

**Understanding the experience of patients with COPD
who access specialist palliative care in Salford**

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ABSTRACT

Abstract of thesis submitted to The University of Manchester for the degree of Master of Philosophy by Catherine Hayle, July 2011:

‘Understanding the experience of patients with COPD who access specialist palliative care in Salford’

The aim of this qualitative study was to gain an understanding of the experience of patients with chronic obstructive pulmonary disease (COPD) who access specialist palliative care services in Salford. Patients who had been accessing any service for greater than one month (if an outpatient) or one week (if an inpatient) were eligible for inclusion. Digitally recorded semi-structured interviews were carried out using a topic guide. After each interview, a reflective diary was completed. Recordings were then transcribed verbatim, and analysed using Van Manen’s approach to hermeneutic phenomenological interpretation. Data collection and interpretation was concurrent, with emerging themes used to guide future interviews.

Results consisted of participants’ experiences of living with COPD, together with their experiences of specialist palliative care. Findings relating to the experience of living with severe COPD echoed those described in previous literature, i.e. breathlessness reducing exercise tolerance and producing physical restriction, thus impacting on the work, social and family lives of patients with COPD, as well as having a negative effect on their psychological wellbeing. A major difference, however, was an understanding among these participants of their poor prognosis, contrary to the lack of awareness described in the literature. This could be a result of specialist palliative care intervention, however it is possible that those people with an appreciation of their limited prognosis are more likely to be offered (and accept) a specialist palliative care referral.

Benefits of specialist palliative care described by participants include reduced frequency of hospital admission, improved physical symptoms, reduced social isolation and a broadened physical environment. The most marked improvements described were in the area of psychological wellbeing (including increased confidence, increased self-worth, and decreased depression). Instrumental to these perceived benefits were factors such as the opportunity for patients to compare themselves to others in a similar situation; a warm, friendly hospice environment; the listening skills of staff and the time available for them to talk with patients; and a sense that specialist palliative staff go ‘above and beyond’ the call of duty, prompting the patients to experience themselves as ‘people who matter’. Although the initial suggestion of specialist palliative care referral sometimes caused distress, prior perceived associations between palliative care and death changed following engagement with services, and fear of discharge became a new problem.

While there is much within existing specialist palliative care services that works well for people with COPD, our findings suggest that it may be desirable to adjust some features of care, for example the discharge policy. Different patterns of service provision should be considered, and models offering a greater emphasis on physical conditioning may be beneficial. Work must be done to raise awareness of the true nature of hospices and specialist palliative care, as negative associations are likely to form a barrier to access, especially for those with non-malignant disease.

DECLARATION

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This work would not have been possible without the understanding of my husband Ilyas, who supported me in so many ways, or without the many hours of childcare provided by my mother, step-mother and mother-in-law (Janet, Judith and Vivienne), to whom I owe a debt of gratitude.

Finally, I would like to thank the participants in this research project who so generously gave their time to share their experiences with me.

DEDICATION

This work is dedicated to the people with COPD I have met throughout my career, and to the participants in this research, who gave their time to share their experiences with me.

INTRODUCTION

The aim of this research is to understand the experience of patients with chronic obstructive pulmonary disease (COPD) who access specialist palliative care. In order to set this work in context, I shall first describe the nature and epidemiology of COPD, before outlining the history and current provision of specialist palliative care in the UK. The literature review will summarise qualitative research into the experience of living with COPD and the experience of those who access specialist palliative care. Finally, I will report, using qualitative data, my findings regarding COPD patients' perspectives on access to specialist palliative care services.

Background

Chronic obstructive pulmonary disease (COPD) is a respiratory disorder characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months.¹ COPD is the preferred term for the conditions that were historically termed 'chronic bronchitis' or 'emphysema' in patients with obstructive airways disease. Although predominantly a disease of smokers (with a history of at least 20 pack-years of smoking), COPD does occur in non-smokers, for example in those with α 1-antitrypsin deficiency.²

An increasingly important global public health problem, the World Health Organisation estimates that 80 million people have moderate to severe COPD, with the condition accounting for 5% of all deaths globally in 2005.³ Unless urgent action is taken to reduce tobacco use, it has been estimated that worldwide COPD deaths will increase by 30% within the next ten years. From the fifth leading cause of death in 2002, it is projected to become the third leading cause of death in the world by 2030.⁴

In England and Wales, respiratory disease is now the third most common cause of death after circulatory disease and cancer.⁵ The UK prevalence of COPD is estimated at 1.5%,⁶ with 27,000 people dying from the condition annually.⁷ However, mortality data are thought to underestimate the true prevalence and death rate from COPD, as it is more likely to be cited as a contributory rather than a primary cause of death.⁸ Whatever its true prevalence, the burden of COPD on the NHS is high, with the disease accounting for one in eight of all hospital admissions, and an average of 25,000 GP consultations per year in an average primary care trust.⁹ The North West city of Salford

(where this research is based) is the 15th most deprived local authority area in England.¹⁰ At 2.7%, the prevalence of COPD in Salford is almost twice national average.¹¹ It therefore represents a significant burden for the local health economy, causing high levels of morbidity and mortality.

Symptom Burden and Social Impact

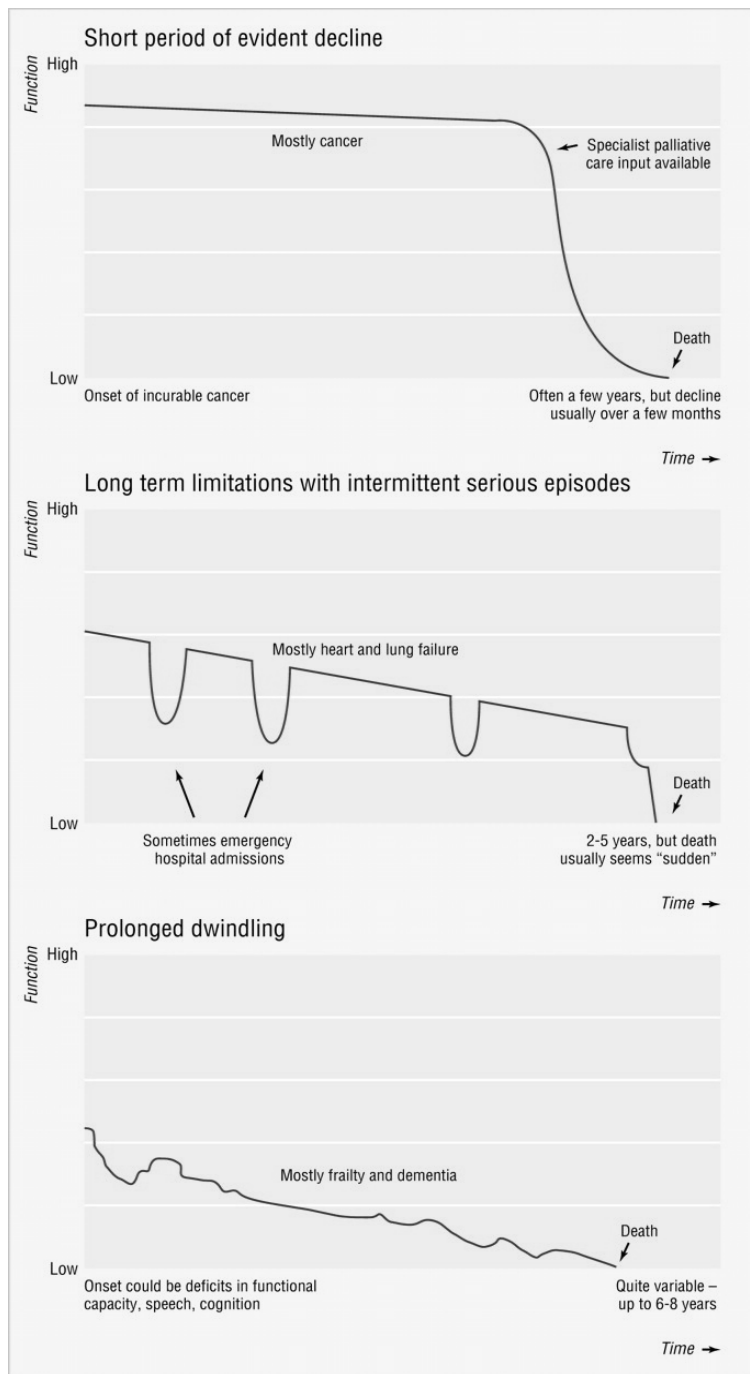
Studies have found that patients with severe COPD experience health-related quality of life comparable to, or worse than that of those with advanced non-small cell lung cancer.^{12, 13} A major contributor to this is likely to be the high physical symptom burden in advanced COPD, which is well described in the literature.¹⁴⁻¹⁷ Typical symptoms include breathlessness, fatigue, cough, pain, nausea, constipation and insomnia. In addition, there is a high prevalence (up to 90%) of psychological distress (anxiety and/or depression) in those with severe disease,^{13, 18} much of which goes untreated.^{13, 19} Unsurprisingly, the high prevalence of physical and psychological symptoms experienced by patients with advanced COPD has a significant impact on their social functioning and the lives of their caregivers.¹⁶ A major contributor to this is physical restriction, due to incapacitating breathlessness and fatigue.¹³ Despite this, access to community-based health and social care has been shown to be poor,^{13, 16, 17, 20, 21} leaving most to rely on informal caregivers for help with personal care.¹⁴

Disease Trajectory and Prognosis

The prognosis for patients with advanced COPD is poor. A recent national audit of patients admitted with an exacerbation of COPD to NHS units across the UK found the inpatient mortality rate to be 7.7%. Within 90 days of hospital admission, 13.9% of patients had died.²² Estimates of one year mortality following hospitalisation for an exacerbation vary between 36% and 41%,^{23, 24} and a large scale (n=1016) prospective cohort study of patients with severe COPD admitted with an exacerbation found that 49% had died at 2 years following admission.²⁵ The five-year survival rate for men and women in the UK with severe COPD is 30% and 24% respectively;²⁶ this compares unfavourably with the 62.7% five-year survival rate for those diagnosed with cancer (although this figure does vary significantly by cancer site and stage at diagnosis).²⁷ The illness trajectory for patients with COPD is also markedly different from that of those

with cancer, as illustrated in Figure 1. Patients with COPD are frequently diagnosed when there has already been some loss of lung function,²⁸ and hence overall functional status. From there, individuals suffer a slow but relentless decline in respiratory and functional capacity (with a progressive loss of independence), punctuated by sudden and unpredictable exacerbations. This contrasts with cancer patients, who often live in relatively good health until a one- to two-month period at the end of life, when they experience a steady deterioration.²⁹ Thus, although overall prognosis is worse for patients with advanced COPD than those with cancer, COPD patients tend to experience disabling morbidity for longer than cancer patients.

Figure i: Typical illness trajectories for people with progressive chronic illness.



Adapted from Murray, SA et al 2005, and Lynn and Adamson, 2003. (With permission from RAND Corporation, Santa Monica, California, USA and the British Medical Journal).^{30, 31}

Prognosticating in COPD proves a challenge, as it is difficult to predict which exacerbation will be the last. Attempts have been made to overcome this, including development of the 'BODE index',³² which is based on body mass index (B), airflow obstruction (O), dyspnoea (D), and exercise capacity (E). However, even those within the highest quartile of BODE index scores have a 2-year mortality rate of 30-40%, so it may not be a useful tool for identifying those whose life expectancy is very short. The Gold Standards Framework (GSF) is a systematic, evidence-based approach to optimising the care delivered by generalists to those nearing the end of life in the UK. With the aim of helping people to live well until the end of life, it concerns care in the final years of life for people with any end-stage illness in any setting.³³ A set of GSF clinical indicators has been produced to help healthcare professionals identify advanced illness in patients with COPD,³⁴ and these are broadly in agreement with the views of others regarding the emerging profile of those at risk of dying within one year.³⁵ They include:

- Disease assessed to be severe e.g. (FEV1 <30% predicted)
- Recurrent hospital admission (>3 admissions in 12 months for exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria¹
- MRC grade 4/5 (shortness of breath after 100 metres on the level or housebound)
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, depression
- More than 6 weeks of systemic steroids for COPD in the preceding 12 months

The Palliative Care Movement

Palliative care has been defined by the World Health Organisation as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.³⁶ Medical activity related to terminal care, care of the dying, hospice care and end-stage cancer is as old as medical practice itself,³⁷ but it is Dame Cicely Saunders, founder of St Christopher's Hospice in South-East London, who is regarded as the founder of the modern hospice movement. Since the opening of St Christopher's in 1967, the movement has seen exponential growth

throughout the UK and across the globe.³⁸ Recognition of palliative medicine as a specialty in its own right first occurred in the UK in 1987.³⁹ Since then, a differentiation between general and specialist palliative care has been made, with the following definitions:⁴⁰

General palliative care: ‘provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care need.’

Specialist palliative care: ‘services provided for patients and their families with moderate to high complexity of palliative care need. The core service components are provided by a range of NHS, voluntary and independent providers, staffed by a multidisciplinary team whose core work is palliative care.’

Cicely Saunders focused her attention on defining a knowledge base of care for those dying from malignancy.⁴¹ Specialist palliative care services have historically only provided care for people with a cancer diagnosis,⁴² with the development of these services concentrating on the needs of those with malignant disease. In recent years however, it has been generally acknowledged that specialist palliative care should be available to all on the basis of need, rather than diagnosis. Specialist palliative care can be provided in a variety of settings: hospice inpatient units; medical outpatient clinics and day therapy services; community palliative care teams providing specialist advice to patients in their own homes; and hospital specialist palliative care teams offering an advisory service to hospital inpatients with complex needs. Although early models of palliative care focused on the care of the dying, there is now widespread recognition that the principles of palliative care should be applied as early as possible in the course of any life-limiting illness, as challenges at the end of life often have their origins at an earlier point in the disease trajectory.⁴³ Whereas this concept is familiar to those working within specialist palliative care services, many healthcare professionals working within different specialties continue to equate palliative care with end-of-life care.⁴⁴

Access to Specialist Palliative Care Services

Given the high degree of physical and psychological symptoms experienced by patients with severe COPD, along with their poor health-related quality of life and limited prognosis, this group of patients may have much to gain from a holistic, palliative care

approach. In addition, those with complex needs are likely to require input from specialist palliative care services. However, access to these services has been repeatedly shown to be poor, with inequalities evident when patients with advanced COPD are compared with patients with lung cancer, despite a similar level of need. Gore et al's 2000 open two group comparison study of 50 patients with severe COPD and 50 patients with unresectable non-small cell lung cancer (NSCLC) found that although 30% of those with NSCLC had accessed specialist palliative care services, none of those with COPD had accessed this support.¹³ These results are echoed in other studies.^{17, 45, 46} More recent data from the National Council for Palliative Care demonstrates ongoing inequalities in access to specialist palliative care services, with cancer patients accounting for 85% of interventions across all settings, despite the fact that only 27% of all UK deaths are due to cancer.⁴⁷ A national survey of 107 respiratory physicians in the UK found that 81.3% perceived there to be gaps in specialist palliative care service provision in their locality for patients with severe non-malignant respiratory disease.⁴⁸ The percentages of respondents reporting 'easy' access to specialist palliative care were low across almost all services: hospice inpatient care (21.7%), hospice day care (32.4%), palliative medicine outpatient clinic (40.0%), multidisciplinary community palliative care (34.3%). Indeed, accessing specialist palliative care advice for hospital inpatients was the only service for which access was described as 'easy' in more than half of respondents (66.0%).

Barriers to specialist palliative care provision for COPD patients are likely to come from three different sources: non-specialist palliative care health professionals, specialist palliative care providers and the patients themselves. Spence et al recently published a qualitative study exploring the views of 23 health and social care professionals.⁴⁴ They found that due to time and resource constraints, professionals reported 'crisis managing' patients with COPD (i.e. often dealing purely with the immediate issues raised rather than taking a coordinated approach to holistic care throughout the illness trajectory). A lack of knowledge about palliative care services was evident among non-specialist palliative care professionals, with many equating palliative care with end-of-life care. For this reason, professionals admitted a reluctance to introduce the concept of palliative care to their patients, for fear of distressing them, or appearing to 'give-up' on curative care. Difficulty prognosticating was also

identified as a barrier, with professionals believing they could not refer until the patient was in the terminal phase of their illness. As shown in Figure I (page 15), it is very difficult to know in advance when this stage will occur for COPD patients.

Within specialist palliative care services themselves, there has been a degree of resistance to broadening access to those with non-malignant disease.⁴⁹ This reluctance is motivated in part by a fear that current services would be ‘overwhelmed’ should they be opened up to all who need them. This view has been shown to be misplaced,⁵⁰ especially if specialist palliative care professionals work to educate non-specialists in generic palliative skills whilst offering specialist services to those with the most complex needs. However, the reality that many specialist palliative care services are funded (at least in part) by cancer charities such as MacMillan Cancer Support and Marie Curie Cancer Care cannot be ignored, together with the fact that services have been designed to meet the requirements of people with cancer.

The final barrier to access to specialist palliative care for those with COPD comes from the patients themselves. While many patients and their caregivers are unaware that COPD is a life-limiting disease,^{46, 51} and palliative care is viewed in the national consciousness as synonymous with care of the dying, healthcare professionals are likely to remain uncertain about discussing palliative care with COPD patients. This research project seeks to understand whether such caution is justified by investigating COPD patients’ perceptions of specialist palliative care prior to referral, and their feelings when referral was suggested. This study also begins to investigate whether specialist palliative care services can fulfil the needs of patients with COPD as well as those with cancer.

Summary

COPD is a global public health problem of increasing prevalence.^{3-5, 7} The disease trajectory is uncertain, with the timing of the end of life phase difficult to predict. Those affected may live for protracted periods of time with distressing symptoms severely impacting their functional status and quality of life.¹⁴⁻¹⁷ Although health-related quality of life with COPD is worse than for patients with advanced lung cancer,^{12, 13} there is inequality in access to UK specialist palliative care services, which have traditionally been designed to meet the needs of cancer patients.^{13, 17} Despite a

national drive to increase access to specialist palliative care for those with non-malignant disease, little work has been undertaken to understand how services can best be adapted to meet the needs of this group of patients. This research seeks to understand how those with COPD who access specialist palliative care experience it currently, in order to begin to understand whether adaptations may be necessary.

I have not found any prior research seeking to understand the experience of a homogeneous population of patients with a diagnosis of COPD who accessed specialist palliative care. Before describing this research project and presenting my findings, I shall therefore review the most relevant qualitative literature available, investigating the experience of those who access specialist palliative care services, and describing the lived experience of COPD.

LITERATURE REVIEW

Introduction

The purpose of this literature review is to summarise available evidence from qualitative studies relevant to the nature of this enquiry, in order to set emerging findings in context. As I have found no published literature on the experience of patients with COPD who access specialist palliative care, I have separated this literature review into two sections, exploring the experience of daily life with COPD and the experience of specialist palliative care separately. Although the experience of living with COPD is not directly relevant to the aim of understanding patients' experiences of specialist palliative care, accounts of day-to-day life with COPD were invariably obtained during participant interviews. The second part of the literature review was therefore added to help put these findings in perspective. This qualitative research project focuses on the experience and perceptions of patients themselves, so I have therefore focused the literature review on qualitative studies investigating the patient experience. Where research papers report data collected from healthcare professionals or caregivers in addition to data from patients, I have separated out and reported the patient data only, when possible.

Part I: The experience of specialist palliative care

Methods and search strategy

Databases were searched for relevant literature from English language peer-reviewed journals published since 1991. As specialist palliative care is a relatively new and rapidly changing field, it was felt that articles greater than 20 years old were unlikely to represent a true reflection of current specialist palliative care services. This research concerns adult services only, therefore studies of paediatric palliative care were excluded. The search terms and databases used are detailed in Table i. After the first search, duplications from subsequent searches were excluded. Additional papers were obtained by scanning reference lists for relevant articles, from discussions with experts in the field, and through personal reading. Where the findings of the study concerned topics other than the experience of specialist palliative care (and therefore not directly relevant to this research), they are not reported.

Overall, the experience of specialist palliative care in general is fairly well described in the qualitative literature, although there are relatively few articles regarding each individual setting, with outpatient clinics in particular being poorly described. I have grouped the tabulated summary of each paper according to the service evaluated under the following headings:

- i. The experience of community specialist palliative care, including outpatient clinics
- ii. The experience of hospice day care
- iii. The experience of inpatient hospice care

Findings are summarised at the beginning of each section.

Table i: Search strategy

<u>DATABASE</u>	<u>SEARCH TERMS</u>	<u>NUMBER OF POTENTIALLY RELEVANT ABSTRACTS REVIEWED</u>	<u>NUMBER OF PAPERS REVIEWED TO DETERMINE RELEVANCE</u>	<u>NUMBER OF ARTICLES INCLUDED IN FINAL REVIEW</u>
Ovid MEDLINE	Terminal care; palliative care; patient satisfaction; patient preference	476	24	7
CINAHL	Palliative care; hospice care; patient experience; patient perception	726	9	6
Ovid PsychINFO	Palliative care; terminally ill patients; client satisfaction; quality of care	190	6	1
Additional sources	N/A	N/A	N/A	6

i. The experience of community specialist palliative care, including outpatient clinics

The literature in this area mainly focuses on the experience of people with cancer. Where primary diagnosis was made explicit, the majority of participants had cancer in all studies except one, (where two thirds of participants had a non-malignant diagnosis, with 40% of the total sample having a primary diagnosis of COPD).⁵² The experience of specialist palliative care in the community was generally positive, with perceived expertise of community specialist palliative care nurses with respect to symptom control reported frequently.⁵³⁻⁵⁶ Emphasis on physical symptom control was noticeably greater within this group of studies than within research conducted within hospice inpatient or daycare settings (where psychosocial effects were predominant). However, community specialist palliative care nurses were also reported to provide psychological support by talking and listening to patients' concerns,⁵⁷ and were felt to have an ease of interaction, allowing participants to develop a feeling to connection with them.⁵⁴ Rabow et al's study of a US outpatient specialist palliative care service (with a majority of participants with non-malignant diagnosis) found that participants were appreciative of the opportunity to discuss sensitive topics such as their wishes for the end of life, and spirituality.⁵² Several studies report a feeling of increased confidence, security and reassurance for those with community specialist palliative care involvement.⁵³⁻⁵⁵ In addition to physical and psychological benefits, practical assistance (for example offering advice regarding financial entitlements, or coordination of services) is provided by community and outpatient specialist palliative care.^{52, 56, 57}

One study reported that a perceived association between specialist palliative care and death led some participants to experience distress when the service was offered.⁵⁷ However, over two thirds of participants in Rabow et al's research would have welcomed specialist palliative care input earlier in their disease trajectory.⁵²

Table ii summarises the papers identified as most relevant to the experience of community specialist palliative care, including outpatient clinics.

Table ii: The experience of community specialist palliative care, including outpatient clinics

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Jarrett NJ et al, 1999⁷⁴ UK	To investigate terminally ill patients' and lay carers' perceptions and experiences of community-based services.	General practitioners (GPs), district nurses (DNs), community MacMillan nurses (CMNs), Marie Curie nurses and domiciliary hospice nurses.	A purposive sample of terminally ill patients and their lay-carers identified as suitable by their community nurses.	12 lay-carers, 9 patients. Interviews focused upon the experiences of 12 patients (11 with cancer, 1 with non-malignant disease). Age range 38-81 years.	Semi-structured interviews. Thematic analysis.	It was not possible to separate patient and lay-carer accounts, therefore both are included. 5 patients with experience of (CMNs), all gave positive accounts. CMN seen as source of information about financial entitlements, symptom control and the hospice & participants perceived they had influence over other healthcare professionals. Experience of hospice domiciliary nurses positive in all cases. Perceptions were of a calm, reassuring manner and expertise in pain control.	Participants were selected by their own nurses, which may have introduced an element of bias.

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
McLoughlin PA, 2002⁷¹ UK	To identify what patients & carers gain from contact with the specialist palliative care (SPC) nurse and what aspects of that care have a positive impact on their quality of life.	A community SPC nursing service.	Patients referred to the community SPC team with a life-shortening diagnosis who had a spouse or partner.	A purposive sample of 4 patients and their carers.	Two focused, non-directive, in-depth interviews (at 3 & 8 weeks post-referral) and self-completed diaries. Thematic analysis.	<ul style="list-style-type: none"> - Lack of knowledge about the role of MacMillan nurse (including that it was the same as SPC nurse) prior to access. - No participant realised that palliative medicine consultant was part of the same service. - Knowledge base of SPC nurses with respect to symptom control was valued, & their advice was viewed as accurate, credible and beneficial - SPC nurses were instrumental in reassuring participants about the value of using an opioid. - Perceived benefit of SPC nurses to participants' quality of life. 	<p>Findings mainly concerned the experience of living with cancer, rather than the experience of specialist palliative care.</p> <p>Participants who did not have a partner were excluded, but perhaps the views of those living alone would have been valuable.</p>

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Richardson J, 2002⁷² UK	To identify & describe palliative patients' perception of factors within the interaction with the community palliative care nurse that enhance feelings of health & well-being and begin to define health promotion in relation to palliative nursing in the primary care setting.	A community specialist palliative care (SPC) nursing and advice service with a 24-hour visiting on-call service.	A purposive sample of patients accessing the service who had not also received hospice inpatient or day care. Those with moderate or severe physical or psychological symptoms based on a scoring system were excluded.	12 (5 male, 7 female) All had incurable cancer.	Semi-structured interviews. Hycner's phenomenological analysis.	<ul style="list-style-type: none"> - Feelings of connection & ease in interactions with the nurses. - Participants felt important to the nurse(s) - Social aspect to visits was important (talked about subjects other than illness) - Positive comments about 'personal' qualities of nurses (e.g. reliability, honesty) & professional qualities (e.g. decisiveness & role as advisor). - Confidence in nurses' specialist knowledge and ability to relieve symptoms. - Participants felt 'confident' & 'more able to cope', as well as secure and reassured due to alleviation of fears and the knowledge that nurses were available and accessible. - Opportunity to discuss emotional concerns & feelings was appreciated. 	- In practice, most patients accessing SPC use more than one service and have at least moderate physical or psychological symptoms. The population from which the sample was taken therefore represents an atypical group of patients.

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Rabow MW et al, 2003 ⁷⁶ US	To ascertain patients' perception of the acceptability and benefits of an outpatient specialist palliative care (SPC) intervention	'Comprehensive Care Team' (CCT), a SPC intervention for those with advanced disease who continue to pursue aggressive management options, using a case management approach. A SPC multidisciplinary team offers written recommendations to the primary care physician across 5 domains of care 6 months for 1 year. CCT members also offer direct care to patients and their families.	Patients with advanced heart disease, lung disease or cancer with a life expectancy of 1-5 years as estimated by their primary care physician who accessed CCT.	35 patients who completed an exit interview Average age 67.9 years. 44% Caucasian 74% female 40% COPD, 34% heart failure, 26% cancer	Semi-structured interview conducted upon exit from CCT service. Series of yes/no questions followed by the opportunity for participants to expand their answers. Thematic analysis by 3 researchers.	<ul style="list-style-type: none"> - Intervention generally acceptable - 68.6% would have welcomed the service earlier in their disease trajectory - Participants appreciated the opportunity to discuss difficult or personal topics e.g. advance care planning, talking about death, spirituality - Improved communication & relations with caregivers, primary care physician & medical centre as a whole - Perceived reduction in healthcare utilisation - Improved coordination of services - Identification of previously undiagnosed medical problems 	Service not typical of specialist palliative care outpatient services in the UK, although there are some similarities (MDT approach, consultancy to primary care).

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Chapple A et al, 2005⁷⁵ UK	To explore patients' perceptions of the work & role of specialist palliative care (SPC) nurses.	Any specialist palliative care service.	Any person living in the UK who considered themselves to be living with a terminal illness and answered an invitation to participate in a national newspaper or was recruited via their consultant, GP, community SPC nurse, hospice nurse, social worker, or at a conference on palliative care.	41 recruited in total. 25 mentioned MacMillan or hospice nurses. Their experiences are reported in this paper. All had cancer.	Patient-led narrative interviews. A qualitative, interpretative approach, combining thematic analysis with a modified grounded theory.	SPC nurses felt to offer: - practical help e.g. advice on financial support, accessing meals on wheels. - talking & listening, providing the opportunity to 'vent feelings' to somebody outside the family. - clinical information - communication e.g. acting as intermediary between patient and other health care professionals or family members. - availability & flexibility: easy access at any time - Association with death, leading some participants to be distressed when introduced to the service. - One felt a MacMillan nurse was too 'matter of fact' & didn't receive the emotional support she needed. - Another had heard of SPC nurses upsetting patients by discussing preferred place of care (death) too early.	Recruiting via an advertisement may have been likely to attract participants with an agenda, or 'story to tell' (either positive or negative).

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Goldschmidt D et al, 2006 ⁷³ Denmark	To elucidate expectations of and evaluation of a specialist palliative home care team	Specialist doctors and nurses visited during weekdays & evenings, providing a consultancy role to GPs & DNs. Telephone advice from nurses available at night.	Danish-speaking palliative home-care patients aged >50 years with a prognosis of >2 months, with no prior experience of specialist palliative care.	9 patients (& 6 carers) pre-home care 6 patients (& 5 carers) completed second interview. All had cancer.	Semi-structured interviews prior to home-care and after 2-4 weeks of home-care. Thematic (template) analysis.	<p>Participants expressed gratitude for specialist attention paid to all symptoms and reduction in symptom severity.</p> <p>A willingness to change treatments and to take patients' wishes seriously was noted.</p> <p>Improved sense of security for some (but not all) participants – one felt he needed daily visits or inpatient care.</p> <p>Participants expressed a need for respite care and also wished night time visits could be offered.</p> <p>It was also suggested that the team should consist of more professional groups e.g. physiotherapist, psychologist.</p>	Patients of < 50 years were excluded as the researchers wished to avoid focusing on the needs of families with young children.

Table ii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Ingleton C 1999⁷⁹ UK	To evaluate a community palliative care service from the perspective of patients and carers.	A community specialist palliative care (SPC) service staffed by one MacMillan nurse, with linked day care & respite care facilities.	All patients receiving day care, community care or respite care. Those staff deemed confused to 'too ill' to participate were excluded. Purposive sampling aimed to capture a variety of services.	28 (14 male, 14 female) completed the questionnaires. 9 patients (& their carers), 6 cancer & 3 non-cancer patients participated in interviews. (3 female, 6 male)	Mixed methods: - Questionnaire survey of patients & carers - Non-participant observation - In-depth interviews using a variant of the 'Critical Incident Technique (CIT)' in which respondents recall incidents that exemplify 'good' or 'bad' practice. - Document analysis	4 main analytic categories: 1. <i>'Being there'</i> : the perception that staff at the service are 'available' – there is 'always someone to turn to' for practical & emotional support. Numerous examples of staff willing to participate in a family's experience 'beyond that which is strictly required'. 2. <i>'The right atmosphere... a home from home'</i> . Comfort in meeting others with a shared experience of terminal illness. 3. <i>'Didn't need to ask'</i> : practical support e.g. equipment, financial advice offered without patients needing to ask. 4. <i>'Different to other places'</i> – intimate & reciprocal relationship between staff and patients.	Unwell patients were excluded, but no information as to how 'unwell' is defined within a palliative care population.

ii. The experience of hospice day care

Again, the majority of studies summarised here included participants with a primary diagnosis of cancer exclusively (where diagnoses are stated). Only one research paper conducted within a day care setting included any participants with non-malignant disease, comprising just 3.9% of that total study population.⁵⁸ The low numbers of participants with non-cancer diagnoses within this body of literature seems to be due to presumed low rates of these patients accessing specialist palliative care at the time this body of research was conducted, rather than due to specific exclusion criteria within the studies themselves. A key feature of day hospice, described in several of the research papers summarised below, is the importance of a friendly, relaxed and welcoming atmosphere – ‘a home from home’.⁵⁸⁻⁶⁰ The opportunity to meet others is seen as a vital way to reduce social isolation,^{58,61} and patients’ shared experiences of life-limiting illness help to create a sense of mutual support and community.⁵⁹⁻⁶³ Three studies report the benefit to participants of exposure to others in similar situations, thus allowing them to compare and normalise their illness experience.^{58,63,64} Ease of access to a variety of staff is valued, as is the sense that staff are ‘available’, with ‘time to talk’,^{59,60} and the opportunity to develop a relationship with a key individual for purposes of continuity.⁶⁵ The holistic care provided in day hospice (including complementary therapies and activities, as well as more mainstream services such as medical assessment and physiotherapy) seems to have wide-ranging benefits, including: increased hope for the future;⁶³ increased confidence;^{61,64} reduced anxiety and a renewed sense of purpose;⁶² and an enhanced sense of self-worth.^{59,64} Despite reported anxieties at the significance of a hospice referral,⁶² two studies report participants’ fears at the prospect of discharge from day hospice.^{61,64}

Table iii summarises the papers identified as most relevant to the experience of hospice day care.

Table iii: The experience of hospice day care

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Hopkinson JB, Hallet CE, 2001⁷⁸</p> <p>UK</p>	<p>To explore the perceptions of patients attending a day care unit, and find out what was important to these people about their day care experiences.</p>	<p>A hospice day care unit</p>	<p>Daycare patients judged by staff as well enough to be interviewed. Purposively sampled – expected by staff to give a range of views from satisfied to dissatisfied.</p>	<p>12 (7 male, 5 female).</p> <p>Age range 50-86 years.</p> <p>All had cancer.</p>	<p>Open, accepting interview style.</p> <p>Phenomenological analysis.</p>	<p>3 phenomena identified by all patients as important:</p> <p>1. <i>Feeling comfortable.</i> Factors contributing to this sense of comfort included feeling welcome, accepted and understood. All mentioned the value of being given ‘time to talk’, either having a general ‘chat’ for pleasure or talking to someone with an understanding of their experience of illness.</p> <p>2. <i>Feeling good.</i> All felt day care enhanced their sense of self-worth e.g. by providing an opportunity to make choices or to participate in activities or learn a new skill.</p> <p>3. <i>Feeling less isolated.</i> Due to socialising with those with shared experiences. Day care appeared flexible and patient-led as it was possible to support those coping with cancer in different ways (tolerating and adapting) equally well.</p>	<p>Participants were selected by the nurses caring for them, which may have introduced an element of bias as described above.</p> <p>Limited description of day care facility in which research was conducted.</p>

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>		<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Goodwin et al, 2002⁷⁷ UK	To describe palliative day care from the patient's perspective	5 UK palliative day care units, all offering medical and nursing therapies and social activities.	Any patient attending day care, without cognitive impairment, who was well enough to be interviewed for 30-45 minutes. All suitable consecutive referrals within the study period were approached.	Baseline interview (2-3 weeks): 102 2 nd interview (6-8 weeks): 59 3 rd interview (12-15 weeks): 40 51% male Age range: 35-87 years 3.9% of the initial cohort had non-malignant disease.	Semi-structured interviews Thematic content analysis.	- Participants identified 3 themes: 1. 'Meeting people' 2. 'Getting out': change of environment – 'it's like a day out' 3. 'The place': relaxed, friendly environment. - Day care also described as a 'distraction' (from morbid thoughts) and a 'place to be normal' during the 2 nd interview. - By final interview, 'meeting people' remained the principle theme.	

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Fincham L et al, 2005⁸⁴ UK	To explore how cancer patients with progressive disease perceived and experienced supportive care at different stages of their cancer journey and to compare this to the perceptions of healthcare professionals	An independent hospice with day therapy and a 32-bed inpatient unit.	Patients with a cancer diagnosis were selected purposively from the day therapy unit.	8 participants (2 focus groups with 4 in each) Age 34-72 years All had cancer.	Semi-structured focus group interviews. Qualitative framework analysis (Miles & Huberman)	- Importance of the opportunity to develop a relationship with a key individual for continuity (e.g. consultant or MacMillan nurse) - 3 participants would have liked have been referred to specialist palliative care earlier in their illness.	- Despite the aim of capturing experience of supportive care, results mainly concern the cancer diagnosis and mainstream hospital treatment. - No clear definition of 'supportive care' - Very limited information on the experience of specialist palliative care (SPC), and patients accessing SPC services other than day therapy were excluded.

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Kennett C, Payne M. 2005⁸¹</p> <p>UK</p>	<p>To explore patients' use of the everyday phrases 'getting out' & 'like day care' to understand the significance of day care attendance & the perceptions of what is offered for individuals living with terminal illness.</p>	<p>The 'Creative Living Centre', a palliative day care providing a psychosocial model of service, aiming to facilitate an environment in which patients are able to access their own innate strengths & resources. Medical & nursing interventions are kept to a minimum.</p>	<p>Patients attending the unit, recruited through a request for volunteers in the day centre newsletter or by facilitators approaching those perceived as physically and emotionally well enough to participate.</p>	<p>34 (23 male, 11 female).</p> <p>Age range 40-95 years.</p> <p>All had cancer.</p>	<p>6 audio taped medical student teaching sessions whereby the facilitator (a staff member) encourages a free-flowing conversation between participants about their experiences before inviting the students to ask questions.</p> <p>Thematic analysis.</p>	<ul style="list-style-type: none"> - Some felt comfortable with the idea of day care prior to attending; others felt anxious at the significance of needing a hospice. - Mood change e.g. reduced anxiety & a renewed sense of purpose was brought about by day care. - Sense of community, belonging, mutual support: 'creative groups not an end in themselves but a vehicle for developing a sense of belonging & making new friends at a time when many social outlets have been lost'. - Some found it a place to forget about illness, others to talk about how illness affected their lives. - Making gifts for loved ones enable them to give, rather than always receive. - Negative aspects: a wish to come > once/week; the sadness experienced when a friend from the centre died. 	<p>A staff member facilitated the sessions, which may have discouraged participants from reporting negative experiences.</p>

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Low J et al 2005⁸³ UK	To explore the experience of people involved in UK palliative day care services and identify the important outcomes of this service.	4 palliative day care units purposively sampled to reflect the wide range of palliative daycare service delivery in the UK.	All first time users of the services who had been attending for < 4 months were invited to participate.	18 patients, mainly female. Median age 60years. Predominantly white British (16/18). (Volunteers, carers & managers were also recruited to separate focus groups).	Focus groups of 3-6 participants, facilitated by a research nurse and senior research fellow. Thematic content analysis.	Benefits: - ease of access to a variety of specialist healthcare professionals in whom the participants had confidence in one location. Perception that this regular monitoring prevented problems. - social support and comparison with others in similar position - access to complementary therapies and other activities that promoted a feeling of wellbeing, increased confidence & self-esteem and sense of achievement. - generally increased quality of life through increased confidence, self-esteem and self-worth due to a realization that it was still possible to contribute to the community. Challenges: -fear at the prospect of discharge.	

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Kernohan WG et al, 2006⁸⁰</p> <p>Northern Ireland</p>	<p>To obtain patient feedback on medical, social and therapeutic outpatient palliative care services provided in a day hospice for quality enhancement purposes.</p>	<p>A 15-place day hospice located within a hospice offering inpatient facilities, staffed by a multi-disciplinary team and volunteers.</p>	<p>All patients attending over a 3-week period were approached.</p>	<p>26 (10 male, 16 female).</p> <p>All had cancer.</p> <p>Duration of attendance from 1-24 months.</p>	<p>Semi-structured questionnaire administered by informal discussion with a trained voluntary lay worker who had not previously worked in day hospice.</p> <p>Content analysis of qualitative data.</p>	<p>Principle benefit: meeting others in a similar situation.</p> <p>Qualitative statements included reduced feelings of isolation, safe environment, opportunity to share feelings, helped to build confidence and forged strong friendships.</p> <p>Many expressed fears and concerns about losing their place in the centre.</p>	

Table iii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Fisher C et al, 2008⁸² Australia	To explore patients' experiences of palliative day care in a Western Australian context.	A palliative day care centre	All English-speaking patients attending day care without cognitive impairment & able to participate in a 30-45 minute interview.	8 (2 male, 6 female) All had cancer Age range 44-82 years	Semi-structured interviews. Constant comparative analysis.	<ul style="list-style-type: none"> - A sense of community, enhanced through social support & interaction typified participants' experiences. - Participants were enabled to leave their home and feel 'free'. - Normalised participants' experience of illness. - A feeling that there was 'hope' for the future while able to attend day care. - Importance of comparison with others in similar situations. 	- Limited description of service offered.

iii. The experience of inpatient hospice care

Those with non-malignant disease were better represented in this group of papers than in those reporting experiences of day hospice or outpatient services. From a geographical point of view, this is a heterogeneous body of work, reporting research conducted across four continents. There is a shortage of UK-based literature, with only one paper exploring the patient experience of UK hospice inpatient units. Five of the six research papers used a hermeneutic (or interpretative) phenomenological methodology, in contrast to the bodies of work exploring day hospice or outpatient care, where thematic analysis was most commonly used. Overall, reported findings seem somewhat richer than in the previous two categories, allowing insight into the participants' feelings as well as their experiences. This is in keeping with the hermeneutic phenomenological approach, which seeks to find the 'meaning and significance of certain phenomena'.⁶⁶ Greater use is made of simile (for example, in Mok's 2004 study of patients perceptions of specialist palliative nursing care, interactions with nurses are described as 'going to a refueling station and being refilled with fuel in order to keep going'),⁶⁷ and metaphor (such as McKechnie et al describing the 'handing over of one's disintegrating body to hospice care').⁶⁸

Fear among participants around the association between hospices and the end of life was found to be common prior to admission.^{68, 69} However, once the person entered the hospice building, several studies describe the perception of hospice as a 'refuge'⁶⁸ or 'sanctuary',⁷⁰ with a relaxing, peaceful atmosphere, providing a safe and secure environment.^{69, 71}

Descriptions of hospice staff within the literature are overwhelmingly positive, with studies describing how nursing staff develop a rapport with patients by listening and taking an interest in the patient as an individual, enabling them experience themselves once again as a person who matters.^{67, 70, 71} Larkin et al contrast the close relationships between hospice in-patients and other patients and staff (who understand the experience of life-limiting illness) with family members (who don't).⁶⁹ Symptom control, as well as assistance with practical tasks such as bathing was valued, along with the comfort of compassionate human contact (including in the form of touch).^{71, 72}

Despite the positive accounts of the hospice inpatient experience, two studies report that the main motivation for accepting a hospice bed is in fact to protect one's family from the potential burden of caring for a loved one who is dying at home.^{68, 69} Table iv summarises the papers identified as most relevant to the experience of inpatient hospice care.

Table iv: The experience of inpatient hospice care.

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Mc Kinlay EM, 2001⁸⁸</p> <p>New Zealand</p>	To explore the patient experience of inpatient palliative care.	An urban hospice offering a complete range of inter-disciplinary inpatient support services.	Patients with at least one inpatient hospice experience who were lucid, English-speaking, not imminently dying, & able to sustain a conversation for at least 15 minutes.	<p>6 (3 male, 3 female)</p> <p>A mix of cancer and non-cancer diagnoses.</p> <p>All died within the year in which the research took place.</p>	<p>Semi-structured interviews.</p> <p>Van Manen's approach to hermeneutic phenomenological analysis.</p>	<p>- <i>'Identity'</i>: SPC professionals perceived as taking an interest in the patient as an individual.</p> <p>- <i>'Keeping control'</i>: respect for patient autonomy & promoting independence.</p> <p>- <i>'Chosen isolation'</i>: patients' ability to choose when to participate in social interaction.</p> <p>- <i>'Being safe'</i>: sense of being in a safe, healing environment & being monitored/watched by staff.</p> <p>- <i>'Relinquishment & relaxation'</i>: the opportunity to relax by allowing others to temporarily take control of certain things.</p> <p>- <i>'Mortality awareness'</i>: most talked of dying, despite the interviews beginning by asking about care.</p> <p>- <i>'Caring qualities'</i> of staff, including physical affection.</p> <p>- <i>'Humour'</i> mixed with professionalism.</p> <p>- <i>'The environment'</i>: described as peaceful, relaxed & happy despite the deaths that occur there.</p>	Participants identified by the staff caring for them, which may have introduced an element of bias.

Table iv (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Mok E, Chiu PC, 2004⁸⁹ Hong Kong	To explore aspects of nurse-patient relationships in the context of palliative care.	Specialist palliative nursing care within a palliative care inpatient unit or in patients' homes in Hong Kong.	Patients with incurable cancer who had been accessing specialist palliative inpatient care for > 1 week or home care for > 4 weeks.	10 (4 male, 6 female)	Open-ended, unstructured interviews. Van Manen's approach to phenomenological analysis.	<p>Through their relationships with nurses, participants:</p> <ul style="list-style-type: none"> - experienced themselves as people who mattered - were enabled to find meaning in life - felt their suffering was eased. <p>A trusting relationship was developed if the nurse demonstrated understanding of the participant's needs and suffering and was found to be caring in action and attitude.</p> <p>Nurses were seen to take on an advocacy role, leading participants to believe that they had 'gone the extra mile'.</p> <p>Participants likened their relationships with nurses as 'going to the refueling stations', with the fuel 'triggering their inner strength' to 'keep on going'.</p>	Only patients with cancer were eligible to participate despite the aim of the study being to explore the nurse-patient relationship in palliative care in general.

Table iv (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Service</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Pevey C 2005⁹⁰</p> <p>US</p>	<p>To investigate hospice patients' perceptions of the care they receive.</p>	<p>A central Texas not-for-profit hospice.</p> <p>(From quotations, the services seem to include inpatient and home care, but this is not made explicit).</p>	<p>Patients with > 4 weeks experience of the hospice judged to be physically 'stable' and able to participate in an in-depth interview.</p>	<p>38 (22 male, 16 female).</p> <p>Age 32-95 years.</p> <p>20 cancer, 17 non-cancer, 1 with both.</p>	<p>Semi-structured interviews.</p> <p>? Thematic analysis.</p>	<p>Participants overwhelmingly found the hospice comforting, with the reasons for this falling into 3 categories:</p> <ol style="list-style-type: none"> 1. <i>Communication.</i> Including the coordination of services and the opportunity for honest communication about death. 2. <i>Human contact.</i> Especially in the form of touch, and also the care and compassion shown by hospice staff. 3. <i>Physical attention.</i> Including symptom control and assistance with practical tasks e.g. bathing. 	<p>No explanation of how 'stability' is assessed in a palliative care population.</p> <p>Nursing staff selected participants, which could have introduced bias.</p> <p>No description of data analysis.</p> <p>No description of the hospice services provided.</p>

Table iv (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Johnston B, Smith LN, 2006⁸⁷</p> <p>UK</p>	<p>To investigate the perceptions of patients and nurses of palliative care and the concept of the expert palliative care nurse.</p>	<p>Two hospices and two hospitals offering specialist palliative care nursing in Scotland</p>	<p>Patients being cared for in one of the 4 study sites with a life-threatening illness and a life expectancy of > 2 years but not < 2 weeks.</p>	<p>22 patients (22 nurses were also recruited)</p>	<p>Semi-structured interviews focusing on informants' experience of their care.</p> <p>Interpretive phenomenological analysis.</p>	<p>Major themes:</p> <ul style="list-style-type: none"> - 'Connecting': nurse as someone to talk to, willing to listen, getting to know the patient. - 'Meeting my needs': e.g. description of 'personal attention' provided by a hospice nurse; nurses spending time with patients and anticipating their needs to help them feel comforted and supported. - 'Hospice as family': encapsulated the importance hospice patients attributed to the atmosphere, safety & sanctuary of the hospice atmosphere, helping them to feel relaxed and secure. 	<p>Limited information provided regarding the characteristics of the sample.</p>

Table iv (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Larkin PJ et al 2007⁸⁵</p> <p>6 European countries</p>	To explore transition experiences of advanced cancer patients.	1-2 centres of palliative care expertise in each country (as recognized by the national palliative care association of that country), either purpose-built hospices or hospital-based palliative care units.	Patients with advanced cancer accessing specialist palliative care (SPC) centres and felt likely (by their clinical team) to progress to terminal care within 6-12 months.	<p>A purposive sample of 100.</p> <p>Age range 45-92 years.</p> <p>Distributed fairly evenly across all countries.</p>	<p>Semi-structured interviews.</p> <p>Van Manen's approach to hermeneutic phenomenological analysis,</p>	<ul style="list-style-type: none"> - Rapid deterioration & resulting loss of independence was a primary reason for transition to specialist palliative care. - Fear about the association between SPC and death. - SPC offered the hope of safety & security to those in distress. - Peace and privacy in the hospice contrasted with other settings. - Hospice as 'refuge, a place of shelter and protection'. - Perceived urgency of the decision to accept a bed when offered, even if not practically or emotionally ready. - Decision to be admitted often based on perceived potential burden to others rather than personal choice. - Participants had limited knowledge of the referral process. - Importance of relationships with clinical staff & other patients in contrast to emotional isolation from family members who 'don't understand'. 	

Table iv (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Services</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
McKechnie R et al, 2007⁸⁶ New Zealand	To gather narratives of the lived experience of palliative care, to explore images of embodiment function in social space, & to understand the ways in which these narratives might inform those involved in palliative care.	A community hospice with an inpatient unit and outpatient clinic.	People diagnosed with a terminal illness receiving palliative care from the hospice.	7 (all female – no suitable men available during the recruitment period). All had cancer. Age range 51-65 years.	Semi-structured interviews. Interpretive phenomenological analysis.	- Hospice as refuge from mainstream care. - Community perception of hospice as ‘the end of the line’. - Participants talked of ‘handing over one’s disintegrating body’ to hospice care to protect their families	

Part II: The experience of living with severe COPD

Method and search strategy

Databases were searched for relevant literature from English language peer-reviewed journals published since 1991. The search terms and databases used are detailed in Table v. After the first search, duplications from subsequent searches were excluded. Additional papers were obtained by scanning reference lists for relevant articles and through personal reading. Where the findings of the study concerned topics other than the experience of day-to-day life with COPD (and therefore not directly relevant to this research), they are not reported.

Overall, the experience of living with COPD is well described in the qualitative literature. I have grouped the tabulated summary of each paper according to its aim under the following headings:

- i. Physical experience and practical impact of COPD
- ii. Social, psychological and existential impact of COPD
- iii. The attitude of COPD patients towards specialist palliative care and the end of life.

There is considerable overlap between these headings within the findings of each paper. Therefore the summary section encompasses pertinent findings from papers outside each group.

Table v: Search strategy

<u>DATABASE</u>	<u>SEARCH TERMS</u>	<u>NUMBER OF POTENTIALLY RELEVANT ABSTRACTS REVIEWED</u>	<u>NUMBER OF PAPERS REVIEWED TO DETERMINE RELEVANCE</u>	<u>NUMBER OF ARTICLES INCLUDED IN FINAL REVIEW</u>
Ovid MEDLINE	Bronchitis, chronic; pulmonary disease, chronic obstructive; pulmonary emphysema; qualitative research	62	16	10
CINAHL	Pulmonary disease, chronic obstructive; lung diseases, obstructive; qualitative studies	88	5	4
Ovid PsychINFO	Chronic obstructive pulmonary disease; pulmonary emphysema	482	13	6
Additional sources	N/A	N/A	4	1

i. Physical experience and practical impact of COPD

The physical symptoms and practical consequences of COPD are well described in the literature, with studies conducted using a variety of research methodologies.

Breathlessness, or dyspnoea, is a universal symptom for COPD patients, mentioned in all the research papers identified. Onset is insidious – almost imperceptible – with severity increasing gradually over time.⁷³⁻⁷⁵ In fact, breathlessness can be broken down into three separate experiences:

1. A constant, background sensation that breathing, once an involuntary physiological process, can ‘no longer be taken for granted’,⁷⁶ especially on exertion.
2. A transient increase in the sensation of breathlessness, often brought on by certain triggers (e.g. smoke, dust, perfume, cold, damp),^{76, 77} or by exacerbations of COPD,⁷⁴ with a consequent further reduction in exercise tolerance.
3. Unpredictable paroxysms of severe dyspnoea, often with associated overwhelming panic and fear that one may be about to die.⁷⁷⁻⁷⁹

A variety of physical coping strategies are described, including the use of medication (including oxygen), lip-pursing, positional change and avoiding known triggers.^{79, 80} The severity of breathlessness can vary from day-to-day and even hour-to-hour, with unpredictability complicating the planning of practical tasks or social engagements.^{77, 79, 81, 82} Although dyspnoea is the most burdensome physical symptom described, others reported include fatigue, muscular weakness, cough, poor appetite, and insomnia.^{75-77, 83-85}

Exercise tolerance reduces over time, due to the increasing severity of dyspnoea (or the fear of precipitating it), fatigue and muscular weakness.⁸⁶ This restricts mobility both within and outside the home.^{82, 87} The space in which the person exists contracts, first with respect to the outside world (as those affected find it more difficult to leave the house), and then within the home itself (as stairs and even short distances between rooms become challenging).⁸⁸ For people using long-term oxygen therapy (LTOT), mobility is further restricted by the need to be in close proximity to an oxygen concentrator or cylinder; time one can be outside the house is limited by the amount of oxygen remaining in the cylinder.^{80, 83} Poor mobility impacts not only on the person’s social and family life, but

also on their ability to access healthcare services.^{83, 87} Reduced exercise tolerance renders those with COPD less able to carry out activities of daily living (such as washing, dressing, cleaning).^{73, 75, 77, 78, 83, 87, 89-92} Several methods patients use to deal with this are mentioned in the literature^{76, 80, 83, 84, 89, 90, 93}.

- i. Adaptation: 'plan and pace' tasks e.g. order the day so that a minimum number of trips upstairs are needed, build rest periods into longer tasks; modify tasks e.g. cleaning the floor sitting down;
- ii. Avoidance: giving up certain tasks altogether
- iii. Delegation: either to family members or paid carers
- iv. Development of new activities/hobbies to engage in

Dependence on informal caregivers for assistance with daily activities and household chores is common, placing pressure on family relationships.^{75, 80, 82, 83, 87}

Table vi summarises the papers identified as most relevant to the physical experience and practical impact of COPD.

Table vi: Physical experience and practical impact of COPD

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Fraser DD et al, 2006⁵⁵ US	To gain an understanding of how COPD affects the lives of older adults.	Patients with severe COPD aged > 55 years, involved in a hospital's case management or pulmonary rehabilitation programme. Non-English speakers and those with cognitive impairment were excluded.	A purposive sample of 10 (5 male, 5 female) Age range: 59-86 years	Structured interviews. Hermeneutic phenomenological analysis.	<p>Dyspnoea varied from easily resolvable episodes to severe and associated with overwhelming panic (especially if usual treatments/strategies had not worked).</p> <p>Each had developed strategies to cope with breathlessness (e.g. use of inhalers/oxygen, lip-pursing, positional change).</p> <p>Sense that others do not understand how frightening breathlessness can be.</p> <p>Physical restriction for those with severe disease (e.g. using only one floor of the house) and loss of independence resulted in feelings of isolation and poor quality of life.</p> <p>Adaptation: daily routines modified to enable completion (e.g. driving to the post office rather than walking to the post box), resulting in a sense of control despite loss of function.</p> <p>Symptoms were unpredictable – e.g. fluctuations in endurance levels and dyspnoea, which contributed to a feeling of loss of control.</p>	

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Kanervisto M et al, 2007⁵⁹ Finland	To describe the experience of people with severe COPD in their everyday lives.	Participants selected by a pulmonary nurse and rehabilitation counsellor from patients attending the department of pulmonary medicine in a Finnish university hospital. Inclusion/exclusion criteria not specified.	5 patients (+4 spouses) 3 male, 2 female All had FEV ₁ < 50% predicted 3 using long term oxygen therapy (LTOT)	Semi-structured interviews. Deductive content analysis.	<p>1. <i>Impairment of body function and structure:</i></p> <ul style="list-style-type: none"> - LTOT restricting mobility - Dyspnoea and muscular weakness <p>2. <i>Activities</i></p> <ul style="list-style-type: none"> - Need to prepare prior to going out - Difficulty with household chores and activities of daily living - Need for help from relatives despite reluctance to depend on others <p>3. <i>Participation</i></p> <ul style="list-style-type: none"> - Light exercise to keep fit - Importance of accessing outpatient COPD services to wellbeing. - Hospitalisation perceived as a relief due to ease of accessing oxygen and other treatment. <p>4. <i>Environment</i></p> <ul style="list-style-type: none"> - Need to adjust to physical restrictions imposed by COPD - Practical difficulties accessing primary care resulted in increased use of secondary care. 	No description of inclusion/exclusion criteria, and participants chosen by a clinician known to them.

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Gullick J, Stainton MC, 2008 ⁵² Australia	To explore the changes experienced by the person living in a body with COPD.	Patients with severe COPD undergoing lung volume reduction surgery for emphysema in New South Wales over a two-year period, and their family members.	15 (9male, 6 female) Age range 55-77 years (+14 family members)	2 focused interviews, 6 months apart. Hermeneutic phenomenological analysis.	<ul style="list-style-type: none"> - Dyspnoea: breathing could no longer be taken for granted, causing limitations in self-care, social activity and mobility. This resulted in changes in temperament e.g. anger, irritability. - The need to stop frequently made breathlessness visible to others. - Dyspnoea often triggered by extremes of temperature, dusty or smoky environments and certain positions; these were avoided. - Activities planned & paced due to fatigue. - Frequent coughing socially embarrassing. - Poor appetite due to difficulty chewing with dyspnoea. - <i>'Forcing the body'</i>: participants pushed themselves to the limit to complete basic household chores. - Coping strategies: hiding breathlessness, keeping busy, maintaining optimism, accepting the limitations of breathlessness and appreciating 'being here'. 	Sample taken from a population undergoing lung volume reduction surgery, which is offered to a very small proportion of COPD patients. The prospect of a surgical treatment for these participants may have engendered a sense of hope not found in others.

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Habraken JM et al, 2008⁶⁹</p> <p>The Netherlands</p>	<p>To gain insight into why patients with end-stage COPD tend not to express a wish for help.</p>	<p>A sample of patients with COPD identified for a previous, quantitative study: 82 patients of >60 years with FEV₁ < 30% predicted, randomly recruited from outpatient clinics of 4 hospitals and one specialist asthma & COPD centre.</p>	<p>Purposive sample of 11.</p>	<p>1 or 2 semi-structured interviews, 6 months apart.</p> <p>(5 completed a 2nd interview, either because the 1st did not cover all topics, or because a change in circumstances had occurred).</p> <p>Thematic analysis.</p>	<p>Breathlessness was the predominant symptom, and caused anxiety.</p> <p>Social limitations due to restricted mobility and fear of catching a viral illness that could cause pneumonia.</p> <p>Activities were modified or avoided altogether due to dyspnoea.</p> <p>Participants did not ask for help because:</p> <ol style="list-style-type: none"> 1. They did not regard themselves as being ill unless experiencing an exacerbation. There was time to adjust to multiple, relatively small deteriorations, therefore life with limitations became normal. 2. They were not aware of the potential to improve their situation. 	<p>Those who participated agreed to take part in two separate studies, and are therefore likely to represent a highly motivated group of COPD patients. This needs to be taken into account when reviewing the findings.</p>

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Wilson DM et al, 2008⁵⁶ Canada	To understand the care needs and care priorities of senior citizens with end-stage COPD.	English-speaking COPD patients attending pulmonary outpatient clinics in one Canadian city of > 64 years on continuous oxygen and with least 1 admission for an exacerbation in the last year. Felt by their physicians or pulmonary nurses to be in the last year of life.	12	Longitudinal ethnography. 3 semi-structured interviews and field notes taken over 8 months. Constant-comparative method of thematic analysis.	<p>1. <i>Maintaining independence.</i></p> <ul style="list-style-type: none"> - Importance of maintaining independence through self-reliance and adaptation. - All relied on informal & professional carers to some extent. - Little or no planning for a time when care needs would be higher. <p>2. <i>Maintaining stable health.</i></p> <ul style="list-style-type: none"> - All safeguarded health through regular check-ups, seeking prompt attention for impending respiratory infections, and avoiding situations that could affect their respiratory status (e.g. crowds, dusty environments). <p>3. <i>Living with constraints.</i></p> <ul style="list-style-type: none"> - Physical restriction due to oxygen including time constraints (potential for cylinder to run out). - Need to plan activities in advance and pace across the day and week. - All required assistance to leave the house. 	

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Kerr A, Ballinger C, 2010⁶⁶ UK	To gain an occupational perspective on how people live with COPD.	20 patients with COPD who had attended an 8-week pulmonary rehabilitation programme within a 6-month period.	9 (6 male, 3 female) Age 62-80 years	Semi-structured interviews. Grounded theory approach to analysis.	Changes and losses in activities they were able to carry out and how they did so due to fatigue and breathlessness. Some developed new activities that they were able to engage in, others adapted prior occupations (e.g. through pacing and planning). Certain tasks were handed over to spouses or paid employees.	

Table vi (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>McMillan Boyles C et al, 2011⁶⁷</p> <p>Canada</p>	<p>To develop an understanding of the meaning of disability for individuals living with COPD.</p>	<p>Patients >50yrs under the care of a physician for COPD who had been hospitalised at least once for an exacerbation.</p> <p>Recruitment via newspaper adverts, COPD community rehabilitation groups and/or programmes.</p>	<p>A purposive sample of 15 individuals from one Canadian community</p>	<p>Focused ethnography, incorporating narrative analysis.</p>	<p>COPD led to invisible disability, unless visible markers (e.g. oxygen, wheelchairs) were present.</p> <p>Dyspnoea caused difficulty with activities of daily living and social functioning.</p> <p>Participants described the dilemmas faced when considering whether to reveal or conceal their impairment, and the need to justify their behaviour in the absence of a visible marker of impairment.</p>	

ii Social, psychological and existential impact of COPD

The profound effect poor exercise tolerance can have on the family, social and work life of COPD patients is well described within the literature. Increased reliance on family members can lead to tensions, with the person with COPD experiencing fear of becoming a burden on their caregivers.⁹⁴ However, family relationships have also been shown to be the main factor impacting on quality of life for these patients, with the ability to maintain an active, mutually beneficial role within the family found to enhance self-esteem and general wellbeing.^{88, 75, 82}

The beneficial effect of a strong sense of community is evident, and social isolation and a sense of hopelessness may result when this is lacking.^{77 88} Also described is the sense among COPD patients that symptoms such as cough and dyspnoea are socially unacceptable.⁷⁶ This could be due to a perception that COPD (usually a smoking-related illness) is 'self-inflicted', with those affected feeling stigmatised.^{77, 84} In addition, the disability associated with COPD has been described as 'invisible' – with no obvious markers unless the person affected is in a wheelchair or using oxygen.⁹¹ A sense of shame is therefore reported to be felt when the poor exercise tolerance manifests itself as, for example, walking very slowly or taking frequent breaks.⁷⁶ Studies describe how the affected person may experience a dilemma as to whether or not they should 'reveal' their impairment so as to justify their behaviour to those around them.⁹¹ There is also a perception among COPD patients that others (including healthcare professionals) do not understand how disabling and frightening breathlessness can be.^{78, 79}

Psychological morbidity (including anxiety, depression and changes in temperament), is common,^{76-78, 87} and suicidal thoughts are reported in several studies.^{82 77, 78} Others develop cognitive coping strategies to help them to live with the symptom burden, loss of control and uncertainties associated with a life with COPD, such as: distraction (e.g. an engaging hobby); self-talk; prayer; relaxation; maintaining optimism; appreciating 'being here'; taking 'one day at a time'; comparing themselves to others worse off; acceptance of the illness and learning to live within the limitations it imposes.^{76, 84 75, 81} A sense of acceptance of COPD and its implications by participants is mentioned frequently in the literature. Pinnock et al's research describes COPD as a 'way of life', with participants passively accepting it as 'something to be coped with the best you can'.⁷⁴ This echoes the 'sense of resignation' described by Elofsson et al, whereby participants 'did not expect

much from life', and 'accepted they could not alter their circumstances or alter the course of their disease'.⁷⁵ Patients are unlikely to ask for formal help, partly because of this passive acceptance of their situation (and the fact that they may not regard themselves as ill unless experiencing an exacerbation), and partly because they are unaware of the potential to improve their situation,^{74, 86, 93, 94} or do not wish to bother healthcare professionals.⁸⁶ Despite the considerable negative impact a diagnosis of COPD can have, one study did report positive features described by participants, including an appreciation of carers, a deepened spirituality; and finding out who their 'real' friends were.⁸⁷

Table vii summarises the papers identified as most relevant to the social, psychological and existential impact of COPD.

Table vii: Social, psychological and existential impact of COPD

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Small SP, Graydon JE, 1993⁵⁷</p> <p>Canada</p>	<p>To describe the perceptions of uncertainty of hospitalised patients with COPD.</p>	<p>In-patients with COPD in 5 large, acute hospitals in one Canadian city.</p>	<p>25 (14 male, 11 female)</p> <p>Age range: 53-81 years.</p>	<p>Semi-structured interview.</p> <p>Content analysis.</p>	<p>Participants worried about how they would cope with daily activities on discharge, especially if discharge on oxygen was planned.</p> <p>They found it difficult to plan for the future due to the unpredictability of symptom severity and the timing of exacerbations.</p> <p>Two mentioned a fear of death and a sense that they were living on ‘borrowed time’.</p> <p>- Positive thinking helped participants to cope, e.g. taking one day at a time, comparing themselves to others worse off, maintaining hope for the future, and accepting the illness & living within its limitations.</p>	

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Guthrie SJ et al, 2001⁶⁴ UK	To understand the experience & behaviour, and also feelings & judgements of patients whose daily lives are affected by severe COPD.	64 patients with severe COPD taking part in a randomized trial of nebuliser vs. high-dose inhaler therapy. Participants were approached sequentially as they were recruited to the nebuliser trial.	37	Each participant completed up to three longitudinal in-depth, semi-structured interviews Narrative accounts Thematic analysis.	Family relationships were the main factor impacting on quality of life (good or bad). Maintaining an active, two-way role in family enhanced self-esteem. Mutuality was important, such as offering child minding in return for practical help. Dyspnoea, and fear of it, caused physical restriction within the home, e.g. participants planned their day to reduce trips upstairs. Difficulty leaving the house due to poor exercise tolerance when faced with a steep hill or the need to 'put a spurt on' to cross a road. A strong sense of community enhanced wellbeing, but when lacking contributed to loneliness and hopelessness. Those who had witnessed others dying from COPD felt fear at the prospect, and several mentioned suicidal thoughts.	No description of exclusion criteria to sampling strategy for the quantitative project (from which the participants for this study were recruited). Those willing to participate in 2 parallel studies are likely to be highly motivated, and this must be taken into account when reviewing the findings. Interviews were not recorded – rather notes were taken afterwards, therefore some of the thick descriptions and powerful quotes may have been lost.

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
O'Neill ES, 2002⁶⁰ US	To explore how women recognise and respond to symptoms of COPD.	English-speaking women with COPD attending pulmonary rehabilitation programmes in two centres in the Northeastern US. Those living in residential care were excluded.	21 females Mean age 67 years (range 45-82 years)	Semi-structured interviews and symptom diaries. Thematic analysis.	Breathlessness reported as the most common and distressing symptom, with others including fatigue, anxiety, depression and insomnia. Only 13/21 attributed their illness to smoking (and only 8 felt this was the only cause). Impact of COPD included losses relating to work, family and social life (including loss of intimacy). Sense of stigmatisation due to the social unacceptability of breathlessness. Practical coping strategies included use of breathing techniques & medication for dyspnoea, planning & pacing, restricting daily activities, and adaptations to physical tasks e.g. washing the floor sitting down. Participants avoided inhaled irritants e.g. smoke and avoided crowds during 'flu season. Cognitive coping strategies included distraction, self-talk, prayer and relaxation.	

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Eloffsson LC, Ohlen J, 2004⁵¹ Sweden	To achieve a deeper understanding of the lived experience of elderly persons who are severely ill with COPD and in need of everyday care.	Swedish-speaking COPD patients of >65 years accessing a home care service or living in nursing or residential care.	A convenience sample of 6 (4 male, 2 female). Age range 78-88 years. 5/6 on home oxygen.	Semi-structured interviews. Hermeneutic phenomenological analysis.	Dyspnoea & fatigue led to difficulties with daily tasks & dependence on carers /medication. Loss of control: having to wait for others to provide assistance. Life considered 'hard work'. Physical restriction (due to dyspnoea & need for oxygen) caused loneliness and isolation. Descriptions of being 'bound to' or 'captured by' oxygen, although some found it reassuring. Others felt the sight of oxygen caused stigmatisation. Some expressed regret for smoking. Gradual deterioration & adaptation. Sense of resignation: did not expect much from life, and accepted they could not alter their circumstances or the course of the disease. Life lacked meaning if unable to maintain previously enjoyed activities, especially for those who had led a life of manual labour. Well-being enhanced by family contact and the ability to maintain a hobby.	'Convenience sample' – no description of how participants were chosen from the population described.

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Barnett M, 2005⁵³ UK	To explore the experience of living with COPD by investigating the subjective phenomenon as described by the patient.	Patients with moderate to severe COPD and no other disabling medical condition attending a chest clinic. Those with different cultural backgrounds & those with large families who were 'known to have a constant stream of visitors' were excluded.	10	Unstructured interviews. Hermeneutic phenomenological analysis.	<ol style="list-style-type: none"> 1. <i>Perception of severity and symptoms</i> <ul style="list-style-type: none"> - Sense that COPD was 'self-inflicted' - Symptoms varied day-to-day & hour-to-hour, and were most severe in the morning. - Insomnia due to breathlessness - Breathlessness was the most distressing symptom, exacerbated by cold & damp. 2. <i>Functional disabilities</i> <ul style="list-style-type: none"> - Assistance required with personal care - Posture affecting dyspnoea – bending forward difficult. - Muscular de-conditioning causing weakness led to a fear of leaving the house. - Eating difficult due to dyspnoea. 3. <i>Emotional trauma of coping with COPD</i> <ul style="list-style-type: none"> - Anxiety, frustration & irritability common - Some had transient thoughts of suicide to 'end the struggle to breathe' - Several described 'panic attacks' associated with breathlessness, when they felt they would collapse or die. 4. <i>Implications surrounding social loss</i> <ul style="list-style-type: none"> - Poor exercise tolerance caused reduced ability to socialise, take holidays. - Inability to make plans due to symptom variation. - Loss of occupation (medical retirement) 	All participants known to the author (a COPD nurse specialist) & this may have inhibited their accounts. Exclusion criteria seem arbitrary e.g. large family size, ethnic origin & co-morbidities

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Robinson T, 2005⁵⁴ UK	To describe the experience of living with severe oxygen-dependent COPD.	All patients with severe (FEV ₁ < 40% predicted) COPD registered within a large, semi-rural area of Northern England.	10 (6 male, 4 female) Age 51-74 years	Unstructured interviews Thematic analysis	<p>Most blamed smoking for their COPD.</p> <p>Breathlessness (the predominant) symptom led to difficulties with personal care.</p> <p>Only one participant received formal care.</p> <p>Emotional effects of COPD included frustration, fear, depression, anger and then acceptance.</p> <p>A sense that people (including healthcare professionals) did not always understand the implications of breathlessness.</p> <p>Attacks of fear and panic associated with dyspnoea.</p> <p>One participant mentioned suicidal ideation</p> <p>Participants discussed needing information about their disease so they could plan ahead, including end of life issues. No participant felt they would rather not know their prognosis.</p>	

Table vii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Pinnock H et al, 2011⁵⁰ UK	To understand the perspectives of people with severe COPD as their illness progresses, and of their informal and professional carers, to inform provision of care for people living and dying with COPD.	Patients with end-stage COPD were identified by primary or secondary care clinicians working within 3 Scottish health boards using the 'surprise question' ('Would I be surprised if my patient were to die in the next 12 months?').	A purposive sample of 21 patients (+ 13 informal carers and 18 health or social care professionals). 14 male, 7 female Age range 50-83 years	A longitudinal study consisting of up to 4 in-depth, participant-led interviews over 18 months. Thematic narrative analysis.	1. Acceptance of COPD as a 'way of life' (rather than an illness that disrupts life): - Passive acceptance of COPD as something to be coped with 'the best you can'. - Participants did not actively seek out information about their condition, with several stating that they would 'rather not know'. 2. The story of COPD. - 'A story with no beginning': impossible for participants to identify a beginning to their COPD story (contrasted to those with cancer) - 'A middle that is a way of life': illness narratives punctuated by exacerbations interrupting 'normal life'. Little sense of a developing trajectory. - 'An unpredictable and unanticipated end: death generally not considered an imminent threat and end of life wishes generally not discussed. - One participant expressed shock at being referred to a local day hospice, due to a perceived association with terminal care.	

iii. The attitude of COPD patients towards specialist palliative care and the end of life.

Although the following collection of research papers has been grouped together for the purposes of this review, it should be noted that their aims are somewhat heterogeneous, ranging from determining palliative care needs, to exploring fears surrounding death and dying, to seeking to understand how the experience of breathlessness influences attitudes towards the end of life. There is very limited information available regarding the views of COPD patients concerning palliative care, and no literature reporting the experiences of those who have accessed specialist palliative care in any setting.

Awareness among those affected that COPD is an ultimately life-threatening disease is variable, with some studies reporting that participants were aware of the terminal nature of their condition, or describing a sense of living on ‘borrowed time’,^{87, 92} while others report limited knowledge of the life-limiting nature of COPD.^{74, 89, 94} This dichotomy is continued into the wish for prognostic information. Three studies report a desire among their participants for the opportunity to discuss prognosis with healthcare professionals,^{73, 78, 87} two report mixed views,^{92, 94} and Pinnock et al found that their participants did not actively seek out information about their condition, with several stating that they would ‘rather not know’.⁷⁴ It is unsurprising, therefore, that several studies found that participants had not planned or prepared for the end of life,^{73, 74} although Robinson et al report that their participants would value the opportunity to do so.⁷⁸

A fear of what dying might be like is discussed in the literature, with some COPD patients expressing a fear of dying with severe breathlessness and a sensation of suffocation,^{89, 92, 94} especially amongst those who had witnessed others dying of COPD.⁸⁸ Hall et al identified elements of a good death, which include: ‘the absence of suffering; leaving this world with peace of mind, knowing that their family and friends would be alright; knowing when death is imminent in order to make the most of time remaining; being in hospital (to avoid being alone or being a burden on family and friends); being surrounded by family and friends’.⁸⁹ As stated above, information regarding COPD patients’ views on specialist palliative care is minimal. One study describes a participant’s shock at being referred to a local day hospice (due to a perceived association with terminal care).⁷⁴ Another states that participants were unaware of the term ‘palliative care’, with some participants believing it would be beneficial, and others not wishing to discuss it, associating palliative care with the end of life and a scenario that nothing more could be done for them.⁸⁶

Table viii summarises the papers identified as most relevant to the attitude of COPD patients towards specialist palliative care and the end of life.

Table viii: Attitude of COPD patients towards specialist palliative care and the end of life.

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Jones I et al, 2004⁶⁸</p> <p>UK</p>	<p>To determine the needs of patients dying in primary care from COPD.</p>	<p>Patients on maximal therapy for COPD from 7 primary care practices in NW England who were, in the opinion of the GP concerned, likely to die within the next year.</p> <p>Patients identified by research group members.</p>	<p>16 (8 male, 8 female)</p> <p>Age 62-83 years</p>	<p>Semi-structured interviews</p> <p>Thematic analysis.</p>	<p>Half of the participants wanted further information regarding their illness, and the other half did not (either feeling that further information would not help, or for fear of what if might be).</p> <p>Over half knew their illness was progressive or incurable.</p> <p>Breathlessness was the predominant symptom, affecting activities of daily living and social interaction.</p> <p>One quarter mentioned a fear of dying.</p> <p>All felt they knew when and how to seek help should they become unwell.</p> <p>Unmet needs were mainly in the area of mobility e.g. lack of a stair lift or wheelchair.</p>	<p>Patients were selected by their own GPs (who were all part of the research groups). This may have affected the validity of the accounts.</p>

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Seamark DA et al, 2004⁶³ UK	To explore the experience of patients with severe COPD & their carers, particularly with regard to ongoing palliative care needs.	COPD patients from one GP practice with either severe disease (FEV ₁ < 40% predicted) or on long term oxygen therapy (LTOT)	10 (9 male, 1 female) Age range 57-85 years 7 /10 on LTOT Mean FEV ₁ 32% (range 20-39%)	Semi-structured interviews. Interpretative phenomenological analysis.	<p><i>Symptoms:</i></p> <ul style="list-style-type: none"> - Dyspnoea and fatigue predominant - Dyspnoea caused fear, anxiety, anorexia <p><i>Losses:</i></p> <ul style="list-style-type: none"> - relating to work, home & social life - increasing dependence & physical restriction - loss of dreams for the future and the opportunity to see their family grow <p><i>Relations with healthcare professionals (HCPs)</i></p> <ul style="list-style-type: none"> - Participants valued the opportunity to discuss treatment options & prognosis with HCPs. - Most acknowledged the severity and terminal nature of their condition. - Participants found getting to hospital clinics difficult & the perceived benefit was variable. - Ambivalence re. role of respiratory nurse specialist - Regular surveillance valued. <p><i>Effect on the carer:</i></p> <ul style="list-style-type: none"> - Participants worried about the pressure on their carers and some reported tensions. <p><i>Adaptations:</i></p> <ul style="list-style-type: none"> - Adaptive difficulties included boredom due to a sedentary life and financial problems. - Some positive features e.g. an appreciation of carers, a deepened spirituality, finding out who 'real' friends were. 	

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Ek K, Ternstedt B-M, 2008⁵⁸ Sweden	To describe the essential structure of the lived experience of living with severe COPD during the palliative phase of the disease.	Swedish-speaking COPD patients on home oxygen receiving care at two different hospitals in Sweden.	8 (3 male, 5 female)	Semi-structured interviews Husserlian phenomenological analysis.	<p>Limitations on living space (due to poor exercise tolerance) had an important impact on daily life.</p> <p>Lack of physical strength resulted in forced dependency on others, a lack of freedom, and the need to forgo social activities, leading to isolation and existential loneliness.</p> <p>Dyspnoea described as the most troublesome symptom.</p> <p>Variation in physical symptoms from day to day contributes to stress.</p> <p>Life sometimes felt meaningless when self-image was challenged by physical restriction, resulting in thoughts of suicide.</p> <p>Being involved in daily life e.g. small chores helped to fill the day with meaning, along with a sense of belongingness and social interaction.</p>	

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Hasson F et al, 2008⁶² Northern Ireland	To explore the potential for palliative care among people living with advanced COPD.	COPD patients on optimal drug therapy with FEV ₁ < 30% predicted or on long term oxygen therapy or non-invasive ventilation with a 'reasonable understanding of the progressive nature of COPD' 23 suitable patients identified by a respiratory nurse specialist	13 (10 male, 3 female)	Semi-structured interviews, content analysis	<p>Dyspnoea = most common symptom</p> <p>Emotional stress due to the realisation that each acute episode could lead to their death.</p> <p>Poor exercise tolerance resulting in social isolation and loss of independence.</p> <p>Disease acceptance and the need to 'get on with things'. A sense that nothing more could be done by their healthcare teams.</p> <p>Health care professionals perceived as busy, participants did not wish to 'bother' them unnecessarily</p> <p>Frequent hospital admissions were exhausting and demoralising.</p> <p>Majority lacked knowledge of emotional or financial support available</p> <p>Participants unaware of the term 'palliative care'. Some believed such care would be beneficial; others did not wish to discuss it, associating it with end of life and a scenario that nothing more could be done.</p>	

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
Gardiner C et al, 2009⁷⁰ UK	To explore the experience of patients with COPD, particularly fears surrounding death and dying.	64 patients participating in a pilot study to explore palliative care needs in COPD. All had moderate-severe COPD (FEV ₁ <50% predicted), with no cognitive impairment. 2 separate geographical locations.	21 (13 male, 8 female) (49 randomly selected for interview, 21 agreed to participate)	Semi-structured face-to-face (42.9%) or telephone (57.1%) interviews (according to participant's preference). Mean age 70.3 years. 61.9% male Thematic analysis.	Most unable to describe their chest complaint in detail, and unaware of the progressive nature of COPD (although some expressed a concern that their condition might deteriorate). No participant reported having discussed prognosis with a healthcare professional. Views differed as to whether they would wish to do so. Most would not initiate a discussion due to a sense that 'nothing could be done' even if they did. Some expressed fear of becoming a burden Many seemed unaware that they could die from COPD. Of those that discussed death, the overriding fear was of dying with breathlessness or suffocation.	

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Gysels M, Higginson IJ, 2010⁴⁹</p> <p>UK</p>	<p>To investigate how the experience of breathlessness in COPD influences patients' attitudes toward the end of life and their quality of life.</p>	<p>COPD patients with problematic dyspnoea, able and willing to communicate their experiences, accessing respiratory clinics, specialist respiratory nurses, Breathe Easy meetings or on the COPD disease register in primary care.</p>	<p>18 (7 male, 11 female)</p> <p>Classification of COPD severity: 10 severe, 6 moderate, 1 mild, 1 missing</p>	<p>In-depth, semi-structured interviews.</p> <p>Narrative analysis.</p>	<p>5 themes occurred across all participants:</p> <ol style="list-style-type: none"> 1. <i>'The onset of breathlessness'</i> <ul style="list-style-type: none"> - Covert & insidious initially, then an abrupt deterioration led most to seek medical help. 2. <i>'First contact with health providers'</i>: <ul style="list-style-type: none"> - Worries about the future/fear of death fell away once cancer excluded. 3. <i>'Back home and breathless'</i>: <ul style="list-style-type: none"> - The effort of routine daily tasks. Ongoing physical decline. 4. <i>'The quest for medical help'</i>: <ul style="list-style-type: none"> - Seeking treatment, anticipating recovery. - Interaction with healthcare professionals (HCPs) did not bring the expected support (time constraints & lack of attention to relevant problems). - Disappointment due to realisation that there were no solutions to their daily struggles. 5. <i>'Past and present, but no future'</i>: <ul style="list-style-type: none"> - Those with advanced disease realised what information had been omitted at time of diagnosis. - Those with advanced disease wished for precise prognostic information from HCPs. - Participants felt the future was uncertain, and did not prepare for the end of life. 	

Table viii (cont.)

<u>Reference & Location</u>	<u>Aims</u>	<u>Population</u>	<u>Sample</u>	<u>Study Design</u>	<u>Major Findings</u>	<u>Comments</u>
<p>Hall S et al, 2010⁶⁵</p> <p>Canada</p>	<p>To describe the perceptions of people living with COPD with respect to the end of life.</p>	<p>French-speaking COPD patients with:</p> <ul style="list-style-type: none"> - severe disease (FEV1 < 40% predicted) - oxygen-dependency - level 4-5 dyspnoea (100yds exercise tolerance or less) - hospitalisation for an exacerbation within the last year. <p>Those with cancer were excluded.</p>	<p>6 (4male, 2 female)</p> <p>Mean age 69 years.</p>	<p>Semi-structured interviews</p> <p>Thematic analysis</p>	<ul style="list-style-type: none"> - Dyspnoea rendered daily activities difficult or impossible. Participants described planning tasks in advance and taking regular breaks. - Living in fear of the next exacerbation (not knowing which would be fatal), including the unpredictability of timing. - Hospitals felt to be reassuring environments. - Most did not consider themselves to be at the end of life. - Participants did not speak openly about death (rather it was alluded to), and found it difficult to discuss dying with family. - Those who had witnessed a person dying with COPD had found the experience disturbing. - Participants expected dyspnoea to be part of the dying experience and expressed a fear of ‘suffocating’. - Perceptions of a good death included knowing when death is imminent in order to make the most of time remaining, being in hospital, and not being alone. - One mentioned a palliative care facility, and stated that she would not wish to be admitted there due to a fear of entering a unit one ‘would never leave again’. 	

METHODOLOGY

Introduction

Access to specialist palliative care for those with non-malignant disease is a fairly recent development. As these services were primarily designed to meet the needs of those with a malignant diagnosis, it is important to determine whether they are also suited to the needs of those with non-malignant disease, specifically COPD. The primary aim of the study is therefore to gain an understanding of the experience of patients with COPD who access palliative care services. As described in the introduction, one barrier to offering specialist palliative care referral for those with COPD is healthcare professionals' fear of distressing the patient due to the association held by many between palliative care and impending death. Participants' prior knowledge of specialist palliative care services and experience of referral will therefore be explored to ascertain whether this reluctance is justified. It was felt that a qualitative approach was best suited to the nature of this enquiry – i.e. to explore experiences and meanings from the point of view of the participants.

Aims and Objectives

AIM:

To gain an understanding of the experience of patients with COPD who access palliative care services in Salford.

OBJECTIVES:

1. To explore how patients with COPD feel when they are first offered a referral to palliative care services.
2. To assess what the term 'palliative care' means to patients with COPD prior to the initial referral.
3. To explore what perceived impact, if any, palliative care provision has on their physical or psychological symptoms, social functioning or spiritual wellbeing.
4. To explore what impact, if any, palliative care provision has on family and/or caregivers as perceived by the patient.
5. To assess what the term 'palliative care' means to patients with COPD who have accessed a specialist palliative care service for greater than one week (inpatient) or one month (outpatient).

Epistemological Approach

Of the qualitative methodologies, I felt that either grounded theory or phenomenology would be most appropriate to this research question; I wished to gain an understanding of the experience of a small subgroup of individuals accessing a service, rather than of a culture or organization as a whole (when ethnography would have been considered). Developed by Glaser and Strauss,⁹⁵ grounded theory seeks to generate theories regarding social phenomena with study designs that entail many cycles of simultaneous data collection and analysis, with emerging themes informing the next cycle of data collection.⁹⁶ In this way, theories are truly ‘grounded’ in the data, and data collection continues until a point of saturation is reached. The numbers of potential participants for this research project were expected to be small (as described later), and I felt it unrealistic to aim for several cycles of data collection. For pragmatic reasons therefore, a grounded theory approach was rejected.

It has been argued that it is valid for the choice of methodology to be informed by the research question or technical considerations rather than by the researcher’s theoretical stance,⁹⁷ and Pope & Mays explain that this ‘may be particularly the case in health services research because of its applied nature: research here tends to be geared towards specific practical problems or issues and this, rather than theoretical leanings, may determine the methods employed’.⁹⁸ Despite discounting grounded theory for pragmatic reasons, I believe a phenomenological approach (specifically hermeneutic phenomenology) was the most appropriate to the nature of this enquiry – i.e. to understand through interpretation of texts (interview transcripts) the experience of the individual with COPD accessing specialist palliative care, as phenomenology aims to ‘provide accounts that offer an insight into the subjective ‘lived’ experience of individuals’,⁹⁹ rather than to generate theories. ‘Phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world’.⁶⁶

Hermeneutics

'Hermeneutics' derives from the Greek verb 'hermeneuein', meaning to express aloud, explain, interpret or translate. Friedrich Schleiermacher (1768-1834) was the first to propose a 'universal' hermeneutics (as opposed to a method related purely to the study of classical languages): the 'art of understanding', the goal of hermeneutic practice being to understand correctly what has been expressed by another.¹⁰⁰ Schleiermacher first described the concept of the 'hermeneutic circle': when analysing a text, one can only understand the parts from an understanding of the whole, but the whole can only be understood from an understanding of the parts. He breaks this impasse by suggesting that 'one must begin with a cursory reading to get an overview of the whole',¹⁰¹ so that specific ideas gathered from subsequent readings can be understood in relation to the general thrust of the text. Once an overview has been obtained, he describes two branches of interpretation: grammatical or technical interpretation of the language and a deeper, psychological interpretation (for which one must understand something of the author's life and times).¹⁰¹

Inspired by the work of Schleiermacher, Wilhelm Dilthey (1833-1911) wished to develop a methodology for the human sciences, believing natural scientific method to be inappropriate to the human sciences. He could, therefore, be considered a founder of the formal qualitative research methodologies. He believed that while causal explanation was the aim of the natural sciences, understanding of mental or spiritual meaning should be the goal in human science research.¹⁰⁰ Dilthey explained that 'on the basis of lived experience and self-understanding and their constant interaction, there emerges the understanding of other persons and their manifestations of life'.¹⁰² Through this cultural attunement, understanding can be achieved as the interpreter [or researcher] recognises the inner state of the other [or participant] by means of that other person's behaviour and expressions.

Phenomenology

Both a philosophy and a research method, phenomenology was first described by Kant in 1764 as the study of 'phenomena' and 'noumena'.¹⁰³ As explained by Roche,¹⁰⁴ one 'can only know the appearance of things, never the things themselves: that is to say, he can only ever know 'phenomena', never 'noumena'.' Phenomenology is therefore the study of phenomena, or the appearance of things. Edmund Husserl (1859-1938), the central figure of the phenomenological movement,¹⁰³ advocated a 'pure' phenomenology, in which 'consciousness must be 'purified' by bracketing any considerations concerning the sources

and success of conscious experience'.¹⁰⁵ Husserl's maxim 'to the things themselves' means that in his view, we should aim to describe experience without incorporating any presuppositions about the meaning of that experience.¹⁰⁰ That is, any prior experience relevant to the subject of the enquiry must be put aside so that, for example, in this research project I should disregard my previous experience of health care, patients with COPD and specialist palliative care when interviewing subjects and analysing transcripts.

The Beginnings of Hermeneutic Phenomenology

Martin Heidegger (1889-1976) studied philosophy under Husserl at the University of Freiburg from 1919-1923, and succeeded him to the Chair of Philosophy in 1928.¹⁰⁶ He rejected Husserl's 'pure' phenomenology, advocating instead an 'existential' phenomenological method, combining phenomenology with Dilthey's theory of understanding.¹⁰⁰ However, Heidegger's phenomenology is subservient to what he calls 'fundamental ontology', centred on the 'question of being'.¹⁰⁵ It was in this area that he focused much of his effort. His major work, *Being and Time*, therefore considers the question 'What is being?', and to do so, he focuses on an entity called 'Dasein', the aspect of our humanness which is capable of wondering about its own existence and inquiring into its own being.¹⁰⁷ The first section is a preparatory analysis of 'Dasein', and the second explored Dasein's temporality. A third section, considering the relationship of being to time was planned but never materialised.¹⁰⁶ By the early 1930s, Heidegger had become sympathetic to Nazism, and saw active service in the Second World War.¹⁰⁶ From this phase of his life onward, his interest in phenomenology seemed to wane – maybe because his Nazi involvement diminished his power of subjectivity,¹⁰³ or maybe out of deference to Husserl, with whom he had ideological as well as philosophical differences (Husserl was Jewish).¹⁰⁸ Despite this, Heidegger's work had forged a link between hermeneutics and phenomenology that would inspire later philosophers such as Gadamer.

A Hermeneutic Phenomenological Approach to Human Science Research

A student of Heidegger's during the 1920s, Hans-Georg Gadamer (1900-2002) is primarily responsible for modern thinking on hermeneutics. His seminal work, *Truth and Method*¹⁰⁹ (first published in German in 1960), builds on Heidegger's description of understanding as a fundamental ontological structure of being (or Dasein) – i.e. we are constantly understanding in one way or another.¹⁰⁰ In this work he focuses specifically on the quest for

truth in human science (as well as in art and philosophy). According to Gadamer, any act of understanding commences with the fore-structures of understanding, or ‘prejudices’ (inherited from our prior experience and cultural tradition). Although the word ‘prejudice’ can have negative connotations, Gadamer believed that there are positive (or ‘legitimate’) prejudices that can lead to correct understanding, and these must be identified and acknowledged.¹⁰⁹ Gadamer describes the prejudices of the researcher as ‘constitut[ing], then, the horizon of a particular present, for they represent that beyond which it is impossible to see’.¹⁰⁹ In order to attain true understanding, we must ‘expand our horizon by including the different and opposing prejudices from the text while calling our own prejudices into question’.¹⁰⁰

I chose to take Max van Manen’s approach to data interpretation, as described in his 1990 work ‘Researching Lived Experience’,⁶⁶ which is heavily influenced by Gadamerian hermeneutic phenomenology. I feel a hermeneutic approach is most appropriate to the nature of my enquiry, as I believe the process of ‘bracketing’ prior experience would have impacted negatively on my working relationship with the research participants. It is important for a researcher-participant relationship to be built on trust, and it would have been difficult to establish such a relationship while pretending that I was something other than I am (i.e. not a doctor and not a specialist in palliative medicine) – although I did not make detailed reference to my background on meeting the participants, simply identifying myself as a researcher. Neither do I believe it would be possible or desirable for me to completely set aside this previous experience during the interpretation of data. I agree with Gadamer’s view that as long as they are acknowledged, these fore-understandings, or ‘prejudices’, can actually enhance the depth of understanding in phenomenological enquiry. Van Manen does not provide a prescriptive approach to analysis: ‘hermeneutic phenomenological method does not offer a procedural system; rather, its method requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience’ (page xi).⁶⁶ Indeed, Gadamer argues that ‘the preoccupation with [objective] method or technique is really antithetical to the spirit of human science scholarship’.¹⁰⁹ However, van Manen does describe a loose structure on which to base the analysis that I found to be a helpful guide. Novel to his approach is the suggestion that the process of writing and re-writing (as concurrent data collection and analysis progresses) forms part of the interpretation itself: ‘research and writing are seen to be closely related, and practically

inseparable pedagogical activities’ (page 4).⁶⁶ He asserts that hermeneutic phenomenological research may be seen as ‘a dynamic interplay among six research activities (page 30):

1. Turning to a phenomenon which seriously interests us;
2. Investigating experience as we live it rather than as we conceptualise it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented pedagogical relation to the phenomenon;
6. Balancing the research context by considering parts and whole.⁶⁶

However, we are cautioned that accounts of lived experience are ‘never identical to lived experience itself. All recollections of experiences, reflections on experiences, descriptions of experiences, taped interviews about experiences, or transcribed conversations about experiences are already transformations of those experiences’ (page 54), and even then, ‘no single interpretation of human experience will ever exhaust the possibility of yet another complementary or richer, deeper description’ (page 31).⁶⁶

When analysing texts (in this case, interview transcripts), van Manen outlines three approaches that can be taken (page 92).⁶⁶

1. wholistic
2. selective/highlighting
3. detailed/line-by-line

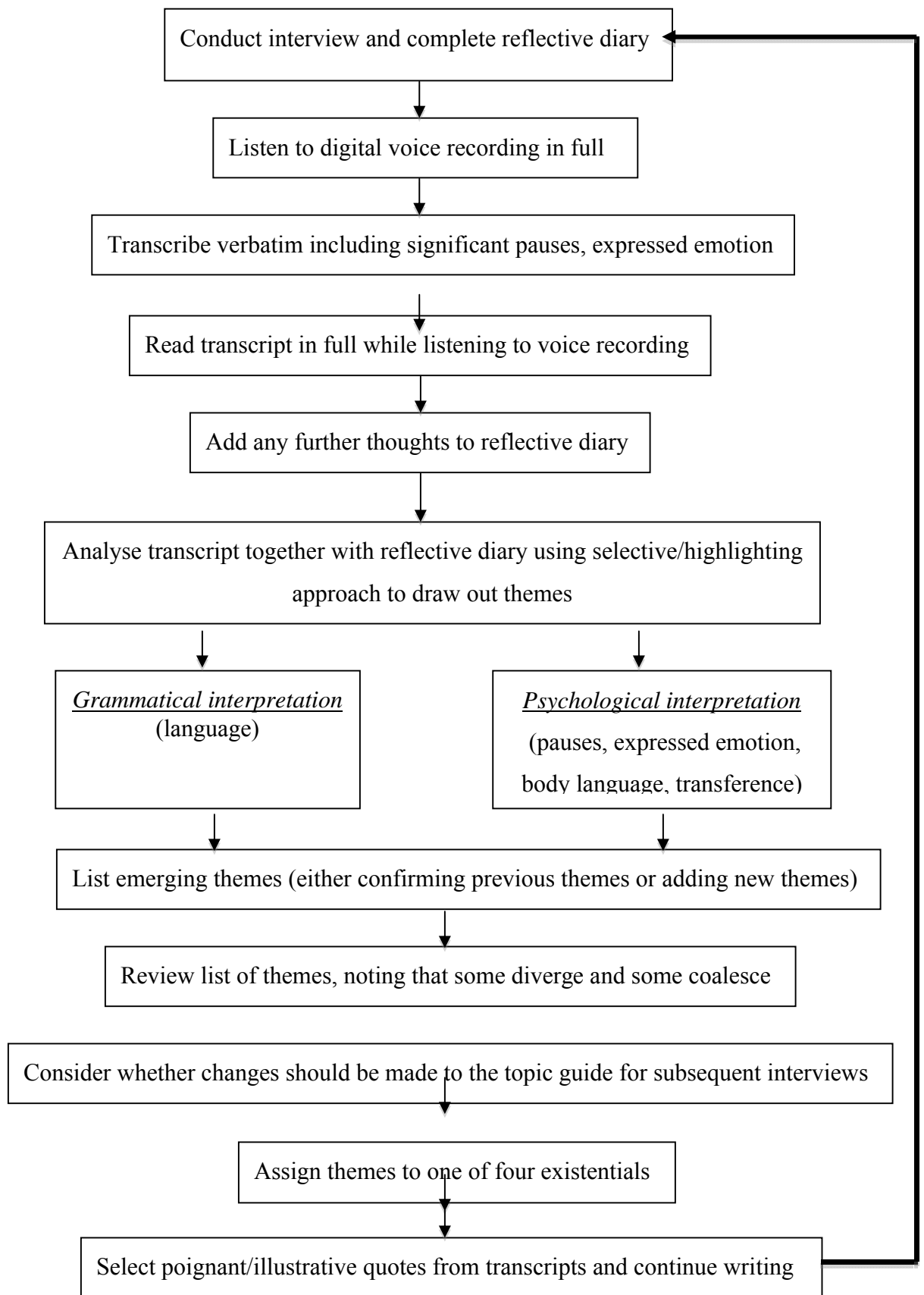
To aid the organisation of these themes, and thus proceed in the process of phenomenological writing, he suggests weaving one’s phenomenological description against the ‘four fundamental existential themes which probably pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness (page 101):

- lived space (spatiality)
- lived body (corporeality)
- lived time (temporality)
- lived human relations (relationality or communality)⁶⁶

As the interpretation progresses, and more data is collected, van Manen warns that ‘in order to ‘do justice to the fullness and ambiguity of the experience of the lifeworld, writing may turn into a complex process of rewriting (re-thinking, reflecting, re-cognising) (page 131).⁶⁶

I have summarised my own approach to data interpretation in the diagram below.

Figure ii: Approach to data interpretation



STUDY DESIGN

Sample

Audit data show that a mean of 20 referrals per year were referred to specialist palliative care services in Salford between 2006 and 2008.¹¹⁰ The annual number of referrals was expected to increase after 2008, as locally developed referral criteria for COPD patients in Salford who would benefit from specialist palliative care were disseminated to health care professionals across all sectors. An initial six-month period of recruitment and data collection was planned to take place between August 2009 and February 2010. It was unlikely that all patients referred during the initial six-month recruitment period would meet the inclusion and exclusion criteria however, and of those that did, not all would choose to participate. Even with the projected increase in referrals, the number of potential research participants was therefore expected to be small.

It has been suggested that in qualitative research, a sample size of six to eight can provide meaningful results if the population is homogeneous.¹¹¹ I felt that the study population described in the inclusion and exclusion criteria below qualified as homogeneous, and therefore aimed to interview a minimum of six patients. If fewer than six patients were recruited within the initial six-month time frame, I planned to seek permission to extend the study period until this number had been reached. If numbers of potential participants exceeded twelve, a purposive sampling frame would be used to ensure that narrative accounts representing a range of experience of different palliative care services were obtained, and data collection and analysis would continue until thematic saturation was reached (i.e. no new themes were being identified).

INCLUSION CRITERIA:

- 1. Patients referred to a specialist palliative care service within Salford with a primary diagnosis of COPD.**
- 2. The patient must have been accessing specialist palliative care services for greater than one month if accessing outpatient services (hospice medical outpatient clinic or day therapy, community Macmillan services or hospital clinic), or greater than one week if accessing inpatient services (hospice or hospital), in order to have experienced a meaningful view of the service(s).**
- 3. Patients from of any age group, gender and ethnic group were included**

(interpretation services were available if required).

EXCLUSION CRITERIA:

1. Patients who lacked the capacity to consent to participation in the study.

2. Patients who were felt to be in the last hours or days of life (i.e. on the Liverpool Care Pathway for the Dying). Time at this stage of life is especially precious, and any participation in a research interviews would reduce the time and energy available for interaction with loved ones. Patients in this situation are likely to be physically weak, and participating in a lengthy interview would be likely to be unacceptably burdensome, or indeed physically impossible.

3. Any patient who was known to the interviewing researcher in a clinical capacity. If the participant and researcher had a clinical relationship, this may have skewed the researcher's questioning (due to prior knowledge of the participant's situation and experiences), and may also have inhibited the participant from giving an honest account of their experiences for fear of offending the researcher or jeopardising their future care.

Recruitment

Recruitment commenced in September 2009, following Local Research Ethics Committee and Research and Development (hospice and acute trust) approval. Doctors and clinical nurse specialists working in the following settings were informed about the study:

- Hospice Inpatient Unit
- Hospice Daycare Unit
- Hospice Palliative Medicine Outpatient Clinic
- Community Specialist Palliative Care Team
- Acute Trust Specialist Palliative Care Team
- Acute Trust Palliative Medicine Outpatient Clinic

Prior to the recruitment phase, the researcher met with consultants, specialist registrars and the lead clinical nurse specialist from each service to describe the research and the recruitment process. A poster was designed to remind healthcare professionals of the study, and a summary sheet was produced detailing inclusion and exclusion criteria. If a patient with COPD was referred to the service, the doctor or clinical nurse specialist leading in their care mentioned the study to them if they fulfilled the inclusion and exclusion criteria, and gave them a letter of invitation (Appendix i). If the patient

expressed an interest in participation after reading the letter of invitation, an information sheet (Appendix ii) and reply slip (Appendix iii) were provided. The reply slip was attached to a stamped, addressed envelope, to be either posted by the patient or handed back to a member of the clinical team for internal posting.

When reply letters expressing interest in participation were received, the researcher contacted the potential participant by telephone if at home, or in person if an inpatient, to enquire if they are still interested. At that point, the study was discussed in detail if the participant wished, with ample opportunity for them to ask questions. It was emphasised that participation or non-participation would not affect their clinical care in any way, and that they would be free to rest, terminate the interview or withdraw consent at any time without giving any reason. A convenient time for the interview was then arranged. Written consent was obtained in triplicate at the time of the interview (one copy was left with the patient, one copy was added to the participant's clinical notes, and one copy was kept by the researcher) (Appendix iv). If the participant agreed, a letter was sent to their GP and specialist palliative care consultant to inform them of their patient's participation in the study (Appendix v). It was explained that should any issues arise that caused psychological distress or revealed an unmet clinical need, permission would be sought to discuss this with an appropriate health care professional (general practitioner, community Macmillan nurse, or member of the clinical hospice team), so that appropriate action could be taken.

Data Collection

Data were collected during in-depth semi-structured interviews, with reference to a topic guide (Appendix vi). All interviews were digitally recorded with the participants' permission. Interviews were conducted in participants' houses or in a private room in the hospice or hospital setting, according to their preference. Family members or carers were present or absent, again, according to the wishes of the participant. As mentioned previously, many of the participants were likely to be breathless on minimal exertion, or even at rest, and may have found a prolonged in-depth interview challenging. Immediately prior to starting the interview, it was therefore re-emphasised that the interview could be halted at any time, and continued after a break or at a later date if they so wished (or discontinued completely). This would have no bearing whatsoever on their future clinical care. Digital voice recordings were then transcribed verbatim by the researcher

Ethical Considerations

BENEFITS

People with a life-limiting illness such as a severe COPD are often perceived as vulnerable by health care professionals and caregivers alike. It can therefore be deemed inappropriate to request their limited time for research participation. This paternalistic approach, however, denies such patients the opportunity to exercise their right to autonomy. Studies have shown that the majority of this group of patients are keen to participate in research projects, and welcome the opportunity for altruism (i.e. to contribute to the effort to improve care for similar patients in the future).^{112, 113} It has been argued that participation in research can 'bring an overriding sense of purpose and meaning to the patient and family',¹¹⁴ and palliative care patients have been shown to be capable of deciding whether to participate in interviews and negotiating how this should happen.¹¹⁵

Following completion of data collection and analysis, the research findings will be disseminated by oral presentation and written publication both locally and nationally, thus contributing to the knowledge base in this area. It is hoped that this will result in improved access to specialist palliative care services that have been tailored to the needs of those with COPD in the future, thus enabling altruism. Participants will be asked if they would like to be informed of the findings of the research once the project is completed. If so, this information will be made available to them in an appropriate format.

BURDENS

Participation carried the potential for psychological distress, due to the possible discussion of end-of-life issues during the interview. As a specialist registrar in palliative medicine, the interviewing researcher had gained experience in providing psychological support in this situation, but was careful not to cross over roles from researcher to clinician unless absolutely necessary. As mentioned above, in the event of any distress caused, or unmet physical need identified, permission would be sought to inform the patient's chosen keyworker (hospice doctor, community Macmillan nurse, social worker or general practitioner), so that appropriate action could be taken.

The interview process may have proved tiring for this group of participants, who were

likely to be breathless on minimal exertion, including conversation. As described above, it was therefore explained that they were free to interrupt or terminate the interview at any time if they so wished. They were not required to give any reason for this, and it was emphasised that doing so would not affect their clinical care in any way. It was hoped that the potential benefit to the participant in terms of altruism and promotion of autonomy would outweigh any distress or discomfort caused.

Breach of confidentiality is a risk associated with any research process. The mechanisms put in place to minimize this risk are discussed in detail below.

Patients may have felt that their decision regarding participation could influence the quality of the clinical care they received, thus jeopardising the integrity of the consent process (patients could have found it more difficult to refuse participation if they perceive that this could be detrimental to their clinical care, or believe that they would receive an enhanced level of clinical care if they took part). To minimise this risk, the interviewing researcher was not involved in the clinical care of any potential or actual research participants.

CONFIDENTIALITY

Information is accessed and stored according to:

- The Data Protection Act 1998
- Caldicott Principles
- The NHS Confidentiality Code of Practice
- The University of Manchester's Code of Practice

In order to ensure and maintain confidentiality, all transcripts were anonymised, and the transcripts, consent forms and analysis are kept in locked cabinets or within password-protected software. All data will be destroyed following the dissemination of research findings. Patient identifiable data (e.g. names and addresses) were separated from interview data at the time of transcription, and each participant was assigned a number.

Only the interviewing researcher has access to the key document listing participant names and numbers. This document is kept in a locked filing cabinet separately from the transcripts.

Achieving Reflexivity

Following each interview, I completed a reflective journal, recording my thoughts regarding the participant's social and cultural environment, non-verbal cues, how I felt

during the interview (transference), and how experiences during that interview might inform my interviewing style and topic guide in the future.

Quality Assurance and Rigour

As experienced researchers, my academic supervisors have provided invaluable input throughout the development of the research protocol. The protocol was also submitted for assessment and review by two experienced qualitative researchers as part of an assignment for a taught MPhil module (Core Research Methods). A Research Steering Group, comprising a Consultant in Palliative Medicine, a Nurse Consultant in Palliative Care and a Respiratory Nurse Consultant, along with the primary researcher and two academic supervisors, informed and guided development of the proposal and accompanying paperwork. As stated above, all transcripts and accompanying analysis were reviewed by my academic supervisors.

The research idea was discussed at a 'Breathe Easy Group' (a British Lung Foundation support group for people with COPD). Members felt that it was a worthwhile study, and that although discussion of palliative care, hospices and end-of-life issues could be potentially distressing, if the topics were discussed sensitively, undue distress could be avoided.

In order to minimize the risks associated with working as a lone researcher in the community, the University of Manchester and participating hospice lone worker policies were adhered to.

RESULTS AND DISCUSSION

Introduction

Recruitment commenced on 1st September 2009. By January 2009, only two interviews had been conducted and permission was therefore sought to extend the recruitment phase by a further six months. The Local Research Ethics Committee and relevant Research and Development departments granted approval for this extension. In total, 18 patients were approached between 11/09/09 and 02/07/10 (please see table ix for details of recruitment settings), and ten expressions of interest were returned.

Table ix: Recruitment settings

<u>SETTING</u>	<u>NUMBER OF PATIENTS APPROACHED</u>
Hospital inpatient	5
Hospice inpatient	3
Day Hospice	6
Community	4
TOTAL	18

Two of the ten potential participants who returned a written expression of interest decided not to take part following a telephone conversation, hence a total of eight interviews were carried out (44% of those initially approached). Five participants were male, and three were female. The mean age of participants was 68.6 years (range 63-77 years). Further demographic details are not reported, and age and sex data has not been linked to individual participants, in order to preserve anonymity in view of the small sample size and limited geographical location in which the research was conducted. Although permission was not sought to access medical records and obtain clinical data regarding the participants, all had a primary diagnosis of COPD that was sufficiently severe to warrant specialist palliative care referral. At the time of analysis, four patients had died (all within one year of their

interview), indicating the severity of the participants' illnesses. Interviews were carried out at the participant's home or in the hospice, according to their preference. Accounts of participants' experiences of all the available specialist palliative care services within the geographical location were obtained (see Table x). Resources available to patients accessing each of the specialist palliative care services recruited from are outlined in Table xi.

Table x: Summary of services attended and interview locations

<u>PARTICIPANT NUMBER</u>	<u>SERVICE(S) ATTENDED</u>	<u>LOCATION OF INTERVIEW</u>
1	Day Hospice	Home
2	Community Specialist Palliative Care Team,	Home
3	Hospice Inpatient Unit, Medical Outpatients	Hospice Inpatient Unit
4	Day Hospice, Community Specialist Palliative Care Team, Medical Outpatients	Home
5	Hospital Specialist Palliative Care Team, Community Specialist Palliative Care Team	Home
6	Hospital Specialist Palliative Care Team, Hospice Inpatient Unit	Hospice Inpatient Unit
7	Day Hospice	Day Hospice
8	Day Hospice	Day Hospice

Table xi: Description of specialist palliative care services

<u>SERVICE</u>	<u>DESCRIPTION</u>	<u>HEALTHCARE PROFESSIONALS</u>
Hospital Specialist Palliative Care Team	<ul style="list-style-type: none"> - Team members visit patients on hospital wards, providing an advisory service to the clinical team responsible for their care. - Available 7 days per week (during the day). - Frequency of input tailored to individual requirements. 	<ul style="list-style-type: none"> - Medical staff (one consultant and doctors in training). - Palliative care clinical nurse specialists. - Specialist palliative care occupational therapist. - Specialist palliative care social worker.
Medical Outpatient Clinics	<ul style="list-style-type: none"> - Clinics based in hospital, hospice and community. - One clinic in each setting per week. - Frequency tailored to individual patients' requirements. 	<ul style="list-style-type: none"> - Consultant with visiting junior doctors. - Community specialist palliative care nurses and hospital clinical nurse specialists attend whenever possible.
Hospice Inpatient Unit	<ul style="list-style-type: none"> - 18-bedded inpatient unit. - 24-hour nursing care and daily medical reviews, with an on-call doctor available at all times. 	<ul style="list-style-type: none"> - Full specialist palliative care multi-disciplinary team including doctors, nurses, occupational and physiotherapy, complementary therapists, psychologists, medical social workers and chaplaincy support together with hospice volunteers.
Day Hospice	<ul style="list-style-type: none"> - Operates 3 days per week. - 12 places each day - Patients usually attend once day per week - A twelve-week course is offered in the first instance, (patients may return for further courses should they be deemed to have ongoing specialist needs). 	<ul style="list-style-type: none"> - Full specialist palliative care multi-disciplinary team (as for hospice inpatient unit) with creative and beauty therapists in addition.
Community Specialist Palliative Care Team	<ul style="list-style-type: none"> - Patients reviewed in their own homes. - Advice offered to GPs and district nurses regarding symptom control, as well as providing psychological support, practical and financial advice to the patients. - Frequency of visits tailored to individual requirements, with telephone contact in between. 	<ul style="list-style-type: none"> - Community specialist palliative care nurses - Occupational and physiotherapy. - Medical support available when necessary.

Results and the discussion are presented together in the following sections of this chapter. As described by Van Manen, 'hermeneutic phenomenological research is fundamentally a writing activity. Research and writing are aspects of one process'.⁶⁶ Figure ii (page 82) illustrates that writing and re-writing of interpretation and discussion of emerging findings was ongoing throughout the data collection process. It therefore felt logical to present the results and discussion together, rather than creating an artificial separation between them.

I have grouped emerging themes according to the four fundamental existential themes which 'probably pervade the lifeworlds of all human beings':⁶⁶ lived body (corporeality), lived space (spatiality), lived time (temporality), and lived human relations (relationality or communality). Accounts of the interaction between the participant and the specialist palliative care service(s) is included within the 'lived human relations' section. Although the aim of this research is to understand the experience of specialist palliative care for people with COPD, accounts of the day-to-day experience of living with the symptoms and consequences of severe COPD were perhaps inevitably obtained. This data has been included in the analysis as it was clearly relevant to the participants, and I believe it adds to the understanding of their lifeworld. Additionally, I felt that factors associated with the experience of COPD (for example, exercise tolerance restricted by breathlessness, or oxygen use), could affect the practical and social experience of specialist palliative care services, further increasing the relevance of these findings.

PART I: LIVED BODY

‘Waiting it out’: the experience of living with multiple exacerbations

The experience of frequent, unpredictable exacerbations of COPD was clearly one of the greatest burdens for several participants. They seemed to attempt to cling on to periods of good health, but their efforts were in vain – a further exacerbation would inevitably occur, at which point they had no alternative than to simply ‘wait it out’. When describing living through these exacerbations, participants often used emotive language; their distress was palpable. The experience was so distressing for one participant that his description was evocative of torture, causing him to contemplate suicide:

P3: ...It comes up every three or four weeks it was no good so – it just felt like drowning, every two or three weeks, it was awful.

.....At that time I wouldn’t have minded not coming out I wouldn’t have minded just dying. Dead, gone. ‘Cause the suffering you go through – it’s not life at all. It’s just like you’re drowning – then coming out of it and then going back through it again and drowning again and coming back every time. Bloody awful.

CH: It sounds like things were really hard for you at that time.....

P3: It was. I – I often felt like committing suicide, you know. Getting out of it.’

P2:the last twelve months I’ve been getting, um, infections about every six weeks, when you go off, um and you have to go on antibiotics and steroids. Taking eight a day, you know, for a week. And feeling so terrible, shocking. And then it goes off and you begin to feel not too bad. So you’re trying to grasp onto as long as possible feeling like that, you know, and I absolutely know now that it’s about to go again. And up to the day before yesterday I was feeling not bad at all, but it’s not – it’s going again.

CH: It sounds like that really gets you down...

P2: Oh God it’s awful, it’s terrible. When it’s at its worst I can barely walk to the toilet, and I hate it. [Pause]’

..... I have to wait it out, just wait it out. It’s terrible. I have to like wait the week out, which I know will be the worst. It’s like coming on for a few days, and going off for a few days, but that week in between, I’ve just got to wait it out.’

For some participants, the exacerbations seemed to occur with such frequency that they completely took over ‘normal’ life so that a cycle of repeated deterioration and recovery became the new normality:

‘CH: How often do you get bad?

P8: Well just, just like recently it was about three times! It seems like every few months like. ‘Cause I have that immunoglobulin as well, that antibody stuff. I go for that every three weeks. But I went in for I think it was seven or nine days on i.v.s, I came out for two and a half, and then I went back again, I was bad again. And I went on it again for seven or nine days or whatever. I come out and I was home for two weeks – or two and a half weeks – and then I ended up back again! So I had a bit of a bad run this year.’

The experience of living in fear of the next sudden, unpredictable exacerbation of COPD features strongly in the published literature, with several studies echoing the frequent fluctuations in symptoms that cause severe emotional stress for those affected – partly due to a consequent feeling of loss of control, and partly due to the awareness that any exacerbation could lead to one’s death.^{79, 81, 86} Indeed, Hall et al describe their participants as ‘living with the constant menace of death’.⁸⁹ Thoughts of suicide are also described, especially if patients are in the midst of a period of poor health.^{77, 78, 82} In the account above, Participant 8 describes a more positive approach to the fear of exacerbations, attending for intravenous immunoglobulin regularly in an attempt to prevent further episodes. Similar pre-emptive strategies, such as avoiding contact with crowds or those with influenza, are reported by Wilson et al.⁸⁰

‘Keeping on top of it’

When questioned about the effect accessing specialist palliative care has had on their lives, several participants mentioned a reduction in the number of hospitalisations for exacerbations of their disease, although it is difficult to know if this was directly attributable to the palliative care service accessed:

‘CH: And do you feel coming up here [day hospice] has had any impact on how you are physically in yourself?

P8: Er.... well I’m not feeling – I’ve not been back in [name of hospital] for quite a while,

and that's not bad! [Laughing]. Touch wood. Yeah – I think so, unless I'm just having a good run – I don't know.'

One participant felt that the frequent monitoring of her condition made possible by a weekly day hospice attendance was the reason for fewer hospital admissions:

P1: Unfortunately I've had quite a number of chest infections since I went there [day hospice], but we've managed to keep it to only one admission to hospital.

.....I'd probably've gone in two or three times.

CH: Right.

P1: And I'd only been in the once.

CH: So what do you think they did to prevent it?

P1: I think they kept on top of it.

CH: Right. In what way?

P1: The monitoring of it.....There was three doctors up there and – they were altering my medication. Erm ...so that we got on top of it very quickly.'

Perceived reduction in hospital admission was not a universal experience, however:

CH: Has [palliative care] made any difference to how often you have exacerbations?

P2: No, nothing does.'

In a US-based study, Rabow et al also mention a perceived reduction in healthcare utilisation as a result of specialist palliative care input (for patients with a variety of diagnoses),⁵² but larger scale, quantitative studies would be needed to investigate this association. Although the participants quoted here seem to view reduced hospitalisation as a positive outcome, there are conflicting views of COPD patients with respect to hospital admission in the literature, with one description of admissions as 'exhausting and demoralising',⁸⁶ and another of hospitalisation as a relief, due to ease of access to oxygen and other treatment.⁸³ Participant 1 seemed reassured by the weekly medical assessments that were available to her in day hospice. Seamark et al also found that reassurance was gained from regular contact with health professionals, with patients expressing a wish for regular surveillance.⁸⁷

Living with breathlessness

Although mentioned by only two of the participants, the descriptions of living through paroxysms of breathlessness were especially powerful. Participant 4 came across as a very independent, proud man, and the effect of being totally disabled by sudden and unpredictable episodes of breathlessness in public places (e.g. the street where he lives, a busy car park) seemed particularly devastating to him. He described an occasion when his seventeen year-old grandson carried him inside from the garden when he was caught in the rain and unable to move due to disabling dyspnoea. Although he made light of the episode, his body language made me feel that this was a particularly painful memory. He also described how the fear of death contributed to his sensation of dyspnoea:

P4: Well breathless is the big thing. Um... I get very jittery, and um – I had some horrible thing outside – some terrible thing. And each time you have a bad do – I mean especially when I first started having bad dos, you don't think you're going to get through it at all, you – it's just horrendous. But you do get through it.It passes eventually, and you – and you realise you're not dead, um, but they slow you down and they make you wary of doing even the stupidest things.'

Another participant described the daily struggle to get dressed, with each action punctuated by breathlessness and consequent anxiety:

P7: Yes, yeah – it takes me an hour to get dressed, 'cause I've got to keep stopping and calm meself down and then put your knickers on and then calm yourself down and put your tights on and calm yourself down and put your pants on [takes deep breaths]

CH: Sounds like hard work.....

P7: It is – it is hard work. Yeah. I've lost about five stone. Yeah – but it's because me doctor says I'm working twice as hard as everybody else, which is true in't it?'

The experience of breathlessness was clearly frightening for participants, causing a spectrum of distress ranging from mild anxiety to overwhelming panic. This is well described in the literature, with descriptions of panic associated with paroxysms of dyspnoea including fear of suffocation⁹³, a choking sensation⁷⁷, and a sense of helplessness and imminent death, especially if previously successful coping strategies have failed.⁷⁹

Symptom Management

Although three participants felt that accessing specialist palliative care had had a beneficial effect on their physical symptoms (specifically in relation to pain, breathlessness and insomnia), the impact on participants' psychological state seemed more marked. Indeed, a recent systematic review of the psychological experiences of attending specialist palliative day care concluded that benefits are likely to be within social, psychological and spiritual domains.¹¹⁶ I noticed that several participants spoke with more conviction when describing these effects than on discussion of any other topics. It was difficult to pinpoint a specific intervention that had resulted in improved mood – accounts were of the beneficial effect of the attitude of members of staff, or the general atmosphere within a setting:

'P3: they've just given me a bit more confidence in meself. It's good surroundings. You know, good nurses, and doctors..... they sit and listen to you and ask you questions. In hospital they, they shuffle in, have a word with you, see what's wrong with you, tell you something and bugger off, that's it. Here they come and sit down and talk to you and if you wanna ask them something, which you can do if you want to...'
..... It makes you feel as though they're taking notice of you. You're not a number, you know you're not a – you're a person.'

Participant 4 described how the debility and lack of independence he experienced as a result of his illness had made him feel worthless as an individual. He felt that attending day hospice had helped to lift his mood by increasing his self-confidence. Similarly to the views expressed by Participant 3 (above), it seems that individual attention and a sense of being listened to by health professionals, together with the opportunity for honest expression feelings and emotions had contributed to this improved self-worth:

'P4: It's made a big difference to me. It's given me something to look forward to. I enjoy talking to people – I've always enjoyed talking to people, um..... and this bringing out these feelings, showing your feelings is um.... I mean I've told other people, you know, I'm a great one for preaching but I never do it meself. But now I'm, I've learned that, er... it's not wrong to show your feelings at all. It's a good thing. And it's given me a bit more confidence as well, and they make you feel important. 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. Which takes a lot of doing really, but they do it.'

.....at [name of hospice] they must, they must practice for twenty years how to make people relax and talk and – unbelievable!..... The people just made you feel – not only did they make you feel relaxed they make you feel as though you're important, which is something you do without when you're getting ill. You, you – you tend to think yourself as being not a full person, and um, you feel, I do anyway, useless.'

Participant 8 felt that it was the caring nature of the staff that helped to lift his mood, while Participant 1 felt that comparing her situation to others worse off than herself, and the realisation that she wasn't alone in her suffering was beneficial:

CH: Now, in terms of how you feel mentally inside yourself, or spiritually, do you think [name of hospice] has had any impact on that?

P1: Yes, yes, yes – I'm not as depressed as I was.....

CH: Right. So depression was a problem....

P1: It was beginning to come in [laughs].

CH: Right, okay. And what do you think they've done to improve that?

P1: Well seeing that there was people worse off than me, erm.... knowing I wasn't the only person in the world, you know, that was suffering. Erm... it's just eased it.'

The sense among participants that it was acceptable to share their feelings about living with serious illness was of utmost importance, and this seems to have been achieved by staff appearing 'available' and interested in them as individuals, with time to listen. The value of staff allowing their patients the opportunity to talk freely is also reported frequently in studies conducted across all specialist palliative care settings.^{54, 57, 60, 70 59, 62} In Ingleton et al's study of a community specialist palliative care service, they describe the comfort associated with the perception of staff 'being there' for the patients, and state that 'perhaps the most important aspect of this is the intimation that patients and their wellbeing rather than the state of the disease actually matter to the health professionals'.⁶⁰ This emphasis on quality of life was noted by Participant 4 in our study, and contrasted with his experience of the attitude of clinicians from other branches of medicine:

CH: So what do you see the doctor for when you're there?

P4: Oh – all sorts and everything. The slightest thing and they'll send you to the doctor! But it- it's not like going... I mean the doctors I have at [name of GP surgery] are all fabulous, really good, but at [name of hospice] it's different. They have this – they all have this mentality that I mean I said to him one day 'why do you let people smoke? You've got a smoking room and you're a doctor!'. And he said 'our aim here is to make you feel better', he said 'I don't care how we do it, but we'll do it'. And I thought how brilliant is that?'

LIVED TIME

Recognition that time is limited

Several participants mentioned the incurable nature of their disease, and I was at times surprised by the matter-of-fact way in which this was discussed:

‘CH: So you didn’t just link it [palliative care] with cancer, you linked it with dying as well...

P2: Yeah, yeah. But I already knew that anyway, that er I knew that I wasn’t going to get better. [Pause]’

.....I don’t think they [palliative care]’re there just because you’re dying – although I do know I am you know, I’m not stupid.’

‘CH: What about the way that you see your illness, and the way that you see yourself as somebody who comes to the hospice once a week. Has that changed how you feel about your illness at all?

P7: I know I’m getting worse and worse, and I know it can’t be reversed. So.... what do you do?’

On realising that time could be short for her, one participant had brought forward a trip to New Zealand to visit family:

‘P1: I had planned to take it the following year, but I knew that my health wasn’t that good so it brought it forward a year..... I just wanted to see it for the last time.’

Participant 4 felt comfortable to use a humorous anecdote when describing the speed of his deterioration:

‘P4: But you do, you go down and, um, when you don’t get many days that are better you think you just – it’s like, there’s an old blues record (that’s my big thing, blues records) - there’s an old blues record called ‘Going down slow’ which is about dying and I always say I’ve – if me brother rings or anything like that ‘I’m going down a lot faster’ [laughs]. Than the record....’

..... there’s only so much they can do, but they chop and change the medication now and again and um, they’re trying all the time to give you new medicines and inhalers

they mess about with a bit and they, they generally try very hard to make you feel that bit better. I don't think I'm ever going to get better.'

It is interesting to note that although published studies of patients with severe COPD report variable knowledge of their prognosis,^{74, 87, 89, 92, 94} all participants who discussed prognosis in this study seemed to be aware of the fact that time was short, and discussed this openly. This may be a result of frank and honest communication being made possible by specialist palliative care input, or it may be that patients who are aware of their poor prognosis are more likely to be offered and accept a palliative care referral. Interestingly, rather than palliative care input taking away hope, an increased sense of optimism for the future was mentioned as one aspect of a change in outlook experienced by participants:

CH: Do you think being in here [the hospice inpatient unit] has changed the way that you think about your illness or about your future in any way?

P3: Oh yeah. Yeah – you can overcome it, if you try, you know with patience, understanding it.'

CH: ... what about how you feel inside yourself. Has that – has that changed at all while you've been in here [the hospice inpatient unit]?

P6: Er yeah it's changed a bit. It's er – I'm not – it's give me a bit to look towards... like light at the end of the tunnel sort of thing. Give me a bit of light at the end of the tunnel.'

One participant felt the opportunity to attend a palliative medicine outpatient clinic provided an element of hope that it may be possible to improve his symptoms in the future:

CH: And did you find that a useful experience?

P3: Well it helps in a way, yeah. Yeah it gives you something to look forward to, anyway.

CH: Right.

P3: Yeah – I suppose, you know, it might make me life a bit easier.'

LIVED SPACE

Physical restriction and loss of independence

Described extensively in the literature review, physical restriction leading to a gradual, progressive contraction in the environment in which the participants could comfortably operate (due to breathlessness) was also major theme in this study. When interviewing Participant 2 in her own home, I realised that although she lived in a fairly large house, the space in which she existed from day-to-day was very compact – the corner of one room. She described how this change had occurred gradually over time:

P2: I went to bed every night, slept in bed, and erm, one night the chair [stair lift] broke and I thought ‘Oh I’ll just sleep down here’, and I did, I slept on the settee and I had the best night’s sleep I’ve had for a long, long time so I thought ‘Oh I must try that, staying down here’, so I bought a bed and stayed down here and I do sleep a lot better down here, so from there it went when I was ill one time and it was a nightmare getting to bed and getting to the toilet. That’s when I had that toilet put in and stayed down here from then on. And I am a lot more comfortable.’

Reduced mobility due to breathlessness seemed to result in a deep sense of frustration and progressive loss of independence for many of the participants:

P3:you’ve got no mobility – and trying to exert meself – it’s, well it’s – this COPD it was just too much. Just every time I did something I’d just stop from being short of breath.

CH: So you say that the loss of mobility is frustrating for you....

P3: Oh yes. That’s a big thing, yeah.

CH: Are you able to go outside of your house?

P3: I can – yeah, I can go out, yeah. But like walking, doing things, I can’t do it. I just can’t - I’m not able to do it. Simple things like getting a shave, sometimes I can’t even do that proper. [Pause]’

Reduced exercise tolerance resulted in many practical problems, including difficulty accessing healthcare services, (again echoing the published literature^{83, 87}), and social care services:

P1:With my GP, when I'm bad I can't move out – can't, no way can I drive myself to the doctor. And it puts me off having to walk down the corridor [laughs] you know, once I get into the waiting room then you've got to go down the long corridor and invariably I'm at the far end. It didn't matter which GP I saw, I ended up in the end office. And so I'd tend not to go.'

P1: ...unfortunately you know, the day - the day care centres that are around all entail stairs'

Participants' social lives were also affected. When Participant 1 described the checks she had to make before visiting a friend or relatives house, she laughed with embarrassment. I had the sense that the need to discuss toilet facilities prior to visiting resulted in a degree of social humiliation for her:

P1: if I go to somebody's house I've got to make sure they've got a downstairs loo.

CH: Right.

P1: And most people don't have a downstairs loo. [Laughs] Cause there's no way I can climb stairs.

CH: And what stops you from getting up stairs?

P1: Breathlessness.

CH: It's your breathing.....

P1: You know, it's – as much as I would love to go to me son's house I daren't.

CH: Right

P1: Because he's got an upstairs loo [laughs]'

The social unacceptability of breathlessness and its consequences are described in O'Neill et al's study of women with COPD,⁸⁴ and it seems that this participant's activities were restricted by the perceived shame of revealing her disability as much as the practical difficulty itself. This sense of shame and social unacceptability of the symptoms and consequences of COPD could be due to a view of COPD in wider society as a self-inflicted disease of smokers.^{77, 84} This may result in a dilemma for those affected as to whether to reveal or conceal their disability, as described by McMillan Boyles et al,⁹¹ and illustrated by Participant 8's experience of leaving the house in a wheelchair; displaying his disability to wider society induced feelings of embarrassment:

P8: Well – er, I can't walk long distances like, you know, but I have a wheelchair, you know. But I get bloody embarrassed when I get in that sometimes.....'

Difficulty keeping up standards that had previously been met (e.g. household cleanliness) due to impaired mobility and increased fatigue was also perceived as embarrassing and shameful by one participant:

P7:it's embarrassing! [Laughs] 'Why have I left that there, why have I left that there?' - 'cause I just haven't got the time or the breath to do it.

CH: So that's a change for you....

P7: Oh yeah. Yeah. Yeah I'm ashamed of it really. I keep threatening to get a cleaner.'

This difficulty achieving previously maintained standards and activities sometimes appeared to result in loss of identity (e.g. proud housewife) and role for participants. For example, Participant 8 told me that he had always been a hard-working painter and decorator, and proudly described to me the years he had spent in college, learning his trade. Being unable to continue in this work had clearly impacted upon his mood and sense of identity:

P8: I'm not feeling sorry for meself but you think 'well I used to be able to do this and be able to do that. It's like sometimes now I still do a bit of decorating and that, but it takes me three times as long and [laughs].... It's hard work you know, but.... eh.Obviously you get fed up and that, because I've always worked and that, you know what I mean? I always worked weekends or was doing foreigners and whatever, you know.'

Interestingly, Elofsson et al found that the inability to carry out practical tasks impacts especially strongly on men who used to lead an active life of manual labour (such as Participant 8),⁷⁵ and Gullick et al described how for their male participants, 'the visibility of their dysfunction and their loss of effectiveness diminished their sense of manhood.'⁷⁶ As with the contraction of living environment, loss of independence appeared to happen gradually, and almost imperceptibly:

P4:I have days – like today I'm not bad today, um, and I look out and I think I should be out there, doing something, and you can't and then you do something – some

silly little thing, you might go in the other room and try and make a cup of coffee and then you're, you start the struggling and it takes you ages to get over it.And you - when every day you think 'I'll be better tomorrow' cause that's what I always say I'll be better – I'll do that tomorrow or that tomorrow, and tomorrow comes and you're not – in fact you might be a bit worse. Then when it goes on like that over a period of time, gradually, it gets at you and you think am I ever going to be able to do this or that, and the answer's probably no.'

Loss of independence inevitably resulted in an increased reliance on caregivers, which appeared to impact on the self-worth of Participant 4, who described himself as 'lazy' as a result:

'CH: How are you able to get around the house?

P4: Generally not bad, um, depends – some days are a lot worse than others. Um.... we have a drinks cabinet at the end there, and I have a whisky at night, and sometimes I can't – I can't walk to the cabinet..... so I - every night now she brings me a drink in, but I couldn't go and get it. I think I'm probably getting lazy, and spoiled rotten as well, um, I don't think that does you any good really, relying on other people. It's very hard to rely on other people to do things for you. Um.... but you have to in many ways. And I think it's harder for the people who look after you, like – you know, carers and that.'

Reliance on informal caregivers is well-described in the qualitative literature.^{75, 80, 82, 83, 87} In the quantitative literature, Elkington et al's questionnaire survey of the informants of deaths from COPD found that 95% of patients with COPD in the last year of life required some help from family or friends, with 60% reliant on informal caregivers for help with personal care. Only 30% received any help with activities of daily living from health or social services.¹⁴

There was a sense from several participants that accessing specialist palliative care had broadened their physical environment again. For one interviewee, who was a hospice inpatient at the time, this change was been brought about by a combination of increased confidence and physiotherapy. Earlier in the interview, this gentleman had described prior episodes of profound depression and suicidal ideation to me, due in part to the experience of breathlessness associated with exacerbations of COPD. However, when describing his

increased mobility, he seemed almost elated:

P3: It gives you a bit more confidence in yourself. Makes you want to do a little bit more, you know, and help yourself a bit more.

CH: With what kind of things?

P3: Like getting up, walking to the door and, running down to the bottom and running back again..... I hope nobody saw me! [Laughs] You know, like, now I walk down to the bottom, I can do that now, cause they taught me how – I can just get up now and go for a walk. [Inaudible] how far I can go, I can go up and down here.

CH: Is that a change?

P3: Oh yeah. Oh aye yeah.

CH: And what do you think it is that's helped you do that?

P3: Just a bit of confidence – they give you confidence I think. [Pause] Yeah, that's it. A bit of confidence.'

The act of attending day hospice was an achievement in itself for one participant, who seemed to feel encouraged that leaving the house for a day (a prospect that had previously caused great anxiety) was possible. When describing this achievement, she appeared physically buoyed:

P7: I felt I'd achieved something when I got home..... that I've been and done it! That I've been, yeah.

CH: So it was the physically getting up, getting here.....

P7: Yeah. Yeah that was me big worry. And when I've done it once, you see, I know I can do it so I've done it again.'

Participant four also felt that increased confidence and mobility were two benefits he would appreciate on discharge from day hospice. These changes seemed to have been brought about by increased motivation, and increased confidence in his own abilities due to comparison with others who were more unwell:

P4:it's done me the world of good, and um, I'm sure the benefit of [name of hospice] will come out this summer when I can go in the garden and um do things.

CH: How do you think [name of hospice] has changed that?

P4: Oh..... they've just brought out things in me that have lain dormant for years and talking to different people – people that are a lot worse off than me.'

The benefits of the opportunity to meet others with a shared experience of life-limiting illness are described in the following section.

LIVED HUMAN RELATIONS

‘The last stand’: preconceptions/expectations of palliative care

When questioned about prior knowledge of the role of specialist palliative care services before their engagement, all participants (and one caregiver) mentioned an association between patients with cancer, and with the dying process or terminal disease. Studies conducted both in the UK and throughout the world echo this finding.^{57, 68, 69} Many participants had heard of palliative care through the experience of friends, acquaintances and family members, and this connection between specialist palliative care and the end of life was also evident within the wider community:

‘CH: Had you heard about [name of hospice] before?

P1: I had yes. A friend of mine had cancer so I knew that she’d – you know – we used to take her up there once a week.’

‘P2: to me palliative care is nursing, specialised nursing of people that are going to die and so I think everybody – everybody does associate palliative care with [name of cancer hospital] - and dying.’

‘CH: So what did the word ‘hospice’ mean to you before you came here?

P7: Death. It’s where you die! [Laughs] Yeah, yeah, that was it.

CH: Had you ever been to a hospice before?

P7: No, no, no.....

CH: Or did you know anybody who’d been to a hospice?

P7: Nobody.

CH: So how did you come to associate a hospice with dying - where do you think that came from?

P7: Well, you just hear people say ‘she’s in a hospice and oh she’s died last week’ and ‘she’s in a hospice and oh she’s died last week’ [laughs]. And that’s how it goes.’

‘P8: Well like I always thought this - er - [name of hospice] was just like for cancer and it was like for a lot of people with terminal cancer, you know

..... it was always like people - their last stand, you know, as we understood it....’

Despite the association with cancer and dying, reports from within the local community of the care received by patients who accessed specialist palliative care services were often very positive:

‘CH: So what did you know about [name of hospice].....?

P1: Only that they looked after everybody very, very well. I never heard a bad....bad remark.

CH: Okay

P1: It was only good input that I received.’

Participant 2 described her daughter’s experiences of palliative care when she had been diagnosed with breast cancer several years previously:

‘P2: I think her name was [name of MacMillan nurse], and she talked [name of daughter] and me through everything, everything. She was absolutely brilliant! Er – in fact she called at [name of daughter]’s house one day to see her décor – it was Christmas time – to see her decorations and, er, [name of daughter] said ‘I felt as if I could talk to her about things I couldn’t talk to [name of son in law] about’, because he, he got too emotional for [name of daughter], you know – she’s not like that. She wanted to talk about things and get answers not, you know, not get all emotional.’

Despite accounts of the good reputation of palliative care services within the local community, it is perhaps unsurprising that two participants reported an element of distress when the option of specialist palliative care was mentioned to them, given the strong perceived association between palliative care services and death:

‘P7:the first time, I said ‘I’m not going’, cause I didn’t know what they did. And any road, I come the second time and they explained it a bit more. Because the first time I come I got all upset cause I thought well..... I mean the word ‘hospice’ frightens you, doesn’t it? I thought ‘I’m not going to go’.....’

‘CH: So how did you feel when it was mentioned to you the possibility of coming to the hospice for daycare, or to come and stay?

P6: Well, basically, when they said come for the daycare I knew what it was then, but before that I was a bit panicked, you know I thought I’m not going to get any better,

I'm just gonna go worse.'

As highlighted above, reassurance and explanation of the role of these services was sometimes necessary prior to the participant agreeing to referral, and one participant mentioned the need for tact when broaching the subject:

CH: How did you feel when [COPD nurse] rang you and first offered you a referral to [name of hospice]?

P1: Well she was very tactful in the way she approached the subject.'

Kennet et al also describe the anxiety experienced by many of their participants at the time of a day care referral due to the 'significance of needing a hospice'.⁶² In our study, it wasn't just the participants themselves who expressed a degree of concern around specialist palliative care referral – several mentioned the initial alarm of family and friends, and the need to allay their fears before accessing the service:

P2: Well the performance, honest to God, [name of friend] – oh, [name of friend] thought I was going into, er, I was going for respite care – [name of friend] thought I was going into [name of local hospice] and never coming back.'

CH: How did they feel when you first mentioned being referred to palliative care?

P3: Well me, me son he says 'Oh with them places you go in and you don't come out'. I said 'shut up'. [Laughs] Well that's what he'd been told.'

CH: How do you think they [the family] felt about it being a hospice you were going to for Day Care?

P1: Erm....I don't think it really affected – you know, cause I had explained to them straight away, I said 'before you start, I'm not going to pop me clogs'. You know, and once I explained it to them they were quite happy with it.'

Not all participants recalled anxiety at the prospect of a specialist palliative care referral; some were grateful for any intervention that had the potential to provide a degree of symptom relief, as were their families:

CH: So how did you feel the first time palliative care was mentioned to you?

P3: I thought well – good. If it's as good as what they say it is, I'm all for it. If it does

me any good. Help me breathing – cause the breathing’s terrible.’

‘**CH**: Did it shock you at all? Was there any.....

P2: No, I don’t think shock’s the word. I think because I was at the stage with this pain where I would grab anybody that could help me with it. No, no I wasn’t shocked at all – I didn’t care who could help me, just as long as somebody could, you know.’

‘**CH**: Okay, and how – how do you think your family felt about you coming to the hospice?

P6: Oh me wife was alright, she’s completely with it, she knew what it was sort of thing, you know. Women know these things, don’t they?’

First impressions

When asked about their initial impressions of care delivered within the hospice building (that is, day hospice and the hospice inpatient unit), several participants mentioned the therapeutic effect of an environment that seemed relaxed and friendly:

‘**P3**: It seemed friendly. More, more compact than a hospital. And anyway, it’s more friendly. And the nurses seem to have more time for you. It seems like a one-to-one, you know what I mean, that sort of thing. Very good. It makes you feel better.

The importance of the hospice environment itself (in terms of atmosphere, or ambience) as a therapeutic entity is a concept that is referred to several times within the literature.^{58, 60, 70,}

⁷¹ It is important for those responsible for specialist palliative care service provision to be aware of the value of a relaxed, peaceful, friendly environment – something that it is difficult to measure, and challenging to re-create if lost. Again difficult to quantify, the caring attitude (including physical affection) displayed by staff was an attribute of the services studied that seemed to have a profound impact on participants. This was described by Participant 4, a day hospice patient:

‘**P4**: it’s helped to bring me out a bit as well, cause I’m one of these sort of male chauvinists that, um, doesn’t show his feelings – I never show my feelings whatsoever. But they’re learning to bring it out of me, because... cause they’re so good at – I mean they’re always hugging you and kissing you and holding your hand, and it’s fabulous. I’m – I could never do that, but now I’m learning to do it and be a bit more open and, um.... and

that, that's fabulous really. And some of 'em is quite old, but they're so caring and – I can't get over them, I can't honestly.

In her 2005 study of inpatients within a central Texan hospice (with both malignant and non-malignant disease, including COPD), Pevey also describes the comfort derived from human contact in the form of physical touch.⁷² Although the use of touch can be powerful in demonstrating compassion and empathy to patients, as well as providing a form of human contact to those who may be socially isolated, it takes great skill on behalf of the healthcare professional to sense when touch would be welcomed and appropriate.

The accounts above are of participants who experienced the hospice environment.

However, the value of a caring attitude outside of the hospice building was also evident in an account of a medical review in the community:

CH: So she's been out to see you at home?

P4: Yeah. I mean they don't do that very often do they, consultants? But she'll come again and see me.....

.....she give me another good examination and – she's very very good. Again, very thoughtful. I don't know how people get this thing into them. You know – to be so thoughtful about people's feelings and things. I suppose it all comes down to experience, doesn't it. But you don't always have to implement it, do you?'

The lengths to which hospice staff would sometimes go to provide individually-tailored care to the patients particularly impressed Participant 4, who recounted several examples of staff and volunteers going 'above and beyond' the call of duty for their patients:

P4: I said to the woman that's generally in charge one day, I said 'if I wanted to go up Mount Everest in me wheelchair, would you push me?' and she said 'of course!'. And I think they would! I think – I don't think that there's anything that they wouldn't do. I mean the other week she asked me 'do you not fancy any snacks or anything to nibble on?'. And I said 'well funny enough the other day me next door neighbour brought me some Pringles – barbecue flavoured Pringles', I said 'they were lovely'. Next minute they'd been out to the shops and bought Pringles – and I get 'em every time I go now.'

P4: I needed me inhaler, me nebuliser – this thing. And I caught her eye at the end of the

room – she was having dinner – and I said ‘I could do with...you know, when you’re ready’, and she just left her dinner – and she’s lovely.....
..... Fabulous her. And she’d do anything – do without her dinner to make sure you’re alright. And they all would.’

He described a conversation with another patient who had spent some time on the inpatient unit:

‘P4:when she first went in there one day she was dying for a cigarette, and it was – they couldn’t get her in the smoking room ‘cause of her bed. And they normally would take her outside and you know wrap her up and everything. But it was absolutely throwing it down and um, the nurse said ‘it’s not a problem’. And three of ‘em came out with her and umbrellas and took her outside in the pouring rain! And I thought how fabulous is that really? I mean none of them probably wanted to go outside in the cold and pouring rain to watch somebody have a fag, but they did it!’

Participant 8 also described the caring attitude of day hospice staff, and echoed Participant 4’s sense that they would do anything possible to help. He initially wondered whether this was due to the fact that they have more time than nursing staff in hospital environment (then later questioned that view – I felt that he was reluctant to imply that the day hospice staff were not working ‘hard enough’):

‘P8: I don’t seem to be getting as down [since attending day hospice]. Not that – don’t get me wrong I wasn’t down all the time, you know – just now and again like, you know?

CH: So how do you think they’ve done that? What’s changed?

P8: I don’t really know, er I don’t know, er..... well they’re very caring and that, aren’t they? Seem to do anything what you’d like, or whatever, you know? I mean don’t get me wrong – every time I’ve been in [name of hospital] they do magic with me, you know, but a lot of times they’re that busy, aren’t they, you know – run off their bloody feet like. But they’ve all been great with me, you know? But - but I don’t know if it’s because these’ve got more time or whatever I don’t know, you know – but I mean these are busy aren’t they? Am I saying all the wrong things here or what? [Laughing].

CH: No, no – it’s very interesting! I don’t think – there isn’t a right or wrong really, I’m just interested to know what things have felt like for you.

P8: Well like I say, they've felt smashing, you know? And I've looked forward to it on a which I never thought I would do, you know what I mean?'

The view among participants that staff went 'above and beyond' what was strictly necessary is similar to that reported in two published studies of patient perceptions of specialist palliative care services, with participants recruited from within inpatient, day hospice and community settings.^{60,67} In our study, however, this was described only in relation to day hospice. Interestingly, both Ingleton and Mok found that a reciprocal relationship between healthcare professional and patient was present and valued, something that was not reported by the participants in this research.

Social isolation & comparison with day hospice – 'going on an outing'

As well as the loss of independence mentioned above, the immobility associated with severe COPD resulted in marked social isolation, and the accounts of profound loneliness were at some times distressing to hear:

'P1: I think a lot of depression comes from when people are, are sat looking outside and there's nothing going on [laughs]. That can be a big problem I think.'

Shortly after saying this, the participant started crying, and stared outside to the quiet cul-de-sac she lives in.

Participant 3 mentioned that he had experienced suicidal ideation, in part related to the fact that he was unable to spend time with his grandchildren:

'CH: Why couldn't you get down to see your grandchildren?

P3: Well I was – I couldn't move, couldn't walk about, couldn't do this, couldn't do that, I couldn't play with them.'

Physical restriction seemed to result in unequal social relationships, with friends now required to make the majority of effort to maintain the friendship:

'P1: Well as I say, I don't have a social life as such now because, um, me friends are all still working, you know, and um although they're the same age as me they've elected to carry on working. So I don't see them. Erm.... no I just don't see any of my old friends at all any more.

CH: Why do you think that is?

P1: Well they're too busy with their own lives, you know, they've got to keep coming down to me all the time because there's now way I – if I go to somebody's house I've got to make sure they've got a downstairs loo.'

Social isolation (as a result of poor exercise tolerance restricting mobility) features heavily in the literature describing the experience of living with COPD,^{76, 77, 79, 82, 84, 86-88, 91-93} and a variety of social losses are evident in the extracts above. It is perhaps no surprise, therefore, that a major perceived benefit of day hospice was the opportunity for social interaction, and this was enhanced by the informal, welcoming environment described by participants:

'CH: What was it like the first time when you went there [to day hospice]?

P1: Erm..... I was made to feel very, very welcome.

CH: Mmm

P1: Everybody came round and introduced themselves and introduced me to everybody else. And thenwithin half an hour I was chatting to everybody. [laughs]

CH: [Laughs] Were you?

P1: Yes.

CH: And when you say everybody, erm, introduced you. Who do you mean by everybody?

P1: Well they have volunteers there. They came and introduced themselves to me, and of course they would always say 'and have you met so and ...you know Margaret here and Barbara there....'

CH: Okay...

P1: 'And you know, Thomas there' [pause]'

'P4: and then you just sit and chat, generally, for a good hour. And that's good for you – that does you good chatting to different people. And everyone's ill, but there's no long faces, they're all – they're all full of beans in there.'

'P8: I'm enjoying it, you know, cause er.... it gets you out a bit more, and you meet different people. You meet people with the same, er, illness... and some with different, you know what I mean? Plus we have a laugh, like [laughs] so, and - I quite enjoy it.....
.....I should imagine it fetches a lot of people out of themselves you know what I

mean?

CH: What do you mean ‘out of themselves’?

P8: You know, if they’re withdrawn in any way – I should imagine it will..... ‘cause they meet other people and that don’t they, and they’re friendly and that and what have you, you know? And I should imagine if you get a person who is withdrawn, it’ll fetch him or her out of themselves.’

One participant mentioned that social relationships were maintained following day hospice discharge:

P1: Yeah I’ve made some nice friends up there.

CH: Have you?

P1: Yeah

CH: Do you keep in touch with any of them?

P1: Just one of them, yes. Yes, unfortunately she can’t speak but, um, we text one another at least once a day.’

Although there seem to be clear social advantages to attending a day hospice, this facility is staffed with a wide-ranging multi-disciplinary healthcare team, all of whom have specialist palliative care skills, together with hospice volunteers. The primary aim, therefore, is to provide high quality specialist care to those who need it most. At times, it seemed that day hospice may have been ‘sold’ to and experienced by participants as more of a social day care facility. In the following account, a participant describes the way in which day hospice was portrayed to him by the referrer:

P7:That you talk, there’s other people there and they do painting and this, that and the other, and they help you have lunch and then tea and biscuits before you come home..... I said ‘oh right, I’ll go then!’. [Laughing]’

Another participant talked as if he had been offered a place at an art class:

CH: And do you think you’ll go to the daycare?

P6: I don’t know – I don’t think so. It doesn’t sound my cup of tea sort of thing, you know.

CH: Have you ever been down to have a look?

P6: No. He said – we’re going to try and go and have a look either this week or next week.

Before I go home.

CH: Okay. So what puts you off that?

P6: Nothing at the moment. Just – just doesn't sound right. I was never good at art – arts any road. So – like a chimpanzee painting! Which is what I was sometimes!'

When asked about their experiences of day hospice, several participants' descriptions sounded more reminiscent of a social day care facility:

'CH: Okay, and what was an average day like when you went.....

P1: Erm..... erm.....it was a very, very pleasant experience, you know I just - it was fine going out on an outing.

CH: Was it?

P1: Yes, for a day out.'

'P8: Well I watch the telly and have a read of the newspaper, and have a laugh with the lads. I say 'lads'! The other week I did a bit of modelling, which I haven't done for years – clay modelling I mean! [Laughs]. And just sit and chat and that and what have you – you know, in general. Have a laugh if you can. And you know, we play that bowls on the Wii. I enjoyed that, you now – just something different I suppose isn't it, you know what I mean?'

Goodwin et al carried out a longitudinal study of day hospice experiences, interviewing participants over a period of 12-15 weeks.⁵⁸ Even at the third interview (when participants had experienced day hospice for at least 3 months), responses within the themes of 'getting out' and 'meeting people' were most commonly cited. A more recent study of an Australian day hospice echoed these findings, with participants valuing the opportunity to 'get out of their houses'.⁶³ As a response to studies often revealing social reasons for patients' attendance at day care, Kennet and Payne designed a qualitative study with the aim of exploring use of the phrases 'getting out' and 'like day care' to understand the significance of day care attendance and the perceptions of what is offered there.⁶² They describe similar findings to those reported here in terms of psychological benefits (for example, improvement in depression and anxiety, and a renewed sense of community and self-worth through creative groups). They concluded that 'the use of everyday language [such as 'getting out'] may make it seem as though they [participants] are referring to a

pleasant superficial interaction of no great importance. It is only when they recount just how and why this is important that the full significance becomes clear'. I would argue that our findings corroborate this view; although participants do recount social aspects of day hospice, descriptions of increased confidence and self-worth, together with improved physical symptoms and improved mood among participants who had attended the day hospice suggest that this service provides more than just social support.

Comparison with others/Altruism

As described in the introduction to this thesis, the illness trajectories for those with cancer and those with non-malignant disease (such as COPD) are markedly different, with cancer patients often experiencing a steady decline in their health and function towards the end of their lives, whereas patients with COPD tend experience short exacerbations with periods of relative stability in between. When exposed to patients with advanced cancer in a social setting such as day hospice, it is therefore likely that patients with COPD will watch several patients with whom they may have formed a friendship deteriorate and die. I wondered whether this could be a damaging or frightening experience. No participant mentioned any negative aspects of mixing with patients more unwell than themselves, however. In fact some felt the experience was of benefit to them, and had positively influenced their own feelings about the dying process:

'CH: Do you think it affects you meeting patients who are very poorly?

P4: Yeah um..... I've met several people there that probably aren't here now. But talking to them and their attitude since coming to [name of hospice], they're not worried about dying at all. Dying's – you know 'so what, so I'm gonna die... so what?'. And they've all got some terrible illnesses. Not perhaps just one, they've perhaps got three or four different things that are all gonna kill 'em. And I feel quite – you know I feel fit as a fiddle compared to some of 'em. So when I'm moaning and groaning I have to think about some of these people. And they just weren't miserable at all. They just had this – I think [name of hospice] gets this thing into you that if you're gonna die you're gonna die. It's not a great it might be a problem more for your family, but for yourself it's not such a big deal.'

Meeting people who were more unwell also seemed to help the participants to gain a sense

of perspective about their own ill-health, and gave a sense of not being alone in their suffering:

P1: Well seeing that there was people worse off than me, erm.... knowing I wasn't the only person in the world, you know, that was suffering. Erm... it's just eased it.'

P8: Er..... well I think sometimes you look around and you think 'I'm not as bad off as some of 'em', you know? But then again, I'm always at [name of hospital] for this, that and the other, and you think then when you – you know there's a lot of people worse off, and you think 'why do I get down?', or 'why do I moan about things?', you know what I mean? There's a lot of people a lot worse than me, you know. And er.....

CH: Do you think that's helpful to you, seeing people more poorly?Or does it upset....

P8: No, no I'm not – I'm not, like being morbid. No, it doesn't upset me, but it's nice to see a lot of 'em smiling and getting on with it, you know what I mean? Rather than being like in the doldrums like, you know what I mean? No – it's er.... it doesn't upset me, you know.'

The benefits of meeting other people with serious illness, providing the opportunity to compare one's own situation to theirs, and thus enabling a 'normalisation' of one's own illness experience have been reported extensively in the literature.^{59-64, 69} In addition to the possibility of comparison with others, one participant expressed that she found the opportunity for altruism beneficial when meeting those more unwell than herself:

CH: Sometimes people have told me though that it's hard seeing people who are more poorly.....

P1: No that doesn't bother me.It doesn't bother me that, because I think it makes me feel that I can help somebody.

CH: Does it?

P1: Yeah, you know if you're just talking to them, or sitting holding their hand.

CH: Right

P1: They get pleasure out of that, and it.....it kind of lifts me, you know knowing that yeah, I've done something useful today.'

Given the physical restriction and loss of independence experienced by those with severe COPD, it follows that they will more often be receiving help than offering it to others. A recent article by Vernooij-Dassen et al emphasises the importance of reciprocity (the normal balance in life between giving and taking) to older people, as a key factor in social inclusion and hence overall wellbeing.¹¹⁷ It seems that in this situation, day hospice provided an opportunity for a participant to ‘give’ of herself in an altruistic act. Similarly, Kennet’s study of day hospice patients highlights the importance of finding opportunities for patients to ‘give something back’, describing how ‘making gifts for friends and relatives gave [participants] enormous pleasure and pride; that it was important for them to be able to give rather than to be always receiving’.⁶²

Discharge – a sense of abandonment?

As the emphasis of specialist palliative care has shifted to focus more on pre-empting problems earlier in the illness trajectory of those with incurable illness, and also moved into caring for patients with a non-cancer diagnosis, it has become necessary to discharge patients from specialist services once their complex needs have been addressed. Following discussion of this issue with a participant during the first research interview, I was left with the sense that she felt abandoned by the service (day hospice in her case) – and that it had been almost cruel to show her a service that she clearly perceived as a great support, only to take it away again. Although the experience of discharge was not included in my original topic guide, this issue seemed to cause such distress to the Participant 1 that I included questions on this topic in all subsequent interviews:

‘CH: How did you feel when it finished?

P1: Very upset. [Pause] Yes I was very upset when it finished. But, but other people have to use it as well as me, I can’t be greedy.....It’s like a kiddie [undecipherable - ?with a toy] having it taken away from them. [Crying]’

Although Participant 1 was the only person interviewed who became markedly distressed when discussing the topic, several participants expressed regret at the prospect of discharge:

‘CH: So I know you said that in a couple of weeks you’ll be finishing at Day Hospice...

P4: Yeah. Yes but I have a plan.

CH: Okay, what's that?

P4: I have told somebody there, but the plan is that I'm gonna take a hostage. [Laughs]. Um... I'm gonna take over two rooms and I'm gonna stay so long as I like! I told the doctor. [Laughs].

One interviewee took her discharge from the community specialist palliative care team to mean that her needs were not sufficient to warrant their attention as she wasn't actively dying:

CH: How do you feel about that, about being discharged from the service?

P2: [Sighing] I don't know really. I, um, I suppose I think that they're thinking that really. That they're thinking 'Well we can't help you', 'if you're going to die we can't help you – if you're not going to die'. Do you know I mean? I suppose it does make you feel like that. Like that 'you're not bad enough for us to help'.'

Although there are guidelines as to the approximate length of intervention for those with an average level of need in some services (in the services studied here, two weeks for hospice inpatient stays and twelve weekly sessions for day hospice), the timing of discharge from specialist palliative care services usually varies according to the individual patient and their specific need(s). This variation, and the fact that the length of stay is subject to the discretion of the nursing and medical staff, was noted by some, as demonstrated by Participant 4's account of the discharge process:

CH: So apart from having plans to take hostages [laughs], tell me how you feel about being discharged from day hospice.

P4: Terrible – or dreadful, I'm dreading it. I – I was dreading it a few weeks ago because I knew generally – I think you stay between six and twelve weeks. But there's a lady there, [name of patient], she's quite an old lady but she's lovely, a – she's a patient. She's been there longer than me, but other than that I'm the longest one going there. And she's been going about nineteen weeks I think and she's still going. But I don't think she's... I don't think [name of patient] can ever leave. She's – it's her life really. I mean she goes three times a week I think. Um, but I knew that for me it was six or twelve weeks or something. And I've already gone beyond twelve weeks I think. And she said 'oh well we deliberately

forgot about you’, but she said ‘obviously we’ve got a waiting list’, and obviously there’s people a lot worse off than I am. A hell of a lot worse off. So she said ‘you know, it’s something we’ve got to think about, but you’ve got to see the doctor first and you’ve got to see the psychologist, and if they say something different then you may end up staying for a bit longer’. And I could bully them, couldn’t I for a start! But I know I’ve got to finish going there, but I’ll just miss it like hell.....

Two previous studies (both conducted in a day hospice setting) have also reported participants’ fears of discharge.^{61, 64} I feel that discharge policy is the aspect of current specialist palliative care provision that fits least well with a non-cancer disease trajectory. Traditionally, patients with cancer who accessed palliative care were late on in their disease trajectory, and their health was likely to be deteriorating fairly predictably and rapidly. Transition points between, for example, day hospice and community care, or community care and inpatient hospice care, would often be determined by the patient’s deteriorating health rather than a seemingly arbitrary number of sessions or the subjective level of ‘specialist need’. Gillon argues the importance of balancing beneficence (doing good) with non-maleficence (the avoidance of doing harm) in healthcare.¹¹⁸ One could argue that specialist palliative care services, especially day hospices, have (unintentionally) compromised the principle of non-maleficence by exposing socially isolated people to a welcoming, sociable environment on a regular basis, only to take that service away again, potentially adding to their sense of loneliness and isolation. Innovative approaches to service provision need to be taken in order to avoid this problem. For example, a hospice-based pulmonary rehabilitation service in Bradford for people with severe COPD offers weekly or monthly exercise sessions for those who have completed the programme as a way of maintaining contact.¹¹⁹

An open door?

At the time of discharge from specialist palliative care, it is often emphasised that patients can re-access the service at a later date should it become necessary, as recalled by Participant 1:

‘**CH:** So do you feel that contact is still there even though you’re not going to Day Hospice each week?’

P1: Yes, yes, yes. They've assured me that, you know, I can just ring them any time. Even if it's just for a chat.

CH: Okay. And do you feel comfortable doing that?

P1: Yes, yes. Oh yeah.'

However, two participants expressed a reluctance to make contact again in the future once they had been discharged, for fear of being perceived as rude or demanding:

'P2: The door's open there for me to phone, although as I said I'm not really one of them people that would. I hate people that are always phoning the doctor for nothing and - erm - I wouldn't know what to say, to tell you the truth.'

'CH: If you were discharged do you think you would want to keep in touch with the hospice, or with palliative care?

P7: Well I'd get in touch with [name of respiratory nurse] at [name of hospital], 'cause she's the respiratory nurse and she's the one that put me on to here. I'd tell her 'is there any chance of going again?'. Yeah..... no I wouldn't ask, I'd wait until she told me I couldn't ask. No, I couldn't ask - well it's rude, isn't it?'

Healthcare professionals working within specialist palliative care should be aware that even if they feel they have 'left the door open' for the patient to re-attend a service, if the onus is on the patient to recognise a new specialist need, and then make the initial contact, some may not feel comfortable with this. Hence more proactive follow-up methods should be employed. This should be done with sensitivity and tailored to the individual patient. One recently discharged day hospice patient mentioned that staff from the hospice contacted her by telephone to see how she was coping post-discharge, but she felt that this was done out of 'duty', implying she felt herself a burden:

'CH: Are the hospice keeping in touch with you in any way?

P1: Yeah.

CH: How are they keeping in touch?

P1: Um...just ringing up to see if I'm alright.

CH: Right. Who does that?

P1: It could be [name of Day Therapy sister], it could be ..er... any one of the nursing staff

at the day centre that ring me up. It's one of those duties I think – I'm a duty! [Laughing].'

Changing perceptions

It is interesting to note that initial fear of specialist palliative care referral among the participants (due to a perceived association with cancer and/or death) often became fear of discharge once they had experienced the services on offer. No participant expressed regret at engagement with specialist palliative care. In fact, two studies have shown that patients may welcome referral to specialist palliative care earlier in their disease trajectory.^{52, 65} Although all participants had initially associated palliative care with cancer and dying, at the time of interview (when they had experienced a minimum of one week of inpatient care or one month of outpatient care), those perceptions had changed. All recognised that care of dying cancer patients was not the sole aim of specialist palliative care (although they realised that this did occur).

'CH: So you were telling me that when first hospice and palliative care was mentioned it worried you because it made you think about death and dying. What does the hospice, or palliative care, mean to you now?

P7: Well I know it's not death. [Laughs]. I mean there's some have been come and go and come and go and come and go! Ah, I'm quite happy with it now.'

'P2:See now, if somebody said to me 'I think you need to go in for some palliative care it wouldn't bother me – or for some respite care, anyway – it wouldn't bother me, it wouldn't frighten me. It wouldn't worry me.'

'P8: Well I always felt like it was a special care, for them who was really really - like I say, really sick, you know – er – really poorly like, er er – I don't know – I don't know how to explain it – I suppose it'd give you alternative things to do, don't they? Like you know, like painting, modelling or whatever..... whatever you're interested in I suppose? You know... er – well it just seems like er.... well like I say I always thought it was for people who was like on their last legs, you know what I mean? But it's not is it?'

The perceptions of family members of participants had also changed:

CH: And what about your family, how do they feel about you coming to the hospice?

P3: Erm..... they're quite happy really. If they're going to make me better – feel better. They've been, and it's - it's a nice place. They'd like to come themselves! [Laughs]

Two participants expressed a view that dispelling myths and educating the wider community about the role of the hospice and specialist palliative care was important:

P2: It's just that if people, if people don't know and are not told, well it's education really. Isn't it?

CH: Yeah.

P2: If that's what you've grown up with, 'Oh she's gone in [name of local hospice], she's about to die'. If you've grown up with that, its there, it's in your head. So you have to educate people that that's not all they're there for. You know, that's what I think..'

P8: when you say [name of hospice], a lot of people go 'oh, is he dying or she dying?'

..... but it's alright now – I tell them it's not! [Laughs].'

One participant had seen information within the media of the changing role of palliative care services:

P2: people associate palliative nurses, [name of hospice], 'she must be dying'. Not that you can go in, get right and come out. You know.

CH: Do you believe that?

P2: I used to. I don't now, but I did – I did used to. As I say, I have told people. And I have read that as well.....I have read something in the paper aboutum, about hospice care not only being for cancer patients, that.... that that's what they're going to do now, be sure that other people were involved and knew about it. I have read that.

CH: How do you feel about that?

P2: I think it's a brilliant idea. I do.'

When asked to describe the role of specialist palliative care as they perceived it following personal experience, one participant described a holistic approach, aimed at improving quality of life:

P4: Um..... it's just that..... the impression I get is that they're just there to help in any sort of way they can... um with breathing difficulties and um.... anything else really. They –

they, if you say something to ‘em they sort of look into it and er - it’s all designed to make you feel better.’

Another participant described the value of specialist palliative care staff taking a coordinating role:

CH: Okay. And what does the term ‘palliative care’ mean to you now?

P1: Erm..... Well all the agencies coming together.

CH: Right

P1: You know, instead of having to go to the GP to ask for this, and then you’ve been referred to the hospital ‘cause you can’t have this until you’ve been tested for that ... it’s like the oxygen I have now, [pause] you know it’s all, all seems to have come together.

CH: Is there anything else that it means to you?

P1: Erm. it gives me peace of mind.....to know that I’ve only to ring - erm the hosp - you know, [name of Day Therapy Sister] at the hospice and she’ll arrange for something, you know, if I’m not well enough or something, you know she will arrange it instead of me having to try and find paperwork, you know, and phone numbers, cause phone numbers are always changing.’

It is clear that negative perceptions and expectations of specialist palliative care became positive associations following even a brief period of engagement with services. As well as holistic care and symptom management, participants identified the role those working within palliative care play in coordination of services. Some expressed the importance of educating the wider community about the true nature of specialist palliative care. Changing perceptions of those that access these services, together with their families, is an important first step in this process.

Reflections on Data Collection and Analysis

Reflexivity can be defined as ‘sensitivity to the ways in which the researcher and the research process have shaped the data collected, including the role of prior assumptions and experience’.⁹⁸ During study design, data collection and analysis, I was constantly aware that my background as a doctor working within Palliative Medicine could add an element of positive bias to the process. I clearly have a vested interest in showing specialist palliative care to be an effective intervention. All interview transcripts and emerging analyses were reviewed by my academic supervisors to ensure they agreed that my reported findings were a fair representation of the transcripts as a whole. As described earlier, I also completed a reflective journal following each interview, recording my thoughts regarding the participant’s social and cultural environment, non-verbal cues, how I felt during the interview (transference), and how experiences during that interview might inform my interviewing style and topic guide in the future. The following sections were written using material from that reflective journal.

Conflicting Roles: Doctor vs. Researcher

During the extended period of data collection (from February to July 2010), I was at times working within units from which we were recruiting. However, I was not involved in the clinical care of any patients with COPD. Although I emphasised to the healthcare professionals making the initial recruitment approach that I should be referred to as a researcher from the University of Manchester, I had the sense that I had been described as ‘one of the doctors’ to some of the participants. I was also a visible presence in the hospice on the inpatient unit and in the day hospice. Participants may have identified me as a doctor working there, or other patients who I did know in a clinical capacity may have referred to me as their doctor. I was concerned when one participant referred to me as a doctor working within the service during his interview, despite the fact that I was on maternity leave at the time and not involved with the service in any capacity:

‘P8:The people are nice – the nurses and nice and doctors are nice [laughing]..... but reasonably fat! [Laughing – CH was heavily pregnant at the time].’

The individual making the initial research invitation must have referred to me as a doctor

working within the service for this comment to have been made. This blurring between doctor and researcher role may have affected the participant's account; he may have been reluctant to speak negatively of the service for fear of causing offence, or may have felt that I was in a position to advocate for him. For example, when a participant became distressed while discussing her recent discharge from the day hospice service, I wondered if she was under the impression that I could arrange for her to be granted a further course of sessions. I did make attempts to ensure participants would perceive me as a researcher rather than a doctor, for example by avoiding reference to my clinical role during the research interaction.

Participant Confidentiality

I was mindful that the information I obtained during interviews should remain confidential unless permission had been given for it to be passed on to a third party for a specific purpose, and this was emphasised during the consent process. This seemed clear cut, but proved more challenging in practice. Two participants mentioned previous suicidal thoughts. Both stated clearly that these thoughts were in the past and that they felt differently at the time of the interview. I did not, therefore, deem it necessary to breach confidentiality for risk-management purposes. However, I found myself in a difficult situation when I walked into an office within the hospice to hear a Community Specialist Palliative Care Nurse discussing one of these previously suicidal patients on the telephone with a District Nurse, stating that day hospice referral would be inappropriate as he had no specialist palliative care needs and had gained little from a recent inpatient admission (during which I had interviewed him). I intervened, and explained that from the research interview I had conducted, I was aware that specialist palliative care intervention had been of great benefit to the patient, and I felt it absolutely appropriate for him to continue to access the hospice services. As I had a good working relationship with the nurse concerned, I was able to explain that I could not elaborate further for reasons of confidentiality and she trusted my judgement. The situation could have been different, however. Had she failed to trust my judgement, it would have been necessary to either contact the participant to seek permission to mention the benefit he had obtained to the clinical staff (and in doing so accept that he would realise there was some disagreement about the appropriateness of his accessing the service), or say nothing, in the knowledge

that he would be denied a necessary healthcare intervention.

Informed Consent

In order to obtain informed consent, it is necessary for the participant to have the capacity to participate in the consent process. I was essentially dependent on the healthcare professional making the initial approach to make this judgement in the first instance, and I routinely asked if there were any concerns regarding capacity prior to contacting a potential participant. On one occasion, however, I felt that there was some doubt regarding a participant's capacity when I arrived at his home. With no access to the medical or nursing records of any participant, I was reliant on my clinical judgement alone in this decision. We discussed the research process, and he seemed to be able to understand, retain, weigh and believe the information I gave him. He experienced no difficulty with the written consent process, so I proceeded to interview him. Unfortunately, it quickly became apparent that he did not have any understanding of what palliative care was or which service I was questioning him about. His carers arrived early on in the interview and we agreed to finish then. His wife, however, was very keen to talk about her experiences of the specialist palliative care her husband had received. I did not have ethical approval to interview caregivers, and therefore had no option but to decline her offer.

The consent process involved obtaining specific permission to take digital voice recording of the interview. The digital voice recorder could therefore only be switched on when attention had been drawn to it. Although completely appropriate, I feel this led to an awareness of the recording being made, and an element of self-consciousness amongst participants. It sometimes felt as if we had been talking freely prior to it being switched on, but that they had to take care not to say the 'wrong thing' once we were being recorded. In fact one participant asked for the recording to be stopped so he could check whether he had said the 'wrong thing' (I had emphasised that the research report would be anonymised, with no names of specific organisations included, and he was concerned that he had mentioned the name of the hospice).

The tension between obtaining rich accounts and minimising distress

With a hermeneutic phenomenological approach in mind, I was keen to obtain as rich and

deep an account as possible of the experiences of participants. However, this was not always forthcoming, and it was important for me to be guided by their cues as to when to drop a line of questioning. For example, participants sometimes left long pauses or changed the subject when the discussion turned to a subject they felt uncomfortable with:

‘P4:a lot of ‘em I’ve spoke to say they don’t want to go home, they’d rather die there [the hospice]. I mean that says everything about the place doesn’t it, really? I mean I think I’d rather die in the garden I think. [Laughs]. [Pointing at television]: That owl’s got a load of chicks hasn’t it? They won’t all survive.’

‘CH: So you feel like you’re getting worse.....

P7: Oh yeah, I know I’m getting worse, yeah. Mmm. You see at home, I wouldn’t be like this now, I’d be sat quietly at the table reading me book. I’ve got me morphine and I’ve got me nebuliser, and I’ve got me oxygen if I get too bad.... ‘cause I don’t watch the telly....’

I felt it was important to respect the participants’ boundaries, and not to push lines of questioning when their discomfort became apparent. However, this was a difficult balance as at times. On reading the interview transcripts and listening back to recordings, I sometimes felt that I could have perhaps explored a topic more fully. In retrospect, I realise that my willingness or otherwise to pursue certain topics was sometimes related to my experience in the preceding interview. For example, one participant became frustrated with my attempts to explore her sense of achievement on attending day hospice:

P7: Oh dear. Do you know, everybody – not just you, but everybody that questions you wants to know ‘why?’. Don’t they? I mean ‘in what way?’, ‘in what way?’ I don’t know in what way!’

I feel that this interaction made me more reluctant to explore topics fully in a subsequent interview

CONCLUSIONS, STRENGTHS, LIMITATIONS AND IMPLICATIONS

Conclusions

Findings reported here relating to the experience of living with severe COPD are resonant of those described in the literature review, namely the universal experience of breathlessness reducing exercise tolerance and producing physical restriction. This impacts on the work, social and family lives of patients with COPD, as well as having a profound effect on their psychological wellbeing. The only significant difference between our results and that of published literature in this area is the awareness of the poor prognosis associated with advanced COPD among our participants. This could be a result of specialist palliative care intervention, however it is possible that those people with an appreciation of their limited prognosis are more likely to be offered (and more willing to accept) a specialist palliative care referral.

Our results indicate that engagement with specialist palliative care may have a variety of beneficial effects on COPD patients' quality of life, including:

- Reduced hospital admissions (due to regular clinical monitoring)
- Improvement in physical symptoms
- A profound effect on psychological wellbeing (including increased confidence, increased self-worth, and decreased depression). This is likely to be brought about by factors such as the opportunity for patients to compare themselves to others in a similar situation; a warm, friendly environment; the listening skills of staff and the time available for them to talk with patients; a sense that specialist palliative staff go 'above and beyond' the call of duty, prompting the patients to experience themselves as 'people who matter'.
- A broadened physical environment due to access to specialist occupational and physiotherapists; increased confidence to make use of techniques they learn in therapy sessions; hospice transport (manned by experienced team members) enabling patients to leave their home and attend day hospice.
- Reduced social isolation

The initial suggestion of a referral to specialist palliative care can prompt fear and distress due to widely held perceptions that specialist palliative care and terminal care are synonymous. Sensitivity and careful explanation of available services and their aims are therefore important when referral is first mentioned. Our findings demonstrate that initial perceptions are likely to change with experience of the service(s), and fear of referral often becomes fear of discharge.

The discharge process is one aspect of the current model of specialist palliative care (particularly day hospice) that our results suggest is not working well for patients with COPD. Due to the nature of their illness, these people have often been living with loneliness and social isolation for a long period of time by the time of referral, and offering them a service that provides an accessible means of social interaction and sense of community, only to take it away again, clearly has the potential to cause distress. Additionally, it is important for palliative healthcare professionals to realise that although these patients may not appear to be gaining from 'specialist' input, the opportunity to meet others in similar situations to themselves, and feel themselves to be a valued member of a community, has important consequences for their psychological wellbeing. I do not believe it would be possible to produce these benefits at a purely social day care facility. Our findings suggest that many of the benefits associated with specialist palliative care for people with COPD stem from factors that are difficult to measure, such as the general atmosphere within the hospice building or the attitude of staff members. Seemingly small touches in the care provided appear to produce profound effects on the quality of life of this group of patients.

Strengths and Limitations

This was a small-scale research project carried out in a single city in the Northwest of England. Results may therefore not be generalisable to other populations. However, that was not the intention of this work. As explained by van Manen, ‘phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world’.⁶⁶ The findings reported here aim to provide an understanding of the experience of individuals, unique to each participant. Rather than enabling us to draw definite conclusions, our results should allow the reader an appreciation of what the benefits, harms and issues may be when patients with COPD access specialist palliative care.

A major strength of this research is the fact that no similar studies have been reported in the literature to date, hence a novel insight into the subject area under review is offered. Although the sample was small, between them the participants interviewed had experienced every specialist palliative care service available within the locality. Every eligible potential participant was approached, thus removing the potential for selection bias. One study characteristic that may have introduced bias, however, is my clinical background within specialist palliative care. I suspected that some participants viewed me as ‘part of the service’ rather than as a researcher, and I fear that this may have introduced an element of bias toward positive accounts. As stated in my earlier reflections on data collection and analysis, the transition from clinician to researcher also risked introducing an element of bias during data analysis. There was a risk that I would be likely to lend more weight to accounts of positive experiences of specialist palliative care. Even were this not the case, qualitative data analysis is necessarily a highly subjective task. I believe that these issues were adequately addressed by ensuring that the transcripts and analyses were reviewed regularly by both research supervisors throughout the research process.

Implications for Service Design

In recent years, several national publications have called for equity of access to specialist palliative care for those with non-malignant disease, and specifically COPD. The National Institute for Clinical Excellence (now the National Institute for Health and Clinical Excellence) published its COPD guidance in 2004 (updated in 2010).^{1,120} This suggested that ‘patients with end-stage COPD and their family and carers should have access to the full range of services offered by multidisciplinary palliative care teams, including admission to hospices’. In a 2008 poll, readers of the British Medical Journal voted ‘palliative care beyond cancer’ as the proposal that would make the greatest difference to health care.¹²¹ The 2008 National End-of Life-Care Strategy advocates high quality end-of-life care for all (with no mention of diagnosis),¹²² and later that year the National Council for Palliative Care published its strategy for meeting the challenge of providing specialist palliative care appropriate to the needs of those with chronic respiratory disease.¹²³ In February 2010, just before the formation of the Coalition Government, the Department of Health published a ‘Consultation on a strategy for services for chronic obstructive pulmonary disease in England’.¹²⁴ One end-of-life care recommendation stated that ‘there should be improved access to high-quality end-of-life care services that ensure equity in care provision for people with severe COPD, regardless of setting’. Whether this strategy will come to fruition remains to be seen.

It seems clear that it is no longer acceptable to provide specialist palliative care on the basis of diagnosis rather than need. Neither is it acceptable to simply extend services that have been tailored to the needs of patients with cancer to those with a non-malignant diagnosis. The results reported here show that there is much within existing specialist palliative care services that works well for people with COPD. However, our findings also suggest that it may be necessary to adjust some features of care, for example the discharge policy.

Different patterns of service provision could be considered (such as offering less frequent attendance for longer periods, or development of social drop-in services for follow-up after specialist input has ended), as could models offering greater emphasis on physical conditioning, such as that developed in Bradford.¹¹⁹ Exploring opportunities to collaborate with respiratory services, using their expertise to help guide service design, and creating opportunities to share knowledge and work together (perhaps developing joint services), is imperative.

It is vital that the qualities of specialist palliative care resulting in perhaps the most profound benefits for patients (namely the general atmosphere within a setting; the attitude of staff members and a sense that they will go ‘above and beyond’ what is necessary to provide individualised care), are valued and preserved, as once lost, these aspects may be difficult to re-create. Despite participant perceptions of a warm, welcoming, positive environment, the wider community seems to associate specialist palliative care only with death. Work must be done to raise awareness of the true nature of hospices and specialist palliative care, as these negative associations are likely to form a barrier to access, especially for those with non-malignant disease.

Suggestions for further research

This small-scale study offers a first insight into the experience of specialist palliative care for patients with COPD. Further research in other localities, using different methodologies and longitudinal design, is necessary to build up a full picture of the experience of these individuals. It would also be beneficial to capture the views of caregivers and specialist palliative care professionals in future research projects in order to add different perspectives. There may be similarities between the experience of COPD patients and that of those with other non-malignant diseases (especially heart failure), so studies recruiting participants with a variety of non-malignant diagnoses would be of value.

It is important that any services adjusted or developed to meet the needs of those of COPD are formally evaluated and reported, so that examples of good practice can be shared. It would be useful to employ quantitative techniques to ascertain whether specialist palliative care involvement reduces healthcare utilisation generally (and specifically hospital admissions) as well as measuring effect on quality of life, mobility and symptom prevalence. It would be necessary to conduct research taking a quantitative approach over a wide geographical area, as the numbers of COPD patients currently accessing specialist palliative care are too low to power studies based within individual localities.

Concluding remarks

The findings reported in this thesis provide a first insight into the experience of patients with COPD who access specialist palliative care. Several potential benefits are described, including reduced frequency of hospital admission, improved physical symptoms, reduced social isolation, a broadened physical environment and improvements in psychological wellbeing. It is important for services to acknowledge what is already done well, and value aspects of their care such as a friendly, supportive environment, and staff that are perceived to go ‘above and beyond the call of duty’, as these factors appear to be instrumental in delivering the benefits described by participants. However, as specialist palliative care services were generally designed to meet the needs of people with advanced malignancy, there are some aspects of current models that should be adapted to better suit those with non-malignant disease, such as patterns of access and discharge policies. Additionally, the potential for enhancing aspects of specialist palliative care services that may be especially beneficial to COPD patients (such as occupational and physiotherapy) should be explored. Our findings suggest that community perceptions of specialist palliative care as synonymous with terminal care or cancer care continue to form a barrier to access, especially for those with non-malignant disease. National campaigns to raise awareness of the true nature of hospices and specialist palliative care are vital if these barriers are to be broken down.

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Appendix i

Dr Ann-Louise Caress
Senior Lecturer in Nursing
Tel: 0161 306 7818
Fax: 0161 306 7707
E-mail: ann.caress@manchester.ac.uk

Date

Dear Sir/Madam

Project Title: Understanding the experience of patients with chronic obstructive pulmonary disease (COPD) who access palliative care services in Salford.

I am writing to invite you to participate in a research project that is being undertaken with patients who chronic obstructive pulmonary disease (COPD) who have used palliative care services.

The research is being carried out by a team of doctors in Palliative Medicine and researchers from the School of Nursing, Midwifery and Social Work, University of Manchester.

This interview-based study seeks to understand:

- What people with COPD feel about being offered referral to palliative care services;
- What the term 'palliative care' means to people with COPD;
- What impact, if any, people with COPD feel palliative care has had on their physical symptoms, social or psychological wellbeing;
- What impact, if any, people with COPD feel palliative care has had on their family or carers.

We hope that the information we obtain will help health professionals design services to better suit the needs of patients with COPD and improve the care of patients with similar problems in the future.

The study involves you being interviewed by a researcher for approximately one hour on one occasion. The interview can be carried out at a convenient time and place. The study does not involve any changes to your treatment or any taking of samples or specimens. If you have any questions about the study, please feel free to ask the researcher or contact me as above.

Thank you for taking the time to read and consider this invitation.

Yours Faithfully,

Dr Ann-Louise Caress

Senior Lecturer in Nursing and Chief Investigator

Patient Information Sheet (11/07/2009, Version 2.0)**Project Title: Understanding the experience of patients with chronic obstructive pulmonary disease (COPD) who access palliative care services in Salford.**

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

This research study seeks to understand:

- What people with COPD feel about being offered referral to palliative care services;
- What the term 'palliative care' means to people with COPD;
- What impact, if any, people with COPD feel palliative care has had on their physical symptoms, social or mental wellbeing;
- What impact, if any, people with COPD feel palliative care has had on their family or carers.

What is the purpose of the study?

COPD is a common health problem, and is becoming more common. We know that people with COPD often experience physical symptoms such as breathlessness, pain and sickness, and psychological symptoms such as anxiety or low mood. COPD can also affect the social and family life of those affected. Palliative care is a speciality that aims to help people with problems such as these. In the past, palliative care services have not always been offered to people with COPD. Although we feel these services may help those with COPD, this has not been studied before. We are therefore interested to learn about your experience of palliative care services.

Why have I been invited?

You have been invited to join the study because you have been accessing palliative care services and you have COPD. We hope there will be about twelve patients in total taking part.

Do I have to take part?

It is up to you to decide whether or not to take part. This decision will not affect the clinical care you receive in any way. Please complete the reply slip and either post it or hand it to a member of your clinical team within a week of receiving it. If you do decide to take part, you are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part in the study, you will be asked to participate in an interview with a researcher. On receiving your reply slip, the researcher will call to arrange a convenient time to visit you. They can meet with you at your home, the hospital, the hospice or another convenient location. If you choose to travel in order to meet with the researcher, your travel expenses will be paid back to you.

Before carrying out the interview, the researcher will answer any questions you may have about the research. If you still wish to take part, they will then ask you to sign a consent form, giving your permission to be included in this research project. We expect that the interview itself will take about one hour, with possible additional brief contact if we need to clarify anything from the interview.

We would like to tape record the interview, but will only do so with your permission. With your agreement, we may wish to use anonymous direct quotations from the interview in publications. If you do not want this to happen, you can still take part in the research. You have the right to stop, start or rewind the audio

recording at any point. The only people who will have access to the tape recordings will be members of the research team. The tapes will be kept in a secure place during the study and will be destroyed at the end of the study. If you do not agree to tape recording, but do still wish to take part in the study, the researcher will take some notes, in order to remember important things that you have said.

If you decide to take part, your treatment will not be affected in any way. You will not be asked to take any new treatments or to change your medication. Sometimes patients with COPD feel breathless when talking. If this happens to you, you can ask to take a break in the interview and carry on another time or finish the interview completely. The researcher will not be upset if you do not answer a particular question or choose to stop the interview early, nor will the health professionals who look after you.

What are the possible disadvantages and risks of taking part?

This study does not involve taking any samples or specimens from you. It does not involve your taking any new medications or changing your treatment in any way.

Talking about ill health can sometimes be upsetting. If you are uncomfortable with a particular question, you do not have to answer it. If you feel upset or wish to stop the interview for any reason, simply tell the researcher and they will stop. You will not be asked to give a reason for this.

What are the possible benefits of taking part?

We cannot promise the study will help you but we hope that the information we obtain will help health professionals design services to better suit the needs of patients with COPD and improve the care of patients with similar problems in the future.

What happens when the research study stops?

The study will last for about six months, although your own involvement will only be one interview of about one hour on one occasion (with possible additional brief contact if we need to clarify anything discussed in the interview). At the end of the study, we will send you a short summary of the study's results if you would like this.

What if something goes wrong?

We will be very careful to ensure that the interviews are conducted sensitively. We will stop the interview whenever you wish. If, however, you are unhappy with any aspect of the way that you are treated, you should inform either your doctor or the project's Chief Investigator (contact details below). We take all complaints seriously. In order to protect you further, the project will be covered by the University of Manchester's insurance for research studies.

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be treated as strictly confidential. Any information about you that leaves the hospital/hospice will have your name and address removed so that you cannot be recognised from it. Your consultant/GP will, with your agreement, be told that you are involved in the study. They will not, however, be told about anything you have said unless you specifically agree to them being told something.

It is possible that the questions asked may raise issues or concerns for you. If this happens, you could ask the researcher to pass these on to the relevant person. If you prefer, you could yourself raise the issues or concerns with your healthcare team instead. The research team are all health professionals and, as such, have a duty of care towards you if you are involved in the study. Therefore, should any issues or problems be identified during the interview which require medical attention, the researchers would, with your permission, bring these to the attention of a relevant member of your healthcare team. They would not do this without asking your permission, and would only speak to the health professionals who are currently looking after you.

What will happen to the results of the research study?

We will produce a report for the healthcare team looking after patients involved in the study. So that other health care professionals can learn from the results, we will write articles for medical and nursing journals and give presentations at health-related conferences and for lung disease patient support groups. We hope that the information we obtain from this study will help us to improve the palliative care of patients with COPD in the

future. We will be careful to ensure that it is not possible to identify you individually in any reports, papers or presentations that we produce.

Who is organising and funding the research?

The research is being managed by a team of nurses, doctors and researchers from Salford Royal Foundation Trust (Hope Hospital), St Ann's Hospice and The University of Manchester. The research is funded by the School of Nursing, Midwifery and Social Work at the University of Manchester. The research forms part of an MPhil programme for a doctor in training in Palliative Medicine.

The Chief Investigator is Dr. Ann Caress, Senior Lecturer at the School of Nursing, Midwifery and Social Work at the University of Manchester. The other investigators are Dr Catherine Hayle, a Specialty Registrar in Palliative Medicine and MPhil student at the University of Manchester, Dr Peter Coventry, MRC Training Fellow in Health Services Research at the University of Manchester and Dr Stephanie Gomm, Consultant in Palliative Medicine at Salford Royal Foundation Trust and St Ann's Hospice.

Dr Catherine Hayle will be carrying out the day-to-day running of the study including carrying out the interviews. The study has an Advisory Group, which is there to help keep the project on track and give independent advice.

Who has reviewed the study?

This study has been reviewed and approved by the Cumbria and Lancashire B Research Ethics Committee.

Contacts for further information

Thank you for taking time to read and consider this information. Please feel free to discuss it with others (e.g. your family) before deciding whether or not to take part. If you have any further queries, please do not hesitate to ask. You can speak with your healthcare team, or you can contact the research team directly as follows:

Chief Investigator

Dr Ann-Louise Caress
Senior Lecturer in Nursing and Chief Investigator
School of Nursing, Midwifery and Social Work
The University of Manchester,
Room 6.341,
University Place,
Oxford Road,
Manchester
M13 9PL

Tel: 0161 306 7818

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Appendix iii

Dr Ann-Louise
Caress

Senior Lecturer in Nursing

Tel: 0161 306 7818

Fax: 0161 306 7707

E-mail: ann.caress@manchester.ac.uk

Project Title: Understanding the experience of patients with chronic obstructive pulmonary disease (COPD) who access palliative care services in Salford.

I am interested in taking part in the study, please contact me.

Signed:.....

Full name:.....

Date:

Appendix iv

Patient Identification Number for this study:

CONSENT FORM: PATIENT

Title of Project: Understanding the experience of patients with chronic obstructive pulmonary disease (COPD) who access palliative care services in Salford.

Name of Researcher: Dr Catherine Hayle

Please initial box:

1. I confirm that I have read and understand the information sheet dated 11/07/09 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study (e.g. interview transcripts) may be looked at by responsible individuals from The University of Manchester, from regulatory authorities or from the NHS Trust. I give permission for these individuals to have access to this data.
4. I agree to my GP/consultant being informed of my participation in the study
5. I agree to take part in the above study.
- 6a. I agree to the interview being tape-recorded.
- 6b. I do not agree to the interview being tape recorded, but give permission for notes to be taken.
7. I give permission for my words to be quoted.

Name of Patient

Signature

Date

Researcher

Signature

Date

1 copy for participant; 1 copy for researcher; 1 copy to be kept with hospital/hospice notes

Appendix v

Dr Ann-Louise Caress
Senior Lecturer in Nursing
Tel: 0161 306 7818
Fax: 0161 306 7707
E-mail: ann.caress@manchester.ac.uk

Insert Consultant/GP's name and address

Date

Dear:

Project Title: Understanding the experience of patients with chronic obstructive pulmonary disease (COPD) who access palliative care services in Salford.

Your patient [INSERT NAME] has kindly agreed to participate in a research project that is being undertaken with patients with chronic obstructive pulmonary disease (COPD) who have accessed palliative care services in Salford.

The research is being carried out by Dr Catherine Hayle (Specialist Registrar in Palliative Medicine), Dr Ann Caress (Chief Investigator), Dr Peter Coventry (MRC Training Fellow in Health Services Research, University of Manchester) and Dr Stephanie Gomm (Consultant in Palliative Medicine, Salford Royal Foundation Trust and St Ann's Hospice).

This qualitative, interview-based study seeks to understand:

- What people with COPD feel about being offered referral to palliative care services;
- What the term 'palliative care' means to people with COPD;
- What impact, if any, people with COPD feel palliative care has had on their physical symptoms, social or psychological wellbeing;
- What impact, if any, people with COPD feel palliative care has had on their family or carers.

We believe that study data will help us to design palliative care services to better suit the needs of patients with COPD, and stimulate further research in this area.

The study is interview-based and does not involve any clinical intervention or changes to your patient's treatment regimen, nor any taking of samples/specimens.

If you have any questions about the study, please feel free to contact me as above.

Yours Sincerely,

Dr Ann-Louise Caress

Senior Lecturer in Nursing and Chief Investigator

PALLIATIVE CARE FOR PATIENTS WITH COPD
SEMI-STRUCTURED INTERVIEW TOPIC GUIDE

What did the term ‘palliative care’ mean to you before you were referred?

- Previous experience of services (relatives, friends?)
- Previous understanding of hospices, MacMillan nurses (or any other service accessed)

How did you feel when you were first offered a referral to (name of palliative care service)

- Who made the referral?
- Did they ask your permission to do this?
- What did they tell you about the referral?
- Did you have any hopes or expectations about what accessing palliative care could achieve?

What was it like when you first went to the hospice/met the MacMillan nurse/attended daycare?

Do you feel palliative care has had any impact on your physical wellbeing?

- If yes, what impact has it had?
- If no, why do you think that is?

Do you feel palliative care has affected your mental or spiritual wellbeing

- If yes, what impact has it had
- If no, why do you think that is?

Do you feel palliative care has affected your social life? If yes, how?

Do you feel palliative care has affected your family/caregivers? If yes, how?

What does the term ‘palliative care’ mean to you now?