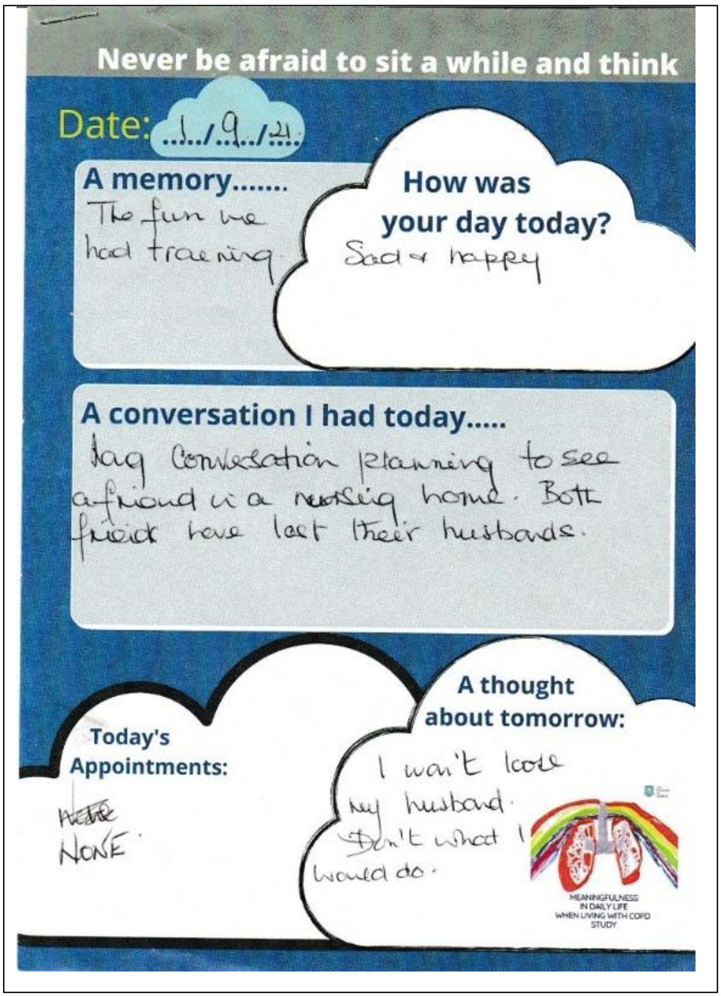
LB *- In your life.*

Sally *- I mean, I don't half hear him in my ear hole quite often. (Laughter) And like everybody else, you know, you - you do still need your own space.*

LB *- Of course, you do.*

Sally *- Um. But I - I really don't know what to do without him.*

As shown, Sally spoke of how she doesn't know what she would do without her husband. This was further echoed within a ThinkPad entry (Figure 32) and photograph of her husband (Figure 33). Documenting her husband as the most meaningful thing to her through a photograph, alongside her ThinkPad entry stating that she will not lose her husband, emphasises the meaning this close relationship brings within her day-to-day life.



Never be afraid to sit a while and think

Date: 1/9/21

A memory.......
The fun we had training

How was your day today?
Sad & happy

A conversation I had today.....
long Conversation planning to see a friend in a nursing home. Both friends have lost their husbands.

Today's Appointments:
~~None~~
NONE.

A thought about tomorrow:
I won't lose my husband. Don't what I would do.

Figure 32 - Sally - Thinkpad Entry – 1st September 2023

Figure 33 – Sally – Photograph

The connections made through her involvement within her local BLF breathe easy support group also generated meaning within Sally's day-to-day life, a redefined set of relationships to meet her personal values through living with COPD.

Sally – Narrative Structure 7

Sally - *Um… Well, I got volunteered, you see, to start with. But it - it - it's - it - it means that we see people who have got the like conditions.*

LB -*Yes*

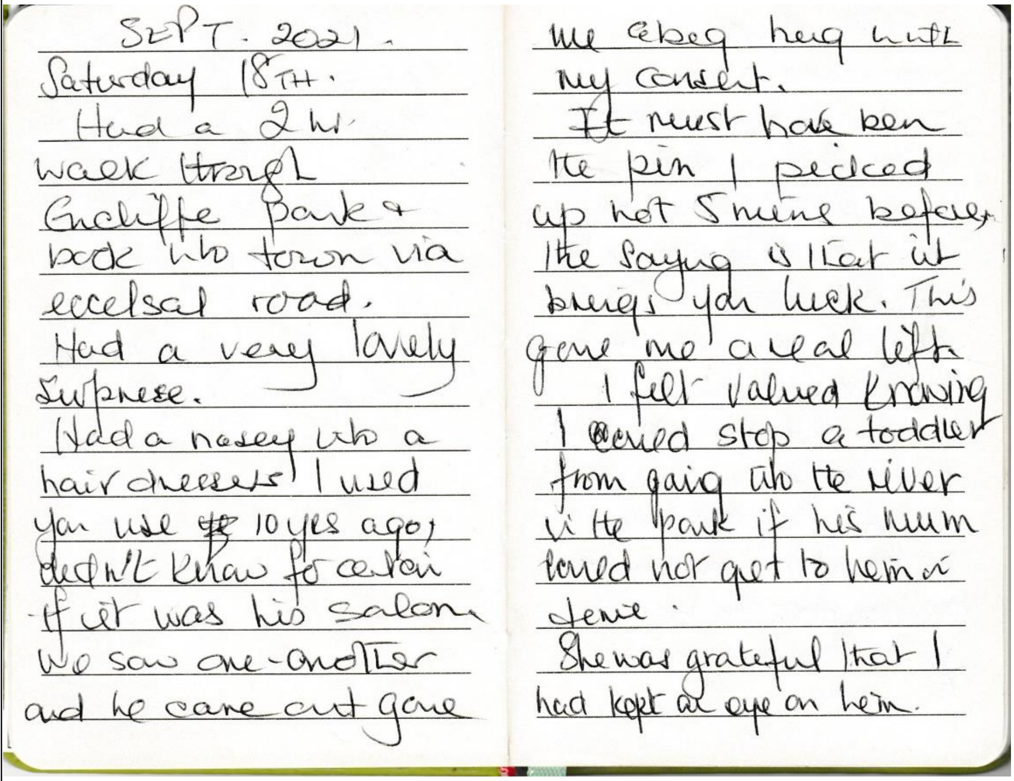
Sally - *Yeah? And lets them know that it's not the end of the world. There are things available. Um. And it's a get together. It's a social atmosphere. Um. I mean when we had the singing as well that was even better. And, hopefully, that is coming back in spring.*

LB - *Yes.*

Sally - *Erm. But we have a laugh. We - We see people. I mean it was brilliant the first time we had, one in September. I didn't recognise some of them because they'd had the cataracts done and they weren't wearing glasses, you know. (Laughter) But everybody was so pleased to see and come out of their four walls, you know.*

As Sally describes within narrative structure seven, the social element of her involvement in the support group has developed connections for her with people *'who have got the like conditions*' such as COPD. The enjoyment Sally receives from this was evident when speaking to her, giving her an opportunity to see people and '*let them know it's not the end of the world*'.

The presence of more casual and unpredictable connections also generated meaning within Sally's life. She documents within her journal (Figure 34), of how she recently met her previous hairdresser by chance.



SEPT. 2021.
Saturday 18TH.
Had a 2 hr
walk through
Endcliffe Park &
back into town via
eccelsal road.
Had a very lovely
surprise.
Had a nosey into a
hairdressers I used
you use ~~to~~ 10 yrs ago;
didn't know for certain
if it was his salon.
We saw one-another
and he came out gave
me a big hug with
my consent.
It must have been
the pin I picked
up not 5 mins before.
the saying is that it
brings you luck. This
gave me a real lift.
I felt valued knowing
I could stop a toddler
from going into the river
in the park if his mum
could not get to him in
time.
She was grateful that I
had kept an eye on him.

Figure 34 - Sally – Journal Entry – 18th September 2021

The meaning this generated for Sally is evident within her writing, describing the unexpected event of meeting her giving her *'a real lift'*. Sally then went on to discuss the impact of this chance meeting within her narrative interview.

Sally – Narrative Structure 17

Sally *- Oh, it was brilliant.*

LB *- And the ki - I could tell by what you'd written just how much it meant to you.*

Sally *- Yeah. And not only that. Um. They've actually won - won an award with the hairdresser association. It was on Facebook. Um. So that was absolutely great, you know.*

LB *- Yeah.*

Sally *- This was only past three weeks, but that was when we were walking that day and I thought…*

LB *- Yeah.*

Sally *- Got to look, got to look. (Laughter) It was brilliant. (Audio breaking)*

LB *- Aw but for her to come out and make a fuss. I bet that was a…*

Sally *- It was. It was really nice, yeah.*

Although this was one brief interaction, with a hairdresser Sally visited ten years previously, the meaning generated for her through such connections is evident in how she speaks of the event, and for her facilitated personal value congruence.

Karen

The presence of relationships and connections within Karen's day to-day life achieves personal value congruence, facilitating the presence of meaningfulness. Karen lives with her husband, and they have a son. There is reference to them within Karen's interview (narrative structure one) and her cultural probes, as she spoke of how her husband is '*really supportive'*.

Karen – Narrative Structure 1

LB *- Okay erm .h and can you just sort of talk me though now your average day living with COPD in terms of the impact that it has really*

Karen *- Well it depends how I'm feeling .h I-I mean the weather does make it .h everything to do so much harder especially when it gets dark and cold and everything else erm (.) I'mmmmm probably not as active as I would like to be but I have-I have a really supportive husband and son and yesterday we actually managed to go for a sort of walk in Chelsea so that was very nice*

Reference within narrative structure one made by Karen, reflecting on herself, her husband and son going for a walk in Chelsea as being '*very nice'* demonstrates meaning is generated from those relationships. Furthermore, the formation of connections with members at her local BLF breathe easy and singing for health support groups is another way Karen met her core personal values of relationships and connections. Describing the facilitator at the singing for health group she attends as '*extremely positive and warm'* demonstrated a significant connection has been made for Karen, meeting her personal values.

Karen – Narrative Structure 11

LB *- Yes-yeah it does strike me from wha-what you've written in the probes and things that you do have .h a good support network around you*

Karen *- Yes-yes*

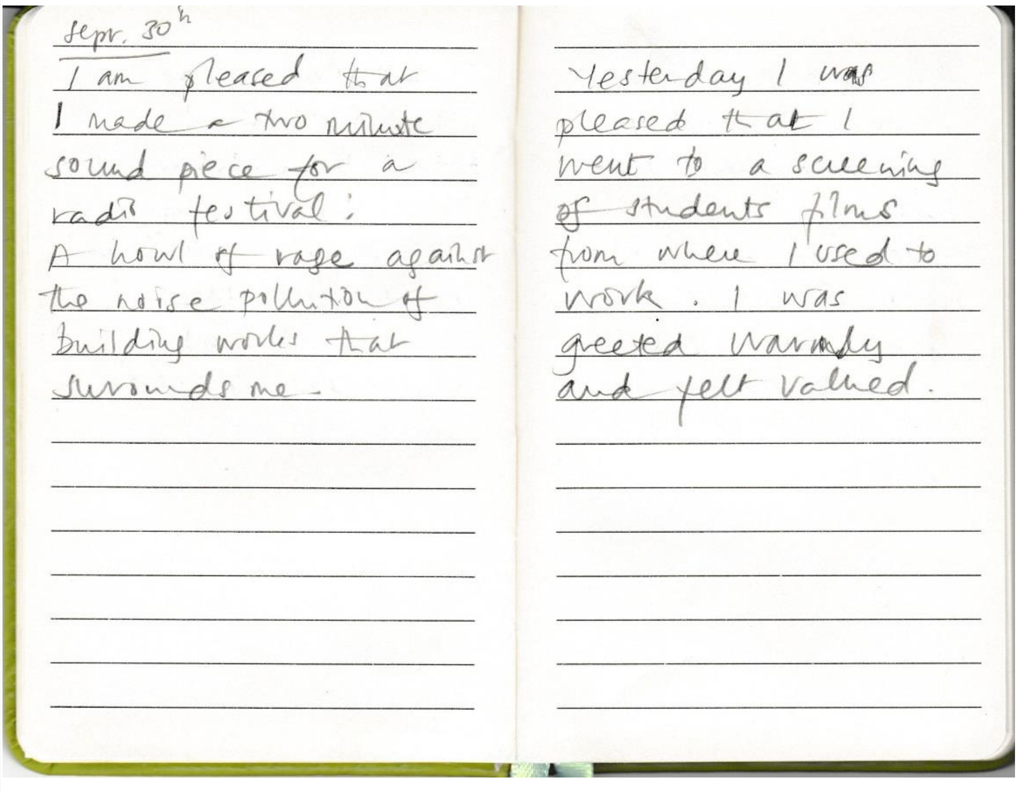
LB *- Erm .h particularly the breathe easy group and-and the singing group ho-how much of an impact do they have on your-your life?*

Karen *- Erm well the breathe easy I had been to a couple of times before the lockdown .h erm the woman who runs it here in Westminster is is extraordinary (2) erm she's not well herself and the amount of information she sends out is sometimes overwhelming (1) she's the one you spoke to in order to speak to our group*

LB *- Yes*

Karen *- Erm and she's-she's fabulous (3) so there is that and yes and then singing for breathing .h I don't know what their conditions are but there's one woman who does it who's-who's just extremely positive and warm and has these good breathing exercises .h cause you know something I haven't had is proper breathing exercises*

Karen identifies meaning within her day-to-day life in multi-dimensional forms. A relationship with former work colleagues when Karen visited her previous place of work, as shown within Figure 35, facilitated her personal value of connections being met.


Sepr. 30h
I am pleased that
I made a two minute
sound piece for a
radio festival;
A howl of rage against
the noise pollution of
building works that
surrounds me.

Yesterday I was
pleased that I
went to a screening
of students films
from where I used to
work. I was
greeted warmly
and felt valued.

Figure 35 - Karen – Journal Entry – 30th September 2021

She also holds a deep connection with her love of books, photographing them is the most meaningful thing to her (Figure 36). This was further explored within her narrative interview, as shown within narrative structure four.

Figure 36 - Karen – Photograph

Karen – Narrative Structure 4

LB - *The one I really liked and found really interesting was around the most meaningful thing to you erm (1) being the bookshelves .h*

Karen - *Yes*

LB - *can you explain that a little bit to me?*

Karen - *well I've always been a reader (1)*

LB - *Ah-ha*

Karen - *(1) and books have a great importance to me [coughs]*

LB *- yes*

Karen *- I love reading and you know there's tales in the words [coughs] and and in the bookshelf is all my history erm .h well recently I had to get rid of a load erm ‘cause I haven’t got room*

LB *- Yeah*

Karen *- Erm and so and erm .h the person downstairs renovated his flat and all the dust came into our flat which was a nightmare erm so from sorting through the books (1) the ones that I have got left are quite meaningful to me*

LB *- Yeah*

Karen *- even though I still mourn the ones I got rid of*

Describing the connection between her and her many books, she spoke of how the ‘*tales in the words’* generated meaning for her. Karen described how she ‘*mourns*’ the one she recently gave away, further emphasising this connection. Reading is a hobby Karen can still undertake despite the limitations of living with COPD, and as such facilitating personal value congruence. Connection with nature also facilitates meaning for Karen. She speaks of the ‘*relationship*’ she has with the Moorhens in Regents Park.

Karen – Narrative Structure 5

Karen *- I like moorhens [coughs] we have a relationship with the moorhens in Regents Park .h [laughing]*

LB *- Ah-ha*

Karen *- we go and visit them erm and they come running to us I mean we’re naughty and disobey the signs saying don't feed the wildlife [laughing] we give them bird seed*

LB *- Yes*

Karen *- and when they come running to you it's (.) just wonderful to watch them*

LB *- Yes absolutely*

Karen *- They are living in the moment [coughs] and when they come towards you (1) they are really comic when they run [laughing]*

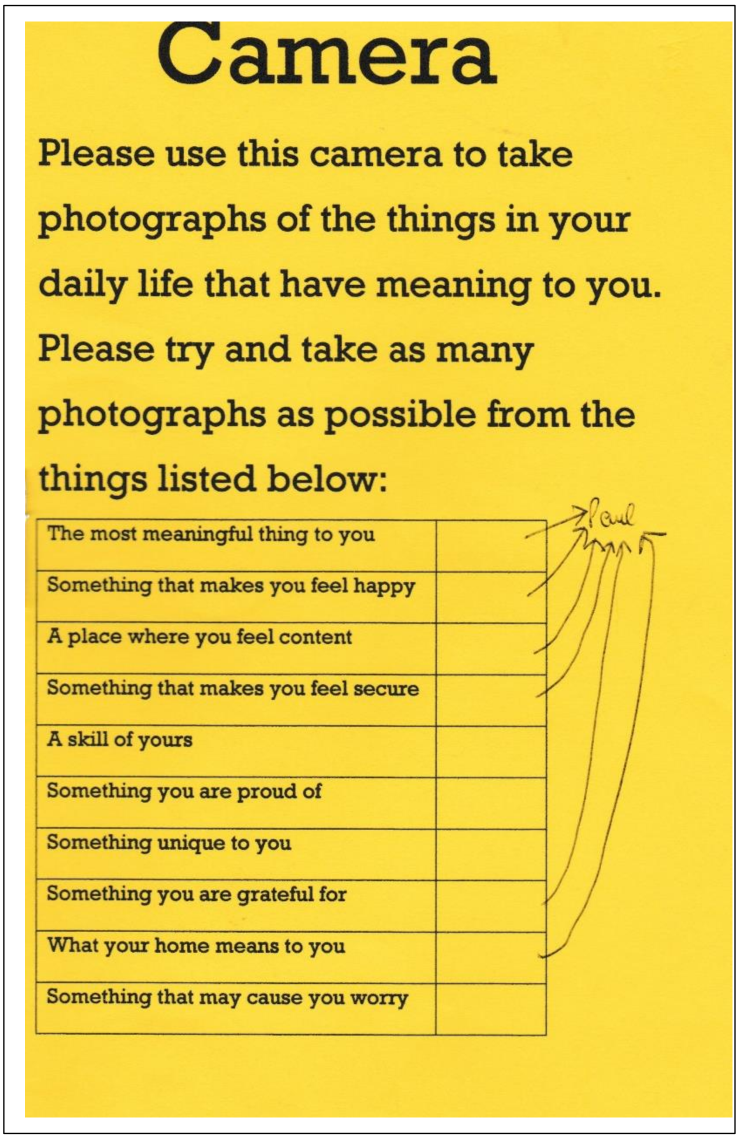
LB *- they are aren't they .h I really-really like what you said there about living in the moment absolutely .h I think that's really important isn't it*

Karen *– yes*

Describing how it's '*wonderful to watch them'* presented the significance of this connection to her, as she portrayed they were '*living in the moment'* which she believes is of importance. The elements captured from within Karen's day-to-day life emphasised how relationships and connections can be in many forms, not just human connections, and each contributed to the presence of meaningfulness within daily life through personal value congruence.

Geraldine

Geraldine revealed the importance of relationships and connections within her day-to-day life, and how these generated the presence of meaningfulness. The significance of these relationships was further emphasised through Geraldine recording the worry and concern she has for each of her family members well-being. Geraldine has a very close and meaningful relationship with her husband, as shown on the photograph prompt card included as a part of her cultural probes (Figure 37).



Camera

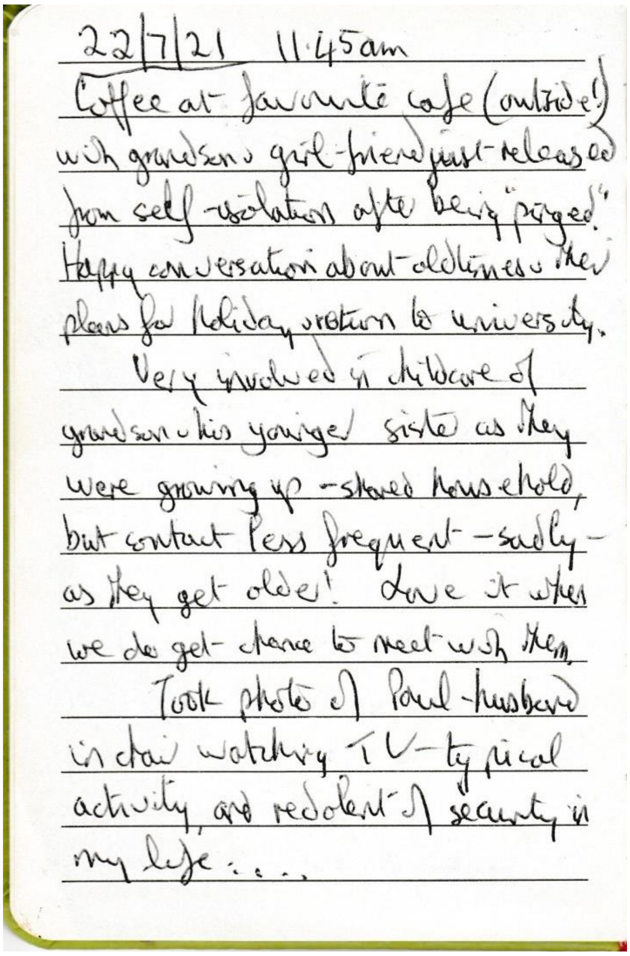
Please use this camera to take photographs of the things in your daily life that have meaning to you. Please try and take as many photographs as possible from the things listed below:

The most meaningful thing to you	
Something that makes you feel happy	
A place where you feel content	
Something that makes you feel secure	
A skill of yours	
Something you are proud of	
Something unique to you	
Something you are grateful for	
What your home means to you	
Something that may cause you worry	

Paul

Figure 37 - Geraldine - Photograph Prompt Card

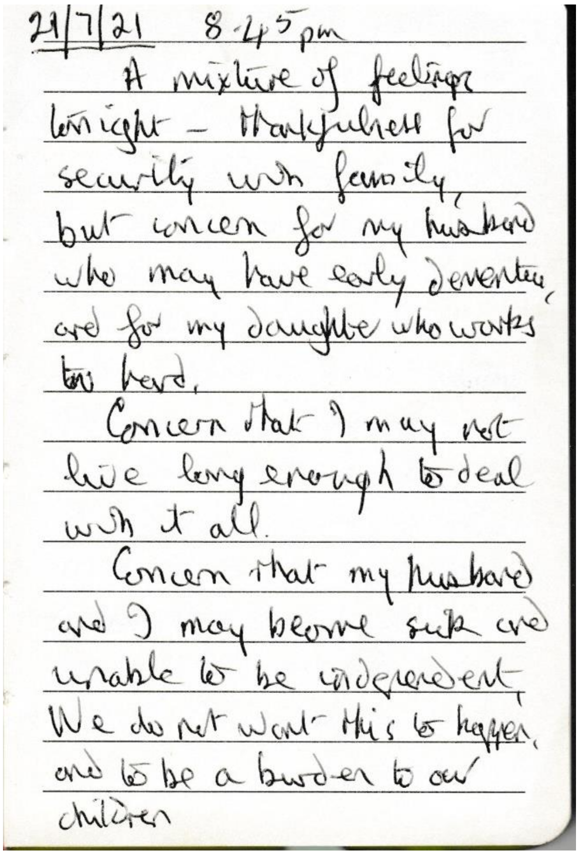
Geraldine identified her husband as not only to be the most meaningful thing to her, but how their relationship also offers happiness, feeling content and security, meeting her personal values. Geraldine was a widow with two young children when she met her now husband, and the immense value of their relationship is evident as she describes him as ‘ *redolent security’* in her life (Figure 38).



22/7/21 11.45am
Coffee at favourite cafe (outside!)
with grandson & girl-friend just released
from self-isolation after being "pinged".
Happy conversation about old times & their
plans for holiday & return to university.
Very involved in childcare of
grandson & his younger sister as they
were growing up – shared household,
but contact less frequent – sadly –
as they get older! Love it when
we do get chance to meet with them.
Took photo of Paul – husband
in chair watching TV – typical
activity, and redolent of security in
my life . . . .

Figure 38- Geraldine – Journal Entry –22nd July 2021

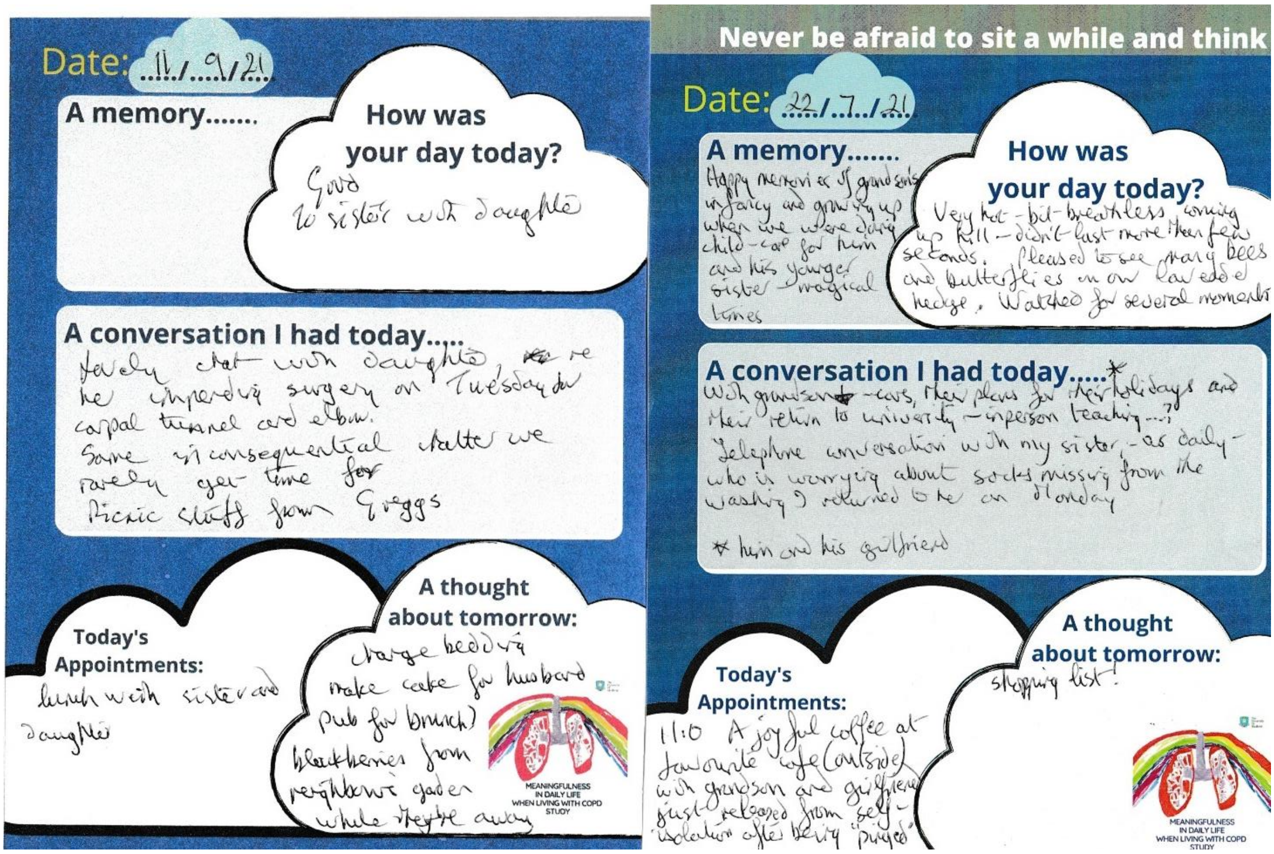
The profound meaning for Geraldine facilitated by their relationship is further echoed through her descriptions of worry around his deteriorating health (Figure 38), and how she may not be '*alive long enough to deal with it*'.



21/7/21 8.45pm
A mixture of feelings
tonight – thankfulness for
security with family,
but concern for my husband
who may have early dementia,
and for my daughter who works
too hard.
Concern that I may not
live long enough to deal
with it all.
Concern that my husband
and I may become sick and
unable to be independent.
We do not want this to happen,
and to be a burden to our
children

Figure 39 - Geraldine – Journal Entry – 21st July 2021

She also has very close relationships with her daughter and her grandchildren, with whom she lives, describing in her journal her gratitude of the security they bring in her day-to-day life (Figure 39). The meaning of these relationships was further expressed through her thinkpad entries (Figure 39), identifying a conversation with her grandson to be of importance and describing a '*lovely chat'* with her daughter.



Date: 11/9/21

A memory.......

How was your day today?
Good
To sister with daughter

A conversation I had today.....
Lovely chat with daughter re her impending surgery on Tuesday for carpal tunnel and elbow.
Some inconsequential chatter we rarely get time for
Picnic stuff from Greggs

Today's Appointments:
lunch with sister and daughter

A thought about tomorrow:
change bedding
make cake for husband
(pub for brunch)
blackberries from neighbours garden while they're away

MEANINGFULNESS IN DAILY LIFE WHEN LIVING WITH COPD STUDY

Never be afraid to sit a while and think

Date: 22/7/21

A memory.......
Happy memories of grandson's infancy and growing up when we were doing child-care for him and his younger sister - magical times

How was your day today?
Very hot - bit breathless coming up hill - didn't last more than few seconds. Pleased to see many bees and butterflies on our lavender hedge. Watched for several moments

A conversation I had today.....
With grandson* - cars, their plans for their holidays and their return to university - in person teaching...?
Telephone conversation with my sister, - as daily - who is worrying about socks missing from the washing I returned to her on Monday

* him and his girlfriend

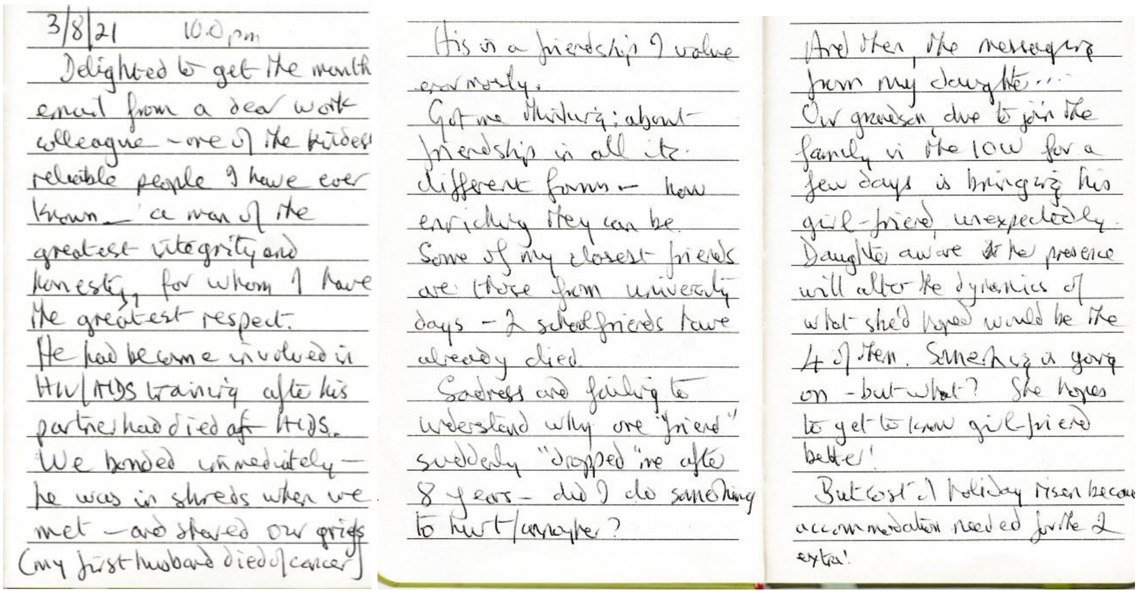
Today's Appointments:
11:0 A joyful coffee at favourite cafe (outside) with grandson and girlfriend just released from self-isolation after being "pinged"

A thought about tomorrow:
shopping list!

MEANINGFULNESS IN DAILY LIFE WHEN LIVING WITH COPD STUDY

Figure 40 - Geraldine – Thinkpad Entries – 11th September 2021 and 22nd July 2021

Meaning is also generated from these close family relationships through shared experiences, such as having coffee at a café with her grandson. Geraldine frequently looked after her grandchildren when they were younger, and as shown within figure 40, the enjoyment of spending time with them now they are older is '*sadly*' less frequent, revealing the importance of these connections to her.



3/8/21 10.0 pm
Delighted to get the month
email from a dear work
colleague – one of the kindest
reliable people I have ever
known – a man of the
greatest integrity and
honesty, for whom I have
the greatest respect.
He had become involved in
HIV/AIDS training after his
partner had died of AIDS.
We bonded immediately –
he was in shreds when we
met – and shared our griefs
(my first husband died of cancer)

This is a friendship I value
enormously.
Got me thinking: about
friendship in all its
different forms – how
enriching they can be.
Some of my closest friends
are those from university
days – 2 school friends have
already died.
Sadness and failing to
understand why one "friend"
suddenly "dropped" me after
8 years – did I do something
to hurt/annoy her?

And then, the messaging
from my daughter...
Our grandson due to join the
family in the IOW for a
few days is bringing his
girl-friend unexpectedly.
Daughter aware that her presence
will alter the dynamics of
what she'd hoped would be the
4 of them. Something is going
on – but what? She hopes
to get to know girl-friend
better!
But cost of holiday risen because
accommodation needed for the 2
extra!

Figure 41 - Geraldine – Journal Entry –3rd August 2021

Friendships are of importance to Geraldine. The detail given within a journal entry (Figure 41), not only describing how she values this friendships, but also '*how enriching'* friendships can be, recognises the meaning such relationships generate for her. Geraldine acknowledged that friendships come in '*different forms'*, which is significant when exploring the many types of relationships and connections that facilitate meaningfulness within the daily lives of those living with palliative care needs arising from COPD.

Patricia

The presence of relationships and connections as a personal value, being the most significant in facilitating meaningfulness in day-to-day life for Patricia, was documented within her narrative interview and cultural probe data. Her relationship with her family offers substantial personal, despite them living a significant distance away from her in Wales and Cornwall (narrative structure 12).

Patricia - Narrative Structure 12

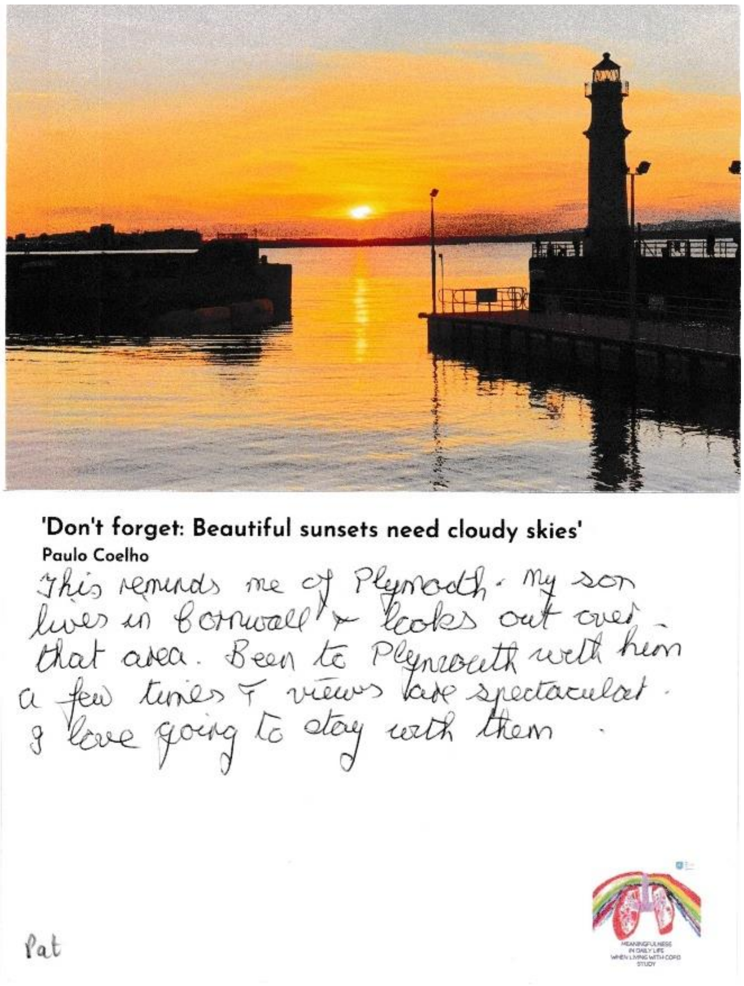
LB *- Yes Yes .h And I can tell just by how you talking just how much your family mean to you as well*

Patricia *- Well it means an awful lot to me .h yes yes*

LB *- And they don't live near you do they? Your family*

Patricia *- No no .h Wales and Cornwall*

Patricia visits them when she can and chose to reflect upon this and the meaning this generates for her upon one of her postcards, expressing her enjoyment at visiting them (Figure 41).



'Don't forget: Beautiful sunsets need cloudy skies'
Paulo Coelho

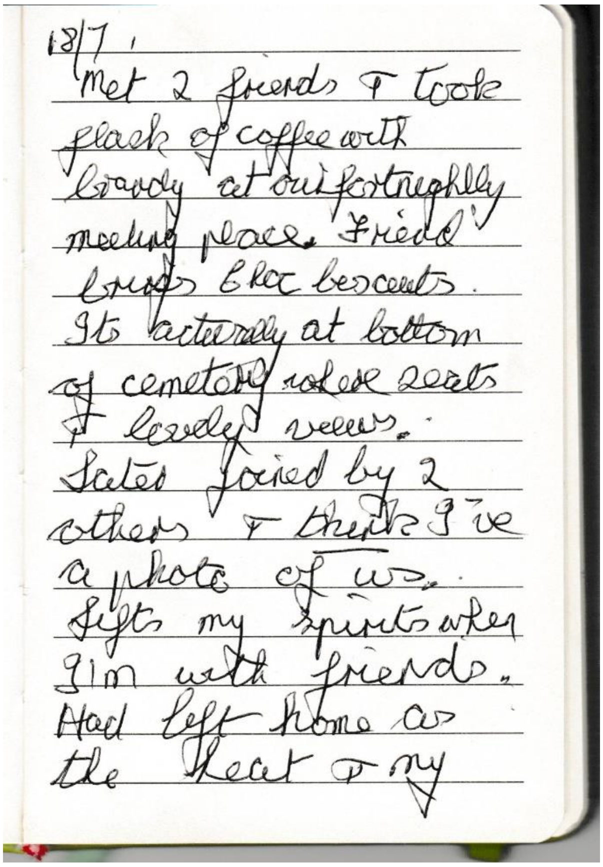
This reminds me of Plymouth. My son
lives in Cornwall & looks out over
that area. Been to Plymouth with him
a few times & views are spectacular.
I love going to stay with them.

Pat

MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

Figure 42 - Patricia – Postcard

Patricia attributes value to the friendships she holds and the meaning they generate within her day- to-day life, describing how spending time with them '*lifts her spirits'* (Figure 43).



18/7.
Met 2 friends & took
flask of coffee with
brandy at our fortnightly
meeting place. Friend
brings choc biscuits.
Its actually at bottom
of cemetery where seats
& lovely views.
Later joined by 2
others & think I've
a photo of us.
Lifts my spirits when
I'm with friends.
Had left home as
the heat & my

Figure 43 - Patricia – Journal Entry –18th July 2021

Patricia expanded upon how friendships generate meaning within her day-to-day life throughout her narrative interview.

Patricia – Narrative Structure 9

LB *- Erm so in-in yeah in the jo- erm in the journal I've kind of well I've read through it all a few times and and again I must thank you for for the commitment that you gave to writing it (1) erm but one-one sort of thing that you've written in there is about that your spirits are very much lifted when you're with your friends .h erm and I just kind of wanted to explore with you really sort of what-what you meant by that and and how much that means to you spending time with them?*

Patricia *- I probably am a people person I don’t know uh I just yeah it's lovely to see them .h you know when you've lived in a place erm how many years .h 66 years 67 years .h you can't go out shopping without seeing people that you know and they’ll [laughing] You know its ‘Hi [name] you alright? .h erm it's lovely to be able to just (.) you know chat with people erm.h people you know when you when you're out shopping erm me good friends yes its lovely to be with them*

LB *- Yes*

Patricia *- It's just the chat erm you know if they’ve got any problems we can talk them over or I’ll talk my things over so er .h you know er*

As shown, she valued the opportunity to talk over any problems she may have, offering her security through these relationships. Some of Patricia's friendships have been generated through living with COPD and her attendance at associated support groups (Figure 44).

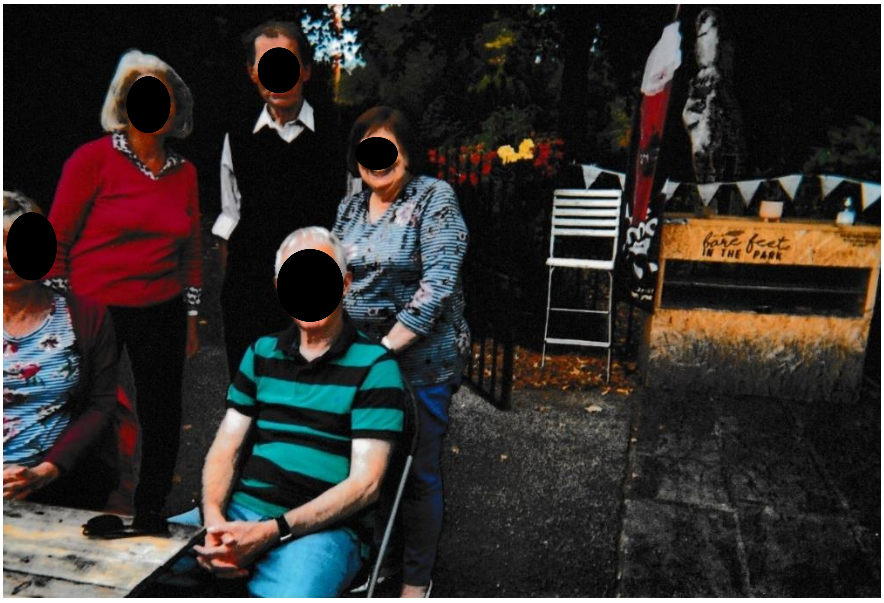


Figure 44 – Patricia - Photograph

She described in her narrative interview how she only knew *‘one or two’* of the group members, however she believed they got along well, and expressed the significance of these connections made which hold meaning for her due to her personal values of relationships and connections being met.

Patricia – Narrative Structure 6

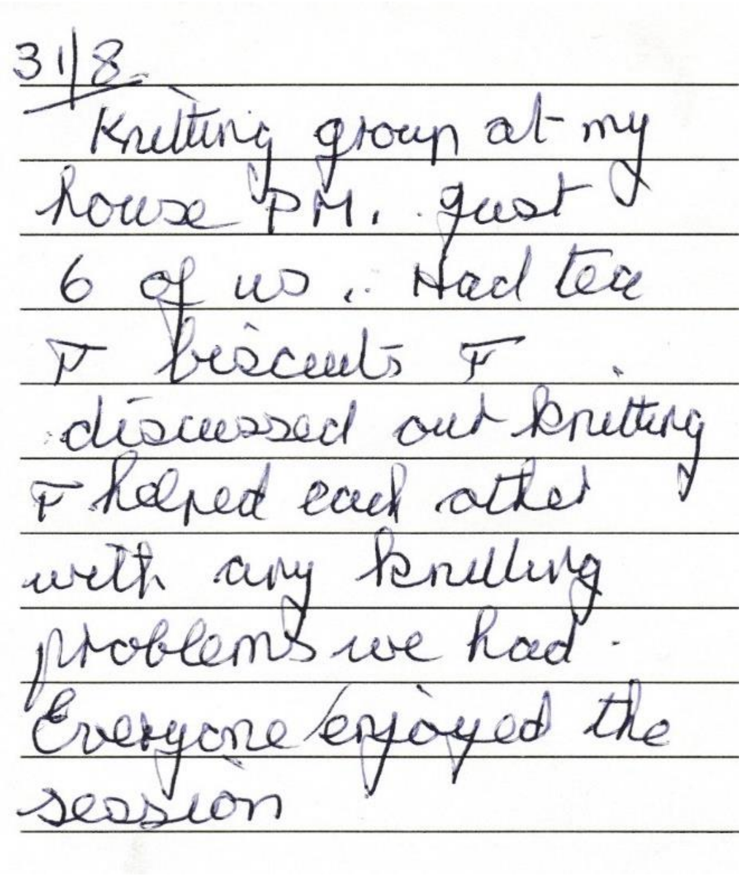
LB - *Yes Yeah .h and how important is that to you, both attending the Breathe Easy group and sort of spending time with your friends?*

Patricia - *I don't know a lot of them .h it was just one or two of them that I know in the Breathe Easy group because .h not a lot of them have been coming to Victoria Park (.) We are having out first meeting (.) I think it's in a fortnight*

LB - *Yes*

Patricia - *At the actual centre .h so erm it depends how many turn up but erm I mean .h but the ones that did turn up we all get on well together .h and it means a lot to me and erm you know*

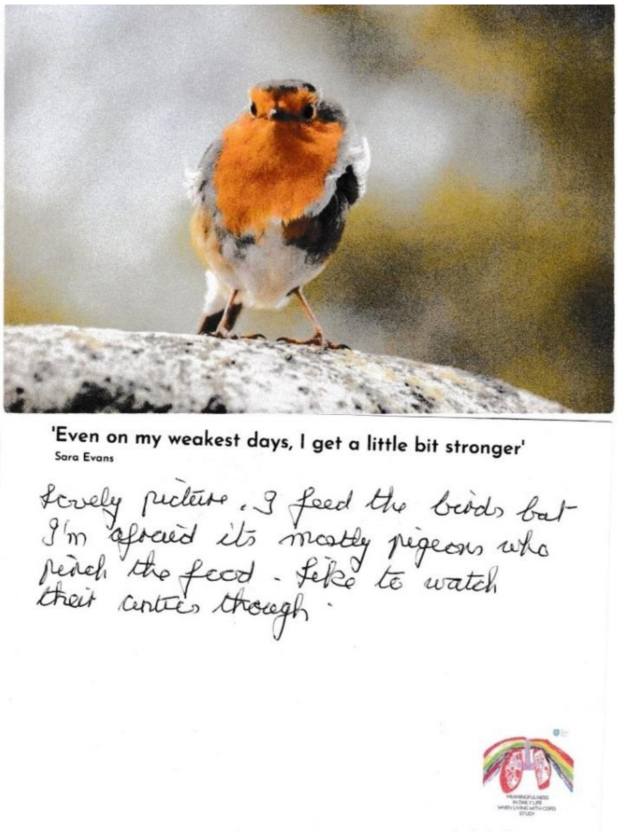
Patricia also attended a knitting group and periodically hosted the group in her home, with long standing friends, something evidently enjoyable, as shown within figure 45.



31/8.
Knitting group at my
house PM. just
6 of us. Had tea
& biscuits &
discussed our knitting
& helped each other
with any knitting
problems we had.
Everyone enjoyed the
session

Figure 45 - Patricia – Journal Entry –31st August 2021

A connection with the birds in her garden was captured by Patricia upon one of her postcard entries (Figure 46). She writes of how she likes to ‘watch their antics’. The meaning this generated for Patricia was further explained within narrative structure seven.



'Even on my weakest days, I get a little bit stronger'
Sara Evans

Lovely picture. I feed the birds but I'm afraid its mostly pigeons who pinch the food - like to watch their antics though.

Figure 46 - Patricia – Postcard

Patricia – Narrative Structure 7

Patricia - *erm I always say I'm very lucky when I look out of both windows .h back and front I've got like something nice to look at (1) especially the birds on the front in my thing .h well pigeons mostly [laughing]*

LB -*Yes so you wrote about those on one of the postcards actually that you like to watch their antics*

Patricia - *They look at me as if to say you've not been out to feed me yet*

LB - *Do you feed them every day?*

Patricia - *Yes.*

LB - *Yeah.*

Patricia - they keep the other birds off but I can't I've got to feed them .h they've come and flown into the window because they've been looking at me

***LB -** Yeah*

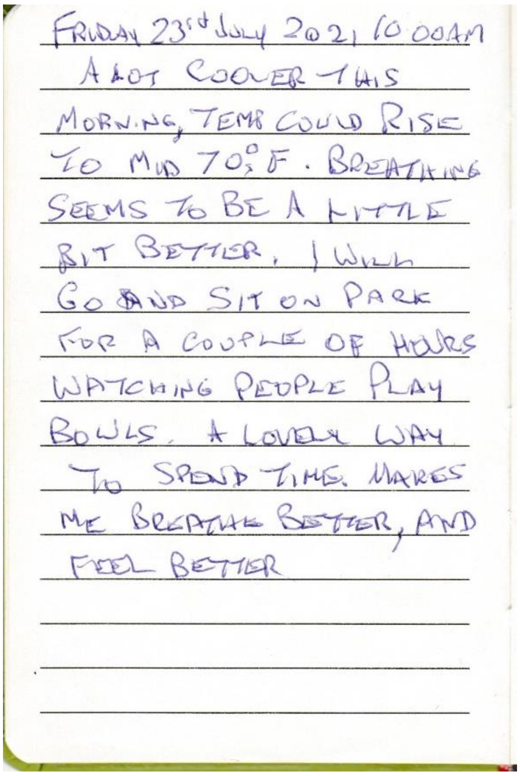
***Patricia -** then I think oh dear I've not fed em .h you know .h its ok I've not got an awful outlook you know*

By ending this narrative structure stating '*I've not got an awful outlook you know'*, it is evident that Patricia was able to identify meaning from such connections made within day-to-day life.

Craig

The importance of meaningful relationships and connections was revealed through Craig's participation, however much less frequently than other participants within this study. Craig lives with his wife; however, their relationship and its meaning was not discussed by him throughout his narrative interview or cultural probes. He also has a daughter and a granddaughter; however, they did not feature within the insights of meaningfulness he gave.

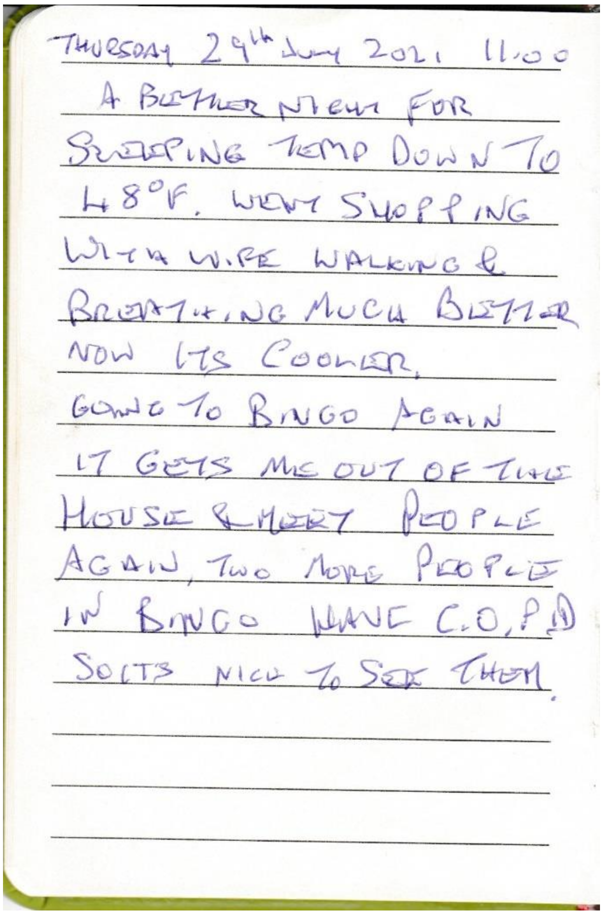
A connection documented within Craig's journal (Figure 47), is spending time watching people play bowls.



FRIDAY 23rd JULY 2021 10.00AM
A LOT COOLER THIS
MORNING, TEMP COULD RISE
TO MID 70°F. BREATHING
SEEMS TO BE A LITTLE
BIT BETTER. I WILL
GO AND SIT ON PARK
FOR A COUPLE OF HOURS
WATCHING PEOPLE PLAY
BOWLS. A LOVELY WAY
TO SPEND TIME. MAKES
ME BREATHE BETTER, AND
FEEL BETTER

Figure 47 - Craig – Journal Entry – 23rd July 2021

He described this as a '*lovely way to spend time'*, despite the frustrations of no longer being able to play bowls due to his COPD, documented within his cultural probes. Craig also identifies how meeting people at a bingo session he attends was a pleasurable interaction for him (Figure 48). The value of opportunities to connect with others living with COPD, who understand the daily challenges was evident.



THURSDAY 29th JULY 2021 11:00
A BETTER NIGHT FOR
SLEEPING TEMP DOWN TO
48°F. WENT SHOPPING
WITH WIFE WALKING &
BREATHING MUCH BETTER
NOW ITS COOLER.
GOING TO BINGO AGAIN
IT GETS ME OUT OF THE
HOUSE & MEET PEOPLE
AGAIN, TWO MORE PEOPLE
IN BINGO HAVE C.O.P.D
SO ITS NICE TO SEE THEM.

Figure 48 - Craig – Journal Entry – 29th July 2021

The six participants within this study are able to identify meaningfulness within their day-to-day lives when their core personal values of relationships and connections are met. Meeting these values is unique to each individual, alongside the types of relationships and connections they each deemed significant enough to generate meaning. Furthermore, it is evident that such relationships may evolve over time, often redefined by each individual to align with the impact of living with COPD and the type of connections they are able to make or identify to facilitate personal value congruence.

6.3 – Fulfilment and Purpose

The six participants within this study were able to identify meaningfulness within their day-to-day lives, through meeting their personal values of fulfilment and purpose. Each participant gave insight into elements of their day-to-day life where they held feelings of satisfaction, of life being worthwhile and being able to make a difference, despite the significant symptom burden when living with palliative care needs arising from COPD. Meeting their personal values of fulfilment and purpose did not always directly result in continuous personal happiness, but more the identification of deep meaning within their day-to-day lives, through opportunities to feel purposeful.

Stephen

Stephen was able to experience feelings of fulfilment and purpose to generate meaning within his day-to-day life through his hobby of writing his life story. As shown within narrative structure twenty-one, Stephen shared his writing with friends and family across the world. As he described, '*they are very interested in it*', enabling feelings of fulfilment and purpose as a result of his writing making a positive difference to others.

Stephen – Narrative Structure 21

***Stephen* -** *did I I did tell you didn't I that I'm writing my life story*

LB *-Yes you did*

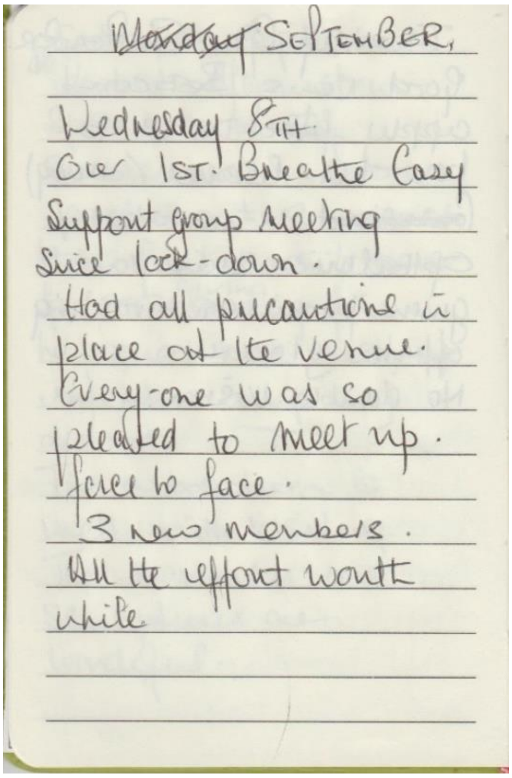
Stephen - *Well [coughs] in fact at five o'clock today that will be the next chapter coming across*

LB - *Oh*

Stephen - *But I have some friends in Cork where I come from (.h) who are very very interested in it because (.h) (3) I'm also describing my childhood which will be familiar to some of them*

Sally

Sally revealed elements from within her day-to-day life meeting her personal values of fulfilment and purpose, alongside revealing how she had shaped and redefined life events to meet these values throughout her disease progression. Before retirement, Sally was a state registered nurse and spoke of how during the COVID-19 pandemic, if she had been physically able, she '*would have been first to go and start vaccinating'*. It is evident that her role as a nurse gave her meaning in life through generating feelings of fulfilment and purpose, and at a time of a global pandemic she still wanted to make a difference to others. However, Sally was able to identify elements within her life to meet these values, most prominently her role as the chair of her local BLF breathe easy support group. Sally reflected on the meaning this generated for her within her journal (Figure 49).

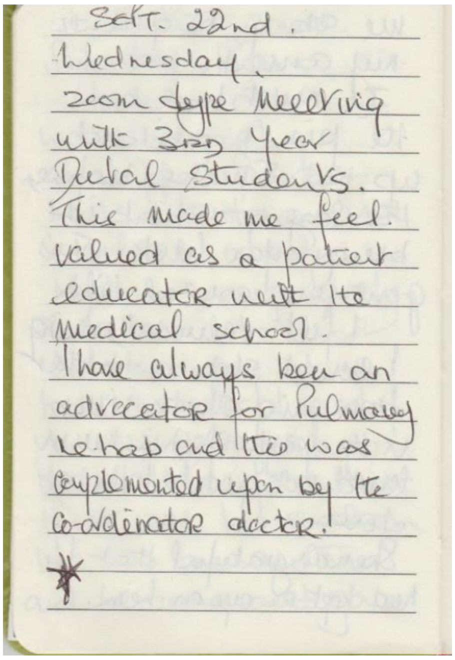


~~Monday~~ SEPTEMBER,

Wednesday 8TH
Our 1ST. Breathe Easy
Support group meeting
Since lock-down.
Had all precautions in
place at the venue.
Every-one was so
pleased to meet up.
face to face.
3 new members.
All the effort worth
while

Figure 49 - Sally – Journal Entry –8th September 2021

Sally's words, '*all the effort worthwhile*' demonstrated the fulfilment that this role has given her. She also undertook a role as a patient educator, as a part of the medical school at her local university. A shown within figure 50, this role enabled Sally to feel valued.



Sept. 22nd.
Wednesday.
zoom type meeting
with 3rd year
Dental students.
This made me feel.
valued as a patient
educator with the
medical school.
I have always been an
advocator for Pulmonary
re-hab and this was
complimented upon by the
co-ordinator doctor!

Figure 50 - Sally – Journal Entry –22nd September 2021

Both of these examples of how Sally achieves meeting her values a fulfilment and purpose have been generated throughout her COPD disease progression, to create harmony between her own values on the environment in which she exists. The ability to do this has allowed Sally to facilitate meaningfulness within her day-to-day life.

Karen

Similarly, Karen has redefined how she will meet her personal values and fulfilment and purpose within her life now she lives with the relentless symptom burden of COPD. The impact upon Karen of retirement from work due to her COPD was significant.

Karen – Narrative Structure 8

Karen *- Erm I said confidence in connecting erm I don't know .h erm h your confidence is shaken as soon as you retire I mean I am still working*

LB *- Right*

Karen *- Erm but there only very little jobs erm*

LB *- What kind of work are you still undertaking*

Karen *- I'm doing external examining and tutoring*

LB *- Oh right*

Karen *- I've got a deadline today to feedback on some work so erm .h which is great I love to have work to do*

Karen expressed within narrative structure eight, but her confidence was '*shaken*' as soon as she retired, indicating her personal value of having a purpose was no longer met. Despite living with COPD being her reason for leaving work, Karen re-shaped how she was going to meet this value by continuing to undertake some work such as '*external examining and tutoring'*, developing congruence between her personal values and living with COPD.

Geraldine

Identifying ways to meet her personal values of purpose and fulfilment has evolved over time for Geraldine, through the symptom progression of living with COPD. Having a purpose in life is something she has often '*pondered*' and acknowledges this can be difficult to identify at times. Geraldine expresses that purpose in life isn't always there, and '*we have to try and make it'*. Prior to the deterioration in her health, Geraldine used to attend demonstrations for issues of importance to her however he is no longer able to do this. Instead, she finds purpose in being a patient educator at her local university.

Geraldine - Narrative Structure 9

LB *- Now (name), what gives you purpose in life, at this stage in life, what gives you sort of purpose and allow you to still be you*

Geraldine *- I enjoy with the medical students and anything else like that to give me you know a bit of a purpose (.h) cause otherwise I don't know really what I'd be for (.h)*

Geraldine also acknowledged how taking part within this research study also gave her a purpose.

Geraldine - Narrative Structure 17

LB - *Ok, thank you. I think that is pretty much everything I wanted to ask you really, that has been so useful so thank you so much for taking part and for your time today and for everything you did with the probes*

Geraldine - *Well I think this relates to your last question (.h) if it's been useful, there's been a purpose if you see what I mean*

LB - *Yes*

Geraldine - *You know and I I can I can give myself several strokes for that*

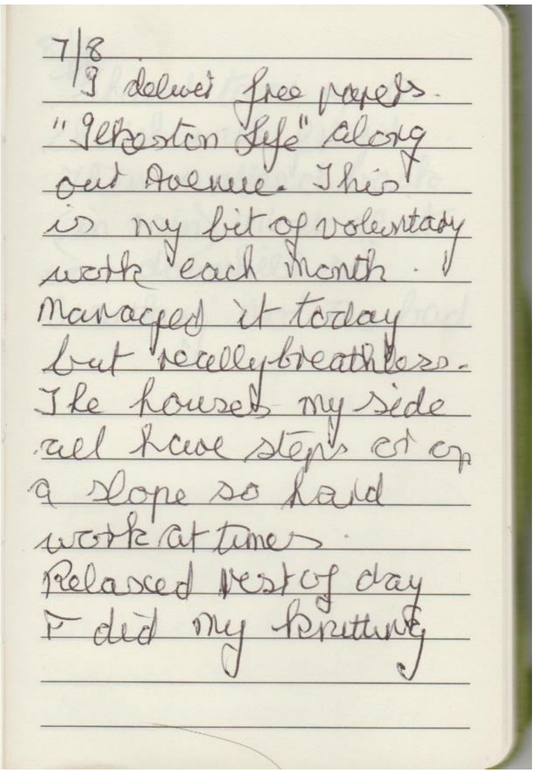
LB - *Yes you can (laughing)*

Geraldine - *Which I do (laughing) if that's alright, you know you're the vector for that if you like (.h) erm so it works both ways Louise that's the thing (.h) that's what I said to the patients as woman initially (.h) that erm you know that the students they mustn't think it was all one way that erm we do get do feel useful as a result of taking part*

Participation within these activities allowed Geraldine to achieve personal value congruence within the limitations of living with COPD, contributing to the presence of meaningfulness.

Patricia

One strategy used by Patricia to achieve fulfilment and purpose within her day-to-day life was to deliver newspapers along the street where she lives. She wrote (Figure 51), of how that particular day she was '*really breathless*' however she pushed herself to overcome this as this voluntary work is an element of her daily life generating meaning.

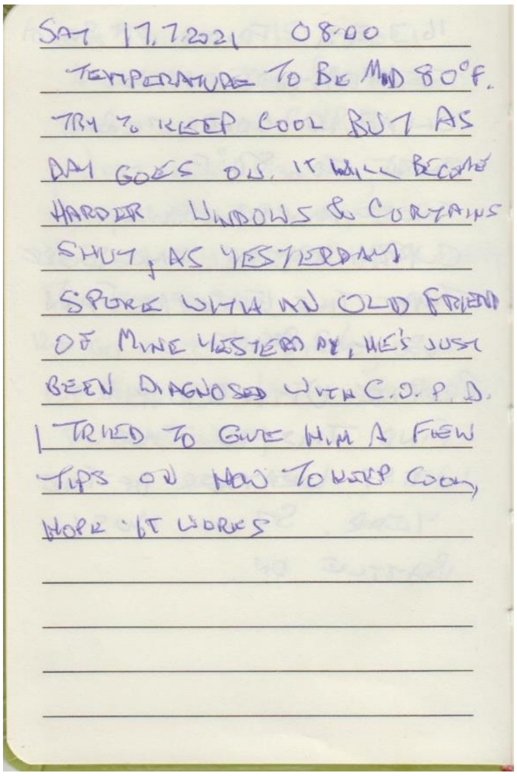


7/8
I deliver free papers.
"Ilkeston Life" along
our Avenue. This
is my bit of voluntary
work each month.
Managed it today
but really breathless.
The houses my side
all have steps or on
a slope so hard
work at times.
Relaxed rest of day
& did my knitting

Figure 51 - Journal Entry – Patricia – 7th August 2021

Craig

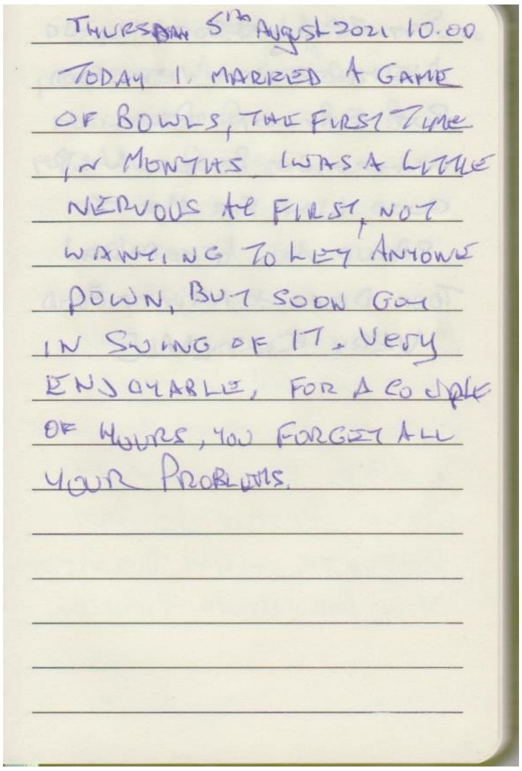
Identifying fulfilment and purpose within day-to-day life was limited for Craig, as his COPD symptom burden prevented him from undertaking many of the activities he previously had. Within his journal (Figure 52), he wrote about sharing his knowledge upon COPD with a friend who had just been diagnosed with the condition, enabling him to have felt useful, and meet his personal value of fulfilment.



SAT 17.7.2021 08:00
TEMPERATURE TO BE MID 80°F.
TRY TO KEEP COOL BUT AS
DAY GOES ON, IT WILL BECOME
HARDER WINDOWS & CURTAINS
SHUT, AS YESTERDAY
SPOKE WITH AN OLD FRIEND
OF MINE YESTERDAY, HE'S JUST
BEEN DIAGNOSED WITH C.O.P.D.
I TRIED TO GIVE HIM A FEW
TIPS ON HOW TO KEEP COOL,
HOPE IT WORKS

Figure 52 - Craig – Journal Entry –17th July 2021

Craig also recorded having been able to recently mark a game of bowls (Figure 53). As shown, Craig expressed feelings of nervousness prior to this as he did not wish to ‘*let anyone down’*, highlighting the importance this activity held for him. He then goes on to state how the experience was ‘*very enjoyable’*, meeting his values of fulfilment and purpose to generate meaningfulness within his life.



THURSDAY 5TH AUGUST 2021 10.00
TODAY I MARRED A GAME
OF BOWLS, THE FIRST TIME
IN MONTHS. I WAS A LITTLE
NERVOUS AT FIRST, NOT
WANTING TO LET ANYONE
DOWN, BUT SOON GOT
IN SWING OF IT. VERY
ENJOYABLE, FOR A COUPLE
OF HOURS, YOU FORGET ALL
YOUR PROBLEMS.

Figure 53 - Craig – Journal Entry –5th August 2021

Each participant was able to meet their core personal values of fulfilment and purpose to achieve personal value congruence, contributing to the presence of meaningfulness within their daily lives. Each participant identified activities within their lives that would meet their individual understanding of having a purpose. For each participant, ways to meet these values have been redefined throughout their disease progression to align with the limitations of living with COPD.

6.4 – Creativity and Self-expression

Achievement of personal value congruence through meeting the values of creativity and self-expression generated the presence of meaningfulness for five participants. One participant, Craig, did not indicate this value was of importance to him, and revealed no elements from within his day-to-day life related to these values.

The values of creativity and self-expression were demonstrated by participants expressing their individuality through engaging in creative activities, reminding themselves they still have a personal identity despite living with COPD. By meeting these core personal values, participants experienced feelings of accomplishment, connection with others, emotional expression and personal growth. These elements collectively contributed to the presence of meaningfulness within day-to-day life.

Stephen

Stephen meets his personal values of creativity and expression through writing his life story in the form of a book. The sense of achievement is evident for him, as shown within narrative structure 21. This process of storytelling was a dynamic form of self-expression that has allowed Stephen to share his thoughts with the world.

Stephen – Narrative Structure 21

Stephen – did I I did tell you didn't I that I'm writing my life story

LB - Yes you did

Stephen – Well [coughs] in fact at five o'clock today that will be the next chapter coming across

LB - Oh

Stephen – But I have some friends in Cork where I come from (.h) who are very very interested in it because (.h) I'm also describing my childhood which will be familiar to some of them

Sally

For Sally, meeting her personal values of creativity and self-expression was achieved through her love of crochet, as shown within figure 54. Sally used this creative craft to unwind and relax. She took these photographs to reflect a skill of hers, demonstrating the sense of achievement the completed blankets gave her.

Figure 54 - Sally – Photograph

Karen

Within her time of being diagnosed with COPD, Karen has undertaken an activity of self-expression based '*precisely upon'* her breath. This was part of an event at her former place of work whereby she created a glassblowing exhibition (Figure 55) to represent the breath.

Figure 55 - Karen – Photograph

Karen speaks about this experience with a real sense of achievement and stated *'I was very proud and very pleased'*. Despite this creative self-expression being many years prior to her participation within this study, having a platform to recall and converse about this facilitated an opportunity for her to meet her personal values. Karen also chose to photograph a tea cosy that she had knitted (Figure 56), to demonstrate another creative skill of hers.

Figure 56 – Karen – Photograph

Geraldine

Geraldine participates in sessions at the university of the third age, aligning with her values of creativity and self-expression, as shown within narrative structure 13.

Geraldine - Narrative Structure 13

Geraldine – *have you heard of U 3 A?*

LB - *Erm no I haven't*

Geraldine - *Its erm its called the University of the third age which is a bit silly as it's not a university but it's a very good organisation of people over fifty (.h) and the Sheffield group its not a professional organisation (.h) the Sheffield group is very large and very active and (.h) we belong to a singing group which of course we haven't been able to meet and we belong to the science and technology group which has interesting monthly lectures (.h) That's because neither of us know anything about science and technology so we thought it would be good for us to join when we moved here.*

This not only reflected her individuality, but also provided a platform for her to share meaningful elements of herself with the world.

Patricia

Patricia used knitting as a way of expressing her creativity and individuality. She engaged in this craft with the purpose of creating thoughtful gifts for her family and friends, effectively expressing herself and her kindness to others. By meeting these core personal values, Patricia is able to identify meaning within her day-to-day life.

As demonstrated, meeting the personal values of creativity and self-expression developed meaning within each participants day-to-day lives, through feelings of purpose and fulfilment. Meeting the personal value of creativity has allowed participants within this study an opportunity for self-expression, allowing them to reveal their individuality despite living with an impactful chronic disease. Through meeting these values, participants were able to maintain elements of their self-identity, generating meaning within daily life.

6.4 – Overcoming challenges

The impact of overcoming challenges within day-to-day life was evident within the reflections given by four participants within this study. This was achieved through them being able to identify feelings of accomplishment, alongside acknowledging appreciation for life, despite living with palliative care needs arising from COPD.

Stephen

Stephen revealed his ability to overcome challenges due to his chronic breathlessness that had previously prevented him being able to leave his house and undertake enjoyable activities. As shown within narrative structure one, prior to the acquisition of a mobility scooter, he described his life as being *'simple repetition day in, day out'*. Overcoming this challenge enabled Stephen to set meaningful personal targets to leave his house each day (narrative structure 6).

Stephen -Narrative Structure 1

Stephen -*because basically all day every day I do exactly the same thing*

LB - *yeah*

Stephen -*now with recent times, very recent times (.) the acquisition of a mobility scooter has changed my daily routine so (h) erm before you erm (.) before filling in the daily report that that*

was before I got the scooter that's why it would have been (.) how can I put it? It would have been simple repetition day in, day out and I I can imagine

Stephen – Narrative Structure 6

Stephen – *(.h) that's just that sort of erm (.h) a sort of a little bit of a cameo of how my life is at the minute you know*

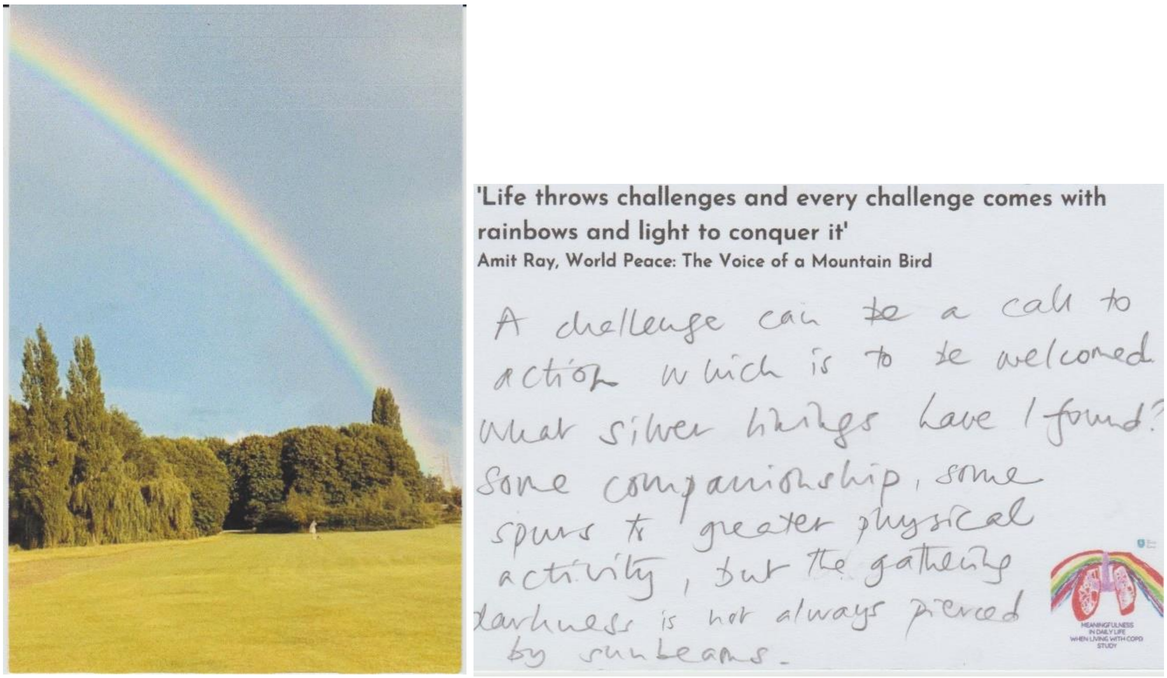
LB - *Yeah, no thank you for (.) thank you for sharing that its erm. So when you have been out on*

these (.) now you have got your scooter as well I can imagine that's really helped in so many ways really so when go out on on these trips around how does that make you feel in terms of a sense of achievement that you didn't have before

Stephen – *well I look forward to it tremendously (.h) and yes I do set myself targets (.h)*

Karen

Karen chose to reflect on how she had overcome challenges within her day-to-day life by using the rainbow postcard (Figure 57) included within her cultural probes. The reflection reveals how companionship and undertaking physical activity, something she describes as '*silver linings'*, has enabled this.



'Life throws challenges and every challenge comes with rainbows and light to conquer it'
Amit Ray, World Peace: The Voice of a Mountain Bird

A challenge can be a call to
action which is to be welcomed.
What silver linings have I found?
Some companionship, some
spurs to greater physical
activity, but the gathering
darkness is not always pierced
by sunbeams.

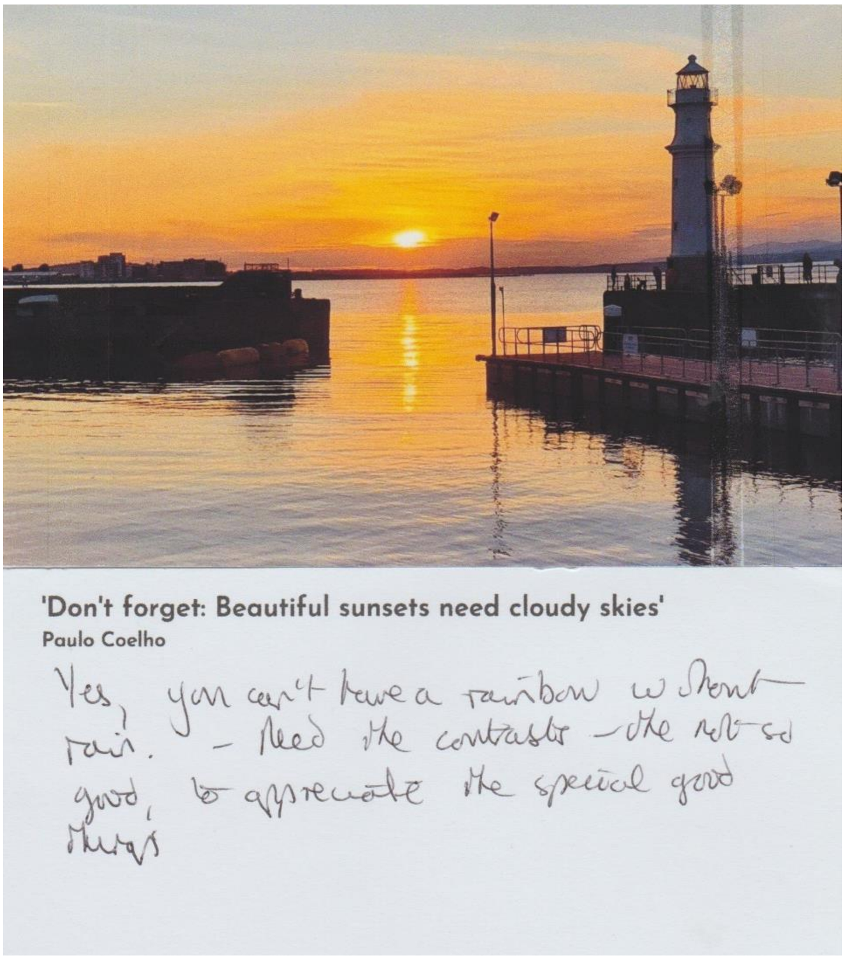
MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

Figure 57 - Karen – Postcard

Karen acknowledged that the challenges are not always able to be overcome, suggesting a disruption in meeting this personal value may interrupt the presence of life meaning. which is further explored within Chapter eight of this thesis.

Geraldine

Geraldine also chose to reveal her feelings upon life challenges via a reflective postcard (Figure 58). She identifies that experiencing challenges in life has enabled her to develop a deeper sense of appreciation for the positive elements, demonstrating the development of resilience. Through adopting this mindful viewpoint upon living with COPD, Geraldine was able to identify meaning within her life through '*appreciating the special good things*'.



'Don't forget: Beautiful sunsets need cloudy skies'
Paulo Coelho

Yes, you can't have a rainbow without rain. – Need the contrasts – the not so good, to appreciate the special good things

Figure 58 - Geraldine – Postcard

Patricia

Patricia demonstrated the importance to her of overcoming challenges throughout her cultural probe entries. Despite the symptoms of COPD she experiences, including significant breathlessness, she pushed herself to undertake exercise within the limitations of her condition most days, generating a sense of fulfilment and purpose by overcoming the challenges these symptoms present. As shown within narrative structure two, she was determined to enjoy life, and is able to identify meaning within it.

Patricia – Narrative Structure 2

Patricia – *Well .h I don't do too badly for my age.*

LB - *I think you do brilliantly ha*

Patricia – *Ha Yeah. I manage fairly well, yeah*

LB - *You've got a really, really positive outlook on life*

Patricia – *Well .h I mean h I'm eighty-eight .h I've not got that many years. Erm I'm determined to enjoy what can*

6.5 – Chapter Summary

This chapter has presented how each of the six participants within this study were able to achieve **personal value congruence**, through the meeting of their core personal values, to facilitate **the presence of meaningfulness** within day-to-day life. The ways in which participants have met their core personal values has evolved over their time living with COPD, through self -evaluation to identify ways to meet them within the limitations of their condition.

Underpinning the meeting of each individuals core personal values, was having the **physical ability** to do so, alongside participants being able to re-evaluate how their values were met within the limitations of living with palliative care needs arising from COPD.

The participants within this study were striving to **meet four core personal values** within day-to-day life to generate life meaning. **Relationships and connections** were necessary for participants to achieve personal value congruence. The types of connections varied between participants, dependent upon whom or what they had developed a connection with. New relationships made because of living with COPD allowed participants to reveal new ways to meet these personal values, particularly through attendance at their local BLF breathe easy support group. Identification of **fulfilment and purpose** within day-to-day life allowed this study's participants to experience meaningfulness. These personal values were met in varying degrees amongst the six participants within this study. Feelings of purpose and achievement, alongside maintaining a sense of self-identity were generated for five participants upon meeting their personal values of **creativity and self-expression**, and subsequently generating life meaning. **Overcoming challenges** within daily life was revealed by four of the participants within this study. This facilitated feelings of accomplishment and an appreciation for life, facilitating the presence of meaningfulness.

The following chapter (Chapter 7) will present how participants within this study were able to identify meaningfulness within their day-to-day lives through taking control of their personal dignity.

Chapter 7.0 – Meaningfulness through taking control of personal dignity

7.1 – Introduction

This chapter presents how participants within this study we're able to identify meaningfulness within day-to-day life through taking control of their own personal dignity. This was underpinned by two sub-themes: asserting and maintaining control over life choices and acceptance of limitations, as displayed within figure 59.

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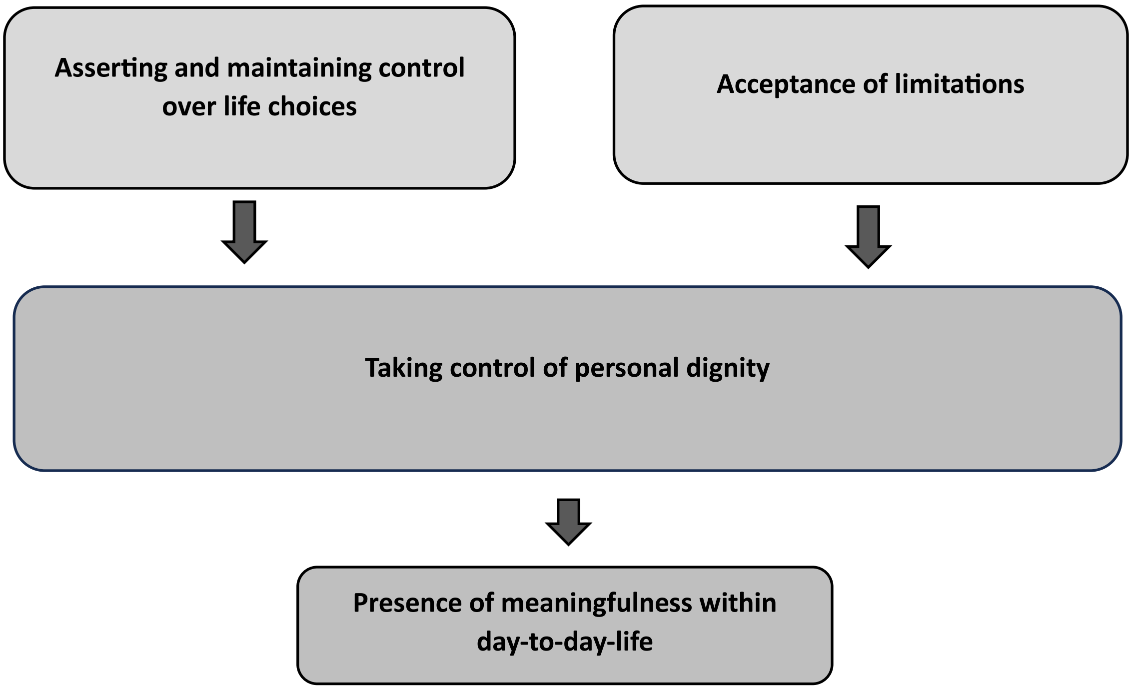


Figure 59 - Meaningfulness through taking control of personal dignity

When a person takes control of their personal dignity, a sense of autonomy is generated, evidenced to positively influence individuals quality of life (Rodríguez-Prat *et al.*, 2016). This powerful and empowering process facilitates a positive impact upon an individual's sense of self-worth, allowing them to identify as a person of value (Oosterveld-Vlug *et al.*, 2013).

Furthermore, when people value their own dignity, they are more likely to make decisions that align with their values and long-term goals, leading to more fulfilling and purposeful life. Taking control of one's personal dignity is an ongoing process that may involve self-reflection, personal growth, and the willingness to adapt to new situations, with deeply rewarding outcomes related to personal fulfilment and a more positive and empowered life. For participants within this study, taking control of their personal dignity enabled meaningfulness to be identified within day-to-day life as a result of this process, via asserting and maintaining control over their life choices and acceptance of their limitations.

7.2 – Asserting and maintain control over life choices

Assessing and maintaining control over their day-to-day lives was a conscious decision by five of the participants within this study, allowing them to maintain their personal dignity. This was not evident from the insight given by Craig into his day-to-day life, as he contrastingly presented the absence of control, and how this interrupted the identification of meaning within day-to-day life, which is further explored within Chapter 8.0 of this thesis.

For the five participants who revealed how asserting and maintaining control within day-to-day life facilitated them being able to take control of their personal dignity, this was facilitated through taking control of setting realistic goals to be achieved in manageable steps within the physical and emotional limitations imposed when living with palliative care needs arising from COPD.

Stephen

Stevens took an active role within decision-making processes around elements impacting his daily life, to facilitate the presence of meaningfulness. He has adopted a positive emotional attitude to living with the physical implications of COPD, as shown within narrative structure sixteen, describing this as a survival technique.

Narrative Structure 16 – Stephen

LB *- You seem to have a very positive mindset*

Stephen *- Well if I may be be honest one or two people have erm commented on that but I I just don't see any other way to do it t:to survive (.h) I I mean er I I should imagine for some people it would be quite easy (.h) to descend into a slower despondency but (.h) I I I've never been like that for me (.h) if if I could paraphrase my my last night er Louise Glasgow Celtic lost four Nil at home*

LB *- Oh*

Stephen *- That's frustrating and disappointing ha but I know that on Sunday they are going to beat Aberdeen Ha You understand where I am coming from with that expression you know it's (.h) that's (.h)It it's what depresses me or what depresses me is not the things that I can't do (.h) because I've accepted that (.h)*

Asserting control over the emotional impact of living with palliative care needs arising from COPD prevented him from descending '*into a slower despondency'*, resulting in him being able to live a fulfilling and meaningful life. Stephen facilitated this by setting himself goals (as shown within narrative structure eighteen), providing him with structure, direction and a purpose within daily life.

Narrative Structure 18 – Stephen

Stephen *- And then last week again as a test (.h) I went to IKEA on the scooter*

LB *- Gosh*

Stephen *- On the footpath (.h) I mean then from here on in if I got to IKEA ill be going on the bus*

LB *- Yeah*

Stephen *- On the scooter but I mean that was a (.h) that was a target I set myself (.h) so having got to IKEA there was there is also a Marks and Spencer's there's a Wilko's there's a Boots chemist. There's all sorts of shops (.h)*

LB *- Yes*

Stephen *- You know and I I these are the (.h) another target for example is pretty soon I'm gonna need to have my hearing aids repaired*

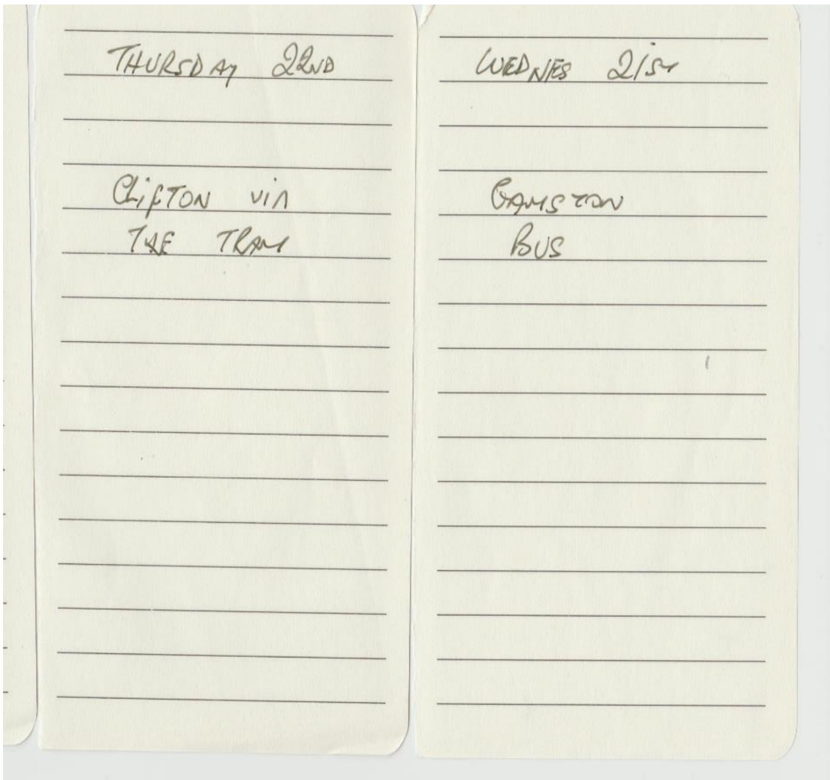
LB *- Right*

Stephen *- (.h) Instead of getting in touch with the Eastwood volunteer bureau to take me in their motor car (.h) ill be bale to go on the bus on me scooter and then when I've had my hearing aid done I'll maybe go across the road to Sainsbury's supermarket (.h) where I haven't been for five years*

LB *-Wow*

Stephen *- (.h) all these things (.h) er there's so many things now that I have access to that previously were inaccessible (.h) er and some of the if you think (.) if I'm giving you the impression that I'm a bit upbeat (.h) that's why*

Setting goals provided Stephen with a framework of accountability to himself, facilitating a sense of responsibility and ownership over his own actions. Achievement of these self-imposed targets allowed Stephen to experience a sense of accomplishment and self-worth, and therefore maintain his own personal dignity. Furthermore, this allowed him to live an authentic life, making choices aligned with his personal values and to achieve his aspiration. In turn, this generated the presence of meaningfulness within Stephen's day-to-day life. This was further embellished within diary entries made by Stephen (Figure 60), highlighting the accomplishment of the goals he set upon visiting places on many occasions.



THURSDAY 22ND

Clifton via
The Tram

WEDNES 21ST

Gamston
Bus

Figure 60 - Stephen – Journal entries – 21st and 22nd July 2021

Stephen explained his mindset upon his future whilst living with COPD, demonstrating how he is asserted control over how this impacts him (show within narrative structure seventeen). Stephen expresses great optimism, despite living with the limitations of COPD. He describes how he is '*enjoying life despite the restrictions*', having fostered personal resilience whilst facing such difficulties. Through embracing a positive attitude, Stephen feels in control of his life, facilitating a more fulfilling and purpose driven existence to facilitate the presence of life meaning

Narrative Structure 17 – Stephen

LB - *Yes yeah erm sort of thinking along that and it's it's a difficult topic to to kind of explore but do you (.) do you have any thoughts about sort of the end of your life really?*

Stephen - *I'm thinking= more about it of recent times (.h) but would I say I'm thinking about it well I'm making sure that er my will is in order*

LB - *Yeah*

Stephen - *And I've had an er I've had a a (.) a deal with the Co-Op about my (   ) for me funeral you know that's er (.h) a plan a funeral plan that they've arranged =for me*

LB - *Yes*

Stephen - *Erm but other than that I I just I don't really think about it too much now erm (.h) I take each day as it comes I'm not one of those who thinks (.h) brilliant I've woke up today I expect to wake up a few long more days yet you know ha*

LB - *Yeah*

Stephen - *Er but yes I suppose (.h) I'll be eighty years of age next February*

LB - *Ah ha*

Stephen - *And so yes I think about what comes next for me you know erm (.) erm like any human being Louise I just want to go on as long as possible I'm enjoying life despite the restrictions and limitations (.h) of COPD I'm enjoying life (.h)*

Sally

Sally asserted and maintained control over her day-to-day life within the limitations of living with COPD through the active decision to participate within her local BLF breathe easy support group. As shown within narrative structure seven, this enabled her to socialise with others living with the same condition she does.

Narrative Structure 7 – Sally

Sally - *It means that we see people who have got the like conditions.*

LB - *Yes*

Sally - *Yeah? And lets them know that it's not the end of the world. There are things available. Um. And it's a get together. It's a social atmosphere. Um. I mean when we had the singing as well that was even better. And, hopefully, that is coming back in spring.*

LB - *Yes.*

Sally - *Erm. But we have a laugh. We - We see people. I mean it was brilliant the first time we had, one in September. I didn't recognise some of them because they'd had the cataracts done and they weren't wearing glasses, you know. (Laughter) But everybody was so pleased to see and come out of their four walls, you know.*

As shown, participation within this support group allows Sally to take control of her own personal dignity through facilitating peer support, enabling her to experience a sense of community, in turn validating her feelings and experiences. This is particularly evident as she speaks of informing the group members '*that it's not the end of the world*'. Through this validation of personal feelings, Sally experienced self-acceptance, that has contributed to a more meaningful experience in day to day life.

Avoidance of thinking about the impact of living with COPD (as shown within narrative structure two), is another example of how Sally exerted control over her day-to-day life.

Through directing her attention away from the impact and limitations imposed by living with COPD, Sally is able to focus upon the positive elements, facilitating an optimistic outlook resulting in the presence of life meaning.

Narrative Structure 2 – Sally

LB - *Um. And can you just kind of talk me through now, um, how COPD affects your daily life?*

Sally - *Back then as to now?*

LB - *So - So now.*

Sally - *Just now?*

LB *-Yeah.*

Sally - *Yeah. Um. I don't try to let it affect me, I'll be honest. I don't consciously think about it all the time. Um. I do what I can do, that which is majority of the housework, but it's not anything heavy. Or, you know, stretching, that type of thing. But that is part of ageing as well, I think.*

Karen

Whilst living with the physically and emotionally challenging circumstances of palliative care needs arising from COPD, Karen has adopted a '*routine of survival'* to impose structure and control within her day-to-day life as shown within narrative structure nine.

Narrative Structure 9 -Karen

Karen - *Well yes we don't always want to think about being-having a condition*

LB - *Of course of course and is that something you try to do regularly is to try and not think about it =or*

Karen - *Yes it makes it a lot worse [laughing] It is to not think about it .h you try to build up you know a routine of of survival type thing.*

Karen chose to try and eliminate thoughts upon living with COPD, exerting control over the emotional impact of living with the condition, enabling autonomy and stability. Exploration of the '*routine of survival'* adopted by Karen identified its context specific nature of living with COPD. As such, the control Karen imposed upon her day-to-day life was largely focused upon undertaking exercise to maintain her health within the limitations of living with the condition. As shown within narrative structure one, Karen described her belief of '*you've got to find what you're ready for and push yourself a bit'*, aligning with her goal setting of undertaking the exercise she's able to. An associated sense of empowerment was evident from Karen's spoken words identifying a sense of independence and self-determination facilitating meaning within her day-to-day life.

Narrative Structure 1 – Karen

Karen - *Erm yes no I tried to keep active I tried to find a new sort of exercise regimes to do but that takes up quite a lot physically .h*

LB - *Yes*

Karen - *Erm .h I've just heard about Buteyko breathing so I'm going to try .h doing that a little bit more*

LB - *Okay do you find erm that the more exercise you make yourself do the-the better you feel?*

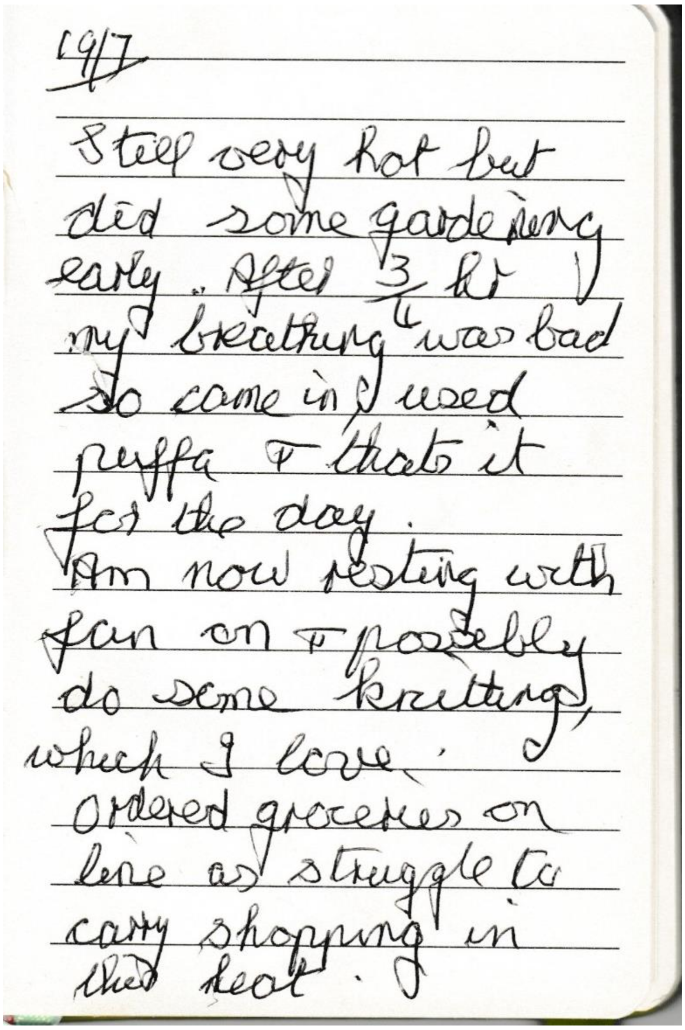
Karen - *Yes of course*

LB - *Yes good*

Karen - *Yes erm well .h you've got to find what you're ready for and push yourself a bit*

Patricia

Patricia asserted and maintained control over her own personal dignity through participation in activities facilitating the achievement of personal goals. She engaged in hobbies that captured her interest, such as knitting and light gardening, contributing to feelings of purposefulness and subsequent life meaning. As shown within figure 61, Patricia wrote about her love for knitting, which is notably a hobby she undertook when the impact of breathlessness is of significance. This demonstrates how Patricia was able to assert control over her own dignity, to complete a hobby aligned with her symptom burden generating feelings of purposefulness and a sense of achievement.



19/7

Still very hot but
did some gardening
early. After 3/4 hr
my breathing was bad
so came in & used
puffa & thats it
for the day.
Am now resting with
fan on & possibly
do some knitting,
which I love.
Ordered groceries on
line as struggle to
carry shopping in
the heat.

Figure 61 - Patricia – Journal Entry – 19th July 2021

Patricia is aware of the benefits of exercise upon lung health, and participation evidently improves her self-esteem. From the insights captured within Patricia's cultural probes, her engagement in regular exercise facilitated a feeling of accomplishment and sense of personal dignity. As shown within one of Patricia 's ThinkPad entries (Figure 62), and reflected within many more, attending virtual exercise classes is something she very much looks forward to and an experience generating meaning for her.

Never be afraid to sit a while and think

Date: 27/7/....

A memory.......
Cooler weather which helps a lot.

How was your day today?
Good

A conversation I had today.....
General chat with friends at a Knitting group. Enjoyable.

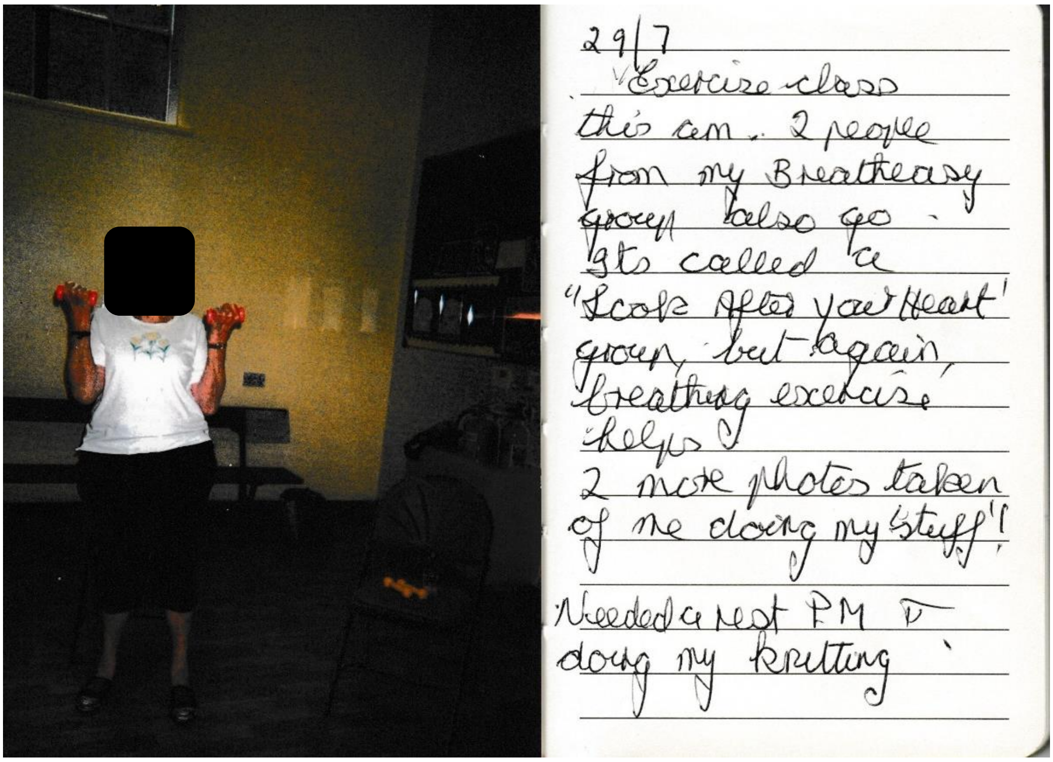
Today's Appointments:
Knit group at friends today. Next week at my house. All very informal

A thought about tomorrow:
Virtual exercise class. Look forward to this.

MEANINGFULNESS IN DAILY LIFE WHEN LIVING WITH COPD STUDY

Figure 62 - Patricia – Thinkpad – 27th July 2021

This was further evident within Patricia's journal entry and photograph (Figure 63), demonstrating how undertaking exercise within the limitations of her condition improves how she feels. Whilst undertaking exercise can at times be challenging, taking control of the activity she participates in within her day-to-day life allowed Patricia to maintain her own personal dignity, generating subsequent autonomy and facilitating the presence of meaningfulness.



[redacted]

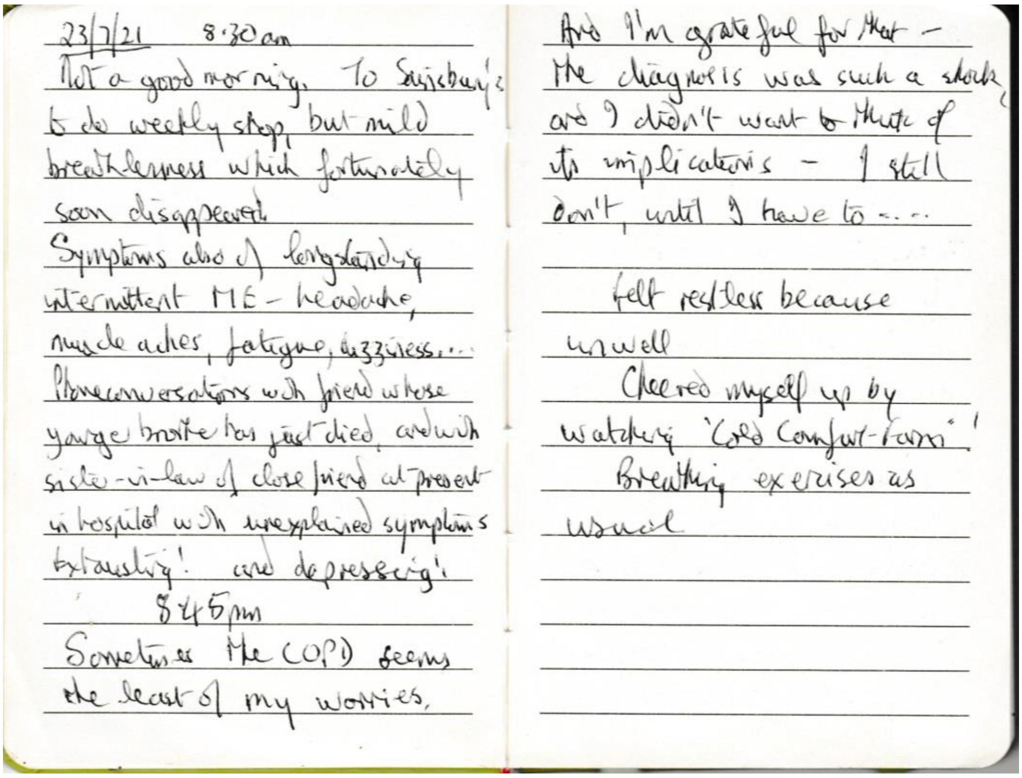
29/7
Exercise class
this am. 2 people
from my Breatheasy
group also go.
Its called a
"Look After your Heart'
group, but again,
'breathing exercise'
helps
2 more photos taken
of me doing my 'stuff'!

Needed a rest PM
doing my knitting

Figure 63 - Patricia – Photograph and Journal Entry – 29th July 2021

Geraldine

Asserting control over elements of her day-to-day life to maintain her own personal dignity was an evident method allowing Geraldine to identify the presence of meaningfulness. Geraldine was aware of the health benefits of breathing exercises to manage the associated breathlessness when living with COPD, and technologies how she undertook these '*as usual*' within her journal (Figure 64).



23/7/21 8.30am
Not a good morning. To Sainsbury's
to do weekly shop, but mild
breathlessness which fortunately
soon disappeared.
Symptoms also of longstanding
intermittent ME – headache,
muscle aches, fatigue, dizziness...
Phone conversations with friend whose
younger brother has just died, and with
sister-in-law of close friend at present
in hospital with unexplained symptoms
Exhausting! and depressing!
8.45pm
Sometimes the COPD seems
the least of my worries.

And I'm grateful for that –
the diagnosis was such a shock
and I didn't want to think of
its implications – I still
don't, until I have to....

Felt restless because
unwell
Cheered myself up by
watching 'Cold Comfort Farm'!
Breathing exercises as
usual

K

Figure 64 - Geraldine – Journal – 23rd July 2021

Undertaking breathing exercises was a choice made by Geraldine towards a dignified approach to self-care when living with COPD. This allowed her to align her response to the physical limitations imposed by the condition to her personal values of enhancing her physical well-being and self-esteem. Feeling in control of her day-to-day life facilitated a meaningful existence for Geraldine.

As shown by five of the participants within this study, asserting and maintaining control in life is integral to taking control of one's own personal dignity, and the presence of meaning in day-to-day life. Taking control signified an active engagement with life, whereby participants made deliberate choices regarding the activities they undertook. This intentional approach encouraged autonomy, allowing them to shape their lives in accordance with their preferences and values. Through this autonomy, the participants within this study asserted their ability to make choices, reinforcing a sense of self-determination that is fundamental to taking control of one's own personal dignity.

7.3 – Acceptance of new limitations

Within this study, five participants revealed they were able to take control of their own dignity through acceptance of the new limitations imposed when living with palliative care needs arising from COPD. The development of personal resilience, facilitating empowerment over making decisions within their day-to-day lives to maintain their dignity underpinned this, alongside them being able to identify themselves as a person of value. This involved accepting and adapting to imposed physical limitations, taking an active role in the self-management of their condition, demonstrating personal resilience. Furthermore, acceptance of the need to rest and recover, whilst still living a fulfilling life, allowed them to identify meaningful experiences within their physical capabilities. Taking an active role within the self-management of COPD enabled participants to make autonomous decisions upon symptom management, generating a sense of being in control of their own life through choices to maintain their personal dignity.

Stephen

Stephen spoke openly about his acceptance of the limitations imposed when living with the significant symptom burden from COPD, as shown within narrative structure four. Through Stephen having '*regulated*' his life accordingly and attempting to overcome the physical limitations of living with COPD, he demonstrated resilience through his ability to adapt and maintain a sense of well-being whilst facing such adversity. He chose to purchase a mobility scooter to mediate the impact of breathlessness upon exertion, and in turn took control of the impact of this symptom upon his day-to-day life, a choice to maintain his personal dignity. As a result, he enjoys using the scooter to facilitate daily trips out of his home.

Stephen – Narrative Structure 4

LB - *Yeah and erm, so since then really, do you feel that your life has been consistent and steady or do you feel that it's been very different to how it was before?*

Stephen - *Well its it's different to how it was before obviously but (.) having accepted the situation, the condition that I'm in (.h) I've regulated my life accordingly (.) I know there are certain things I can and can't do. Erm, for example Louise (.h) just just to get back to the scooter deal (.h)*

LB - *yeah*

Stephen - *I go into the garden shed, I undo the door I sit on the scooter (.h) I get it on my drive by which time I have started to breathe a little bit heavily. But I then sit and within second__ within minutes say (.h) I'm breathing quite normally because I'm sat on the scooter totally relaxed*

LB – *mmm*

Stephen - *Then I got to Hilltop to catch the bus and that's when I have my first problem so to speakI have to manoeuvre this scooter into a certain position and (.h) despite having two hours tuition last Sunday morning from a driver (.h) I'm struggling it it it's a bit of a nightmare for me at the moment*

LB – *Yeah*

Stephen - *I know that eventually I will get used to it but because I'm (.h) struggling its its its its causing me to breathe a bit more heavily you know*

LB - *Yes Yeah*

Stephen - *But again once I get into position er and settle down er within seconds well a minute I say (.h) I'm breathing normally again you know.*

Stephen also spoke of how the acceptance of his physical limitations, and the implementation of ways to overcome these, alleviates frustrations within his day-to-day life as shown in narrative structure fifteen. Actively deciding to no longer face difficulties when going upstairs in his home due to the installation of a stairlift allowed Stephen to take control of his own dignity, as being able to sleep upstairs in his bedroom was of importance to him.

Stephen – Narrative Structure 15

Stephen *- Well that's that is a point yeah I mean I went to a before I had a stairlift installed incidentally (.h) I could remember one particular week (.) two nights in succession I couldn't make it I couldn't make it to bed I just didn't I don't mean just physically intellectually I couldn't bring myself to go upstairs to bed (.h)*

LB *-No*

Stephen *-Er but then (.h) erm the irony is Louise once I has the stairlift installed I thought to myself (.h) you fool you should have had this installed two years ago*

LB *– Ha*

Stephen *- You know I did and er incidentally similarly with the scooter (.) you know (.h) but er the the stairlift has made a has impacted on my life for the better*

LB *-Yeah*

Stephen *- Erm sort of that was one of the sort of frustrating things that you've asked me to explain but as I said that was eliminated by the stairlift*

Stephen continues to take control of his own dignity through active decision making in the self-management of living with palliative care needs arising from COPD. As shown within narrative structure thirteen, Stephen uses oxygen therapy at home when needed. Stephen speaks of how the availability of oxygen, to use when he feels breathless facilitates a feeling of '*confidence*'. The adversity experienced during an episode of breathlessness presented uncertainty and challenge. Deciding to use the oxygen when needed gives Stephen an opportunity to take control of his personal dignity, through the opportunity to make autonomous decisions upon the management of his health and symptoms.

Stephen – Narrative Structure 13

Stephen *- But they did er I've got I've got two oxygen cylinders here supplied by (.h) the NHS well BOC by the NHS (.h) so as soon as one's empty I ring em up and it's replaced*

LB *- Oh good*

Stephen *- Yeah (.) you see its one of those little things that gives me a little bit of confidence you know*

LB *- Ok (.) so it makes you feel more confident having it?*

Stephen *- It does make me feel more confident that (.h) if I ever got to to a stage when I was really gasping for breath as distinct from struggling a little bit (.h) I know that I've got the oxygen there to help*

LB *-Yes (.) yes*

Stephen *- Oh yes it's a confidence booster*

Stephen has accepted that he will no longer be able to undertake some activities within his life that he would like to because of the associated symptoms of living with COPD, such as visiting friends in another country. As shown within narrative structure 21, Stephen describes how accepting that this is not possible allows it to become '*less frustrating*'.

Stephen – Narrative Structure 21

Stephen - *(.h) and quite a few of them which at least half a dozen Louise (.) I'm not exaggerating here (.h) at least half a dozen have said for god sake can't you get on an aeroplane and come across (.h) and come and see us we'll put you up we'll do this we'll do that and the other you know(.h) and I would like to think I could do that I would do that but I know I can't and wont*

LB – *Yeah*

Stephen - *Although they say they say there is no such thing as £never you know£ (.) but that's the sort of frustrating things (.h) for me*

LB – *Yeah*

Stephen - *But it becomes less frustrating when I realise that I can't do it anyway so you know (.h) yeah*

This reflection of his realistic self-perception allows Stephen to focus upon what is realistically achievable within his day-to-day-life. Acknowledging and accepting the limitations imposed by living with palliative care needs arising from COPD has allowed Stephen to redirect his efforts and energy towards goals and activities in day-to-day life that are achievable.

Sally

Sally has chosen to take control of her personal dignity through the adjustment of her expectations, allowing her to find alternative ways to meet her life goals. She actively participates within the self-management of her COPD, and views exercise within the limitations of her symptoms an effective strategy. She speaks within narrative structure sixteen upon her enjoyment of dancing lessons online, suitable for those living with the condition. Dancing is a hobby Sally has enjoyed throughout her lifetime. Through acceptance of the limitations imposed when living with the condition, Sally has identified a way to maintain participation in an adapted format of dancing, facilitating personal fulfilment. This contributes to positive self-perception and emotional well-being for Sally, allowing her to be in control of her personal dignity.

Sally – Narrative Structure 16

Sally – *All the clubs used to have a dance floor and what have you. Um. And… Well, it's just as a life progresses somethings go out of the way, but I still love dancing.*

LB - *Yeah. Yeah.*

Sally – *Um. And that - and that's when - when it is up again and running, dancing for health, because that's ballroom dancing as well.*

LB - *Right. Okay.*

Sally – *So that's great, yeah.*

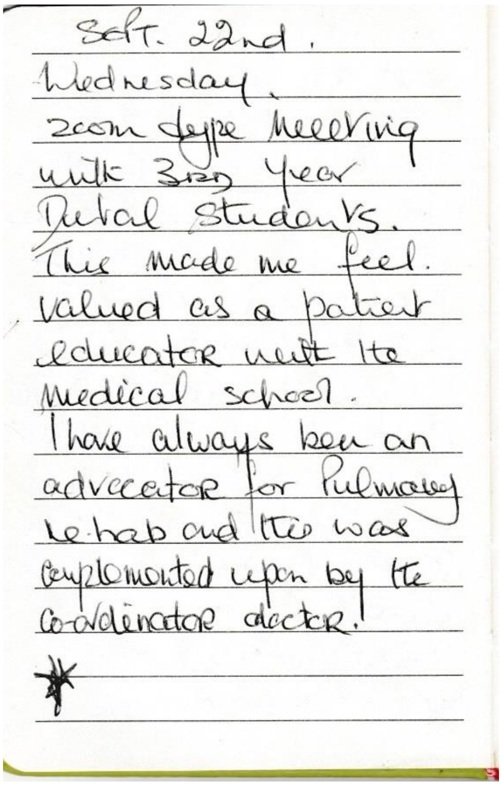
LB -*Yeah.*

Sally - *It's the same lady that does the seated dancing.*

LB - *Ah, brilliant.*

Sally - *Yeah. So, it - it's like, you know, that's how we first came into it.*

Acceptance of having COPD and the associated symptom burden has enabled Sally to become a patient educator at a local university. As shown within figure 65, this enables her to be a person of value. By becoming a patient educator, Sally has been able to take control of her personal dignity through becoming an advocate for her own health. As shown, she writes of how supporting pulmonary rehabilitation for those living with COPD was '*complimented upon'* by the doctor co-ordinating the session she attended. This role allowed Sally to voice her needs as someone living with COPD, assert her opinion and experiences, fostering a greater sense of personal dignity. This active engagement allows Sally to feel empowered through the sharing of her knowledge, facilitating feelings of purpose and value and associated meaning within day-to-day life.

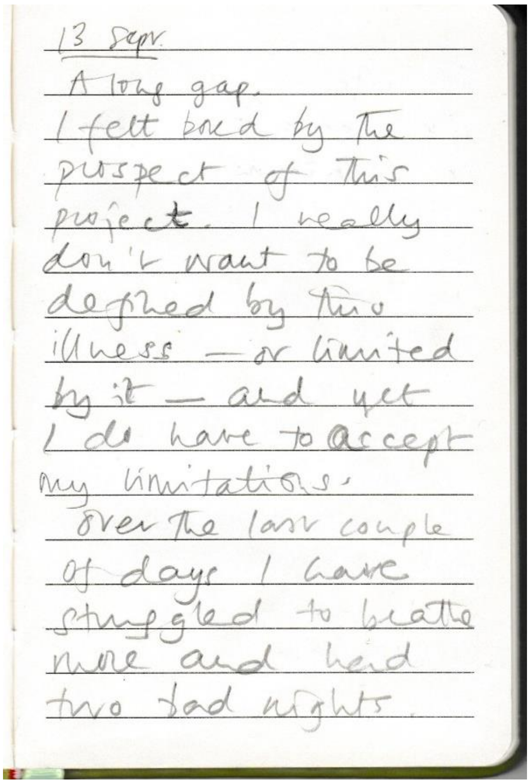


Sept. 22nd.
Wednesday.
zoom type meeting
with 3rd year
Dental students.
This made me feel.
valued as a patient
educator with the
medical school.
I have always been an
advocator for Pulmonary
re-hab and this was
complimented upon by the
co-ordinator doctor!

Figure 65 - Sally – Journal Entry – 22nd September 2021

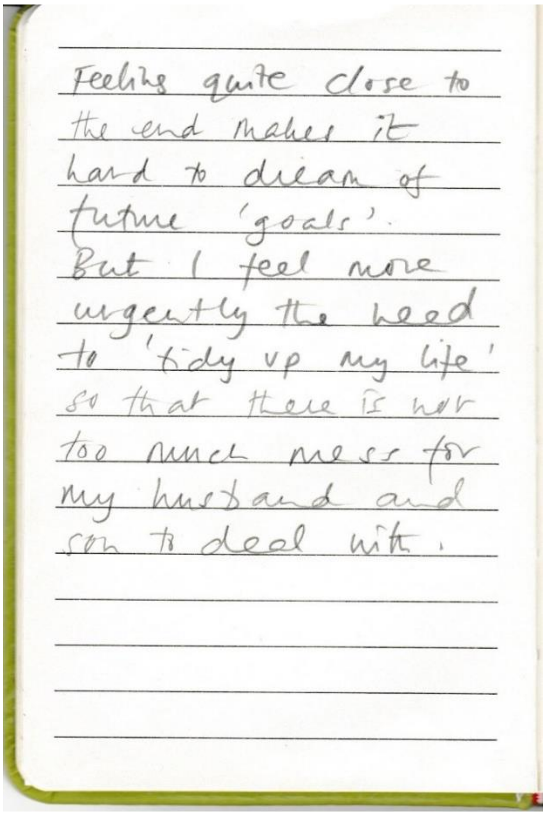
Karen

From her contributions to the study, Karen revealed that she is earlier in her journey of disease acceptance than other participants. As shown within Figure 66, Karen writes of how she does not want to be defined by her condition, nor limited by the imposed symptoms. Alongside this, this journal entry revealed how participation within this study had focussed her attention upon the limitations imposed by living with COPD, with acknowledgement given to how she '*needs to accept'* them. This unique insight into the beginning of an acceptance process of the imposed limitations when living with COPD was further embellished as she wrote of needing to '*tidy up her life'* due to believing she is nearing the end of her life (figure 67).



13 Sept.
A long gap.
I felt bored by the
prospect of this
project. I really
don't want to be
defined by this
illness — or limited
by it — and yet
I do have to accept
my limitations.
Over the last couple
of days I have
struggled to breathe
more and had
two bad nights.

Figure 66 - Karen – Journal Entry – 13th September 2021



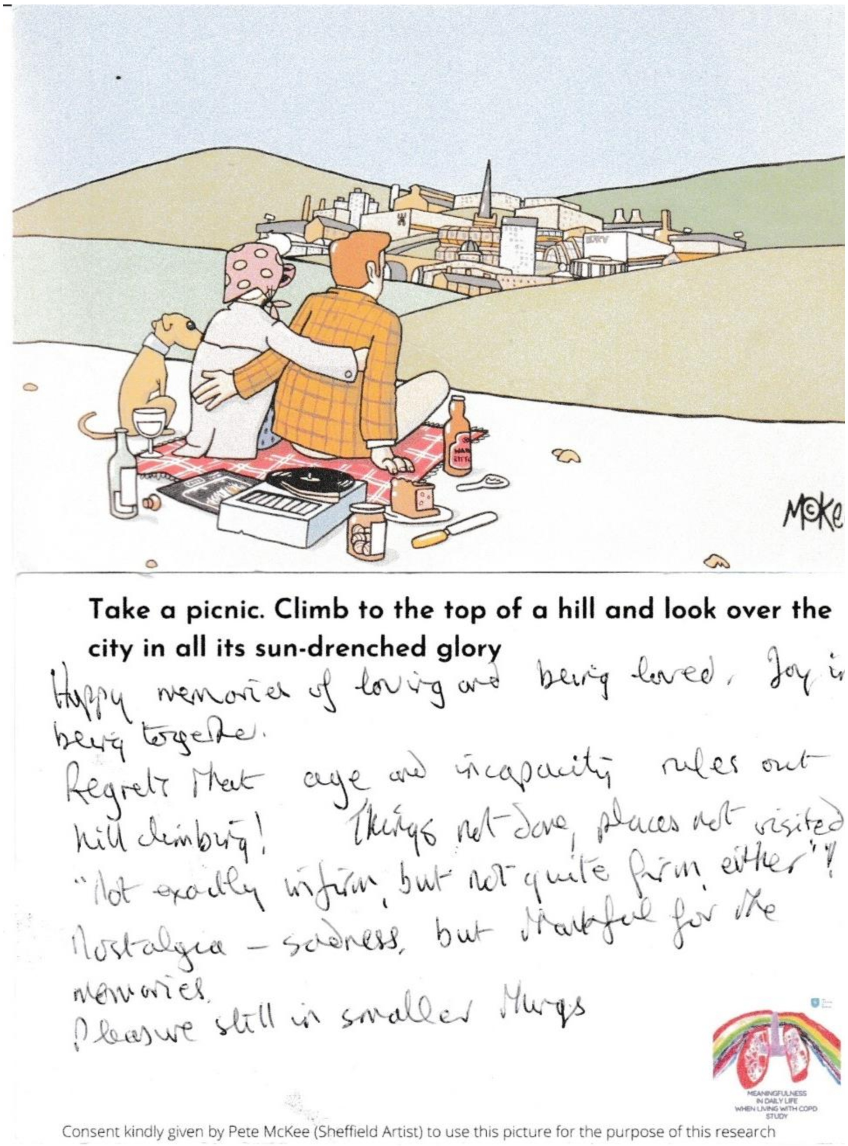
Feeling quite close to
the end makes it
hard to dream of
future 'goals'.
But I feel more
urgently the need
to 'tidy up my life'
so that there is not
too much mess for
my husband and
son to deal with.

Figure 67 - Karen – Journal Entry – 4th November 2021

This is evidently a profound and challenging process for Karen, however beginning to make autonomous life choices, such as beginning to accept the limitations imposed by COPD is representative of her beginning to take control of her own dignity.

Geraldine

A reflection written upon one of the cultural probe postcards (Figure 68), revealed how Geraldine has taken control of her own personal dignity through being able to identify '*pleasure still in smaller things*'.



Take a picnic. Climb to the top of a hill and look over the city in all its sun-drenched glory

Happy memories of loving and being loved. Joy in
being together.
Regrets that age and incapacity rules out
hill climbing! Things not done, places not visited
"Not exactly infirm, but not quite firm either"!
Nostalgia – sadness, but thankful for the
memories.
Pleasure still in smaller things

MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

Consent kindly given by Pete McKee (Sheffield Artist) to use this picture for the purpose of this research

Figure 68 - Geraldine – Postcard

This reflection demonstrates how Geraldine has accepted the imposed limitations of living with palliative care needs arising from COPD, and how finding pleasure in the smaller things is a way of fostering a positive and meaningful approach to day-to-day life for her, contributing to a sense of well-being and self-respect.

Another way in which Geraldine takes control of her personal dignity is through her role as a patient educator at her local university, as shown within narrative structure fifteen. Engagement within this role allows her to share her knowledge of living with COPD, generating feelings of purposefulness. This allows Geraldine to take control of her personal dignity through identifying as a person of value.

Geraldine – Narrative Structure 15

Geraldine – *Well I think this relates to your last question (.h) if it's been useful, there's been a purpose if you see what I mean*

LB - *Yes*

Geraldine – *You know and I I can I can give myself several strokes for that*

LB - *Yes you can (laughing)*

Geraldine – *Which I do (laughing) if that's alright, you know you're the vector for that if you like (.h) erm so it works both ways Louise that's the thing (.h) that's what I said to the patients as woman initially (.h) that erm you know that the students they mustn't think it was all one way that erm we do get do feel useful as a result of taking part*

7.4 – Chapter Summary

This chapter has revealed how five of the six participants within this study have identified the **presence of meaningfulness** within day-to-day life through **taking control of their personal dignity**. For one participant, Craig, this was not evident. He revealed feelings upon how living with COPD has inhibited his ability to plan and reach personal goals, which is further explored within Chapter eight of this thesis.

Underpinning the ability to take control of their personal dignity was **asserting and maintaining control over life choices**. This was achieved through realistic and achievable goal setting within the limitations of living with palliative care needs arising from COPD. Participants set individualised goals of importance to them, to facilitate living a dignified life with fulfilment and meaning.

Accepting the limitations imposed from living with palliative care needs arising from COPD enhanced each participants ability to meet the goals set, again enabling them to take control of their personal dignity. Participants embraced the need for changes to both physical and emotional limitations imposed by the condition, and actively participated in making the required adjustments in day-to-day life to accommodate this. This enabled participants to feel in control of making dignified adaptations acceptable to them.

The next chapter (chapter eight), presents how participants revealed an interruption in identifying meaning within day to day life through personal value incongruence.

Chapter 8.0 – Barriers to identifying life meaning through Personal Value Incongruence

8.1 – Introduction

This chapter presents how participants within this study experienced barriers to identifying meaning withing day-to-day life when living with COPD, resulting in personal value incongruence. As shown within figure 69, the barriers to identifying meaning were due to the presence of future worries and a sense of a loss of control.

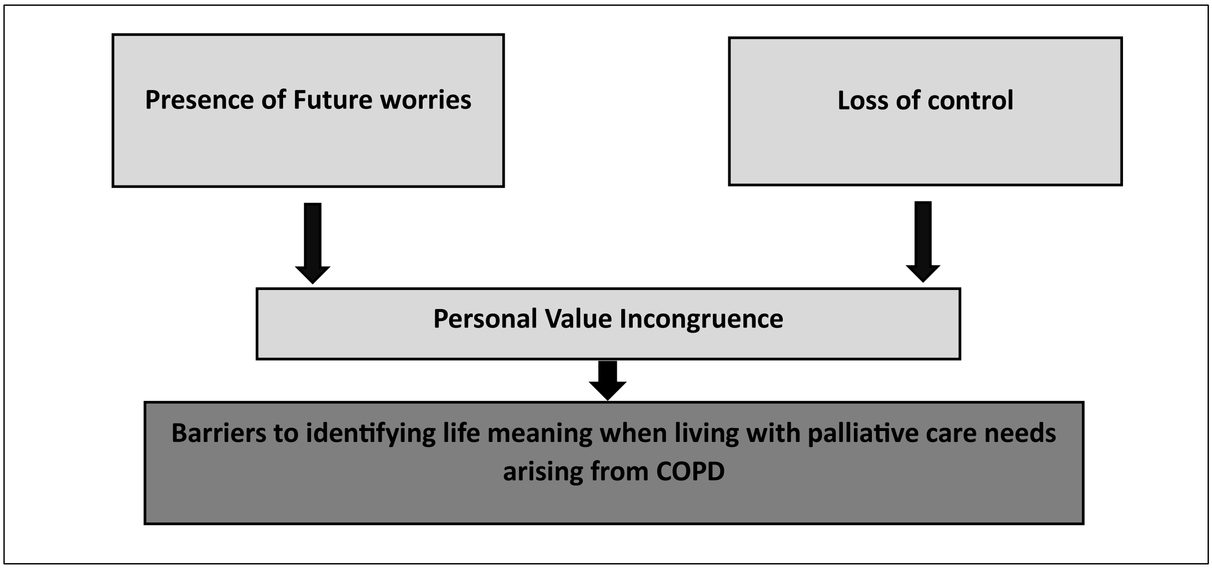


Figure 69 - Barriers to identifying life meaning through Personal Value Incongruence

Personal value incongruence, the misalignment between an individual's values and the actions they are able to take in life, can have a number of negative effects on a person's well-being and overall life satisfaction (Chochinov *et al.*, 2011). For those experiencing the inability to meet their personal values, due to limitations of living with a chronic condition, this can lead to internal conflicts and a sense of inner turmoil (Chochinov *et al.*, 2002). When individuals are forced to act in ways that contradict their deeply held values, psychological disharmony, causing stress and discomfort may manifest (Chochinov *et al.*, 2002) . Furthermore, those experiencing value incongruence may feel a lack of direction or purpose in life. Without a clear alignment between values and actions, it can be difficult to set meaningful goals and pursue a fulfilling path. When personal values are not considered in decision-making, individuals may find it challenging to make choices that are truly satisfying (Chochinov, 2002), evident for those within this study.

8.2 – Presence of Future Worries

The presence of future worries generated because of living with palliative care needs arising from COPD and the associated physical and emotional impact was revealed by four of the participants within this study. These future worries interrupted participants ability to identify meaning within day-to-day life.

Stephen

Stephen did not reveal the presence of future worries within day-to-day life throughout his cultural probe entries and narrative interview. When asked about concerns he may have for the future, he responded by explaining how he has *'no reason to be morose'*. He went on to explain how, as shown within narrative structure sixteen, he understands that for some people '*it would be quite easy to descend into a slower despondency'*.

Narrative Structure 16 – Stephen

LB – *Yeah, you seem to have a very positive mindset*

Stephen - *Well if I may be be honest one or two people have erm commented on that (.h) but I I just don't see any other way to do it t:to survive (.h) I I mean er I I should imagine for some people it would be quite easy (.h) to descend into a slower despondency but (.h) I I I've never been like that for me (.h)*
Stephen ended this element of his narrative interview stating '*I just want to go on as long as possible. I'm enjoying life despite the restrictions and limitations of COPD. I'm enjoying life'*.

From exploring day-to-day life with Craig throughout his cultural probes and narrative interviews, he chose not to reveal the presence of any future worries related to living with palliative care needs arising from COPD. Craig focussed upon the immediate impact of living with the condition and from his narrative interview, it was evident he did not wish to discuss how he saw his future living with the condition (Narrative Structure 6). From this interaction, the decision was made by the researcher to cease exploring this topic to respect Craig's wishes. Craig did however reveal the difficulties he faced in day-to-day life to meet his personal values. The presence of future worries led to feelings of frustration, discomfort and difficulty in identifying future goals and making future plans for other participants. In turn, this prevented them from identifying ways to meet their personal values and for some, interrupted the presence of meaning within day-to-day life.

Narrative Structure 6 - Craig

LB – *Yes. Do you think about what life will be like over the next few years Craig? Just with you saying about how you used to be able to play bowls and now you can't*

Craig – *No duck (.h) no point. Can't do anything I want to now (.h) not even go round Morrisons with the wife*

LB – *Ok*

Craig – *No (.h) (silence)*

Sally

Sally revealed within narrative structure thirteen, how her most significant cause of worry for the future is the prevention of being able to care for her husband should he need it, due to the imposed limitations of living with COPD.

Narrative Structure 13 – Sally

LB - *The last thing I wanted to - to explore with you, really, was if you had any concerns about your future, particularly when thinking about living with COPD. Is there anything that's particularly worrying you or…?*

Sally - *Oh, I'll be honest. I - I don't like the idea of dying.*
LB *- No. No.*

Sally - *Um. Although I've seen death probably more than - Like yourself, a lot of people have (.h)*

LB - *Yeah.*

Sally *- Um. Again - Again, it's the fear of the unknown because you get all these, uh, people saying, "Well, this will happen, that u'll happen." Who knows? They don't, they don't, do they. Um. And I know I would hate anything to happen to (Husbands name). And the only thing that, um, would upset me is if - if (Husbands name) was ill and I couldn't manage him physically because he's a big fella yeah? Uh. And - And that would grieve me.*

LB *- Yeah. Because you want - you'd want –*

Sally *- I'd still like to look after him. (Laughter)*

LB *- Of course, you would, of course you would.*

Sally – *Yeah*

LB *- Yeah.*

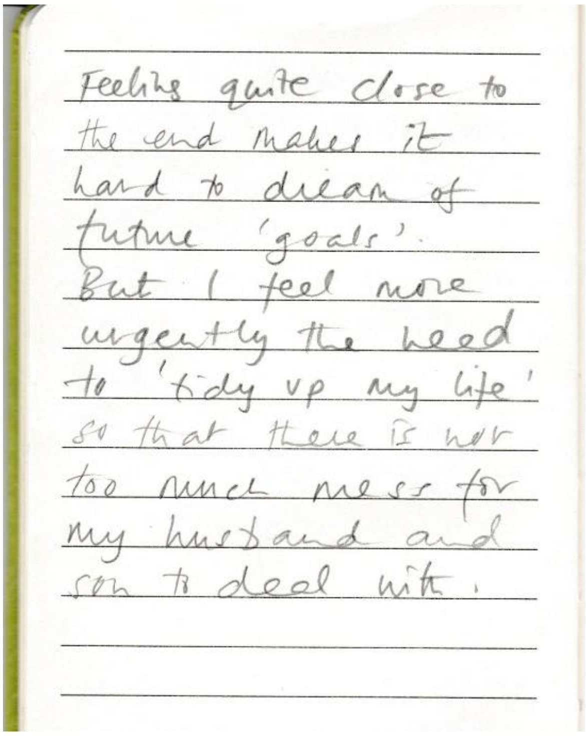
Sally *- Um. But I think we're going to have to just cross bridges as we come to them*

LB *- A good way to -*
Sally *- I don't think we can really plan. Um. Lit - You don't know what's around the corner. Nobody does, does he?*

Being able to care for her husband is of great importance to Sally, with caring for others being one of her personal values of importance. Sally is aware that as her COPD progresses, this may not be possible for her to achieve, interrupting her ability to identify how she will meet this personal value and the meaning crated from doing so. This example is underpinned by Sally's '*fear of the unknown'*, with her understanding of living with the unpredictable disease trajectory of COPD preventing her from planning for the future. This uncertainty holds the potential to impact upon Sally's ability to meet her personal values.

Karen

Karen shares insight into her future worries throughout her cultural probe entries and her narrative interview. She wrote of when living with COPD, it was difficult to dream of future goals (Figure 70), and of how this has exacerbated her need to make arrangements within her life so as not to be a burden upon her immediate family.



Feeling quite close to
the end makes it
hard to dream of
future 'goals'.
But I feel more
urgently the need
to 'tidy up my life'
so that there is not
too much mess for
my husband and
son to deal with.

Figure 70 - Karen – Journal Entry – 4th November 2021

This journal entry was further explored within Karen's narrative interview (Narrative structure ten), where she revealed how she was fearful to make future goals. The impact of this became evident as Karen revealed how one of her future goals was to apply for French nationality, with the intention of moving to live in France.

Narrative Structure 10 – Karen

LB *- Erm one other thing I'd like to sort of ask you about erm (.) within the journal .h you'd written something around feeling close to the end and its difficult to dream of future goals .h*

Karen *– Yes*

LB *- Is that something that consumes your thoughts a lot, or*

Karen - *Yes well it's all tied up with trying so much to live and how to make that work*

LB *– Yes*

Karen *- Erm well yes I did write that yes h well its got to be done*

LB *- Yes and so you find that you can't sort of make goals that you'd like to achieve for the future (.) is that what you were meaning in that statement?*

Karen *- I think you feel a bit fearful*

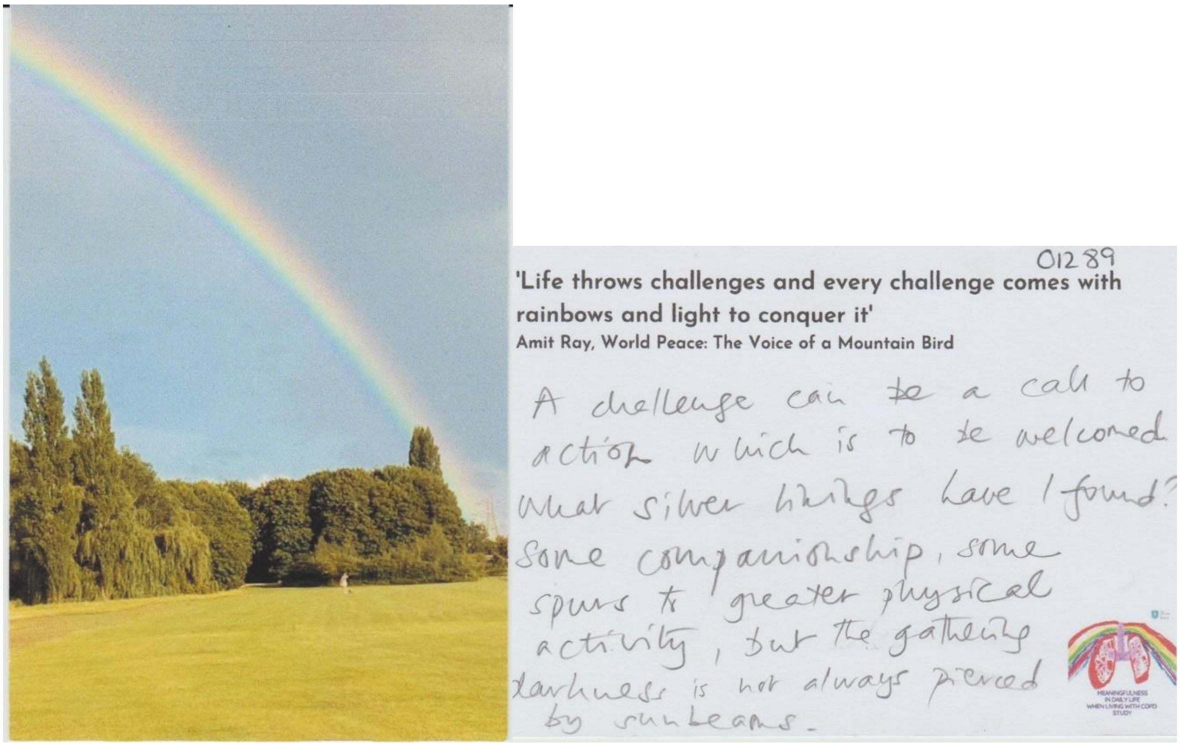
LB *– Yes*

Karen *- When you have got this condition*

LB *– Yes*

Karen *- Erm so I mean this year the big project was to apply for (.h) to get French nationality (.h) I have this week now got all of the papers together but the idea of doing it and going to live in France fills me with miserable fear now*

Due to the impact of living with COPD, the necessary involvement to achieve this goal is described by Karen as filling her with '*miserable fear*'. Karen acknowledges another limitation to being able to identify and meet future goals is the impact of COPD forcing her to try '*so much to live and how to make that work*'. The impact of the condition upon her ability to meet her personal values was poignantly recorded upon one of her cultural probe postcard entries (Figure 71).


01289

'Life throws challenges and every challenge comes with rainbows and light to conquer it'
Amit Ray, World Peace: The Voice of a Mountain Bird

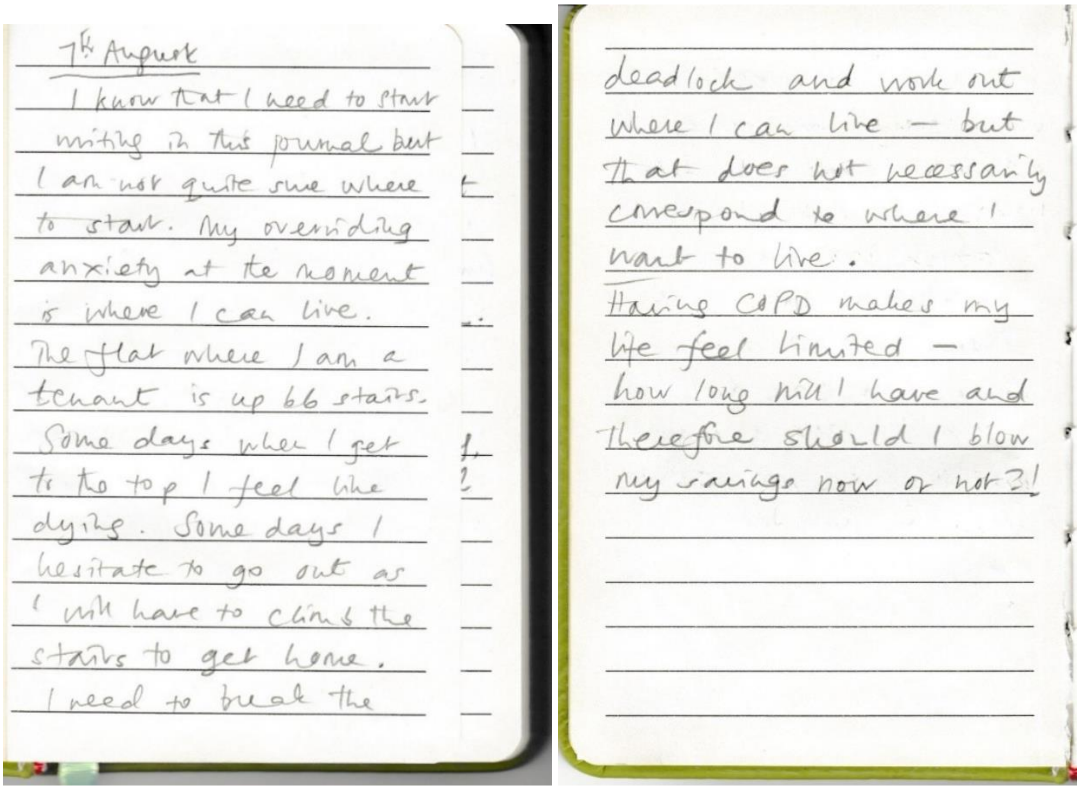
A challenge can be a call to action which is to be welcomed. What silver linings have I found? Some companionship, some spurs to greater physical activity, but the gathering darkness is not always pierced by sunbeams.

Figure 71 - Karen – Postcard

Karen's words '*but the gathering darkness is not always pierced by sunbeams'* reflects her thoughts upon the difficulties of identifying meaningful solutions to challenges faced. Whilst some challenging elements of day-to-day life impacted by COPD can be overcome by Karen, such as new ways to undertake physical activity and identifying the benefit of companionship, difficulty in overcoming all challenges is evident. This was further demonstrated when Karen revealed how due to the impact of living with COPD, her current housing circumstances were becoming unsuitable. Karen chose to photograph the sixty-six stairs she must climb to gain access to the flat in which she lives (Figure 72), as a representation of something causing her to worry.

Figure 72 - Karen – Photograph

The impact of this was further described within one of Karens journal entries (Figure 73). Karen describes the impact of this situation as an '*overriding anxiety'*, as some days when she has climbed the stairs, she '*feels like dying'*. She goes onto explain how this situation prevents her from going out due to the fear of facing climbing the stairs when she returns, describing how living with COPD makes her life feel '*limited*'.



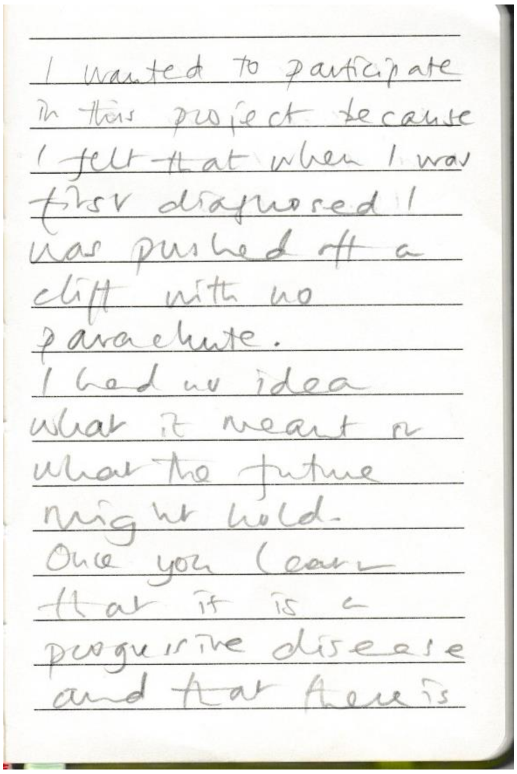
7th August

I know that I need to start
writing in this journal but
I am not quite sure where
to start. My overriding
anxiety at the moment
is where I can live.
The flat where I am a
tenant is up 66 stairs.
Some days when I get
to the top I feel like
dying. Some days I
hesitate to go out as
I will have to climb the
stairs to get home.
I need to break the

deadlock and work out
where I can live – but
that does not necessarily
correspond to where I
want to live.
Having COPD makes my
life feel limited –
how long will I have and
therefore should I blow
my savings now or not?!

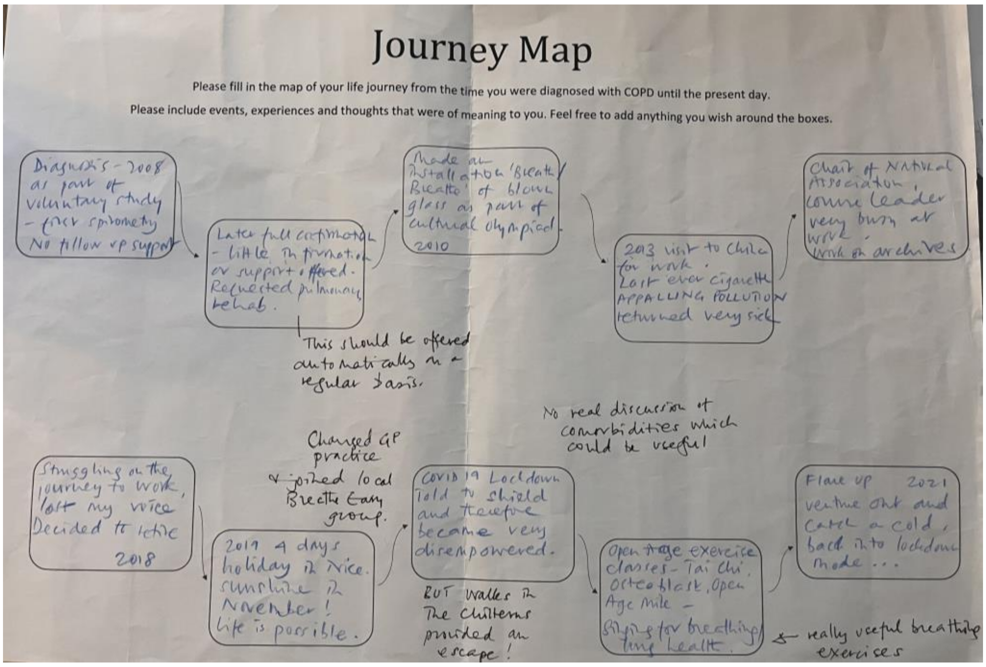
Figure 73 - Karen – Journal Entry – 7th August 2021

Within this journal entry, Karen also revealed that she wonders how long she will live for, and as such finds it difficult to make decisions upon future plans. This impact of the physical symptoms burden and uncertain future has been worrying for Karen from the point of diagnosis. As shown within figure 74, Karen identifies the need for '*help and support'* to navigate understanding how living with COPD will impact her life and allow future plans to be made. This was further reflected within her journey map (figure 74), particularly around the need for information upon living with the condition and its associated impact and what to expect within day-to-day life from the point of diagnosis and beyond.



I wanted to participate in this project because I felt that when I was first diagnosed I was pushed off a cliff with no parachute.
I had no idea what it meant or what the future might hold.
Once you learn that it is a progressive disease and that there is

Figure 74 - Karen – Journal Entry – 13th September 2021



Journey Map

Please fill in the map of your life journey from the time you were diagnosed with COPD until the present day.
Please include events, experiences and thoughts that were of meaning to you. Feel free to add anything you wish around the boxes.

Diagnosis - 2008 as part of voluntary study - free spirometry
No follow up support

Later full confirmation - little information or support offered.
Requested pulmonary rehab.

This should be offered automatically on a regular basis.

Made an installation 'Breath/Breatto' of blown glass as part of cultural olympiad.
2010

2013 visit to China for work.
Last ever cigarette
APPALLING POLLUTION
returned very sick

Chair of National Association, course leader
very busy at work.
Work on archives

No real discussion of comorbidities which could be useful

Struggling on the journey to work, lost my voice
Decided to retire
2018

Changed GP practice & joined local Breathe Easy group.

2019 4 days holiday in Nice.
sunshine in November!
Life is possible.

COVID 19 Lockdown
Told to shield and therefore became very disempowered.

BUT walks in The Chilterns provided an escape!

Open ~~Age~~ exercise classes - Tai Chi, Osteoblast, Open Age Mile -
Singing for breathing, lung health.

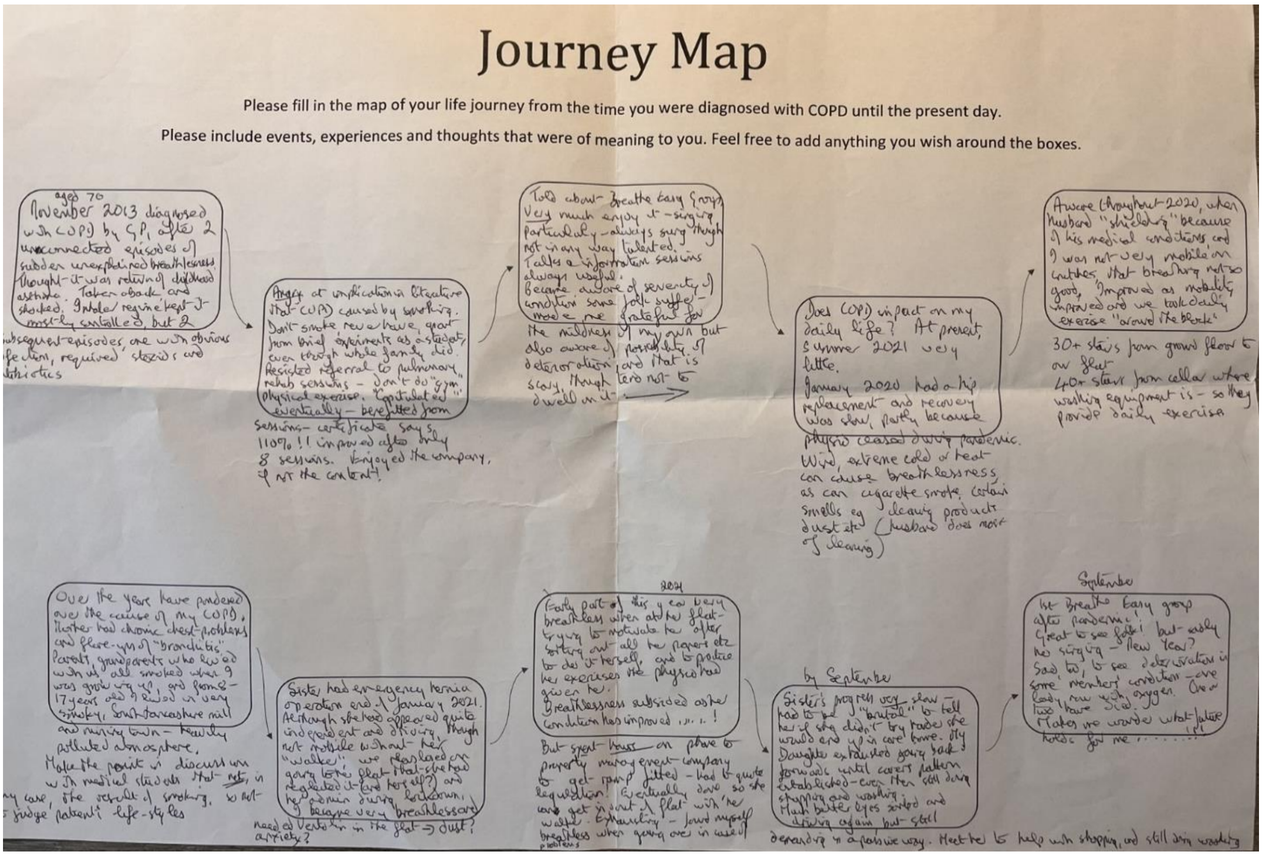
← really useful breathing exercises

Flare up 2021
venture out and catch a cold, back into lockdown mode . . .

Figure 75 - Karen – Journey Map

Geraldine

Geraldine identified the presence of future worries and its potential impact on personal value congruence when she reflected on her life since the point of COPD diagnosis via her journey map (figure 76).



Journey Map

Please fill in the map of your life journey from the time you were diagnosed with COPD until the present day.

Please include events, experiences and thoughts that were of meaning to you. Feel free to add anything you wish around the boxes.

aged 70
November 2013 diagnosed with COPD by GP, after 2 unconnected episodes of sudden unexplained breathlessness. Thought it was return of childhood asthma. Taken aback and shocked. Inhaler regime kept it mostly controlled, but 2 ubsequent episodes, one with obvious fection, required steroids and tibiotics

Angry at implication in literature that COPD caused by smoking. Don't smoke, never have, apart from brief experiments as a student, even though whole family did. Resisted referral to pulmonary rehab sessions – don't do "gym" physical exercise. "Capitulated" eventually – benefitted from sessions – certificate says 110%!! improved after only 8 sessions. Enjoyed the company, if not the content!

Told about Breathe Easy Group. Very much enjoy it – singing particularly – always sung though not in any way talented. Talks & information sessions always useful. Became aware of severity of condition some folk suffer – made me grateful for the mildness of my own but also aware of possibility of deterioration, and that is scary, though tend not to dwell on it →

Does COPD impact on my daily life? At present, summer 2021 very little. January 2020 had a hip replacement and recovery was slow, partly because physio ceased during pandemic. Wind, extreme cold or heat can cause breathlessness, as can cigarette smoke, certain smells eg cleaning products dust etc (husband does most of cleaning)

Aware throughout 2020, when husband "shielding" because of his medical conditions and I was not very mobile on crutches, that breathing not so good. Improved as mobility improved and we took daily exercise "around the block". 30+ stairs from ground floor to our flat 40+ stairs from cellar where washing equipment is – so they provide daily exercise

Over the years have pondered over the cause of my COPD. Mother had chronic chest problems and flare-ups of "bronchitis". Parents, grandparents who lived with us all smoked when I was growing up, and from 8-17 years old I lived in very smoky, South Lancashire mill and mining town – heavily polluted atmosphere. Make the point in discussion with medical students that not, in y case, the result of smoking, so not judge patients' life-styles

Sister had emergency hernia operation end of January 2021. Although she had appeared quite independent and driving, though not mobile without her "walker", we realised on going to the flat that she had neglected it (and herself?) and her admin during lockdown. I became very breathless and needed Ventolin in the flat → dust? anxiety?

2021
Early part of this year was very breathless when at her flat – trying to motivate her after sorting out all her papers etc to do it herself, and to practise her exercises the physio had given her. Breathlessness subsided as her condition has improved ....! But spent hours on phone to property management company to get ramp fitted – had to quote legislation! Eventually done so she can get in and out of flat with her walker. Exhausting – found myself breathless when going over in case of problems

by September
Sister's progress very slow – had to be "brutal" to tell her if she didn't try harder she would end up in care home. My Daughter exhausted going back & forwards until carers pattern established – even then still doing shopping and washing. Much better. Eyes sorted and driving again but still demanding in a passive way. Meet her to help with shopping, and still doing washing

September
1st Breathe Easy group after pandemic! Great to see folk! but sadly no singing – New Year? Sad, too, to see deterioration in some members' condition – one lady now with oxygen. One or two have died. Makes me wonder what future holds for me ....!!

Figure 76 - Geraldine – Journey Map

The last entry upon the journey map reveals how Geraldine has developed worries over what the future holds for her as a result of attending the BLF breathe easy support groups and seeing the deterioration and death of other attendees. This interesting reflection was further explored within Geraldine's narrative interview (narrative structure 6), where she revealed how seeing someone at the group using long term oxygen therapy forced her to consider the impact of the condition, and how it will affect her in the future.

Narrative Structure 6 - Geraldine

LB - *That was one thing that erm that I did pick up on actually in terms of erm sort of thinking about your future and any concerns you have about you future and one of the things (.h) you wrote was that you wonder what the future holds through seeing other people at the Breathe easy groups (.h) Does thinking about your future concern you at all, have you got any concerns about that?*

Geraldine - *Y-Yes (.h) I can't say its erm (.h) its never there it is (.h)*

LB – *Yeah*

Geraldine *- And particularly say se.. erm just last year we lost one of the particular (.h) people at Breathe Easy that I I was friends with he he was a lovely man his wife still comes which is nice or she did you know (laughing)*

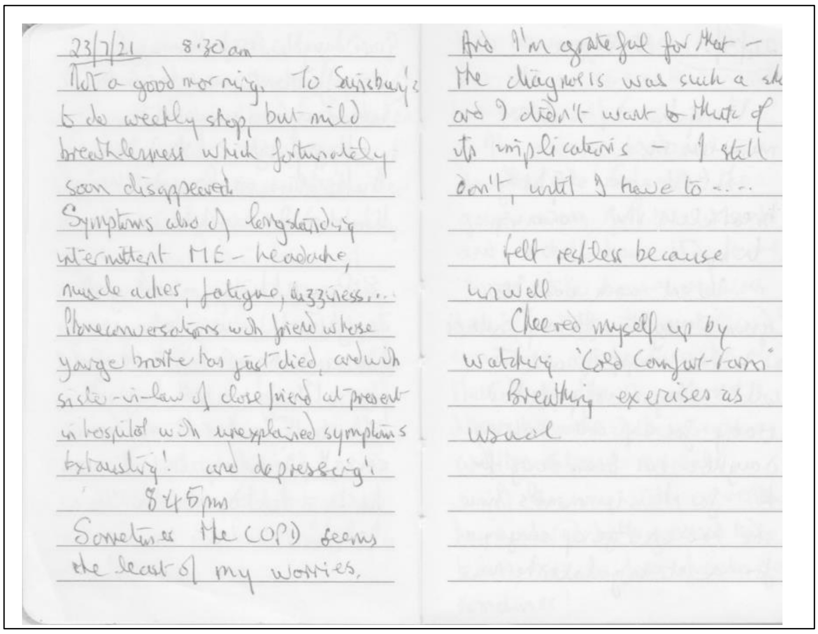
LB – *Yeah*

Geraldine *- Although (.h) we've been cancelled again this month because of Omnicron (.h) but erm he he was a lovely singer and that was one of the things that I erm that I enjoy about breathe easy of course we've not had that for the two years and that's obviously good isn't it for the breathing (.h)*

LB – *Yes*

Geraldine *- Erm but he used to come erm dragging his oxygen erm cylinder behind him (.h) and that sort of thing yes it did make me think you know I'm I'm aware that the it's it's a permanent condition (.h) its possibly erm degenerative (.h) erm it may be terminal but because it doesn't impede as much as it might do with some other people (.h) I can push it to the back of my mind.*

Whilst Geraldine is able to '*push it to the back*' of her mind at present, this suggests seeing others further on in disease progression has the potential to exacerbate future worries. The implications of living with COPD was further explored within Geraldine's journal. As shown within figure 77, she does not wish to think of the future impact of living with COPD until she is forced to do so, suggesting acknowledgement of the imposed limitations would facilitate future worries upon how to overcome them.



23/7/21 8.30am

Not a good morning. To Sainsbury's to do weekly shop, but mild breathlessness which fortunately soon disappeared.

Symptoms also of longstanding intermittent ME – headache, muscle aches, fatigue, dizziness...

Phone conversations with friend whose younger brother has just died, and with sister-in-law of close friend at present in hospital with unexplained symptoms exhausting! and depressing!

8.45pm

Sometimes the COPD seems the least of my worries.

And I'm grateful for that – the diagnosis was such a sh and I didn't want to think of its implications – I still don't, until I have to....

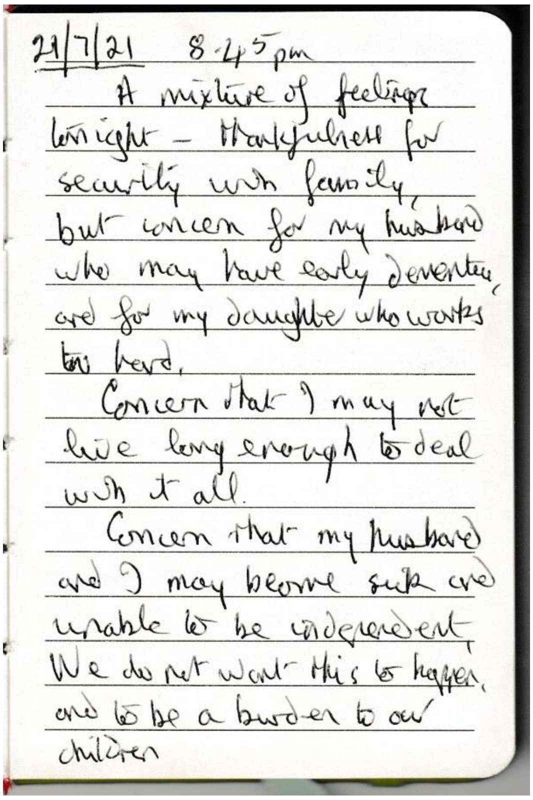
Felt restless because unwell

Cheered myself up by watching 'Cold Comfort Farm'

Breathing exercises as usual

Figure 77 - Geraldine – Journal – 23rd July 2021

Becoming a burden to others was a future worry documented by Geraldine within her journal (figure 78), via concerns around her ability to remain independent, a personal value of importance to her.



21/7/21 8.45pm

A mixture of feelings tonight – thankfulness for security with family, but concern for my husband who may have early dementia, and for my daughter who works too hard.

Concern that I may not live long enough to deal with it all.

Concern that my husband and I may become sick and unable to be independent. We do not want this to happen, and to be a burden to our children

Figure 78 - Geraldine – Journal – 21st July 2021

This was further explored within her narrative interview (Narrative structure 2), as she describes how becoming a burden is something both her and her husband '*very much want to avoid'*.

Narrative structure 2 - Geraldine

Geraldine - *Yes its interesting because when erm (.h) our daughter erm suggested that we joined forces and erm shared this house here in Sheffield (.h) erm I I mean I'd already been treated and survived breast cancer I mean that's probably in the stuff I gave you at some point (.h) and that was far more threatening I think life threatening (.h)*

LB – *Yeah*

Geraldine - *Erm obviously and erm (.h) really quite very scary at the time (.h) and I'm lucky its twenty years now and I'm still here (.h)*

LB – *Yeah*

Geraldine - *But it was erm my son said to (.h) she said afterwards my daughter (,h) she said afterwards that her brother had sad to her that er did she realise that that meant that when er (.h) or if erm my husband and I did become frail and er dependent that she'd have all the burden of it (.h) and it is something that we very much want to (.h) very much want to avoid*

Geraldine has a very positive relationship with her family and as previously presented within chapter six of this thesis, she believes she makes valuable contributions to the household she shares with them. Becoming a burden is a future worry for her as she does not wish to place any strain upon their relationship as it is of such importance to her. Furthermore, Geraldine meets her personal value of purposefulness through her contributions in the family home, something facilitating meaning within her day-to-day life. Should this not be possible in the future, this would interrupt the generation of meaningfulness within Geraldine's day-to-day life.

Patricia

A personal value of importance to Patricia is that of achievement. One of the ways Patricia has met this personal value throughout her life is working very hard to able to own her own home.

Within her narrative interview (narrative structure 13), Patricia voiced how a future worry she holds is that she would not be able to leave the property to her family, if her health deteriorated to such an extent that she needed to move to a care home.

Narrative Structure 13 – Patricia

LB - *do you erm if you're sort of thinking about (.h) your future [name] do you have any concerns or worries about that at all?*

Patricia - *I do h yeah .h erm (1) I've got power of attorney but equal (1) no decisions can be made without them discussing it and both agreeing .h*

LB – *Yeah*

Patricia - *The care home that I would like best .h both of my daughters said you've set up to be fine where you are on one level .h we can take it in turns to come .h there is plenty of room upstairs you know .h and we-we would much prefer you had a carer .h paid a carer to be coming into you if you'd prefer to stay at home so you're not going in a home (2) so I don't know if she'd be able to stick to that .h I said well I might have to if I get Alzheimer's I don't want to be walking about in the night in me nightie*

LB - *no-no*

Patricia - *she said if you were going to get Alzheimer's you'll have had it by now [laughing] .h I don't know whether that's true .h but (.) I hope that I would be able to just manage at home you see I'm on one level*

LB – *yes*

Patricia - *You know I've got the en-suite room .h and I needn't go upstairs at all .h and erm I could have carers but it depends on what condition I get into*

LB – *Yes*

Patricia - *and they can't forever be over here .h you know my son and daughter (.) so it depends .h it all depends*

LB – *Yeah*

Patricia - *the only thing I don't want to do is lose the house after all the things you pay you know*

LB – *yes*

Patricia *- but that's a worry with everybody .h I want the house to be divided .h between well between my family*

LB *– Yes*

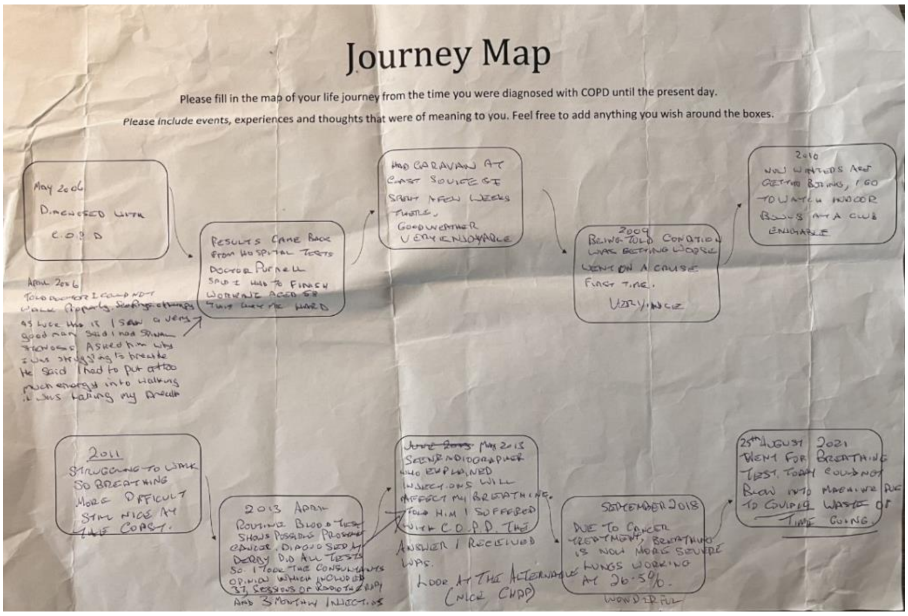
Patricia *- And I just want the .h I've worked so hard for it so I don't want to lose it*

Patricia wished for her family to benefit from the hard work she has undertaken, acknowledges this may not be possible due to the potential care needs and associated financial implications from living with COPD. This worry gave instability to Patricia meeting her personal values of responsibility and care, demonstrating her commitment to wanting to provide for her family when she is no longer present.

For four participants within this study, the presence of future worries has facilitated personal value incongruence, due to the acknowledgement that the limitations imposed due to living with COPD has or will prevent them from meeting their personal values. This has revealed barriers for these participants to be able to identify meaning in relation to these circumstances within day-to-day life. For one participant, Craig, this was not evident, yet a sense of a loss of control facilitated personal value incongruence, which will now be presented in section 8.3 of this thesis.

8.3 – Loss of Control

For one participant within this study, Craig, a sense of a loss of control facilitated personal value incongruence, and associated barriers in him identifying meaning within day-to-day life. This loss of control resulted in an overwhelming sense of a loss of personal autonomy, feelings of hopelessness and feeling judged by others. As shown upon Criag's journey map (figure 79), since his diagnosis of COPD in 2006, his symptom burden has significantly increased, and was further exacerbated by the treatment he received for prostate cancer. The physical symptom burden experienced by Craig was the most significant out of the participants within this study.



Journey Map

Please fill in the map of your life journey from the time you were diagnosed with COPD until the present day.

Please include events, experiences and thoughts that were of meaning to you. Feel free to add anything you wish around the boxes.

May 2006
DIAGNOSED WITH
C.O.P.D

April 2006
TOLD DOCTOR I COULD NOT
walk properly. Seeing a therapy
as luck has it I saw a very
good man said I had spinal
stenosis. Asked him why
I was struggling to breathe
He said I had to put a too
much energy into walking
it was taking my breath

RESULTS CAME BACK
FROM HOSPITAL TESTS
DOCTOR PURNELL
SAID I HAD TO FINISH
WORKING AGED 58
THIS HIT ME HARD

HAD CARAVAN AT
COAST [illegible]
SPENT A FEW WEEKS
THERE,
GOOD WEATHER
VERY ENJOYABLE

2009
BEING TOLD CONDITION
WAS GETTING WORSE
WENT ON A CRUISE
FIRST TIME.
VERY NICE

2010
NOW WINTERS ARE
GETTING BORING, I GO
TO WATCH INDOOR
BOWLS AT A CLUB
ENJOYABLE

2011
STRUGGLING TO WALK
SO BREATHING
MORE DIFFICULT
STILL NICE AT
THE COAST.

2013 APRIL
ROUTINE BLOOD TEST
SHOWS POSSIBLE PROSTATE
CANCER, DIAGNOSED BY
DERBY DID ALL TESTS
SO I TOOK THE CONSULTANTS
OPINION WHICH INCLUDED
37 SESSIONS OF RADIOTHERAPY
AND 3 MONTHLY INJECTIONS

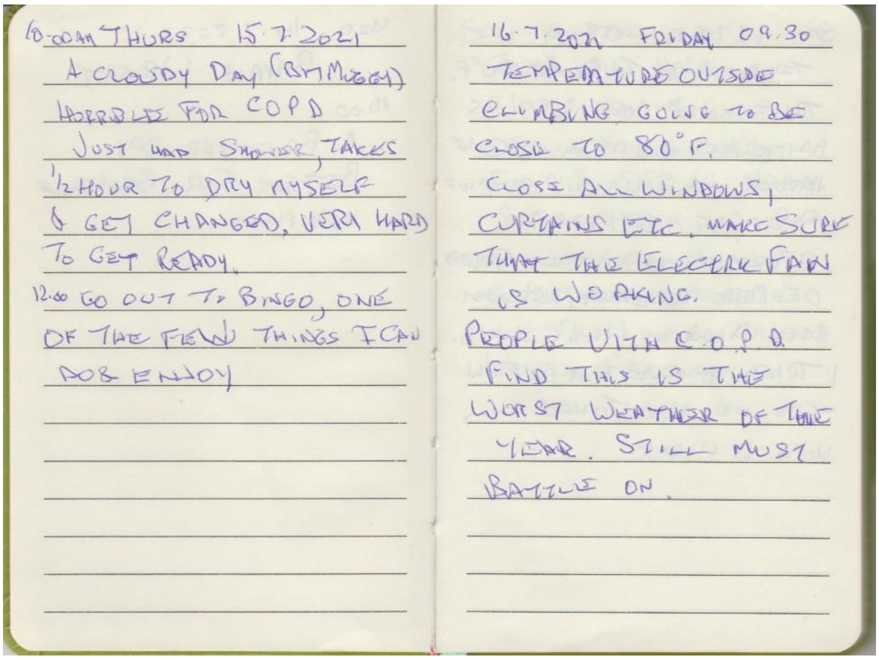
~~JUNE 2013~~ MAY 2015
SEEN RADIOGRAPHER
WHO EXPLAINED
INJECTIONS WILL
AFFECT MY BREATHING.
TOLD HIM I SUFFERED
WITH C.O.P.D. THE
ANSWER I RECEIVED
WAS.
LOOK AT THE ALTERNATIVE
(NICE CHAP)

SEPTEMBER 2018
DUE TO CANCER
TREATMENT, BREATHING
IS NOW MORE SEVERE
LUNGS WORKING
AT 26.5%.
WONDERFUL

25th AUGUST 2021
WENT FOR BREATHING
TEST. TODAY COULD NOT
BLOW INTO MACHINE DUE
TO COVID19 WASTE OF
TIME GOING.

Figure 79 - Journey Map – Craig

Within his cultural probe entries and his narrative interview, Craig revealed how external circumstances increasing the symptom burden associated with COPD led him to experience feelings of hopelessness within day-to-day life.



10-00AM THURS 15.7.2021
A CLOUDY DAY (BIT MUGGY)
HORRIBLE FOR COPD
JUST HAD SHOWER, TAKES
1/2 HOUR TO DRY MYSELF
& GET CHANGED, VERY HARD
TO GET READY.
12.00 GO OUT TO BINGO, ONE
OF THE FEW THINGS I CAN
ROB ENJOY

16.7.2021 FRIDAY 09.30
TEMPERATURE OUTSIDE
CLIMBING GOING TO BE
CLOSE TO 80°F.
CLOSE ALL WINDOWS,
CURTAINS ETC. MAKE SURE
THAT THE ELECTRIC FAN
IS WORKING.
PEOPLE WITH C.O.P.D
FIND THIS IS THE
WORST WEATHER OF THE
YEAR. STILL MUST
BATTLE ON.

Figure 80 - Journal Entry – Craig – 15th and 16th July 2021

As shown within figure 80, the weather dramatically affects Craig's COPD symptom burden, and this was a recurrent theme throughout his interactions with this study. Within his narrative interview, Craig revealed the impact this had upon his daily life (narrative structure 3), describing it as making his life '*miserable and impossible*'.

Narrative Structure 3 - Craig

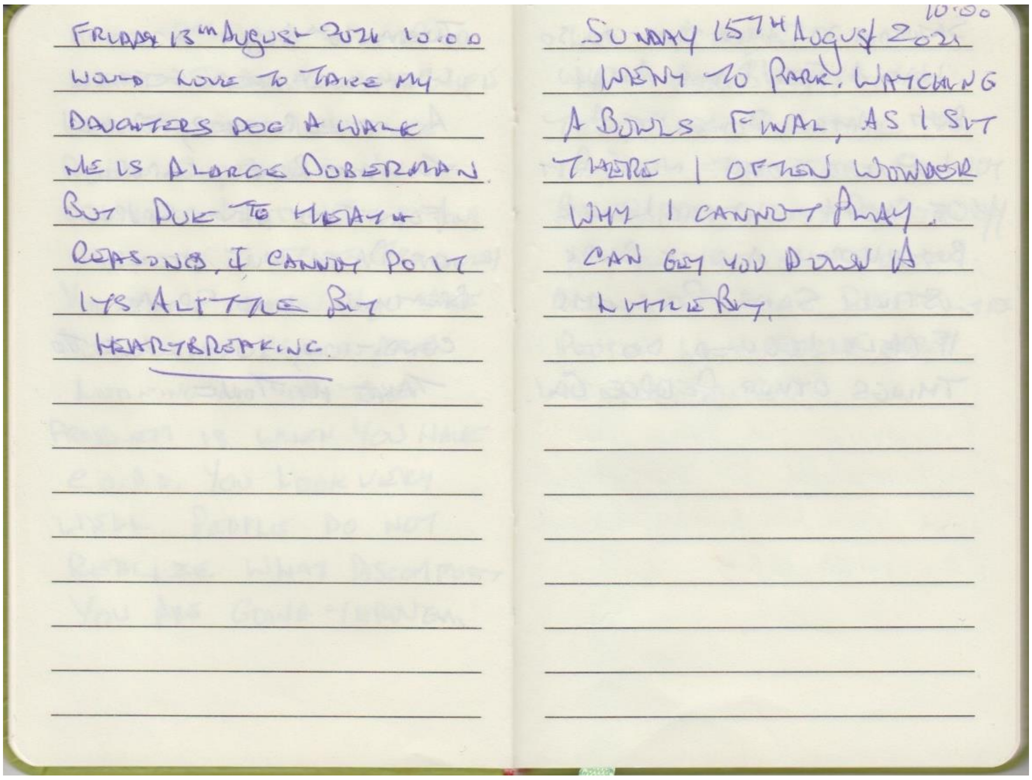
LB – *So, erm, you have written a lot about the weather affecting your breathing Craig in your journal. Is that something that really makes you struggle?*

Craig – *(.h) Yes duck (.h) like today, its muggy (.h) this is the worst for COPD muggy weather (.h) you can't do owt at all because you are fighting all the time (.h)*

LB – *Yeah*

Craig- *It makes my life miserable and impossible weather like this*

Further journal entries describe how his current COPD treatment appears less affective in such weather conditions, and he is forced to '*just struggle on*'. The absence of control and associated impact within day-to-day life was further revealed as Craig began to describe experiences within his life whereby the COPD symptom burden had prevented him from undertaking an activity he wished to. As shown within figure 81, Craig wrote of how he wished to be able to take his daughters dog for a walk. He did not believe this was possible due to his symptom burden, and as such described this as '*a little bit heartbreaking*'. Furthermore, he describes how now being unable to play bowls impacts his emotional state, again contributing to feelings of hopelessness due to a loss of control within day-to-day life.

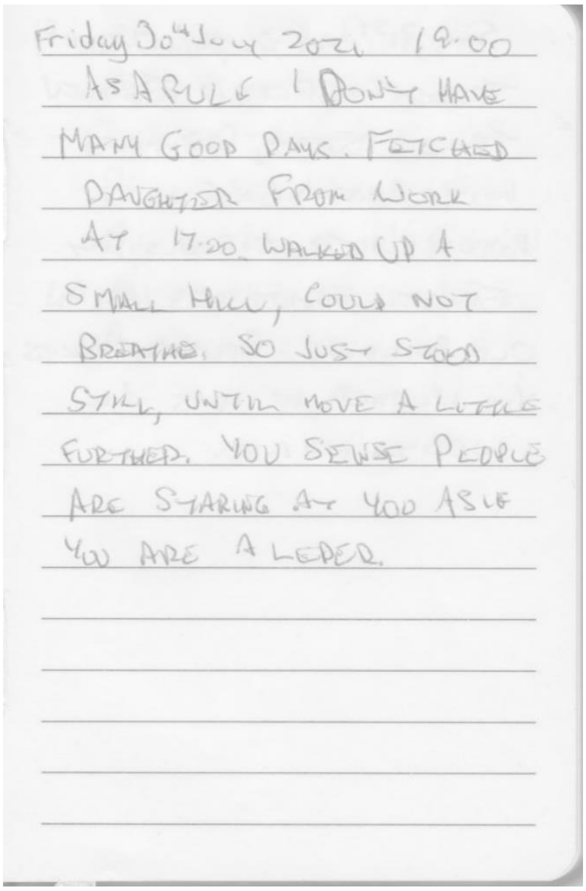


FRIDAY 13th AUGUST 2021 10.00
WOULD LOVE TO TAKE MY
DAUGHTERS DOG A WALK
HE IS A LARGE DOBERMAN
BUT DUE TO HEALTH
REASONS, I CANNOT DO IT
ITS A LITTLE BIT
HEARTBREAKING.

10.00
SUNDAY 15TH August 2021
WENT TO PARK, WATCHING
A BOWLS FINAL, AS I SIT
THERE I OFTEN WONDER
WHY I CANNOT PLAY.
CAN GET YOU DOWN A
LITTLE BIT.

Figure 81 - Craig – Journal entry – 13th and 15th August 2021

The impact of living with palliative care needs arising from COPD is impactfully described by Craig within a journal entry where he states '*as a rule, I don't have many good days*' (Figure 82). This statement reflects how the presence of a loss of control within his day-to-day life has presented barriers to identifying meaningful experiences he is able to identify with. This entry also reveals how he believes he is perceived by others, as when he was shopping with his daughter, he believed people were staring at him '*as if you are a leper'*. The impact of feeling judged by others contributes to a sense of a loss of control within day-to-day life for Craig.



Friday 30th July 2021 19.00
AS A RULE I DON'T HAVE
MANY GOOD DAYS. FETCHED
DAUGHTER FROM WORK
AT 17.20 WALKED UP A
SMALL HILL, COULD NOT
BREATHE. SO JUST STOOD
STILL, UNTIL MOVE A LITTLE
FURTHER. YOU SENSE PEOPLE
ARE STARING AT YOU AS IF
YOU ARE A LEPER.

Figure 82 - Craig – Journal Entry – 30th July 2021

8.4 – Chapter Summary

This chapter has presented how four of the six participants within this study have **experienced barriers to identifying the presence of meaningfulness** within day-to-day life as a result of the **associated COPD symptom burden preventing them from meeting their personal values**. Underpinning **this personal value incongruence** was the **presence of future worries** and a **sense of a loss of control** in day-to-day life.

The presence of future worries upon how living with COPD will progress throughout life led to discomfort and difficulty in making future plans. This **hindered participants from identifying ways to meet their personal values** in the future, identifying **barriers to the presence of meaning**.

For one participant, Craig, a sense of a loss of control over day-to-day life facilitated feelings of hopelessness, a loss of personal autonomy, and being judged by others. This resulted in him experiencing **personal value incongruence** and the presence of barriers to identify meaning within his day-to-day life.

The next chapter (chapter nine) explores the use of cultural probes as a research method in populations with palliative care needs. Its acceptability and usability are presented within the context of this study.

Chapter 9.0 – The use of Cultural Probes as a research method in populations with palliative care needs.

9.1 – Introduction

This chapter presents participants experiences of using cultural probes as a research method. The potential influence of the Hawthorne effect on cultural probe completion is then discussed. Consideration is then given to the use of cultural probes being a potential facilitator of meaningfulness. A reflective account by the researcher upon the insights gained into participants day-to-day lives and the usability of cultural probes as a research method is then presented.

9.2– Acceptability and usability of Cultural Probes by research participants

Each participant within this study was able to select which of the six cultural probes they were comfortable with using. Table 33 presents a summary of the cultural probes used by each participant.

Table 33 - Summary of used Cultural Probes by each participant

Total Number of Probes completed 25						
Narrative Interviews	**Postcards**	**Journal**	**Journey Map**	**Rosette**	**Camera**	**Think-pad**
Stephen	0	1	0	0	0	1
Craig	1	1	1	0	0	0
Patricia	1	1	0	1	1	1
Sally	1	1	0	1	1	1
Geraldine	1	1	1	0	1	1
Karen	1	1	1	0	1	1

At the beginning of each narrative interview, time was spent exploring participants experiences of using the cultural probes, particularly focussing upon their usability and acceptability with each individual.

Stephen

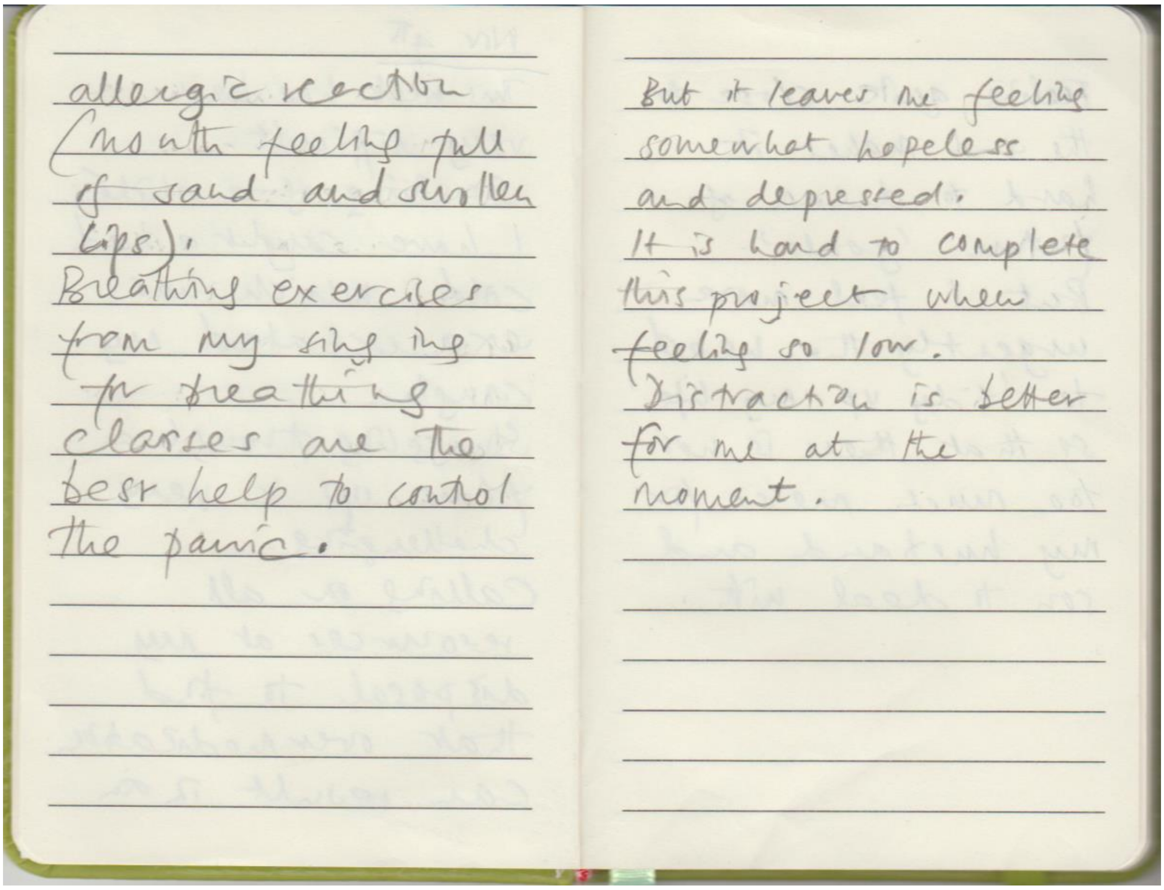
Stephen chose to use the journal and the think pad throughout his participation within the study. He made fifteen journal entries and completed four thinkpad entries over the two-month period when using the probes. This was the least amount of cultural probe entries made by a participant. Upon exploration with Stephen as to why he chose these specific probes to use, he revealed how after around seven days, he felt he was recording '*more or less exactly the same thing'*. He went on to explain how he believed that at some stage he would begin to '*manufacture things just to comply with the requirement'*. This was due to Stephen believing '*all day every day*' he undertakes the same activities, and that '*it would not have been of any use*' due to the '*simple repetition day in, day out'*. Furthermore, he revealed that if he did not complete the cultural probes to his perception of a high standard, he would be '*completely letting myself down'*. This is further explored within section 9.3 where consideration is given the potential influence of the Hawthorne effect within this study.

Sally

Sally chose to use five of the cultural probes throughout the time in which they were available to her, omitting to use the journey map. She did however include a piece of paper with her completed cultural probes with key dates such as her COPD diagnosis and attendance at Pulmonary Rehabilitation classes written upon it. Exploring Sally's cultural probes of preference revealed she was '*quite happy using all of them'*. Upon receipt of the cultural probes, it took her some time to begin to use them, however once she did, she found using them '*quite easy'*. Keeping a diary is something Sally undertakes within her day-to-day life outside of this study. Within her narrative interview, Sally explained that if she forgot to complete her cultural probes at any point, she used her diary to remind herself of each day's events, enabling her to complete them retrospectively. Interestingly, Sally was the only participant wished to keep her cultural probe data, requesting that a copy of the photographs she took were sent to her following participation in the study.

Karen

Karen used five of the cultural probes available to her, choosing not to use the reflection rosette. She made the highest number of cultural probe entries out of the six participants who completed them. Karen stated she was '*surprised*' by what had been sent to her, and being a retired academic, showed great interest in how the data captured would be analysed to develop the study findings. A unique insight given by Karen upon using the probes was recorded within her journal, and further explored within her narrative interview. As shown within Figure 83, she wrote of how she found it difficult to complete the cultural probes at times, due to feeling low in mood. As the focus of the study was entirely upon her experiences of living with COPD, Karen felt that at a time of feeling depressed, she wanted to enable distraction from living with the condition. Completing the cultural probes at this time would have presented a reminder to her of its impact.



allergic reaction
(mouth feeling full
of sand and swollen
lips).
Breathing exercises
from my singing
for breathing
classes are the
best help to control
the panic.

But it leaves me feeling
somewhat hopeless
and depressed.
It is hard to complete
this project when
feeling so low.
Distraction is better
for me at the
moment.

Figure 83 - Karen – Journal Entry – 4th November 2021

Geraldine

Geraldine selected five out of the six cultural probes to use throughout her participation within this study. She did not use the reflection rosette. There were no cultural probes that Geraldine preferred over others. She found the journey map an interesting probe to use, describing using this as an opportunity to '*put it all into perspective*'. She explained that when using the postcards she had to '*think quite a lot*' to determine what to write upon them, although acknowledging how they were '*deliberately vague*' to trigger thoughts of things that were '*very personal and meaningful*'.

Geraldine expressed how writing in the journal became a part of her evening routine, as she would complete it once she had settled for the evening. She described this task as '*quite relaxing'* and that '*it didn't seem too much of a chore'*.

Patricia

Patricia used five of the cultural probes sent to her and chose not to use the journey map. Upon exploration of her experience of using the probes, she explained '*I found them all okay'*. Patricia voiced how she did not feel that she needed to use all of the postcards, as '*only a couple of them brought back memories'*. Whilst discussing the use of the journal, Patricia voiced how she felt she did not fully understand what was expected of her, and as such thought she '*had better just write in it most days'* about the events of the day alongside her thoughts and feelings.

Craig

Craig selected to use the postcards, the journal and the journey map to reveal insight into his day-to-day life. Upon exploring with Craig his experience of using the probes, he described his participation as '*giving me something to do*'. Craig chose not to use the camera throughout his participation as he did not wish to '*have photo's of stuff in my home'* within this study.

9.3 – Potential influence of the Hawthorne Effect

Given the commitment asked of each participant within this study to complete a range of cultural probes over a period of time, the potential of the Hawthorne effect has been considered as participants may have altered their behaviour due to the experience of observation (Parsons, 1974; Wickstrom and Bendix, 2000). As explained by Stephen, he stopped using the cultural probes as he believed he would begin to '*manufacture things just to comply with the requirement*'. Despite Stephen being the only participant to voice this, acknowledgment has been given to how other participants may have altered their responses due to being observed (Bryman, 2016), such as answers they deemed acceptable, that do not reflect their true thoughts and behaviours (McCambridge, Witton and Elbourne, 2014). Utilising multiple data collection methods, offered some mitigation to this, as the content recorded within the cultural probes was further explored and confirmed within each narrative interview.

9.4 – Cultural Probes as a potential facilitator of meaningfulness

Taking part in this study is acknowledged by one participant, Geraldine, as an experience within her life giving purpose. This has highlighted the need for exploration on how study participation may have enabled a greater sense of meaningfulness. Contrastingly, Karen documented within one of her cultural probe entries (Figure 83), how she needed to take some time away from completing the cultural probes due to them being a constant reminder of the limitations imposed when living with COPD.

Participation in research is acknowledge to facilitate a sense of purposefulness from involvement in a contribution to greater good (Sheridan, Martin-Kerry and Hudson, 2020).

Furthermore, by discussing within a narrative interview their life story, this may have assisted the recognition of values of importance and the associated meaning they evoke. Being given a platform to have their voices heard may have contributed to feelings of empowerment, alongside the discovery of new understandings on their own health and behaviour. This process has the potential to provide clarity around life direction, identifying life elements giving a sense of purpose. Reflection around these potential influences of participation on life meaning has suggested there is a further need to explore the use of cultural probes as a meaning-making intervention. This is further explored within section 10.9 of this thesis.

9.5 – The use of Cultural Probes as a research method - a researcher's reflection

This reflection is written in the first person to convey a rich reflective insight into the researcher's experiences.

The use of such a novel research method, cultural probes, was an exciting and interesting approach within my doctoral study. Selecting this approach to data collection was underpinned by my desire to see beyond the verbal recollections of people's experience of living with COPD alone, and discover the subtle revelations, captured in the moment of existence, so as not to be forgotten.

I knew that accessing the reality of day-to-day life in a population living with palliative care needs would be challenging, given the impact of such a situation upon individuals physical and emotional state. Using cultural probes as a research method has facilitated me gaining a privileged insight into the daily lives of those living with palliative care needs arising from COPD that has not been revealed before.

Designing the probes was approached with caution, as I was conscious that I did not wish to impose unnecessary burden upon participants within the study. I valued the contributions of the study PPI group and gained reassurance that using this approach to obtain an insight into the presence, absence and impact of meaningfulness within this study population was acceptable. I also used their advice to ensure participants were aware that they did not have to use every cultural probe given to them, only the ones they were comfortable to use.

The data collected from participants by the cultural probes was overwhelming in terms of its depth and richness. The participants within this study embraced the use of the probes more than I had anticipated, with such raw and honest insights into the existential impact of living with COPD documented. Having the completed cultural probes to scaffold the narrative interview phase of this study enabled discussions of significance to be had upon the most meaningful elements of day-to-day life with each participant, something I believe would have not been articulated as deeply without them.

The completed cultural probes have also allowed me to present honest and meaningful insights into participants lives within this thesis, allowing their own words, descriptions and images to speak to the reader. When exploring such a personal concept as meaningfulness, I do not feel there is a better way to portray its presence and absence than with the direct records of those experiencing it.

9.6 – Chapter Summary

This chapter has presented the **use of cultural probes** within this study, as a research method exploring elements of day-to-day life with individuals living with palliative care needs.

The **patient and public involvement group** for this study made a valuable contribution to understanding the acceptability and usability of the six cultural probes used. Their feedback upon their appearance and how they would be interpreted by people living with COPD was considered. Changes such as the inclusion of more specific instructions were made as a result.

The **acceptability and usability of the cultural probes by each participant** within this study was presented. Each participant chose to use the cultural probes they were comfortable to use. All six participants found using them acceptable. One participant decided to cease using them after around a week as they believed, due to him undertaking similar activities each day, he would begin creating things to record. Another participant found that using the probes during a period of feeling low in mood was detrimental to her wellbeing as at that time, distraction from living with COPD was required.

A **reflection written by the author** of this thesis explained the deep and rich insight into the presence and absence of meaningfulness within participants day-to-day lies was captured, having being recorded in real-time when emotions were felt by participants. This has given a **unique insight** into the life experiences of this study population.

The next chapter (Chapter ten) – the discussion – will place the findings from this study into the context of the wider literature to make recommendations for future clinical practice, research and education.

Chapter 10 – Discussion

10.1 - Introduction

The aim of this study was to explore, through a narrative ethnographic approach, the presence, absence, and impact of meaningfulness within the day-to-day lives of those living with palliative care needs arising from COPD. Figure 84 presents an overview of the study findings, highlighting how the presence, and a concurrent interruption in meaningfulness in day-to-day life is evident and identified for the participants within this study.

This chapter will present the novel findings within the wider context of existing literature. It will also present the development of a conceptual framework of how those living with palliative care needs arising from COPD identify meaningfulness, and face barriers to its identification. The final framework is presented within section 10.6.1. Section 10.8 brings together the findings from the integrative literature review (chapter 3), and the empirical study findings to discuss the potential elements required to develop an intervention focussed on supporting those living with palliative care needs arising from COPD to identify and enable meaningfulness within day-to-day life.

The implications of this study 's findings will then be discussed in relation to clinical practice, policy, education, and further research. The study strengths and limitations will then be presented.

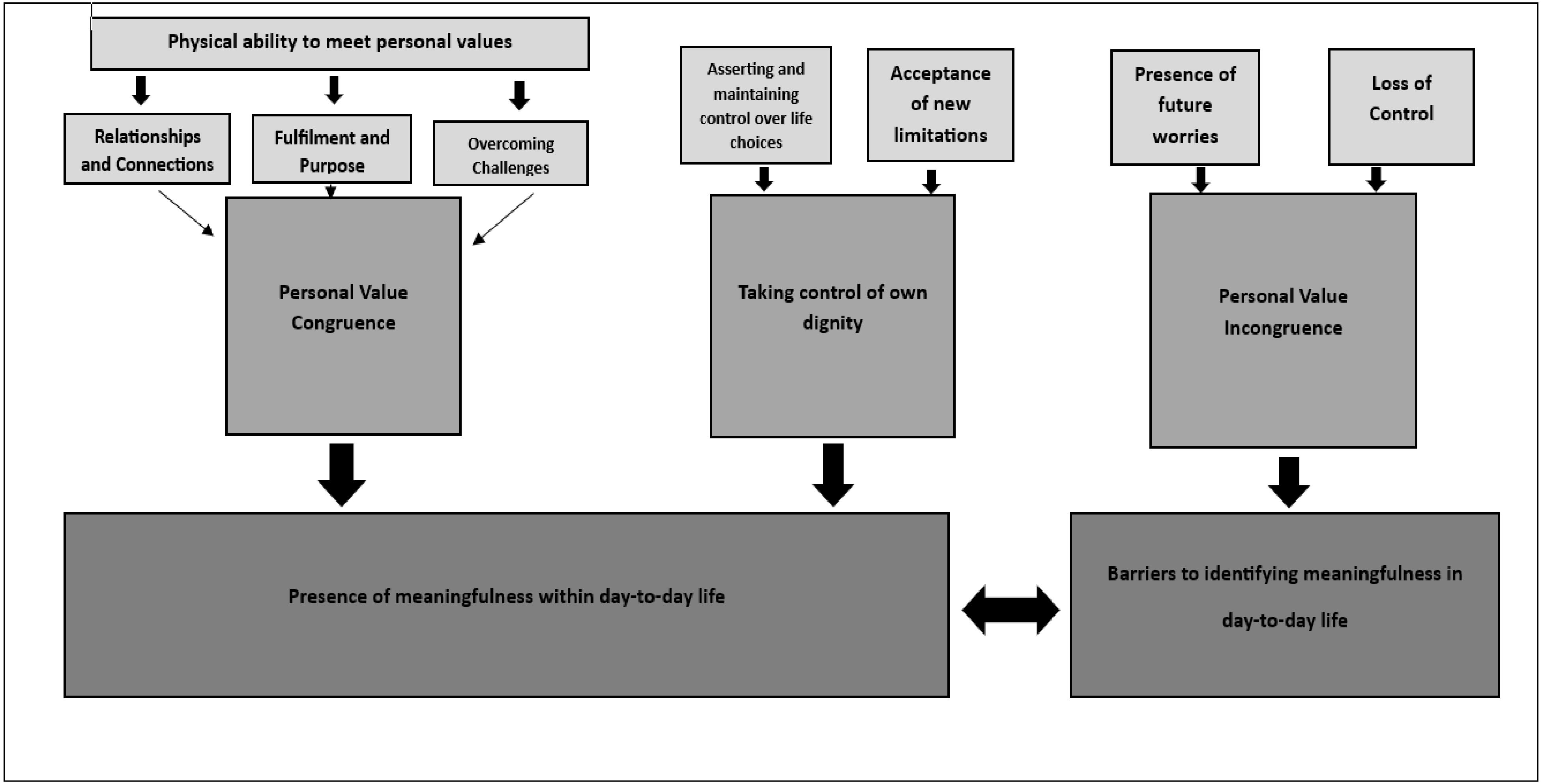


Figure 84 - Overview of Study Findings

10.1.1 – Meaningfulness through personal value congruence

Three overarching themes were identified within the study findings; meaningfulness through personal value congruence, meaningfulness through taking control of personal dignity and barriers to identifying life meaning through personal value in congruence.

By identifying the achievement of their core personal values, participants within this study were able to achieve personal value congruence, to facilitate the presence of meaningfulness within day-to-day life. Adaptation throughout disease progression to identify ways to meet their personal values within the limitations of living with COPD was evident. Participants within this study were striving to meet three core personal values; relationships and connections, fulfilment and purpose and overcoming challenges.

Relationships and connections of value of were of importance to each participant. These relationships were not only generated with people, but also objects and experiences that had meaning to them within day-to-day life. Furthermore, new relationships made because of living with COPD, such as connections with others at BLF breathe easy support groups facilitated participants meeting this personal value. The ability to meet the core personal value of fulfilment and purpose allowed the study participants to identify meaningful experiences within day-to-day life. The ability to identify experiences to achieve a feeling of fulfilment undertaking purposeful activities had been adapted throughout disease progression to align with the impact of individuals COPD symptom burden.

Opportunities within day-to-day life to undertake activities meeting the participants personal values of creativity and self-expression facilitated the presence of meaningfulness. Variation in types of creative activities for each participant was evident, dependent upon their individual symptom burden and interests. Having the ability to overcome challenges was a core personal value of importance for participants within this study, and when met, generated the presence of meaningfulness within day-to-day life.

Underpinning each of these three personal values of importance to each participant was having their physical ability to do so. When participants were no longer able to undertake activities due to the physical restrictions imposed by their condition, re-evaluation to identify alternative ways to meet their core personal values facilitated personal value congruence.

10.1.2 – Meaningfulness through taking control of own dignity

Meaningfulness was present within the day-to-day lives of five participants within this study by taking control of their own dignity, generating a sense of autonomy and feelings open being a person of value. The process of taking control of their own dignity enabled participants to make life choices of significance to align with their core personal values, leading to meaningfulness generated from a purposeful and fulfilling life. Being able to take control of their personal dignity was facilitated by participants asserting and maintaining control over their life choices and the acceptance of new limitations imposed when living with palliative care needs arising from COPD. Through asserting and maintaining control over life choices, by realistic goal setting and achievement within the limitations of the condition, meaningfulness was present. Emotional adaptation to the setting of realistic goals within day-to-day life further enabled this.

Acceptance of new limitations imposed by living with COPD enabled participants to identify elements of meaning within day-to-day life. The development of personal resilience, facilitating empowerment over decision making enabled them to take an active role in the self-management of their condition, in a dignified manner acceptable to them.

10.1.3 – Barriers to identifying meaningfulness in day-to-day life

Participants within this study revealed that although they were able to meet their personal values and take control of their own dignity to identify the presence of meaningfulness within day-to-day life, barriers to its identification arose concurrently. The presence of personal value incongruence, where participants were unable to meet their core personal values due to the imposed limitations of living with COPD became prevalent due to the presence of future worries and a sense of a loss of control over day-to-day life. The presence of future worries are attributed to the inability to meet core personal values leading to a sense of inner turmoil and internal conflict between how they wished daily life to be and the reality. An inability to complete activities of importance to them, such as undertaking the shopping or not being able to care for loved ones should they require, contradicted their deeply held values.

The feeling of a loss of control over day-to-day life resulted in a sense of hopelessness, a loss of personal autonomy and a sense of being judged for one participant, Craig. The impact this imposed upon his ability to meet his core personal values facilitated personal value incongruence and interrupted his ability to identify meaningfulness within day-to-day life.

10.2 – Cultural Probes as a research method within palliative care populations

This study also presents a novel insight into the use of cultural probes as a research method exploring the day-to-day lives of individuals with palliative care needs arising from COPD. The use of cultural probes to gain a unique, deep and privileged insight into their lives was supported by the study patient and public involvement group, who were an essential element of the process in determining the acceptability and usability of this method. Furthermore, their contribution to understanding how the cultural probes would be interpreted and used by a population living with palliative care needs arising from COPD influenced adaptations to the probe designs, such as the inclusion of more specific instructions on their intentions and use.

Participants within the study found the cultural probes to be an acceptable task to be asked to undertake. Having the opportunity to use some, or all of the cultural probes was welcomed by participants. The most popular probe amongst participants was the journal, and the least popular being the Rosette and reflection card. One participant identified that using the probes during a period of low mood was detrimental to her well-being at that time, as she required distraction from living with COPD. Reflections from the researcher revealed an insight beyond the verbal recollections of individuals lived experiences, through gaining detailed recordings of the more subtle revelations within the day-to-day lives of participants as they were recorded at the time they occurred. Some of the cultural probes used within this study have been widely used as standalone data collection methods in palliative care and wider healthcare research. The use of participant photographs, to explore difficult to verbalise topics is one evidenced benefit of a photo-elicitation technique approach (Tishelman *et al.*, 2016). The approach enables deep engagement with abstract concepts such as life meaning. This technique is particularly effective in helping participants articulate complex feelings or beliefs they may not have fully recognised, enhancing the richness of data collected (Glaw *et al.*, 2017). This was evident within this study through each participant revealing personal values of importance to them that they may not have consciously recognised otherwise. Whilst some evidence suggests that images are subject to differing interpretations from the researcher and the participant, the associated influence on the validity of using the images captured to underpin an interview allows for the opportunity of member checking to address trustworthiness by developing a collective interpretation of meaning (Glaw *et al.*, 2017). This chapter will now present a reflection on the study population, to give context to the discussion followed by the study findings within the wider context of existing literature.

10.3 – Reflection on the circumstances of the study population

The six participants within this study were an engaged and motivated group of people, who actively sought ways within day-to-day life to identify and enable meaningfulness. They each has accepted having and had adapted to living with COPD. This resulted in them having generated alternative ways to meet their personal values within the limitations of the condition. This participant population did not reveal the same significantly impactful symptom burden as is evidenced across the wider COPD population. Each participant was still, despite COPD impacting their day-to-day life, able to leave home and undertake meaningful activities. Whilst this study population could be acknowledged as a potential limitation, given the absence of representation of the wider COPD population, the insight they have given is also of benefit. Interpretation of the study findings, to determine how those with a more impactful symptom burden, and in need of support, as evidenced within the wider literature (Gardener *et al.*, 2018), has allowed for recommendations to be made to inform the development of an intervention to support the wider COPD population.

The underlying cause of development of COPD may correlate with an individual's ability to experience meaningfulness in day-to-day life. For those who have developed the condition from cigarette smoking, the acceptance process can be complex, due to a personal sense of responsibility resulting in self-blame, potentially leading to feelings of embarrassment (Klinke and Jónsdóttir, 2014). This may lead to a person choosing to socially isolate themselves, due to the visibility of physical symptoms, or that they are no longer able to meet their own expectations (Klinke and Jónsdóttir, 2014; Harrison *et al.*, 2017). This has the potential to compromise the ability to undertake meaningful experiences. When the underlying cause is something out of a person's control, such as a genetic disorder or passive smoking, there is an evidenced shift in the impact on a person's existential situation. As revealed by one participant in this study, Patricia, she developed COPD through passive smoking. Feelings of anger and frustration were reflected upon towards the individual she believed responsible for this, her late husband. Similarly, for those living with COPD due to a genetic condition, feelings of injustice or frustration may be present, making it difficult for them to accept their condition and identify a sense of purpose. Living with a chronic condition enforced outside of a person's control may hinder the ability to experience meaningfulness within life due to a complex mix of physical symptoms and emotional responses.

10.4 – Identifying meaningfulness in the face of adversity

The findings from chapters seven and eight offer an alternative perspective than that discussed within the integrative literature review within chapter three of this thesis. Participants within this study revealed limited evidence of existential suffering within day-to-day lives. Findings demonstrated how despite living in the face of adversity due to the palliative care needs associated to living with COPD, the presence of meaningfulness was identified in day-to-day life. The presence of life meaning in the face of adversity is vastly debated within the wider literature. The seminal work of the existential theorist Victor Frankl (1963) presents the concept of '*will to meaning'*. Following his time in a concentration camp throughout World War two, alongside his later work as a psychologist, Frankl utilised his observations from these experiences, to develop this concept, arguing how the innate human driver within life is not the pursuit of pleasure, but the search for meaning (Frankl, 1963; Längle, 2003; Bailey, 2022). He suggested how even in the most difficult of circumstances, individuals have freedom to choose their attitude and response towards a difficult situation, enabling them to discover meaning and purpose in life, proposing the notion that meaning already exists and individuals need to locate it (Frankl, 1968, 1976). The proposal that meaning is generated through the achievement of '*creative, experiential and attitudinal'* values gave a deeper understanding to this theory (Frankl, 1968). Creative values motivate individuals to create and achieve, typically through work or hobbies. Experiential values encompass positive human experiences like love and connections, and attitudinal values prompt individuals to adopt a particular stance when confronted with inevitable negative circumstances, encouraging them to face injustice with dignity (Debats, 1996). Findings from this study agree with this notion, as participants revealed they were able to identify meaning within day-to-day life through personal value congruence. The personal values able to be met were:

relationships and connections, fulfilment and purpose and overcoming challenges related to living with palliative care needs arising from COPD.

Critics present viewpoints on the concept of '*will-to-meaning'* based upon the significant responsibility upon everyone to adopt an attitude conducive to identifying meaning in life, and state this is not always possible (Landau, 2019; Bailey, 2022). Interestingly, this study's findings contradict this criticism, with participants exerting resilience and adaptation, to find alternative ways to meet their personal value of overcoming challenges, and in turn, were able to identify meaning in life. Furthermore, Frankl did not state that everyone had the ability to find meaning, more that they had the freedom to, through the application of a personal attitude of wanting to do so (Frankl, 1968). This insight invites an exploration of how individuals, given suitable interventions, can be supported in this journey, provided they possess the willingness to identify meaning in their lives.

A contrasting theoretical viewpoint upon the identification of meaning within life is presented by Maslow (1943), within his proposed '*Hierarchy of Needs'*, whereby until the lower human needs such as breathing, sleep, safety and security are met, individuals find little motivation in achieving their personal values to identify meaning in life, and subsequently reach the higher need of self-actualisation. From this perspective, it is argued that life meaning is the existing property of an individual, and until they can meet their hierarchy of personal values, an individual will find little motivation towards identifying meaning in life (Maslow, 1970). Frankl (1966) offered a critique of this viewpoint in highlighting how some individuals can bypass the meeting of the lower physical needs, and directly fulfil those holding higher value. The findings from this study support this criticism. Individuals living with palliative care needs arising from COPD live with symptoms of chronic breathlessness, interruption in sleep, alongside feelings of worry and fear in day-to-day life (Elkington *et al.*, 2004; Gardiner *et al.*, 2009, 2010). Despite living with such a significant symptom burden and in a life of uncertainty and worry, the participants within this study were able to still identify meaning within their day-to-day lives by meeting their personal values. This was achieved through their engagement within meaningful activities, and the development of new ways to achieve them, within the limitations of their condition.

The concept of engagement presented by Yalom (1980: p482), that '*a sense of meaningfulness is a by-product of engagement'* suggests how engagement within life's activities allow an individual to develop a sense of control, facilitating the ability to identify meaning. This study's findings revealed participants held a strong desire to engage in life, with each taking control of life events and experiences to facilitate the presence of meaningfulness. This was particularly evident from participants actively seeking meaningful relationships and connections, undertaking activities facilitating a sense of fulfilment and purpose and making adaptations within day-to-day life to overcome challenges.

For those living with palliative care needs arising from COPD, meaningful components of individuals day-to-day lives are revealed within the wider literature, such as experiences of undertaking purposeful activities, involvement in hobbies and pleasurable activities, and identifying a sense of achievement (Elofsson and Ohlen, 2004; Ek and Ternestedt, 2008; Lindqvist and Hallberg, 2010; Sheridan *et al.*, 2011; Strang, Ekberg-Jansson and Henoch, 2013; Hayle *et al.*, 2013; Disler *et al.*, 2014; Stridsman *et al.*, 2015; Dunger *et al.*, 2015; Brien, Lewith and Thomas, 2016; Doyle *et al.*, 2017; Keil *et al.*, 2017; Reijnders *et al.*, 2018; Gardener *et al.*, 2018; Vitacca *et al.*, 2019).

However, to the best of the authors knowledge, there is no study published offering a conceptual framework upon how meaning is generated for this patient population. This study offers a novel insight into **what is required** by those living with palliative care needs arising from COPD to identify meaningfulness, through personal value congruence and taking control of their own dignity.

10.4.1 – Conceptual Framework – Phase One

From this study's findings, alongside their placing within a wider literature context, a conceptual framework has been developed to illustrate how individuals living with palliative care needs arising from COPD are able to identify, and concurrently face interruption to meaningfulness in day-to-day life. The framework will be constructed for the reader throughout this discussion chapter. Each subsequent section of this chapter will present the justification from the wider literature upon each stage in the process of individuals living with palliative care needs arising from COPD identifying the presence and interruption of meaningfulness in day-to-day life.

Placing the findings from this study within the context of existential philosophy, two central requirements to begin to identify the presence of meaningfulness within day-to-day life have been revealed and are presented within figure 85.

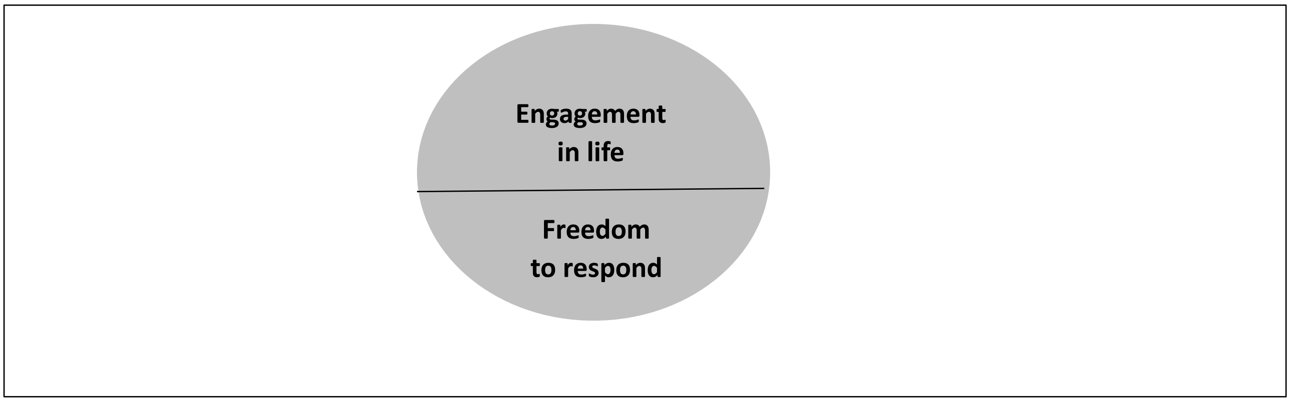


Figure 85 - Required elements of meaningfulness identification

The findings, as discussed, have demonstrated that for individuals living with palliative care needs arising from COPD, being engaged within their day-to-day life, through the desire to meet their personal values, has allowed them to identify the presence of meaningfulness. This was facilitated by participants having the freedom to respond to the imposed limitations of living with the condition. Participants revealed a commitment to creating their own life meaning within the face of adversity, with the meeting of their personal values playing a crucial role in this process.

10.5 – Meeting core personal values to facilitate meaningfulness

Through the meeting of their personal values of relationships and connections, fulfilment and purpose and overcoming challenges, participants within this study were able to identify the presence of meaningfulness within day-to-day life as a result of personal value congruence.

Personal value congruence, the alignment between an individual's values and the actions and choices they're able to make, plays a crucial role in contributing to a sense of meaning in life. When individuals pursue activities in accordance with their values, they experience a sense of autonomy, competence, and relatedness, leading to increased well-being and a more meaningful life (Deci and Ryan, 1985). As previously described within section 5.2.2, the meeting of personal values is achieved in coordination with an individual's life experience at that time (Rogers, 1959), through a degree of harmony between an individual's values and the environment in which they exist (Burns, 1978; Shamir, House and Arthur, 1993). The findings from this study revealed as participants navigated day-to-day life with variations in symptom burden present each day, they were able to continuously shape and redefine ways to meet their personal values within these limitations.

The values identified to be of importance to individuals within this study (relationships and connections, fulfilment and purpose, and overcoming challenges) align with the theory of basic human values (Schwartz, 1992). This theory has been presented within section 5.2.1, with figure 85 presenting an overview. Ten basic values are identified by Schwartz (1992) to be of importance to individuals, underpinned by their motivation to achieve them, and are grouped into four categories; openness to change, conservation, self enhancement, and self transcendence (Schwartz, 1992). Figure 86 presents how the personal values revealed to be of importance within this study align with this theoretical perspective.

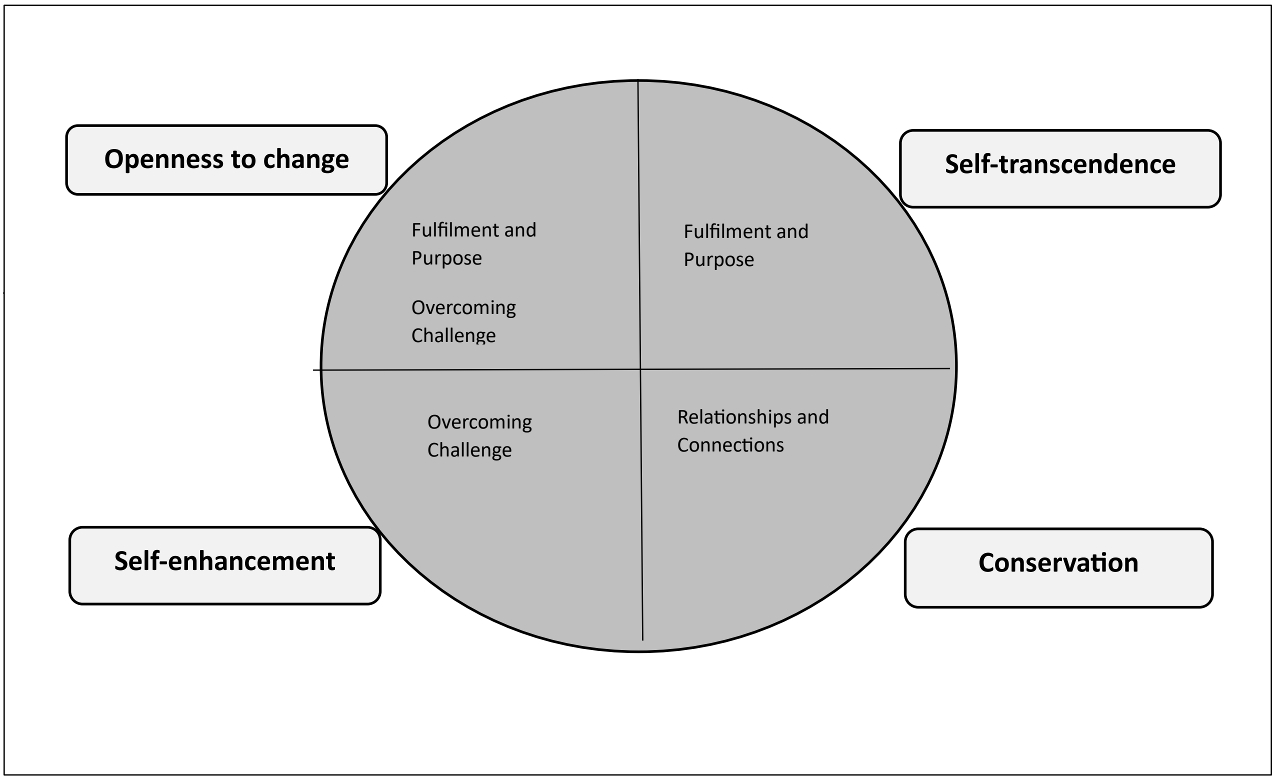


Figure 86 - Study participants personal values aligned to Schwartz (1992) Theory of Basic Human Values

Participants identified the presence of life meaning by meeting their personal values of fulfilment and purpose, underpinned through contributing to the well-being of others and making a positive contribution to the world, aligning to the notion of self-transcendence. Self-transcendence values are considered to be associated with a focus on the collective good, empathy, and a sense of interconnectedness with others and the world (Schwartz, 1992).

By overcoming challenges within day-to-day life, participants in this study revealed their openness to change, alongside a desire for self-enhancement. Self-enhancement values are associated with a focus upon individual goals. Individuals who prioritise self-enhancement values are likely to engage in behaviours and make choices that emphasise their own well-being, personal achievements, and individual interests facilitating the presence of meaningfulness within their lives (Schwartz, 1992). Conservation values were met by the participants within this study through the presence of relationships and connections, providing them with a sense of stability, order and a connection to society.

Meeting the three personal values of relationships and connections, fulfilment and purpose, and overcoming challenges is presented in the wider literature when living with COPD, supporting this study's findings of how achieving personal value congruence facilitates the presence of meaningfulness in day-to-day life. Studies exploring the experiences of living with COPD identify the presence of relationships and connections as a life experience generating meaning for study participants (Williams *et al.*, 2007; Ek and Ternestedt, 2008; Disler *et al.*, 2014). Within a meta synthesis of qualitative research upon the experience of advanced COPD (Disler *et al.*, 2014), the synthesis of 22 included studies revealed how the presence of meaning in life is strongly underpinned by social connectedness. Furthermore, a phenomenological study upon the lived experiences of COPD at the end of life (Ek and Ternestedt, 2008), revealed that being of significance to others was important to study participants, alongside a sense of belonging and the opportunity to interact socially with others. A more recent study, using a co-production approach with forty-four patients diagnosed with COPD, to determine '*what matters to people with COPD'*, also revealed the significance of the presence of meaningful relationships as an important life element (Early *et al.*, 2019). This finding is echoed within the wider literature exploring life experiences for those living with COPD (Milne, Moyle and Cooke, 2009; Early *et al.*, 2019), although has not been placed within the context of how meeting this personal value facilitates the presence of meaningfulness. An interpretive phenomenological study exploring the presence of hope when living with COPD identified that a determination to live life as '*normal*' is possible, through a process of adaptation to identify fulfilment in life as it occurs (Milne, Moyle and Cooke, 2009). Achievement of life ambitions was revealed by participants within a study exploring important life elements when living with COPD (Early *et al.*, 2019), again suggesting these personal values are of importance to this patient population.

Much of the wider literature upon how individuals with palliative care needs arising from COPD identify the difficulties faced by this population in meeting the values of fulfilment and purpose, leading to the presence of meaninglessness in day-to-day life (Elofsson and Ohlen, 2004; Gale and Sultan, 2013; Strang, Ekberg-Jansson and Henoch, 2013; Harrison *et al.*, 2017). The findings from this study contradict this, as participants were able to meet these values through feelings of satisfaction in life, identifying life as being worthwhile and being able to make a difference as presented within section 6.3. One explanation for this is an attitude of engagement in life, and the ability to exercise their freedom to respond to meeting personal values. This enabled participants to overcome the challenges they faced from living with the condition, to achieve personal value congruence. What remains absent from the wider literature is a broader exploration of the facilitators to individuals living with palliative care needs being able to engage within daily life to enable them to exercise their freedom to respond in the face of adversity, to meet their core personal values, thus supporting meaningfulness.

10.5.1 – Conceptual Framework – Phase Two

The meeting of core personal values to facilitate personal value congruence is the next phase of the conceptual framework developed from this study's findings to better understand the process of identifying meaningfulness within the day-to-day lives of those living with palliative care needs arising from COPD. This is presented within figure 87.

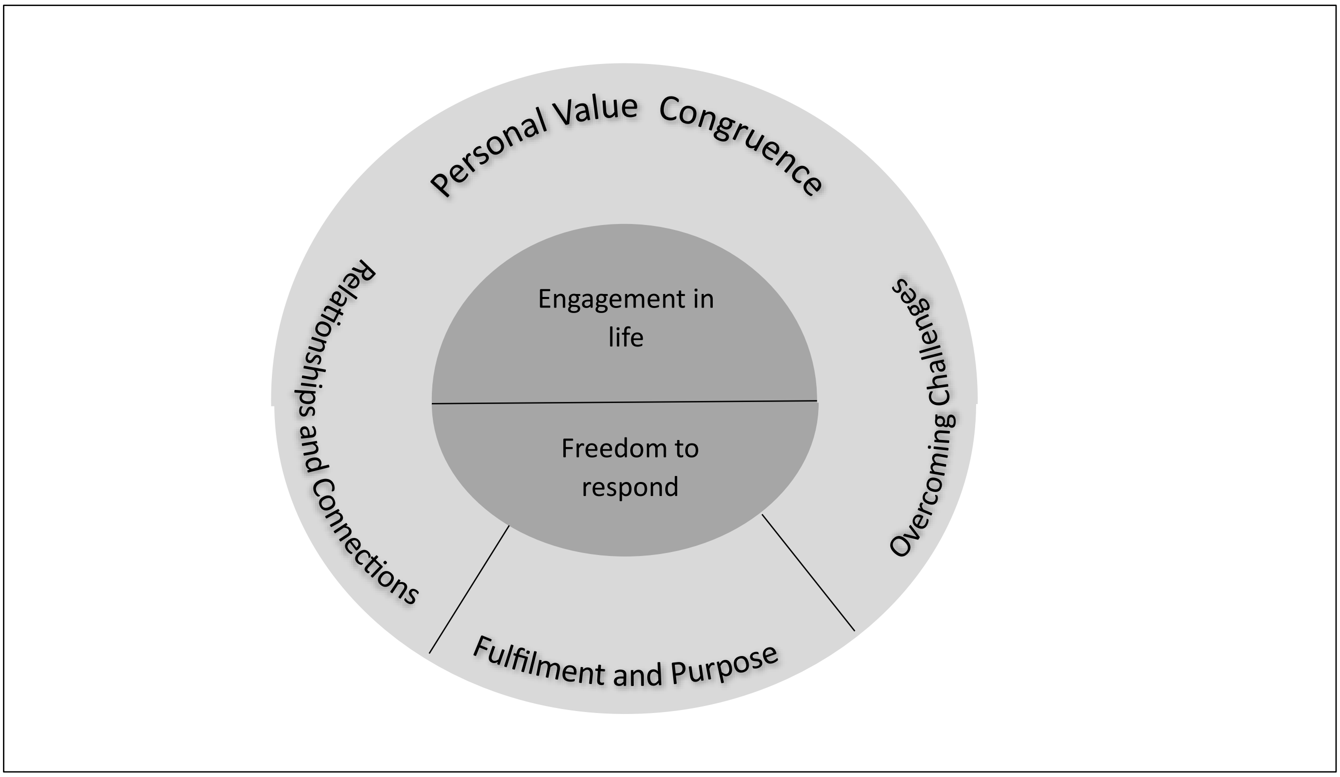


Figure 87 - Identification of meaningfulness through personal value congruence

The findings from this study revealed that for participants who achieved personal value congruence, this provided a framework for understanding the significance of their actions, which in turn contributed to a sense of purpose, enhancing their control over personal dignity leading to a greater sense of meaning in life.

10.6 – Taking control of personal dignity to identify meaningfulness

When participants took control of their personal dignity, through asserting control over life choices and acceptance of the imposed limitations, they were able to identify the presence of meaningfulness in day-to-day life. As presented within section 5.2.4 of this thesis, personal dignity is a concept underpinned by an individual's sense of self-worth, and perceived value in life (Oosterveld-Vlug *et al.*, 2013; Laranjeira and Dourado, 2022). Personal dignity is both subjective and fluid, often shaped by external influences and changing life circumstances presenting variations in its achievement amongst individuals (Chochinov, 2002; Tranvåg and Naden, 2015). For those living with palliative care needs arising from COPD, frequent changes in life circumstances are present, resulting in the need for them to assert control over life choices, and accept their ever-changing limitations, to enable them to maintain their personal dignity to live a meaningful existence. The exploration of the impact of maintaining personal dignity for individuals specifically living with palliative care needs arising from COPD is little explored within the wider literature, making this study's findings a novel contribution to the evidence base. The wider literature does however present a plethora of evidence highlighting the impact of the interruption or absence of personal dignity within this patient population (as presented within chapter three). This is largely associated with the inability for individuals to meet their personal values of fulfilment, purpose and self-worth, resulting in feelings of despair, hopelessness and a loss of control over life (Elofsson and Ohlen, 2004; Ek *et al.*, 2011; Cooney *et al.*, 2013; Brien, Lewith and Thomas, 2016; Bolton, Seymour and Gardiner, 2022). Whist this study did identify interruptions in participants being able to identify the presence of meaningfulness within day-to-day life, as presented within section 10.6, this was not solely related to the absence of personal dignity to the extent reported within the wider literature.

The development of a model of dignity-conserving care following the explorations of fifty individuals perceptions of dignity whilst living with advanced cancer identified three domains underpinning personal dignity; '*illness related concern'*, '*dignity-conserving repertoire'* and '*social dignity inventory'* (Chochinov, 2002). The model is deemed appropriate for application across wider populations receiving palliative care. The domain of 'dignity-conserving repertoire' identifies that a component of personal dignity was having control over life circumstances, alongside a sense of autonomy. Furthermore, acceptance and adaptation to the variable impact of illness and associated limitations was deemed necessary for individuals to maintain their personal dignity. This study's finding aligns with the notion of dignity-conservation, with participants asserting and taking control over life choices by setting realistic goals to be achieved in manageable steps within the physical and emotional limitations imposed when living with palliative care needs arising from COPD.

Asserting and maintaining control over life choices to maintain personal dignity has been explored with individuals living with advanced COPD, identifying the need for independence over decision making in day-to-day life to enable a sense of autonomy, facilitating a meaningful existence (Laranjeira and Dourado, 2022). Interestingly the content of autonomous decisions within this study are echoed within the work of Laranjeira and Dourado (2022), with participants in both studies undertaking forms of exercise in day-to-day life due to their understnding of the benefits to lung health. The use of dignity therapy within a population of 165 terminally ill patients, to explore its impact compared to usual palliative care upon the reduction of psychological, existential, and spiritual distress demonstrated findings of relevance to this study (Chochinov *et al.*, 2011). Dignity therapy is focussed upon individuals recognising through interviews, elements within daily life giving meaning and purpose, alongside a holistic sense of dignity (Chochinov *et al.*, 2011), with findings revealing its statistical significance in individuals achieving meaningful life goals. A further study, utilising the principles of dignity therapy developed by Chocinov *et al* (2011), explicitly explored its use within a population of individuals living with COPD at the end of life, to identify its potential benefits (Brożek *et al.*, 2019). Findings revealed that the use of dignity therapy, to improve participants sense of dignity in life, offered a positive impact upon the presence of meaningfulness (Brożek *et al.*, 2019). The findings from these studies further support the notion of the presence of and control over personal dignity leads to a more meaningful existence.

Acceptance of living with COPD in the context of this study does not imply resignation to the condition but involves acknowledgement of the reality of the illness and adaptation to its challenges. Furthermore, acceptance enabled participants within this study to take control of their personal dignity. This was achieved through the adoption of an attitude of '*living in the moment'*, alongside taking an active role in the self-management of their condition. Disease acceptance involves acknowledging and coming to terms with the existence of the illness, enabling an individual to adjust to their new reality (Piotrkowska *et al.*, 2021). This process includes individuals re-establishing their own self-identity to find new ways to live through the process of self-reflection (Telford, Kralik and Koch, 2006). For participants within this study, they were able to maintain their own personal dignity by identifying and undertaking adapted daily activities within the limitations of COPD to generate the presence of meaningfulness. The process of identifying adapted activities suggests a level of disease acceptance. This finding is markedly different from the wider literature relating to disease acceptance in COPD, as discussed within section 3.6.1 of this thesis. The non-acceptance of living with COPD contributed to a sense of living within a liminal space, hindering adaptation to new life circumstances (Lindqvist and Hallberg, 2010; Disler *et al.*, 2014; Dunger *et al.*, 2015). This contributed to the presence of existential suffering for those living with palliative care needs arising from COPD, including the absence of meaningfulness in day to day life (Bolton, Seymour and Gardiner, 2022). The process of disease acceptance for participants within this study could offer an explanation to underpin how they identified the presence of meaningfulness within day-to-day life. Embracing disease acceptance can be a transformative journey, generating the presence of profound life meaning (Park, 2010; Quinto *et al.*, 2022). Instead of viewing chronic illness as an obstacle in life, individuals who are able to accept and integrate their illness challenges into daily life and their personal identity often experience a shift in perspective (Park, 2010). As presented by Frankl (1968), finding purpose in the face of adversity is necessary for human growth. Through application of this perspective to those living with palliative care needs arising from COPD, participants within this study were able to identify new sources of meaning through the difficulties faced from living with the condition.

This notion is further explored within the field of psychology research upon post-traumatic growth (Tedeschi and Calhoun, 2004). Individuals facing life altering events, including chronic illness, are able to develop personal growth, resilience and a deeper appreciation for life. The process of disease acceptance facilitates such responses, enabling a sense of coherence and purpose. A significant portion of evidence exploring chronic disease acceptance focusses upon its absence, with some identifying how individuals may be judged as being in denial about their condition by healthcare professionals (Telford, Kralik and Koch, 2006). The findings from this study offer an alternative perspective to this, encouraging healthcare professionals caring for those living with palliative care needs arising from COPD to listen to the narratives of individuals upon how they identify the presence of meaning in day-to-day life, to offer insight into their acceptance of living with the condition.

10.6.1 – Conceptual Framework – Phase Three

Taking control of personal dignity is the third phase of development of the conceptual framework to capture the presence and interruption of meaningfulness in day-to-day life of those living with palliative care needs arising from COPD. Figure 88 presents this.

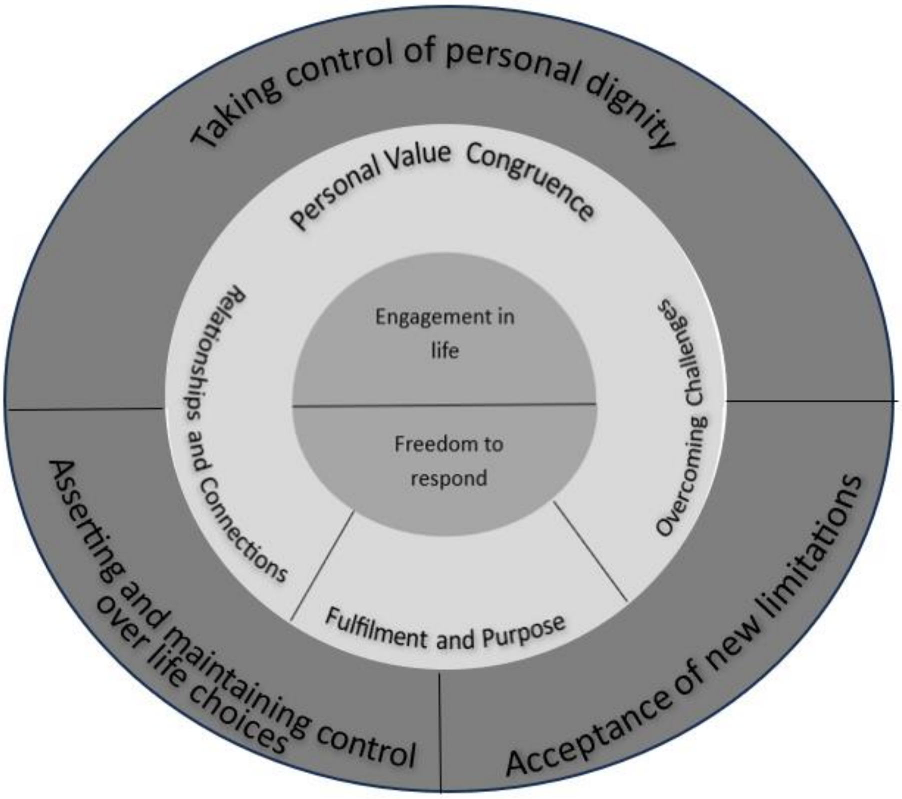


Figure 88 - Identification of meaningfulness through taking control of personal dignity

The findings from this study presented how participants were able to take control of their personal dignity through asserting and maintaining control over life choices and the acceptance of new limitations. Interruptions to the identification of meaningfulness in day-to-day life were present and are further explored within section 10.6.

10.7 – Concurrent interruptions to meaningfulness

The findings presented within chapter eight revealed how participants were able to identify the presence of meaningfulness in day-to-day life, whilst concurrently experiencing interruptions in its identification. These interruptions were present when participants personal values were unable to be met, with barriers to doing so evolving from the presence of future worries and a sense of a loss of control. Such barriers were not permanently present within participants day-to-day lives, however, did generate fluctuations within their existential situation.

The interruption of identification of meaningfulness in day-to-day life for those living with palliative care needs arising from COPD echoes the experiences presented within the wider literature. The presence of future worries when living from COPD is evident within the wider literature (Ek and Ternestedt, 2008; Giacomini *et al.*, 2012; Strang, Ekberg-Jansson and Henoch, 2013). A study exploring the experience of anxiety amongst thirty-one patients with severe COPD (Strang, Ekberg-Jansson and Henoch, 2013), revealed two types of future worries; '*life anxiety'* and '*death anxiety'*. The unpredictability of the future when living with COPD caused individuals to experience '*life anxiety'* through a fear of the unknown. Furthermore, fears upon the end of life and dying were described as '*death anxiety'*. The work of Strang, Ekberg-Jansson and Henoch (2013) support the findings from this study that despite such interruptions in day-to-day life, participants were able to re-adjust how they identified the presence of meaningfulness from achieving smaller goals within the limitations of their condition.

Experiencing a sense of a loss of control over life is discussed within the wider COPD literature, with a recent co-produced set of six priorities, developed with forty individuals living with COPD identifying its presence and negative impact upon individuals mental health (Early *et* *al.*, 2019). Living with COPD commonly forces symptoms of anxiety and depression, which are often linked to a perceived loss of control over their health status (Lacasse, Rousseau and Maltais, 2001; Hill *et al.*, 2008). A systematic review of sixteen papers upon illness perceptions and COPD suggests that the loss of control over physical health often prompts individuals to develop adaptive or maladaptive coping mechanisms to manage the emotional toll of the condition (Kaptein et al., 2008). For those within this study, adaptation to how they met their personal values overcame the presence of personal value incongruence. Personal value incongruence, when an individual is unable to meet their personal values due to life circumstances, masks clarity in identifying life meaning (Rogers, 1959). When there is significant disparity between a person's ideal self and their real self, this can lead to inner conflict and a sense of dissatisfaction (Rogers, 1959). When living with COPD, meeting all personal values may not always be possible, as revealed from the study findings. However, coping with the interruption in being able to meet personal values, and adjusting personal goals to find new ways to meet them within their illness limitations may be due to the presence of hope.

The presence of hope allows individuals to navigate periods of uncertainty over time, and enables them to '*hold conflicting expectations simultaneously'* (Folkman, 2010 p:905). Within this study, future worries of significance, such as not wishing to be a burden to others and finding difficulty in identifying how to achieve future goals did not remove the presence of meaningfulness in day-to-day life. With the presence of hope, they were able to cope with life changes by the achieving new life goals within the limitations of the condition, allowing them to generate meaning through a new sense of purpose (Park and Folkman, 1997; Folkman, 2010).

This study offers insight into how an interruption in the identification of meaningfulness in day-to-day life when living with COPD can occur alongside the presence of meaningfulness. Healthcare professionals are encouraged to explore the hopes of individuals living with COPD as an avenue to begin to understand the impact of their existential situation upon their day-to-day life.

10.7.1 – Conceptual Framework – The presence and interruption of meaningfulness in day-to-day life when living with palliative care needs arising from COPD

Figure 89 presents the final conceptual framework to illustrate how individuals living with palliative care needs arising from COPD identify and concurrently face interruption to meaningfulness in day-to-day life.

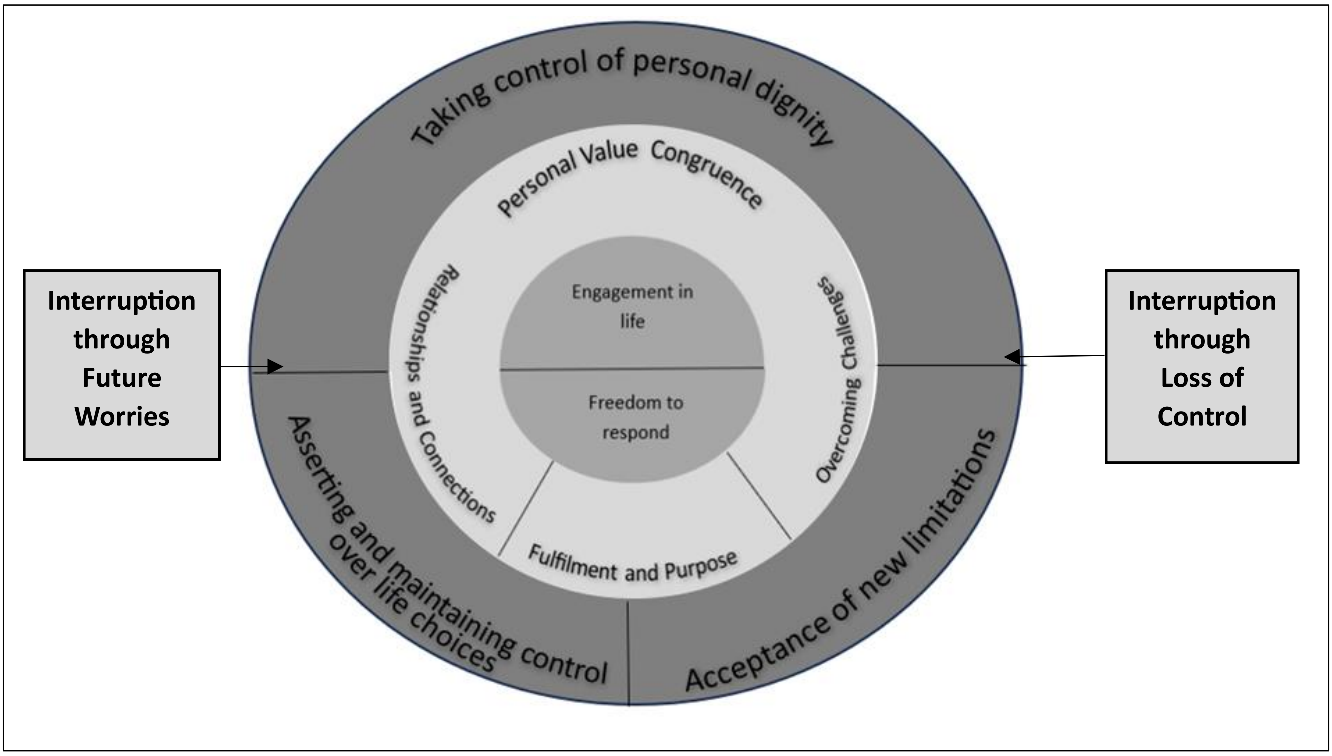


Figure 89 - The presence and interruption of meaningfulness in day-to-day life when living with palliative care needs arising from COPD

10.8 – Cultural Probes – A research method within palliative care populations

The use of cultural probes as a research method within research in populations with palliative care needs is a novel approach. The use of this method has facilitated participants exploring beyond immediate situations to explore personal 'beliefs, desires and cultural preferences' (Gaver, Dunne and Pacenti, 1999; Burrows, Mitchell and Nicolle, 2015 p:920). The findings from this study, as presented within chapter ten of this thesis are markedly different to published work upon life meaning when living with COPD. One explanation for this may be the adoption of this research method. The cultural probes used within this study were specifically designed for this study population, as an approach to capturing insight into daily life in a known difficult to reach study population (Hemmings *et al.*, 2002; Gaver *et al.*, 2004). It is however important to acknowledge the engagement and motivation demonstrated by the people recruited to this study, and how this may have influenced their ability to seek meaningful activities within day-to-day life. It is however acknowledged that from using this approach, valid insights have been evoked that may have remained hidden when using alternative research methods. A co-production approach to the design and development of the cultural probes was undertaken with individuals living with COPD and their carers. This meaningful patient and public involvement ensured the probes were both acceptable and usable within that patient population (Forbes *et al.*, 2010; INVOLVE, 2012). Despite this, the researcher has remained aware throughout the duration of this study of the potential significant burden from participation, given the expectation of using up to six cultural probes for a two-month period, followed by a narrative interview. Furthermore, the personal subject under exploration, meaningfulness, is deeply personal and has the potential to evoke emotions and feelings of distress and sadness when explored. The participants within this study reported no concerns related to this throughout this study. However, had a participant population have been recruited via the original recruitment strategy of NHS settings, this may have facilitated recruitment of those representing the wider COPD population. There is a possibility that when used with people living with palliative care needs arising from COPD who are not as engaged in meaningful activities in daily life, the risk of significant participant burden alongside potential psychological distress is present. Therefore, using this approach within future research requires careful consideration.

10.9 – Suggested meaningfulness intervention components

Findings from the integrative literature review (chapter three), and this research study have highlighted key components that could inform the development of an intervention to assist people living with palliative care needs arising from COPD to identify meaning in life. As previously explored within this thesis, COPD is a progressive, life-limiting condition that often leads to existential challenges, making the search for meaning a necessary action to improve quality of life. Through the integration of existing literature and the first-hand accounts captured within this study from individuals living with COPD, several themes emerged underpinning the importance of personal value exploration, social connection and value-based goal setting to maintain control over life choices to enable a sense of meaning and purpose for this patient population. This patient population are evidenced to welcome intervention input, as participation enables them to believe they are deserving and are a person of value (Gale and Sultan, 2013; Hayle *et al.*, 2013).

The identification of personal values of importance to an individual, to underpin the setting of value-based goals, within the imposed limitations of living with COPD allowed participants within this study to have clarity on exactly which elements of day-to-day life are meaningful to them. This was a process they had taken independently however, for many who live with the impactful interconnected physical, psychological and social challenges associated with COPD, this is not possible. The significant physical symptom burden of living with COPD may cause individuals to be consumed with the day-to-day management of immediate needs, making it difficult to reflect on personal values of importance and long-term goal setting (Hirai, Morita and Kashwagi, 2003; Hayle *et al.*, 2013). Furthermore, as COPD progresses, individuals may experience a loss of former self (Elofsson and Ohlen, 2004; Disler *et al.*, 2014; Harrison *et al.*, 2017), which may have previously defined them as a person. This loss can lead to feelings of uncertainty, making it difficult to recognise personal values of significance and how to meet them within the imposed disease limitations. A necessary intervention element to support this patient population is to support them in identifying a hierarchy of core personal values. This will then enable them to being to identify value-based goals to work towards achieving and generate the presence of meaningfulness.

Evident from the integrative literature review (Chapter 3), when personal values are not able to be met, existential suffering may manifest. Experiences within this patient population include feelings of worthlessness, hopelessness and a loss of personal liberty, interrupting the presence of meaning in day-to-day life (Elofsson and Ohlen, 2004; Dunger *et al.*, 2015; Brien, Lewith and Thomas, 2016). Participants within this study were able to avoid a situation of existential suffering through value-based goal setting within the limitations of the condition. This was evident from the insight given by Stephen, who revealed how he sets himself 'targets' that when achieved generate meaning. Patricia also demonstrated the ability to meet her personal values through the achievement of goals. She no longer has the physical capability to undertake all the necessary gardening at her home. Patricia has accepted this and has employed a gardener. She does however still undertake the amount of gardening she is able to manage, facilitating a sense of achievement and purpose, meeting her personal values. Therefore, a suggested element of an intervention to support this patient population is to build upon the hierarchy of personal values developed and support them in developing value-based goals within the limitations of their physical symptom presentation. The process of identifying value-based goals encompasses acknowledgement of imposed limitations, may also contribute to acceptance of living with COPD for some. Given the potential negative impact of disease non-acceptance of having the condition, such as non-adherence to symptom management and associated anxiety and depression (Boven *et al.*, 2014; Uchmanowicz *et al.*, 2016), this could be a further benefit of this intervention component.

Upon the development of value-based goals, further intervention content is required to guide the person living with COPD towards understanding ways to achieve them. This is required given the difficulties faced by this patient population through the presence of existential suffering, suggesting that for some knowing how to do this within the limitations of the condition would be challenging. Elements to be considered, extracted from the experiences revealed by the participants within this study, include practical suggestions upon how to meet common core personal values such as relationships and connections, purposefulness and social interactions. Possible examples of suggestions form this study include information on local support groups, such as BLF breathe easy, information on how to become involved in a patient educator role, information on local befriender services and descriptions of suitable social classes such as online seated dancing and others to reflect a broader range of interests. The inclusion of case studies, giving information to intervention users, from people living with COPD on how they have adapted to the condition and live a meaningful life may also be of benefit.

A suitable approach to develop the specific intervention content and method of delivery would be that of experience -based co-design, utilising the expertise of those living with COPD, specialist healthcare professionals and other relevant stakeholders (Raynor *et al.*, 2020), to consider it's usability and acceptability by all involved to enable maximum benefit. Given the insight revealed by participants, alongside the underpinning methodology of cultural probes, consideration for the use of specifically designed probes to be used as a part of an intervention to assist in the identification of meaningfulness may be possible. In particular, the rosette reflection card may be of benefit in guiding users towards remembering the value and contribution they have and do still make, allowing them to explore feelings of purposefulness. This would require further research to establish its suitability and validity for this purpose.

10.10 – Study strengths and limitations

The use of multiple data collection methods, cultural probes and narrative interviews, underpinned by a narrative ethnographic methodology, was a significant strength of this study. This methodology and associated research methods have not been used within studies exploring populations of people living with palliative care needs arising from COPD. The ethnographic insight into participants day-to-day lives, through the use of the cultural probes, allowed for unique thoughts and emotions to be revealed that may have remained hidden with alternative approaches (Gubrium and Holstein, 1995). Alternative research methods would have relied solely on recollection of thoughts and emotions, preventing the presentation of such detailed insights of meaningful elements in day-to-day life. Furthermore, the use of cultural probes with a narrative interview allowed for an understanding of personal and cultural influences upon participants day-to-day lives, and is coupled with a deep narrative exploration of their life experience and its impact.

The significant patient and public involvement throughout this study is another strength. The PPI group gave input into the study protocol design and topic of exploration. They contributed to the design of the cultural probes, by giving feedback upon their usability and acceptability within COPD patient populations. This valuable input gave confidence that this study is exploring an area of importance to those living with COPD (INVOLVE, 2012).

The pre-existing knowledge of the author of this thesis upon COPD and its care and management, due to previous experience as a respiratory specialist nurse was a strength of this study. This allowed the development of a good rapport with participants, who when discussing living with the condition, were confident in doing so. This was due to the development of a mutual understanding of its complexities, through an empathetic approach by the researcher. The risk of bias associated with this pre-existing knowledge, through the researcher potentially making assumptions upon participants day-to-day lives due to prior nursing experience was minimised through exploration of the study findings with the supervisory team.

A limitation of this study is that all participants attended a BLF breathe easy support group and were very engaged in their health and well-being. Participants revealed they were very aware of the benefits of self-management strategies when living with COPD and each identified purposeful activities within day-to-day life that in turn, generated the presence of meaning. This may have influenced the findings from this study and requires consideration when applying them to wider COPD populations. The sample size of six participants did not meet the calculated target of between 10-20, presenting limitations to the generalisability of results.

A further limitation of this study is that all participants were from the United Kingdom, therefore, the findings are culturally sensitive. This may hinder the generalisability across global COPD populations.

10.11 – Study Implications

The findings from this study present implications for healthcare professionals, for higher education and further research, and for consideration by policy developers.

10.11.1 – Implications for Clinical Practice

The findings from this study offer a novel perspective upon how meaningfulness is derived within the day-to-day lives of those living with palliative care needs arising from COPD, through personal value congruence and taking control of their personal dignity. Furthermore, the findings have revealed how an interruption in meaningfulness is also present due to a sense of a loss of control and the presence of future worries. The development of a conceptual framework to illustrate this can be used by healthcare professionals to inform evidence-based practice. The development of an intervention to support those living with palliative care needs arising from COPD, to identify meaningfulness within day-to-day life, will enable healthcare professionals to contribute towards addressing existential suffering within this population by signposting patients towards it. Consideration needs to be given to the format of such an intervention to ensure its usability within the restraints of clinical practice.

10.11.2 – Implications for Policy

The findings give insight into the impact of the presence and interruption of meaningfulness within day-to-day life for those living with palliative care needs arising from COPD. Current healthcare policy upon palliative care for those living with COPD suggests individuals' existential needs are met, however there is little guidance upon how to assess their existential situation and meet their individual needs (NICE, 2018; Global Initiative for Chronic Obstructive Lung Disease, 2023; Janssen *et al.*, 2023).

Policy developers may wish to consider the significance of the presence and interruption of meaningfulness in day-to-day life for individuals living with palliative care needs arising from COPD, and utilise this study's findings alongside the wider evidence base to make recommendations for clinical practice to ensure holistic palliative care delivery. The presence of meaningfulness is of importance to individuals living with the condition, and as such, requires formalising as a part of their assessment and care planning.

10.11.3 – Implications for education

For academics delivering healthcare education to future healthcare professionals, the findings of this study will inform them of a novel perspective upon the existential situation of those living with palliative care needs arising from COPD. The findings offer opportunity for exploration within teaching sessions upon the concepts of personal value congruence, personal dignity, and personal value incongruence to allow learners the opportunity to better understand the Asklepian elements of palliative care.

10.11.4 – Implications for further research

This study has made a novel contribution to the existing evidence base upon how individuals living with palliative care needs arising from COPD identify, and experience interruption to, the presence of meaningfulness within day-to-day life. There is the need for further research to build upon the findings from this study to develop an intervention to support this patient population.

Firstly, the development and evaluation of an assessment tool to identify the personal values of importance to those living with COPD, and how they are currently met is required. This work will then inform the content required to develop, implement and evaluate a value-based intervention to support individuals with COPD to meet their personal values, and offer support and signposting in meeting them. The impact of this intervention will require further evaluation in the context of meeting the participants existential need of life meaning. An experience-based co-design approach would be an appropriate method to adopt.

Further research is required to determine the use of cultural probes in other patient populations receiving palliative care, to better understand the unique insights into day-to-day life it is able to capture. The evaluation of the co-production of the cultural probes would also offer an interesting and valuable insight into the use of this novel research method within palliative care research.

Chapter 11 – Conclusion

This study aimed to explore the presence, absence and impact of meaningfulness in the day-to-day lives of those living with palliative care needs arising from COPD. The study findings present a novel insight into how the presence of meaning in day-to-day life is generated through personal value congruence and taking control of personal dignity. Interruptions to the presence of meaningfulness occur due to personal value in congruence.

Narrative ethnography was a methodological approach of value, enabling a multi-dimensional insight into how those living with palliative care needs arising from COPD generate meaning in day-to-day life. Figure 89 presents a conceptual framework to illustrate how participants identified and faced interruption to the presence of meaningfulness in day-to-day life. The seminal work of Victor Frankl (1963) upon 'w*ill-to-meaning'*, alongside the concept of engagement within life presented by Yalom (1980) have been valuable in explaining how individuals are able to generate meaning in life. Engagement in life and exercising their freedom to respond enables the individual to identify personal values of importance to them, alongside ways to meet these values. This enables individuals to take control of their own dignity, through asserting control over their life choices, underpinned by an acceptance of the new limitations imposed by COPD.

Interruptions to the presence of meaningfulness were evident, with the concept of 'hope' being a useful insight into interpreting this. The presence of hope facilitates individuals being able to navigate periods of uncertainty over time.

Further research is required to develop an intervention to support those living with palliative care needs arising from COPD to identify meaningfulness within day-to-day life as a contribution towards improving palliative care provision for this patient population.

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Appendices

APPENDIX A – Integrative Review included paper study characteristics

Reference Author (year) Country	Study Purpose	Recruitment Setting and Sample Size	Severity of COPD	Participant Characteristics	Methods	Analysis	Findings
1. Brien et al (2015) *United Kingdom*	Explore and understand variances in coping strategies and experiences in COPD	Purposive sample from primary and secondary care sites – maximum variation sample across disease severity. 34 Participants	14 participants classified as having either severe or very severe COPD	9 participants had a very high score on health-related QOL impact of COPD.	Semi-structured interviews	Thematic analysis	Coping strategies commonly used are medication, pacing with activities of living and distraction. Challenges to coping are psychological and co-morbidities
2. Cooney et al (2013) *United Kingdom*	To understand the meaning of COPD for people and their response to the disease.	Purposive sample leading to theoretical sample from primary care settings. 26 Participants	Participants from within PRINCE RCT (2012) – 31.5% of intervention group (interviewed in this study) had severe COPD	26 participants 15 Male/11 Female	Grounded Theory study design. Semi-structured Interviews	Constant comparative technique	The meaning of living with COPD includes hiding from the disease, older patients attribute symptoms as a normal part of growing older, COPD presents significant restrictions upon daily life
3. Cruz et al (2017) *Portugal*	To determine the impact of COPD upon family caregiving	Integrative Review. 18 included studies	Included studies had participants with severe/advanced/terminal COPD	N/A	Integrative literature review	Thematic synthesis	Caring for someone with COPD is a stressful experience, carers perceived a loss of identity and personal freedom.

Reference Author (year) Country	Study Purpose	Recruitment Setting	Severity of COPD	Participant Characteristics	Methods	Analysis	Findings
4. Disler et al (2014) *Australia*	To understand the experience and ongoing needs of people living with COPD	Qualitative Systematic Review. 22 included studies	Review focus upon individuals with advanced COPD	N/A	Meta-synthesis of Qualitative data	Thematic synthesis – descriptive and analytical themes	Themes identified for use when caring for those with COPD included a better understanding of the condition and the unrelenting psychological impact.
5. Dunger et al (2015) *Germany*	Explore the meaning of breathlessness in patients with COPD and lung cancer at the end of life	Primary and secondary care including palliative care units .10 patients with COPD	Sample constructed of participants with Severe or Very severe COPD. Focus upon symptoms at end of life	10 participants with COPD 4 Male/6 Female	Topic-guided in-depth interviews	Framework analysis	The impact of breathlessness causes disruption to how life is lived. This disruption causes feelings of despair and hopelessness.
6. Ek and Ternestedt (2008) Sweden	An exploration of the lived experience when living within the palliative phase of COPD	Secondary care 8 participants	Advanced COPD	1 male/3 female All participants with COPD receiving long-term oxygen therapy	Semi-structured interviews	Phenomenological-hermeneutical analysis	Living with COPD in a couple resulted in living with uncertainty, a changed intimate relationship and developing new ways of living together
7. Ek et al (2011)	An examination of couples experiences of living together when one has COPD	Primary Care	Considered to be in the final phase of COPD disease progression	4 couples/8 participants	Repeated interviews over an 8-month period	Dialectical movement analysis	An awareness of the importance of personal values facilitating daily structure

Reference Author (year) Country	Study Purpose	Recruitment Setting	Severity of COPD	Participant Characteristics	Methods	Analysis	Findings
8. Eloffson & Ohlen (2004) *Sweden*	To achieve a deeper understanding of the meaning of the lived experiences of those with COPD needing everyday care	Secondary care. 6 participants	Advanced COPD	Aged 78-88 years' old	Narrative dialogues	Phenomenological analysis	Participants had feelings of resignation and sadness . they had little interest in hobbies and found living with COPD to be a hard life. Socialising was important to give the individual a sense of identity.
9. Gabriel et al (2014) *Portugal*	Explores the perspectives of patients and family members upon the impact of COPD in family life	Primary and Secondary care. 40 participants	60% of participants	20 patients – 16 male/14 female 20 family member's – 12 spouses, 8 adult children	Open-ended question interviews	Descriptive statistical thematic analysis	Coping strategies used to handle the difficulties of living with COPD included socialisation, help from professional networks and seeking relevant information about COPD.
10. Gale and Sultan (2013) *United Kingdom*	To understand how participants with COPD incorporated telehealth technologies into their everyday life	Community setting. 7 participants	6 participants has severe/very severe COPD	5 male/2 female	Situated interviewing	Thematic analysis	The telehealth intervention gave participants peace of mind through contact with healthcare professionals and through increasing their own self-confidence.

Reference Author (year) Country	Study Purpose	Recruitment Setting	Severity of COPD	Participant Characteristics	Methods	Analysis	Findings
11. Gardener et al (2018) *United Kingdom*	Qualitative systematic review of the support needs for those living with COPD	Not Applicable 31 included papers	Within included studies, participants all symptomatic of breathlessness – palliative need	N/A	Qualitative Systematic literature review	Thematic analysis mapped to palliative and end of life care policy.	Identified support needs of patients included understanding COPD, managing feelings and worries, families and close relationships and social and recreational life
12. Gardener et al (2019) *United Kingdom*	To develop a support tool to enable patients to express their support needs to healthcare professionals	Primary Care	All participants had advanced COPD	57 participants - patients/carers/healthcare professionals	Focus groups	Content Analysis	Development, refinement and review of support needs tool to enable delivery of person-centred care
13. Harb et al (2017) *Australia*	Patient perceived treatment burden of COPD	Primary Care	Severe COPD	26 participants – 15 Female/11 Male	Semi-structured interviews	Framework analysis	COPD has a substantial treatment burden
14. Hayle et al (2013) *United Kingdom*	To evaluate the experiences of patients with COPD who accessed Palliative care	Community or Hospice setting	All receiving palliative care	5 male/ 3 female	Semi-structured interviews	Hermeneutic phenomenological approach	Specialist palliative care was perceived to have a positive impact upon psychological symptoms.

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
15. Lee et al (2018) *Canada*	To explore how individuals with COPD experience pain	Community setting	7 participants had severe or very severe COPD and pain	6 male/ 2 female	Semi –structured interviews	Interpretive Phenomenological Analysis	COPD participants found difficulty in explaining pain resulting in feelings of frustration and loss of self-worth
16. Lindqvist and Hallberg (2010) *Sweden*	Theoretical development of the main concerns for those living with COPD	Secondary care 23 participants	13 participants had severe COPD	10 male/ 13 female	Semi –structured interviews	Grounded theory	Suffering from COPD resulted in feelings of guilt as a result of self-infliction. This was linked to management strategies including making sense of existence, adjustment to bodily restrictions, surrendering to fate.
17. Lovell et al (2019) *United Kingdom*	To review the main concerns of people with advanced illness experiencing breathlessness	Qualitative systematic review. 38 included studies	Total of 672 participants within included studies	Participants within included studies had severe/very severe COPD	Qualitative systematic review	Thematic synthesis	The importance of social participation and activities is of importance to individuals with COPD

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
18. Marx et al (2016) *Germany*	An exploration of what it means to live with COPD as an incurable and constantly progressing disease	Community setting 17 participants	All participant had advanced COPD	10 male/ 7 female	Qualitative longitudinal study Narrative semi-structured interviews	Grounded theory	Patients with COPD have difficulties accepting their life situation and feel at mercy of the disease
19. May et al (2016) *United Kingdom*	Qualitative systematic review to characterise the factors influencing patient and caregiver experience of chronic heart failure, COPD and chronic kidney disease	Qualitative systematic review 53 included papers	Participants within included papers had severe/very severe COPD	Not applicable	Qualitative content analysis	Thematic synthesis	People living with COPD have significant pathophysiological deterioration. COPD disrupts social networks and gives associated feelings of dependence and vulnerability.
20. Olsman et al (2015) *Netherlands*	To describe hope, hopelessness and despair as experienced by palliative care patients	Community and Hospice setting 29 participants	COPD participants had significant palliative care needs	10 participants had COPD	Qualitative longitudinal method Semi-structured interviews	Thematic analysis	COPD presents feelings of hope for the future, hopelessness and despair

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
21. Russell et al (2018) *United Kingdom*	Qualitative systematic review of the barriers and facilitators to self-management in COPD	Qualitative systematic review 33 studies included in review	Participants within included papers had severe/very severe COPD	Participants from within included studies Male/ Female	Qualitative content analysis	Thematic analysis	Over time, COPD can consume existence and reduce motivation. Family support may prove vital yet trigger feelings of being a burden
22. Sheridan et al (2011) *New Zealand*	An exploration of how patients with COPD experience helplessness	Community setting 29 participants	Participants had server/very severe COPD	15 Male/ 14 Female	Semi-structured interviews	Thematic analysis	All participants expressed feelings of helplessness in managing their condition.
23. Strang et al (2014) *Sweden*	An exploration of severe COPD patients experiences of anxiety	Community and clinic settings 31 participants	14 participants had severe/very severe COPD	15 Male/ 16 Female	In-depth interviews	Thematic content analysis	Three themes identified contributing to anxiety associated with COPD – death anxiety, life anxiety and counterweights to anxiety.
24. Stridsman et al (2015) *Sweden*	Describe the experience of well-being amongst people with COPD	From a previous study	All participants had severe/very severe COPD	10 participants	Semi-structured Interviews	Latent Qualitative Content Analysis	Participants adjusted to new limitations through acceptance and undertaking new activities

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
25. Chochinov et al (2016) *Canada*	The identification of 4 non-cancer population whom may benefit from a palliative care approach alongside a comparison of dignity related distress	Outpatient departments, care homes, inpatient care settings	Participants with COPD classified as very severe	100 participants with advanced COPD, End stage renal disease, Amyotrophic lateral sclerosis	Prospective multi-site approach.	Descriptive statistics using Patient Dignity Inventory.	Participants with COPD face a loss of personal dignity. Patterns of existential distress identified.
26. Doyle et al (2017) *Australia*	RCT to investigate the impact of CBT and befriending on anxiety and depression in people with COPD	Community setting 95 Participants	32% of participants had severe COPD	37 Male /73 Female	Pragmatic RCT	Intention to treat analysis	CBT Therapy reduced depression symptoms but not anxiety.
27. Harrison et al (2016) *Canada*	To explore how self-conscious emotions are expressed and linked to adverse health outcomes in those with COPD	Community setting 15 participants	9 participants had severe or very severe COPD	6 male/ 9 female	Mixed method study. Semi-structured interviews and Questionnaires	Inductive thematic analysis Pearson correlations	Self-conscious emotions were related to elevated anxiety and depression.

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
28. Ivziku et al (2018) *Italy*	To assess the impact of anxiety and depression upon quality of life in COPD and caregiver dyads	Outpatient setting 80 Participants	49 participants had severe or very severe COPD	45 Male/ 35 Female	Patient health questionnaire Generalised Anxiety Disorder questionnaire 12-Item Short form health survey	Descriptive statistics Pearson's product-moment correlation coefficients	Caregivers psychological distress influences patient's physical quality of life.
29. Keil et al (2017) *Germany*	To investigate the potential protective factors sense of coherence, resilience and social support and their relationship to different outcomes	Community setting 531 participants	406 participants had severe/very severe COPD	260 male/ 271 female	Online survey utilising COPD disability index, Hospital Anxiety and Depression Scale, Antonovsky's sense of coherence scale, 13-item Resilience Scale	Multiple linear regression analyses	Sense of coherence and resilience hold potential to assist adjustment to living with COPD.
30.Low et al (2013) *Canada*	An exploration on the perspectives of ageing for those living with COPD	Community Setting 87 Participants	38 participants had severe COPD	40 male/ 47 female	Cross-sectional survey study	Multiple analysis of variance	Participants downplayed their symptoms of COPD and psychosocial impact.

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
31. Reijnders et al (2018) *Germany*	An examination of the association between loneliness and outcome measures for pulmonary rehabilitation	Inpatient setting 104 participants	45 participants had severe/very severe COPD	73 Male/ 31 Female	Face to face questionnaire completion -6 minute walk test, De Jong Gierveld Loneliness Scale, The patient health questionnaire, Health-related quality of life questionnaire	Hierarchical linear regression	Loneliness identified in COPD and impacts upon ability to undertake pulmonary rehabilitation. Loneliness associated with poor exercise function.
32. Stenzel et al (2015) *Germany*	An investigation of how socio-demographic variables, illness severity, psychological distress and disease-specific anxieties predict end of life fears in COPD	Inpatient setting 131 participants	101 participants had severe/very severe COPD	76 Male/ 55 Female	Self-report questionnaires	Regression and mediation analysis.	End of life care should not only be based upon physical illness symptoms but also upon psychological distress and disease-specific anxieties.

Reference Author (year) Country	**Study Purpose**	**Recruitment Setting**	**Severity of COPD**	**Participant Characteristics**	**Methods**	**Analysis**	**Findings**
33. Vaske et al (2017) *Germany*	An investigation into the illness perceptions and coping on HR-QOL in COPD	Secondary Care	342 participants had severe or very severe COPD	216 Male/228 female	Online Questionnaires: Illness Perceptions Questionnaire/Essener Coping Questionnaire/HR-QOL Short Form	Hierarchical regression and moderation analysis	To prevent reduced HR-QOL in COPD, treatment needs to include promotion of coping with the disease and functional illness perceptions.
34. Vitacca et al (2019) *Italy*	To test the feasibility and acceptability of an advanced care plan for COPD at home with telehealth follow up to manage palliative topics	Inpatient and outpatient settings	All participants had severe/very severe COPD	8 Male/ 2 Female	Self-report questionnaires	Data expressed as an absolute number of percentage	Bad days of life, negative emotions and perception of disease deterioration were topics discussed by patients. Telehealth is accepted by patients.
35. Rosa et al (2017) *Italy*	Mixed methods study to explore the application of the concept of resilience to chronic illness management in adults with COPD	Integrative Literature Review 20 papers reviewed	Included papers contained participants with severe/very severe COPD	Not applicable	Integrative Literature review	Thematic synthesis	Resilience is a useful concept when understanding family caregiving within COPD.

APPENDIX B – Quality Assessment of Included Studies in Integrative Review

Paper No	Author/Date	Clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to meet aims?	Recruitment strategy appropriate to meet aims?	Data collected to address research issue?	Reflexivity considered?	Ethical consideration?	Rigorous data analysis?	Clear statement of findings?	Value of research
1	Brien et al (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for new research.
2	Cooney et al (2013)	Yes	Yes	Yes	Yes	Yes	Not Clear	Yes	Yes	Yes	Contributes new knowledge.
3	Cruz et al (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for new research.
4	Disler et al (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for new research.
5	Dunger et al (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for new research.
6	Ek & Ternestedt (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for new research.

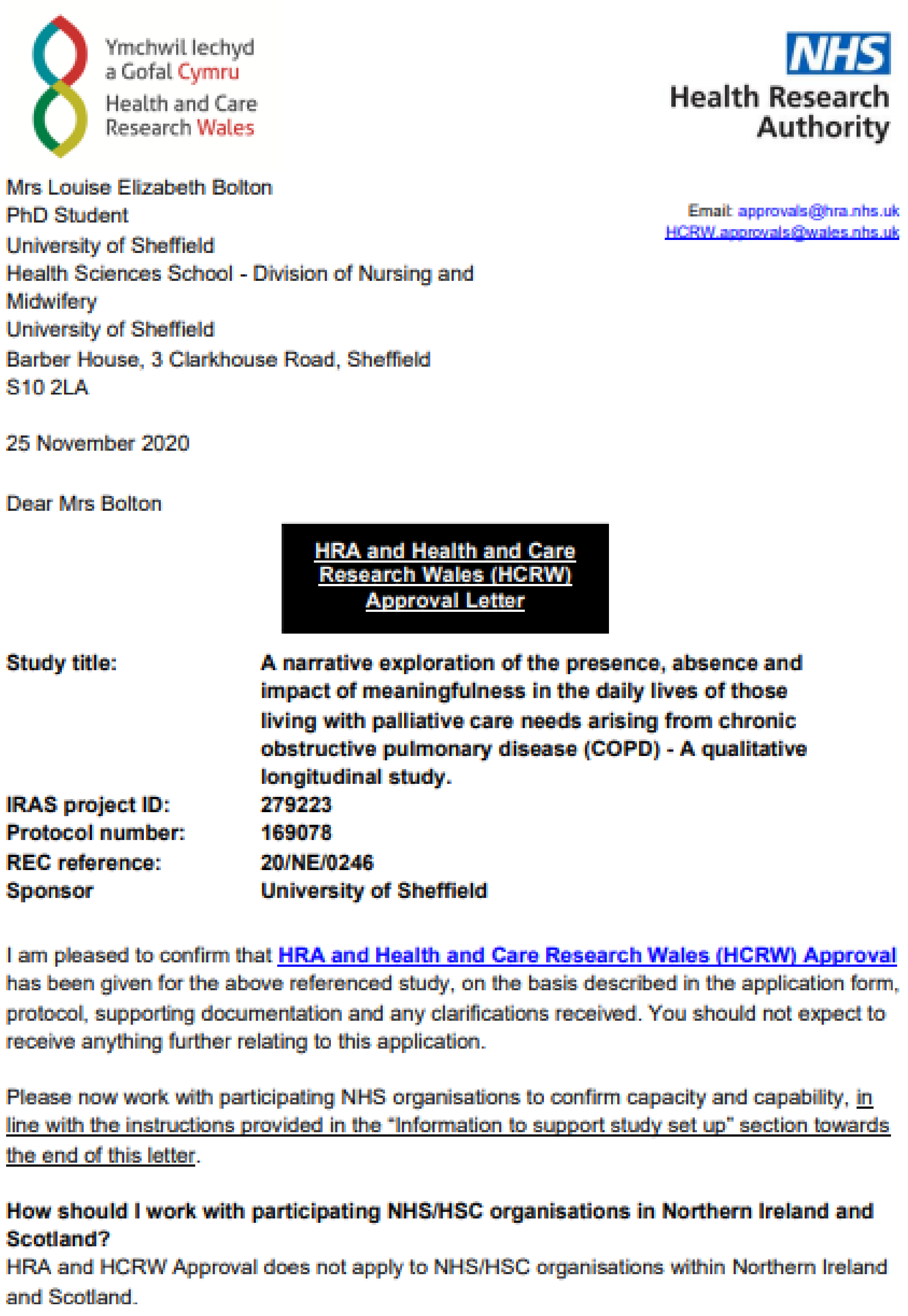
Paper No	Author/Date	Clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to meet aims?	Recruitment strategy appropriate to meet aims?	Data collected to address research issue?	Reflexivity considered?	Ethical consideration?	Rigorous data analysis?	Clear statement of findings?	Value of research
8	Eloffson & Ohlen (2004)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies implications for clinical practice
9	Gabriel et al (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies need for further research
10	Gale & Sultan (2103)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge
11	Gardener et al (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies implications for clinical practice
12	Gardener et al (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge and identifies further empirical work.
13	Harb et al (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes to new knowledge. Clear implications for clinical practice given

Paper No	Author/Date	Clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to meet aims?	Recruitment strategy appropriate to meet aims?	Data collected to address research issue?	Reflexivity considered?	Ethical consideration?	Rigorous data analysis?	Clear statement of findings?	Value of research
14	Hayle et al (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge and identifies further empirical work.
15	Lee et al (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	yes	Contributes new knowledge
16	Lindqvist & Hallberg (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contribution to new knowledge
17	Lovell et al (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contribution to new knowledge. Identifies need for further research
18	Marx et al (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge
19	May et al (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge
20	Olsman et al (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contribution to new knowledge. Identifies need for further research
21	Russell et al (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contribution to new knowledge. Identifies need for further research

Paper No	Author/Date	Clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to meet aims?	Recruitment strategy appropriate to meet aims?	Data collected to address research issue?	Reflexivity considered?	Ethical consideration?	Rigorous data analysis?	Clear statement of findings?	Value of research
22	Sheridan et al (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contribution to new knowledge. Identifies need for further research
23	Strang et al (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies implications for clinical practice
24	Stridsman et al (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge. Identifies implications for clinical practice
27	Harrison et al (2017) Mixed Methods Study	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge
35	Rosa et al (2015) Mixed Methods Systematic Review	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Contributes new knowledge

Paper No	Author/Date	Clear cause and effect?	Participant comparisons similar?	Participants receiving other treatment?	Control group?	Multiple outcome measurements?	Follow up complete?	Outcomes measured in the same way?	Outcomes measured reliably?	Appropriate statistical analysis?
25	Chochinov et al (2016)	n/a	n/a	n/a	n/a	Yes	n/a	Yes	Yes	Yes
26	Doyle et al (2017)	Yes	Yes	No	No	Yes	Yes	Yes	Yes	yes
27	Harrison et al (2017) Mixed Methods Study	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	yes
28	Ivziku et al (2019)	Yes	Yes	Yes	n/a	Yes	n/a	Yes	Yes	yes
29	Keil et al (2017)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes
30	Low et al (2013)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes
31	Reijnders et al (2018)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes
32	Stenzel et al (2015)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes
33	Vaske et al (2017)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes
34	Vitacca et al (2019)	n/a	n/a	n/a	n/a	Yes	Yes	Yes	Yes	Yes

APPENDIX C – Health Research Authority – Research Ethics Committee Approval Documents



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Louise Elizabeth Bolton
PhD Student
University of Sheffield
Health Sciences School - Division of Nursing and Midwifery
University of Sheffield
Barber House, 3 Clarkhouse Road, Sheffield
S10 2LA

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

25 November 2020

Dear Mrs Bolton

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**A narrative exploration of the presence, absence and impact of meaningfulness in the daily lives of those living with palliative care needs arising from chronic obstructive pulmonary disease (COPD) - A qualitative longitudinal study.**
IRAS project ID:	**279223**
Protocol number:	**169078**
REC reference:	**20/NE/0246**
Sponsor	**University of Sheffield**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **279223**. Please quote this on all correspondence.

NHS
Health Research
Authority

North East - Newcastle & North Tyneside 2 Research Ethics Committee
NHS BT Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

28 June 2021

Mrs Louise Elizabeth Bolton
Health Sciences School - Division of Nursing and Midwifery
Barber House
3 Clarkhouse Road, Sheffield
S10 2 LA

Dear Mrs Bolton

Study title: **A narrative exploration of the presence, absence and impact of meaningfulness in the daily lives of those living with palliative care needs arising from chronic obstructive pulmonary disease (COPD) - A qualitative longitudinal study.**
REC reference: **20/NE/0246**
Protocol number: **169078**
Amendment number: **180154700**
Amendment date: **24 May 2021**
IRAS project ID: **279223**

The above amendment was reviewed on 29 June 2021 by the Sub-Committee in correspondence.

Ethical opinion

The Sub-Committee did not raise any ethical issues. The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment Tool - IRAS 279229]	180154700	24 May 2021

Letters of invitation to participant [Invitation to participate letter - Carer - IRAS 279229]	2.0	11 June 2021
Letters of invitation to participant [Invitation to participate letter - Participant - IRAS 279229]	2.0	11 June 2021
Participant information sheet (PIS) [Participant Information Sheet - Version 3.0 - IRAS 279229]	3.0	11 June 2021
Research protocol or project proposal [Study Protocol - Version 3.0]	3.0	24 May 2021
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Overview - IRAS 279229]	2.0	11 June 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

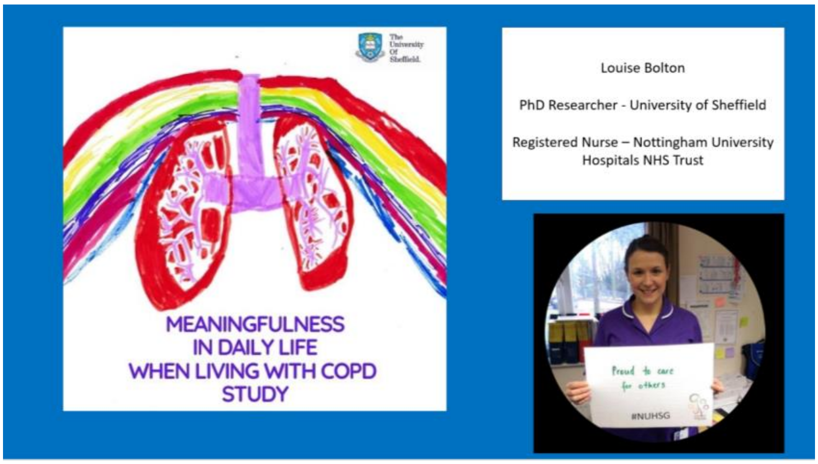
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 279223: Please quote this number on all correspondence

Yours sincerely

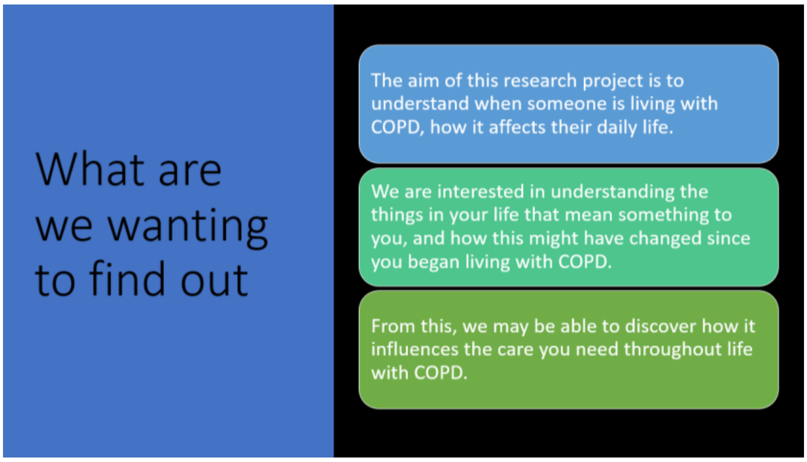
APPENDIX D – Study Recruitment Presentation


MEANINGFULNESS
IN DAILY LIFE
WHEN LIVING WITH COPD
STUDY

Louise Bolton

PhD Researcher - University of Sheffield

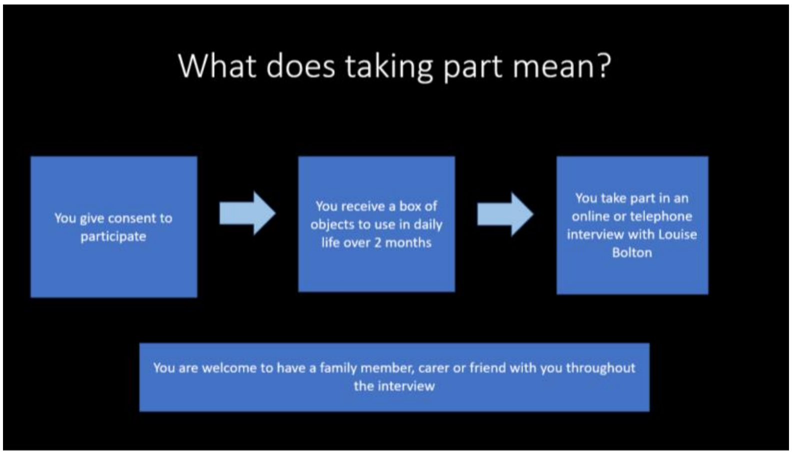
Registered Nurse – Nottingham University Hospitals NHS Trust


What are we wanting to find out

The aim of this research project is to understand when someone is living with COPD, how it affects their daily life.

We are interested in understanding the things in your life that mean something to you, and how this might have changed since you began living with COPD.

From this, we may be able to discover how it influences the care you need throughout life with COPD.


What does taking part mean?

You give consent to participate

You receive a box of objects to use in daily life over 2 months

You take part in an online or telephone interview with Louise Bolton

You are welcome to have a family member, carer or friend with you throughout the interview

Objects?

- You don't have to use them all – just the ones you feel comfortable with
- Posted to you and return postage arranged

Who do we need to take part?

- Have a diagnosis of COPD
- Under the care of a COPD team
- Over 65 years of age
- Attends Breathe Easy support groups
- You believe that living with COPD impacts your ability to undertake daily activities

How can I get more information?

Give	Give your contact details to your Breathe Easy group leader and information will be sent to you.
Telephone	Telephone Louise Bolton (Lead Researcher) on [redacted]
Email	Email Louise Bolton (Lead Researcher) on [redacted]

APPENDIX E – Invitation to Participate Letter

Division of Nursing and Midwifery
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxxx
Email:xxxxxxxx

Date: 30th July 2021

Dear xxxx ,

The 'Meaningfulness in daily life when living with COPD' study is a research project being undertaken by a student researcher at the University of Sheffield as a part of her PhD. The project aims to understand what means something to people living with COPD in their daily lives, and how this may have changed throughout living with the condition.

The project aims to recruit 10-15 people living with COPD over the next six months to help with this important research. The research team are looking for participants who meet the following criteria:

- Over 65 years of age
- Under the care of a COPD team
- Attends Breathe Easy support groups
- Believes that living with COPD impacts their ability to undertake daily activities

Taking part in the project involves using some objects to capture things that mean something to you, like a camera and keeping a journal. After using these objects for two months, you will be asked to take part in an interview to discuss them which will last no more than two hours. The interview will be very informal and would happen via the telephone or online via Zoom or Skype, to minimise any inconvenience to you. Your responses in the interview will be audio recorded (not video recorded), and will be kept strictly confidential. Each interview will be given a unique code to ensure your personal information is not revealed when the results are analysed and published.

The research team understand that talking about personal feelings and experiences may cause you to feel anxious about taking part in a research project. If preferred, a spouse, partner or family member may be with you during the interview. The research team also understand that talking for excessive periods of time may not be possible due to your lung condition and this will be considered throughout the interview process.

Should you decide to take part and then change your mind at some point in the project, then you are free to leave the project at any time without giving a reason.

There is no compensation for taking part in this study. However, taking part will be a valuable addition to our research and findings to inform future care for people living with COPD.

If you are interested in taking part and would like some more information, please contact Mrs Louise Bolton (Lead researcher) using the details below:

Mrs Louise Elizabeth Bolton
Doctoral Student
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxxx
Email:xxxxx

Thank you for taking the time to read this letter and I look forward to hearing from you.
Yours sincerely

Louise Bolton

APPENDIX F – Participant Information Sheet

Participant Information Sheet

Meaningfulness in daily life when living with Chronic Obstructive Pulmonary Disease (COPD)

Investigators:

Mrs Louise Bolton (PhD Student, University of Sheffield)

Dr Clare Gardiner (Senior Research Fellow, University of Sheffield)

Professor Jane Seymour (Emeritus Professor, University of Sheffield)

Dear Participant,

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read this information carefully. You may want to talk to other people about taking part before you decide. Please ask us if there is anything that is not clear, or if you would like more information.

Take time to decide if you wish to take part. Thank you for reading this.

Why are we doing this project?

The aim of this research project is to understand when someone is living with COPD how it affects their daily life. In particular, we are interested in understanding the things in your life that mean something to you, and how this might have changed since you began living with COPD.

We would like to look at this by giving you some items to use over a 2-month period, such as a camera and a journal. You will be invited to take part in an interview with the lead researcher to discuss the items and how COPD affects your daily life.

By doing this research project, it will give us information to share with doctors, nurses and other healthcare professionals to help improve the care and support we give to people with COPD. This project is expected to be finished before February 2022.

The lead researcher for this project (Mrs Louise Bolton) is completing it as a part of a programme of education at the University of Sheffield under the supervision of Professor Jane Seymour (Emeritus Professor, University of Sheffield) and Dr Clare Gardiner (Senior Research Fellow, University of Sheffield).

Why have I been chosen?

You have been asked to think about taking part in this project as you live with the lung condition COPD.

We are looking for between ten and fifteen people living with COPD to take part in the project who meet the following criteria :

- Over 65 years of age
- Under the care of a COPD team
- Attends Breathe Easy support groups
- Believes that living with COPD impacts their ability to undertake daily activities

Do I have to take part?

No. taking part in this project is your choice. If you choose not to take part, this will not affect your care in any way.

If you do take part and then change your mind at any point within the project, then you can inform the research team by telephone or email (using the details at the end of this information sheet), and you immediately stop being involved. You do not need to give a reason for you choosing to stop.

What will happen to me if I take part? What do I have to do?

Taking part in this project will last up to 6 months. You will have contact, via telephone or an online audio call (Via Sype or Zoom), with the lead researcher between 4 and 6 times.

If you choose to take part in the project, you will be sent some items to use in your daily life (including a camera, a journal and some postcards). The items that you are given to use are called Cultural Probes. They have been specifically designed to be used in this project. The purpose of the cultural probes is to allow you to record things in your life that mean something to you in your own time. You would have these items for 2 months, and then return them to us before you took part in an interview upon the things in your life that are meaningful to you. A pre-paid courier will be arranged for them to be returned.

During this 2-month period, the lead researcher would speak with you twice times to discuss how to use them and make sure you still wish to take part.

The data we collect from these items, such as the photographs and journal entries will be converted into securely stored digital computer files. The original items will then be destroyed or returned to you if you would like to keep them. The data will be made anonymous when we store it by using a unique number allocated to you. There will be no reference to your name when it is stored.

Some of the data you are providing may identify you or others, such as photographs or journal entries. As such, this data is not able to be made completely anonymous. These images may be used when the research team present the results in healthcare journals or at conferences. Please be assured the research team will never share any personal details of whom the data belong to. We will only use it for the purposes of sharing the study findings to improve patient care for people living with COPD.

We would then ask you to take part in an interview, either via telephone or via an online video call (such as Zoom or Skype). The call will be audio recorded (not video). As soon as the interview is completed, the audio recording will be transcribed. This will be completed by the lead researcher and checked by her supervisors. The original audio file will then be permanently deleted. The transcription will be anonymised by again using a unique number allocated to you so you are unable to be identified from the transcription.

The interviews will be very informal to allow you to feel comfortable in telling your story. There will be very few planned questions as we will use the cultural probes that you have used to decide what we talk about. During the interview, the lead researcher will make notes upon things you have said, any emotions you expressed and other observations of the conversation. These are referred to as ‘field notes’. As soon as the interview is complete, these field notes will be scanned to digital files, anonymised with your unique number and the originals securely destroyed. The digital files will be securely stored.

The steps of the project are outlined on the next page:

The Process of taking part:

Telephone Call	Purpose	Length of meeting and location
1 You will contact the lead researcher to gain information on taking part in the project.	To explain the project and answer any questions. If you choose to take part, you will be given the opportunity to give consent to do so within this telephone call. If you do give consent to take part, you will then be sent, by courier, the items we would like you to use. Each item has an instruction card attached. postcards) over the next 2 months. Following this telephone call, your GP and COPD Nursing team will be informed that you are taking part in the study.	Up to 60 minutes via telephone. The lead researcher will telephone you back to ensure you do not pay for the cost of the call.
2 **(Optional)**	If at telephone call 1 you decided you wanted more time to think about taking part, a second telephone call will be arranged to answer any questions and for you to give consent to take part. If you do give consent to take part, you will be sent via post some items to use with instructions (such as a camera, journal, postcards) over the next 2 months. Following this telephone call, your GP and COPD Nursing team will be informed that you are taking part in the study.	Up to 60 minutes via telephone. The lead researcher will telephone you to ensure you do not pay for the cost of the call.
3 & 4	The lead researcher will telephone you to ensure you remain comfortable with using the items you have been sent and remain happy to continue. If you have any questions, they can be answered within these conversations. The lead researcher will ask you within these telephone calls if you are experiencing any changes in your emotions as a result of taking part, and if so, advise you contact your GP, COPD Nursing team or self-referral mental health service.	Up to 30 minutes per telephone call. The lead researcher will telephone you to ensure you do not pay for the cost of the call.
Telephone Call	**Purpose**	**Length of meeting and location**
5	You will be asked to take part in an interview allowing you to explain the things that give you meaning in your life when living with COPD. The items you have completed will be used to help this discussion.	Up to 2 hours – via telephone/zoom or skype. 2 hours is an absolute maximum

	The interview will be very informal, giving you the opportunity to openly talk.	and you will guide the length of time you wish to speak for. Full instructions on how to use will be sent to you via email. If at any time in the interview you wish to stop, the interview can be finished at another time.
6 **(Optional)**	If after the first interview, you and the researcher decide that a second interview is needed, this can be arranged to complete the discussion.	Up to 2 hours – via telephone, Zoom or Skype. Full instructions on how to use will be sent to you via email.

What are the possible disadvantages and risks of taking part?

The research team understand that by using the cultural probes and talking about how your life may have changed through having COPD, you may feel changes in your emotions. Please be assured that the research team have considered this.

Should you agree to take part in the study, you GP will be informed so they are aware you may experience potential changes in your emotions. If at any time during the study you feel that you need some emotional support as a result of taking part, you will be able to contact your GP or COPD Nursing team for assessment. The lead researcher will also provide you with the details of local self-referral mental health services at the time you receive your cultural probes.

The lead researcher will contact you twice throughout the 2-month period you are using the cultural probes to ensure you remain comfortable to carry on using them and to answer any questions you have.

If at any time throughout the study you wish to no longer take part, you are able to stop and do not have to give a reason.

What are the possible benefits of taking part?

There is no financial compensation for taking part in this study. However, taking part will be a valuable addition to our research and findings to inform future healthcare.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Date of Birth
- Address
- Email address
- Information from you on your diagnosis of COPD

People will use this information to do the research and to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to Louise Bolton - nra05leo@sheffield.ac.uk
- by ringing us on 07851293275

What will happen to the data collected, and the results of the research project?

The data collected within this project will only be accessed by the research team. The data will be made anonymous as soon as physically possible after it has been collected, this will be completed by the lead researcher.

When the project is completed, the results will be published at conferences and in health care related journals. You will not be able to be identified within these publications.

Your personal data (name, address, date of birth) will be destroyed as soon as you have completed your interview. Your anonymised data (interview notes and transcripts, digital files of photographs and journal entries) will be saved in secure and password protected computer files for ten years after the end of the project.

Who is organising and funding the research?

This research project has been funded by the Royal College of Nursing.

Who is the data controller?

The University of Sheffield will act as the Data Controller for this study. This means that they are responsible for looking after your personal information and using it properly.

Who has ethically reviewed the project?

This research project has been ethically approved by the Health Research Authority who assess and monitor that the research ensures participants are at minimal risk of harm, they are able to make an informed choice to participate and their information is kept confidential throughout.

What if something goes wrong and I want to complain about the research?

If you wish to raise a concern about the research, you can contact the following person who is independent of the study:

Professor Tony Ryan
Head of Division
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxxx
Email: xxxx

Contact for further information
For further information and to register your interest in the project, please contact:

Mrs Louise Elizabeth Bolton - Lead Researcher
Doctoral Student
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxx
Email: xxxx

Should Mrs Bolton be unavailable, please contact her academic supervisor and member of the research team at the University of Sheffield:

Dr Clare Gardiner
Senior Research Fellow
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxx
Email: xxxx

APPENDIX G – PARTICIPANT CONSENT FORM

The
University
Of
Sheffield.

Meaningfulness in daily life when living with COPD Project

Participant Consent Form

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated INSERT DATE/VERSION OF DOCUMENT or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include me using objects such as a camera, journal, Dictaphone, map over a 2-month period at home. I will receive guidance on how to use these. I agree to then participate in an interview, which will be audio recorded that will last no longer than two hours. The interview will take place online via Skype.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study **at any time**. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
I understand that my GP will be informed of my participation in this project.		
I understand that If, when I meet with the lead researcher at any point in the study, I disclose information that may lead her to think you or someone else is at the risk of harm or danger, she will report this to the necessary authority.		
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed] Signature Date

Name of Researcher [printed] Signature Date

Project contact details for further information:

Lead Researcher:
Mrs Louise Elizabeth Bolton - Lead Researcher
Doctoral Student
Health Sciences School
Division of Nursing and Midwifery
Barber House
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxx

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APPENDIX H – Participant Risk Assessment

Risk Assessment Form – Participants

Meaningfulness in daily life when living with COPD Research Study

Assessment by: Mrs Louise Bolton

ACTIVITY	HAZARD	RISK	PERSONS IN DANGER	EXISTING CONTROL MEASURES IN PLACE	CONTROL MEASURES REQUIRED
Participating in an interview to discuss the presence and absence of meaning in daily life	Discussion of potentially emotionally distressing topics	Participant experiences negative changes in mood and feelings	Research study participants	Participants GP will be informed of their consent to participate within the study. COPD care team informed of participation in the study.	At the end of each contact with participant, the lead researcher will give them information upon self-referral to mental health support services. Lead researcher will liaise, if necessary with participants GP and COPD care team to inform them of the expressed mood changes. Participant is able to withdraw from the study at any time. Any member of the research team is able to withdraw the participant from the study should they feel it is having a negative impact upon their mental health

ACTIVITY	HAZARD	RISK	PERSONS IN DANGER	EXISTING CONTROL MEASURES IN PLACE	CONTROL MEASURES REQUIRED
Participating in the research study	Exposure of taking part within research study	Loss of confidentiality	Research study participant	Robust secure data collection, handling and storage processes.	Personal data collected strictly contained to what is essential to the study. Early coding of data and pseudonymisation. Strictly only members of the study team will have access to the data. Data collected in this study will not be shared or used elsewhere.

APPENDIX I – GP NOTIFICATION LETTER

Louise Bolton
PhD Researcher
School of Health Sciences
Division of Nursing and Midwifery
Clarkehouse Road
Sheffield
S10 2LA
Telephone: xxxx
Email: xxxx

GP Notification Form

Title of Study: Meaningfulness in daily life when living with COPD

IRAS Reference: 279223

Name of Researcher: Louise Bolton

Details of Participant:

Dear
Your patient has consented to participate in the Meaningfulness in daily life when living with COPD study. Please see the enclosed information sheet for more details on the study. They will be using a number of objects, such as cameras, keeping a journal and writing postcards for a 2 month period, exploring the presence and absence of life meaning. They will then participate in an interview at the end of this period.

As a result of taking part, your patient may experience alterations in their mood due to the study topic being focussed upon the presence and absence of life meaning. Your patient has been advised to contact you should they begin to feel distressed or upset during participation.

Furthermore, they have been given details of the local self-referral mental health support services (Turning Point – Nottinghamshire Mental Health Helpline) should they wish to access this at any point.

If you have any questions, please contact the Lead Researcher, Mrs Louise Bolton using the contact details given above.

Yours sincerely,
Louise Bolton
PhD Researcher
University of Sheffield

Enc: Patient Information Sheet