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UNIVERSITY OF SOUTHAMPTON

FACULTY OF ENVIRONMENTAL AND LIFE SCIENCES

School of Health Sciences

Palliative care communication in COPD – patients' preferences and clinicians' judgements

by

Nuno Tavares

Thesis for the degree of Doctor in Philosophy

December 2019

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF ENVIRONMENTAL AND LIFE SCIENCES

School of Health Sciences

Thesis for the degree of Doctor in Philosophy

PALLIATIVE CARE COMMUNICATION IN COPD – PATIENTS' PREFERENCES AND CLINICIANS' JUDGEMENTS

by

Nuno Caixinha Tavares

Chronic obstructive pulmonary disease (COPD) is a life-limiting illness characterised by progressive breathlessness and chronic cough that affects around 3 million people in the United Kingdom (UK). Patients with COPD have a high symptom burden, which is typically managed by means of aggressive and invasive treatments as patients approach the end of life. Although mortality rates are high, identifying with accuracy when patients are approaching the end of life is difficult and so there is uncertainty on when and how to initiate conversations about appropriate care plans with patients. To date, little research has focused on understanding patients' and clinicians' thoughts about the timing and nature of palliative care conversations.

This study aimed to understand COPD patients' preferences for palliative care discussions; and explore clinicians' opinions and experiences when holding these conversations.

The study is divided into 4 different phases that complement and inform each other. Phase 1 consisted of a systematic literature review that explored current evidence about palliative care discussions in COPD. The second phase looked at COPD patients' preferences for palliative care discussions with clinicians. Thirty three patients at different stages of disease severity were interviewed, which included 8 patients with mild, 15 patients with moderate and 10 patients with severe and very severe COPD. Interviews used a semi-structured approach and data analysis was guided by interpretative phenomenological analysis (IPA). The third phase included interviews with 14 healthcare professionals that provided direct care to COPD patients. Clinicians from four different professional backgrounds were interviewed, including: general practitioners, practice nurses, COPD specialist nurses and COPD consultants. Interviews explored clinicians' thoughts and

experiences when holding conversations with patients, and were analysed using a thematic analysis approach. The fourth and last phase of the study comprised the data integration of the three research phases described above. The findings from the previous phases were combined using triangulation methods, integrated and discussed, to clearly answer the research question.

The overall findings suggest that palliative care discussions were conducted by unfamiliar clinicians to the patient, at a late stage in the illness trajectory and when patients were admitted to hospital. Late discussions seemed to be caused by difficulties in timing and initiating discussions, service rationing and clinicians' and patients' poor understanding about palliative care and COPD. As an example, palliative care was seen as end of life care and exclusive of life-sustaining treatments. Poor understanding about palliative care and COPD seemed to increase clinicians' and patients' reluctance in discussing palliative care, undermining open discussions about preferences for future care and the development of action plans. Furthermore, data integration suggests that patients and clinicians had opposing perspectives about the optimal timing and nature of discussions, which increased the complexity of conversations and prevented their start.

In contrast to current practice, some patients and most clinicians recommended early, gradual and informative discussions about palliative and future care/treatments. Early discussions were thought to facilitate the initiation and conduct of discussions and to reduce their emotional impact, enabling patients to participate fully. Thus, early discussions provide an opportunity for clinicians to understand how patients view and experience their condition and its treatments, and offer a treatment philosophy that suits patients' preferences and is guided by principles of Burden of Treatment theory.

The current approach when discussing palliative care advocates a sudden change in care, from aggressive treatments to end of life care and does not meet patients' needs. A new way of thinking about consultations where there is a dialogue that focuses on addressing patients' needs, symptoms and priorities, whilst reducing treatment burden throughout the disease course is recommended. This new approach can create individualised care plans that meets patients' needs and preferences.

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Research Thesis: Declaration of Authorship

Print name: Nuno Tavares

Title of thesis: **Palliative care communication in COPD – patients' preferences and clinicians' judgements**

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

Tavares N, Jarrett N, Hunt K and Wilkinson T (2017) Palliative and end-of-life care conversations in COPD: a systematic literature review. *ERJ Open Research* 3(2)

Signature: Date:

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Abbreviations

ACP - Advance Care Planning

ATS – American Thoracic Society

BODE index- BMI, Airflow obstruction, Dyspnoea and Exercise capacity

BTS – British Thoracic Society

CLAHRC – Collaboration for Leadership in Applied Heath Research and Care

COPD – Chronic Obstructive Pulmonary Disease

CRIS – Community Respiratory Integrated Service

DoH – Department of Health

DOSE Index - Dyspnoea, Obstruction, Smoking, Exacerbation Index

DNACPR - Do Not Attempt Cardiopulmonary Resuscitation

FEV1 – Forced expiratory volume at 1 second

GP – General Practitioner

HADS – Hospital Anxiety and Depression scale

IPA – Interpretative Phenomenological Analysis

ITU – Intensive Care Unit

kPa – Kilo Pascal

LTOT – Long-term oxygen therapy

LOT – Lower-order themes

MDT – Multidisciplinary Team

MRC Breathlessness scale – Medical Research Council Breathlessness scale

NICE - National Institute for Clinical Excellence

NCPC – The National Council for Palliative Care

NHS – National Health Service

Abbreviations

NICE – National Institute for Health and Care Excellence

NIHR – National Institute for Health Research

NIV – Non-Invasive Ventilation

PaO2 – Partial pressure of oxygen in the arterial blood

PIS – Participant Information Sheet

PPI – Patient and Public Involvement

REC - Research Ethics Committee

SOT – Super-ordinate themes

UK – United Kingdom

US – United States of America

WHO – World Health Organization

Chapter 1 Introduction to the document

This document is submitted in consideration of a PhD degree at the School of Health Sciences, Faculty of Environmental and Life Sciences, University of Southampton. The research study was partially funded by the NIHR CLAHRC Wessex and Portsmouth Hospitals NHS Trust. The document follows the structure of a PhD by publication, where four papers published or of publishable quality are presented. This document describes a research study of communication about palliative and future care between COPD patients and healthcare professionals. The following chapters present a review of published literature, and the research methods, findings, discussions and conclusion of this study.

This research study originated from an issue that I frequently encountered while working as a nurse in the Respiratory High Care Unit (high dependency ward). The patients admitted to the unit were very unwell, so aggressive treatments were offered in an effort to improve their condition, such as ventilation, intravenous medication and frequent blood tests. However, if these treatments did not improve the patient's clinical condition, they were stopped, machines switched off and patients were *"made comfortable."* This often rapid transition between aggressive and active treatments to non-active end of life care was usually done within minutes. The speed meant that there was limited time for discussion and explanation, which often resulted in patients, relatives and staff being distressed and in futile treatments being provided. Moreover, most patients were troubled by severe symptoms, such as breathlessness, which were difficult and poorly managed, due to the lack of time and planning. This lack in care planning resulted in poor quality of life and in increased suffering for patients. Most patients had advanced COPD, previous admissions to the unit and other comorbidities. Despite their poor condition, patients were recurrently admitted, did have not action plans for future deteriorations, and did not seem to be aware of the seriousness of their condition.

This repeated pattern of care led me to explore other options for these patients, in an effort to improve the care provided at the end of life. The patients I met in hospital had not discussed palliative or advance care planning with a clinician before their final admission. This lack of communication prevented patients from planning the future, communicating their wishes and in receiving care based on their preferences. Thus, poor and/or late communication seemed to be a contributing factor for the late provision of palliative and end of life care to COPD patients.

COPD patients experience acute and severe exacerbations which may lead to hospital admissions, aggressive treatments and poor experiences at the end of life (European Respiratory Society and American Thoracic Society 2004). In order to prevent this, the World Health Organization (WHO)

suggested that people with life-threatening illnesses, such as COPD, should receive palliative care in order to improve their and their relatives' quality of life (WHO 2011, 2016). Palliative care focuses on preventing and relieving suffering through early identification, holistic assessment and support of patients' and relatives' physical, psychosocial and spiritual concerns (Gore et al. 2000; NICE 2011b; WHO 2011; NCPC 2012; Public Health England 2014; WHO 2016). Thus, palliative care should aim to meet the patient's needs regardless of their prognosis (Okumura et al. 2018). Previous literature have shown that COPD patients were willing to discuss their preferences for future care and treatments, however these conversations rarely occurred in clinical practice (Dexter et al. 1998; Halliwell et al. 2004; Knauft et al. 2005; Janssen et al. 2011b; Au et al. 2012; Leung et al. 2012; Philip et al. 2012; Seamark et al. 2012; Celli et al. 2015; Houben et al. 2015). The absence of a clear transition to an end stage in COPD seems to have led to uncertainty on when to initiate palliative care and discussions with patients (Shipman et al. 2008; Crawford et al. 2013).

The research conducted and reported is focused on exploring the preferences of people with COPD and clinicians' opinions for palliative care communication. Ultimately, the study aims to increase the provision and quality of palliative care for patients with COPD, by ensuring that patient's perspectives and preferences are understood so they can be kept at the core of all their care.

1.1 Structure of the Thesis

This research study was divided into 4 interconnected phases. These phases complemented and informed each other. Phase 1 informed phase 2, which in turn informed phase 3. The 4 phases are described below:

- The first phase of the study comprised a systematic review of published and unpublished literature about palliative care discussions in COPD. The review findings guided the design and development of the 2 subsequent phases. As an example, the review identified a lack of evidence on patients' preferences for the timing and nature of palliative and future care discussions.
- Semi-structured interviews with COPD patients in the second phase of the study explored their preferences for conversations with clinicians. Thirty three patients with COPD were interviewed and data analysis was guided by Interpretative Phenomenological Analysis (IPA).
- The third phase of the study included interviews with clinicians who provided care to people with COPD. Data gathered in phase 2 was used to generate discussion with

clinicians. As an example patients' preferences were presented to clinicians and their thoughts were sought.

- The fourth and last phase of the study synthesized and integrated the findings from the previous three phases, resulting in the final paper. The data generated from this integration became the overall findings of the whole study.

Each of the phases described above was reported in journal paper format, of which 1 paper has been published and 2 are currently undergoing the Journals' peer-review process (Tavares et al. 2017; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). The data integration paper will be submitted for Journal review later in the year, by December 2019. Consequently, each phase has its own introduction, background, research questions, methods, findings, discussion and conclusion.

This thesis starts by describing the personal and professional development attained since the start of the doctoral fellowship - please refer to the subchapter below. The following chapters of the thesis are described as follows:

- Chapter two presents an overview of the literature on COPD, palliative care in COPD and palliative care communication in COPD.
- Chapter three describes the study design, research question, aim, and methods of the study.
- Chapter four presents Phase 1: a systematic literature review focused on palliative care communication in COPD.
- Chapter five presents Phase 2, which explored COPD patients' preferences for palliative care conversations.
- Chapter six describes Phase 3 that looked at healthcare professionals' thoughts and experiences regarding palliative care discussions with patients.
- Chapter seven comprises the fourth and last phase of the study, and integrates the research findings from the previous phases.
- Chapter eight presents a critical discussion of the research findings and methods considering the existing body of knowledge.
- The last chapter (chapter 9) provides a conclusion to the study.

1.2 Personal and professional development

Over the last five years, different strategies and interventions were used to help achieve the required level of knowledge and skills to overcome the barriers posed at the different stages of the doctorate. These strategies included: supervisory meetings, quantitative and qualitative

research-related training sessions, presentations and networking with multidisciplinary professionals involved in developing, implementing and disseminating research studies.

Face-to-face and phone supervisory meetings were used to discuss complex topics that required further consideration/discussion and expertise, whilst simpler communications were shared via phone or email. These meetings provided invaluable information that helped steer the research study in the most appropriate direction, but they also helped monitor the progress and trustworthiness of the research study. In addition, this study was part of the CLARHC Wessex Theme 1 – Integrated Respiratory Care. The multidisciplinary working group met quarterly and the progress of the study was reported and discussed with the team. These meetings provided invaluable feedback and allowed the critical analysis of the different stages of the research study.

In the last 5 years, I attended several research-related training sessions including: “Designing, Implementing and Communicating Research,” “Good Clinical Practice,” “Statistics Course,” “Improvement Academy,” “Qualitative interviewing,” “EDGE and CPMS training,” “Managing your PhD and literature reviews using Nvivo,” “Qualitative data analysis using Nvivo,” and the “Qualitative skills masterclass.” These training sessions allowed me to gather expertise in conducting research in healthcare and opened up my horizons to further explore different research methods and approaches.

As part of the doctoral studies, three milestones were submitted as requested at different timelines. Milestone one included the presentation of different research questions and was submitted in January 2015. The research questions were focused on end of life care conversations between COPD patients, relatives and healthcare professionals. Milestone two reported the results of a systematic literature review related to the research topic and was submitted in June 2015. The last milestone was submitted for peer-review in February 2016 and contained a research proposal with detailed information on the different stages of the research study. The three milestones evolved from a general concept to a specific research topic that aimed to address a pressing issue found in clinical practice.

Oral presentations throughout the doctoral studies proved very valuable in gathering opinion and expertise on the research study. A total of nineteen oral or poster presentations within and outside the University were carried out. The findings from the systematic literature review and interviews with patients were presented in the format of posters in national (such as APM Palliative and Supportive Care Conference – Bournemouth) and two international conferences (European Respiratory Society Congress – Italy and the European Respiratory Society Congress – Madrid). Lastly, the systematic literature review entitled: “Palliative and end of life care conversations in COPD” was published in the European Respiratory Journal – Open Research in

April 2017. Phase 2 and Phase 3 of the study have also been submitted for journal peer-review (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b).

The creation of a multidisciplinary network is key when undertaking doctoral studies. This network was developed over time and included different clinicians and patients. Healthcare professionals formed the foundation of this research network that included palliative care nurses and doctors; respiratory specialist physiotherapists, nurses and doctors; community matrons; and other professionals that facilitated and integrated research in clinical practice. Discussions about the research topic were held with various COPD-related stakeholders and their clinical practice observed.

Informal observations of clinical practice and discussions with healthcare professionals provided their perspectives about the current palliative care delivery and palliative care conversations with COPD patients. As an example, COPD consultant clinics and community and hospital-based palliative care consultations were observed. In COPD consultant clinics, patients with increased or complex needs or approaching the end of life were seen. These clinics aimed at managing and reducing symptom burden, but also to introduce palliative and advance care planning to patients. The COPD consultant reported discussing palliative care on a daily basis, however no discussions were observed in 2 different clinics composed of 8 patients. The COPD consultant believed that most patients did not seem ready to engage in palliative care conversations. On the other hand, the palliative care consultations observed only included cancer patients. Palliative care clinicians seldom managed COPD patients and found COPD patients difficult to manage, due to their complex symptoms and unpredictable disease trajectory. In addition, a community palliative care team only managed patients that did not receive curative treatments and that had a terminal diagnosis.

A wide network of COPD patients was also established through local peer-support groups (Living Well with COPD and Breathe Easy groups). As an example, Patient and Public Involvement (PPI) champions and respiratory patients provided feedback on the focus and design of the study, reviewed the patient information sheet and participated in *"mock"* research interviews. The data gathered from the different conversations and observations with patients and clinicians informed the design, development and implementation of the research undertaken. A detailed timeline of the PhD candidature can be found in Appendix A.

The following chapter will introduce and provide a rationale for the study, by examining and reporting previous literature about palliative care communication in COPD.

Chapter 2 Introduction to the study

2.1 Introduction

This chapter explores and defines the core concepts of COPD, palliative care and palliative care communication central to this research and offers a general overview of palliative care delivery in COPD.

2.2 COPD

COPD is a chronic illness that causes persistent airflow obstruction, resulting in progressive and irreversible breathlessness (Department of Health 2011a; NICE 2011a). Other symptoms associated with COPD include chronic cough, anxiety, depression, lack of energy, anorexia and limited mobility (Sullivan et al. 1996; Wilson et al. 2008; Department of Health 2011a; NICE 2011a; Qaseem et al. 2011a; Halldórsdóttir and Svavarsdóttir 2012; Momen et al. 2012). Despite these debilitating symptoms, some patients view COPD as part of ageing (Habraken et al. 2008). COPD is an umbrella term that includes chronic bronchitis and pulmonary emphysema (NICE 2011a). In the UK, it is estimated that 3 million people have COPD, which equates to 13% of all the population in England aged 35 and over (NICE 2010; Department of Health 2011a; Smith and Kirkpatrick 2013). COPD is the second largest cause of emergency admissions in the UK and accounts for more than one million 'bed days' annually (Department of Health 2011a; NICE 2011a; British Thoracic Society 2014). Healthcare use increases throughout the disease trajectory, which results in a fifty fold difference in healthcare costs between mild and very severe COPD (Department of Health 2011a).

2.2.1 Prevalence, risk factors and COPD diagnosis

The most significant risk factor associated with COPD is cigarette smoking (Brashier and Kodgule 2012). Tobacco smoking accounts for almost 85% of all COPD cases, only 15% of cases are attributed to non-smoking factors (Centers for Disease Control and Prevention 2008; Brashier and Kodgule 2012). Other risk factors associated with COPD include: genetics – such as alfa-1 antitrypsin; exposure to toxic particles- dust and smoke; reduced lung volume; female gender; social isolation and low socio-economic status (Brashier and Kodgule 2012). Health disparities and low socioeconomic status have an evident impact in the aetiology and outcomes in COPD, due to increased exposure to tobacco and biomass fuel smoke and lower education levels (Grigsby et al. 2016; Pleasants et al. 2016). In fact, recent research has suggested that the lowest socioeconomic

groups are up to 14 times more likely to have respiratory disease than the highest group (Grigsby et al. 2016; Pleasants et al. 2016). The socioeconomic gradient in COPD is greater than most illnesses and a low socioeconomic status was associated with limited healthcare access for patients (Tottenborg et al. 2017; Collins et al. 2018). In addition, a recent study suggested that deprived patients were less likely participate in pulmonary rehabilitation programmes, but more likely to require more and longer hospital admissions (Collins et al. 2018).

COPD is considered the third main cause of death worldwide and global prevalence is showing a steep rising trend (Brashier, 2012). In England and Wales, COPD is the fifth most common cause of death, accounting for 25,000 deaths annually (Department of Health 2011a; NICE 2011a). Thus, premature mortality from COPD in the UK was the double than the mortality registered in Europe in 2008 (Department of Health 2011a). Mortality rate is particularly high in older patients with frequent exacerbations, chronic respiratory failure and a maximum symptom burden (Choudhuri 2012). Other risk factors for COPD mortality include the presence of other comorbidities, such as anxiety and depression (Almagro et al. 2002; Groenewegen et al. 2003; Hartl et al. 2016).

COPD diagnosis is established based on patients' clinical history and their pulmonary function tests (NICE 2010; Qaseem et al. 2011a). The diagnosis should be considered in patients over 35 with a smoking history presenting with chronic cough and sputum production, exertional dyspnoea, wheeziness and frequent bronchitis (NICE 2010; Qaseem et al. 2011b). The presence of respiratory symptoms and of airflow obstruction (as defined by a spirometric value of Forced Expiratory Volume at 1 second over Forced Volume Capacity (FEV1/FVC) ratio post-bronchodilator of less than 0.70) confirms the diagnosis of COPD (NICE 2010; Qaseem et al. 2011a).

2.2.2 Pathophysiology

The pathophysiology of COPD is complex and largely undiscovered (Brashier and Kodgule 2012). COPD causes physiological abnormalities that include mucous hypersecretion, ciliary dysfunction, airflow obstruction, hyperinflation, impaired gas exchange, pulmonary hypertension, and systemic effects (MacNee 2006). All smokers have inflammation in their lungs, but those who develop COPD have an abnormal response to inhaled toxic agents (MacNee 2006). This abnormal pulmonary inflammation is an innate and adaptive immune response to the long term exposure to noxious gases, particularly cigarette smoke (MacNee 2006). This amplified response to smoke results in mucous hypersecretion (chronic bronchitis), tissue destruction (emphysema), and disruption of normal repair and defence mechanisms causing small airway inflammation and fibrosis (bronchiolitis) (MacNee 2006). The inflammatory and structural changes in the airways increase with disease severity and persist even after smoking cessation (MacNee 2006). Systemic effects of COPD are common and include general inflammation and muscle-skeletal wasting

(MacNee 2006; Brashier and Kodgule 2012). These factors contribute to limited mobility, worse prognosis, and increased risk of cardiovascular disease, regardless of disease severity (MacNee 2006; Brashier and Kodgule 2012).

2.2.3 COPD management

COPD symptoms can severely impact the lives of patients, resulting in reduced quality of life, overall health status and prognosis (NICE 2010; Miravitlles and Ribera 2017). Debilitating symptoms caused by COPD, such as disabling breathlessness, result in patients being unable to participate in socially important activities or take holidays (Department of Health 2011a). To minimize symptom burden, clinical recommendations suggest that patients should receive an individualised and comprehensive management plan, which includes relevant high-quality information about their condition and its management (NICE 2011a). To meet this, NICE recommends regular assessments of patients' degree of breathlessness, frequency of exacerbations, presence of hypoxaemia and comorbidities (NICE 2011a; Chatwin et al. 2014). These regular assessments should be used to identify the need for palliative care in patients with advanced COPD, in an effort to address physical, social and emotional needs (NICE 2011a).

Pharmaceutical and non-pharmaceutical treatments in COPD can improve symptoms, health status, and exercise capacity, and reduce the frequency and severity of exacerbations (Safka and McIvor 2015; Negewo et al. 2017). Therapies for COPD management include smoking cessation, immunization, inhaled therapy, oral medication, oxygen therapy, non-invasive ventilation and pulmonary rehabilitation (NICE 2010; Safka and McIvor 2015). In addition to these treatments, people with COPD are often prescribed multiple therapies, to effectively combat other comorbidities, which results in complex treatment regimens and increased suffering caused by invasive treatments (Berglund et al. 2012; Negewo et al. 2017). Previous literature has suggested that patients with worse health status, increased symptom burden and increased exacerbations and hospital admissions were more likely to have complex treatments regimens prescribed, than patients with milder forms of COPD (Harb et al. 2017; Negewo et al. 2017).

Complex treatment regimens require an investment of significant amount of time and effort, which results in patient workload (May et al. 2014). This workload is related to patients navigating through health services, interact with multiple health professionals and undergo multiple tests (May et al. 2014; Harb et al. 2017; Dobler et al. 2018). However, in some instances, patients lack the capacity to fulfil the requirements of maintaining these regimens, causing disruptions to their daily functioning and wellbeing (Shippee et al. 2012; May et al. 2014; Harb et al. 2017). As a consequence, treatments can become a burden for patients, since the treatment workload outweighs their capacity to fulfil the requirements of treatment (Harb et al. 2017). Indeed, burden

of treatment comprises the workload and resources that patients devote to healthcare-related activities and its direct effect on their functioning and wellbeing (Boyd et al. 2014; Dobler et al. 2018).

The imbalance between workload and capacity, and high treatment burden have been previously associated with nonadherence, increased risk of drug interactions, poor disease control, and increased illness cost (Negewo et al. 2017). Non-adherence to treatments is common in COPD and complex treatment therapies have been identified as a critical factor (Rand 2005). Adherence to management therapies can prevent and treat exacerbations, reduce hospital admissions and mortality, relieve symptom burden, improve exercise tolerance and health-related quality of life (Bourbeau and Bartlett 2008; Qaseem et al. 2011a). As a consequence, it is important that clinicians explore patients' beliefs and concerns about the safety and benefits of treatments, in an effort to reduce their workload and increase their capacity to manage that workload (Rand 2005; Bourbeau and Bartlett 2008).

Considering the above, palliative care is recommended in COPD, since it can provide the basis for reducing treatment and symptom burden, whilst supporting and improving patients' coping capacity (NICE 2010; WHO 2016). In addition, palliative care clinicians can facilitate patients' access to supportive services, such as palliative care services and hospices (NICE 2010).

Historically, most treatments in COPD have been palliative in intent, due to its incurable character. Symptom control has been achieved by means of inhaler therapy and complex medication regimens. However, in recent years, new invasive therapeutic options have emerged and become more accessible to most COPD patients. These new therapies have the potential to modify the disease altogether or the disease trajectory. These therapies include lung volume reduction surgery and biological therapies. The impact of these new treatments in COPD management requires further understanding of patients' perspective before instigating them treatments, further reinforcing the need for this research work.

2.2.4 COPD Exacerbations

A COPD exacerbation is an acute onset of a prolonged worsening of the patient's symptoms from their usual stable condition and beyond their normal day-to-day variations (Papi et al. 2006; NICE 2010). Exacerbations can have diverse causes including infections, air pollution and changes in ambient temperature (MacNee 2006; Papi et al. 2006; Wilkinson et al. 2017). Despite proactive self-management, a proportion of patients will inevitably experience episodes of acute exacerbations (Department of Health 2012b). Health status and quality of life of patients are influenced by the presence and frequency of acute exacerbations (Papi et al. 2006). Exacerbations

can lead to a decline in lung function and increase patient mortality (Papi et al. 2006; Department of Health 2012b).

Respiratory symptoms during exacerbations include worsening breathlessness and cough, increased sputum production and changes in sputum colour (NICE 2010). These symptoms are related to airway narrowing, increased metabolic state and a mismatch in the ventilation–perfusion ratio (Papi et al. 2006). Exacerbations often require a change or increase in medication and/or hospital admissions, which result in changes in self-management and distress to patients (Wilkinson et al. 2004; NICE 2010, 2011a; British Thoracic Society 2014). Predicting COPD exacerbations is particularly challenging due to the inherent heterogeneity of COPD patients and exacerbations (Al Rajeh and Hurst 2016).

The number and severity of exacerbations are usually lower in patients with milder disease, whilst patients with severe disease experience approximately 3 exacerbations a year (Papi et al. 2006). Exacerbations become more frequent and severe as COPD progresses, reaching a peak when patients approach the end of life (Anzueto 2010). Therefore, frequent exacerbations are seen as key factors when considering initiating palliative care in COPD (Curtis 2008; Barnett 2012). Long-term oxygen treatment (LTOT), frequent exacerbations, previous episode/s of pneumonia, respiratory failure and use of maintenance oral corticosteroids can result in a poor treatment outcome and increased mortality risk after an exacerbation (Papi et al. 2006).

Exacerbations impact patients' lives in different ways throughout the disease trajectory and their effects can last for several weeks (Donaldson et al. 2005; Wedzicha and Wilkinson 2006). These episodes lead to deconditioning and reduced functionality, which in turn result in increased breathlessness (Wedzicha and Wilkinson 2006). Thus, frequent exacerbations intensify the decline in functional status and patients are more likely to become housebound (Donaldson et al. 2005; Wedzicha and Wilkinson 2006). Patients suffering from prolonged exacerbations report worse health status and quality of life, and increased fatigue (Miravitlles et al. 2004; Boer et al. 2018).

2.2.5 Prognosis and disease trajectory

COPD is a complex and heterogeneous illness, therefore no single measure is able to adequately assess patients' disease severity (NICE 2010). Patients' individual rates of disease progression acts as a barrier for accurate prognostication (Sullivan et al. 1996; Tavares et al. 2017). Various tools have been suggested as aids for prognosticating in COPD or to identify when patients are approaching the end of life, however most tools have inadequate prognostic ability. These tools include the BODE index, the DOSE score, the surprise question and the Acute Physiology and Chronic Health Evaluation (APACHE) II score (Turner et al. 1991; Donnelly 1996; Claessens et al.

2000; Powrie 2004; Curtis 2008; Sundh et al. 2012; Luckett et al. 2018). Despite being more accurate in predicting mortality than single measurements, such as FEV1 predicted, these tools do not provide sufficient confidence for clinicians to prognosticate in COPD (Esteban et al. 2010). The difficulty in accurately predicting prognosis is argued to be one of the reasons that led clinicians to delay palliative care and to underestimate prognosis (Spence et al. 2009; Crawford et al. 2013). Despite this, assessing disease severity and mortality risk is important as it dictates treatment therapy and relates to prognosis (NICE 2010). **Table 1** presents the staging of COPD patients according with their airflow obstruction (NICE 2010; Vestbo et al. 2013). As an example, a patient with a FEV1/FVC ratio of less than 70% (which suggests the presence of airflow obstruction) and a FEV1 % predicted of more than 80% (which identifies the degree of airflow obstruction) is classified as having mild or stage 1 COPD.

Table 1 Staging in COPD **(NICE 2010)**

		National Institute for Health and Care Excellence (NICE) guidelines 2010
POST-BRONCHODILATOR FEV1/FVC	FEV1 % predicted	Severity of airflow obstruction
< 0.7	> 80%	Stage 1 – Mild
< 0.7	50-79%	Stage 2 – Moderate
< 0.7	30-49%	Stage 3 – Severe
< 0.7	< 30%	Stage 4 – Very severe

In the past, the disease trajectory in COPD was characterised as a single-organ failure and followed a chronic illness trajectory, see **Figure 1**. This trajectory encompasses a slowly declining health route, which is punctuated by acute exacerbations that can result in the patient's death (Lynn and Adamson 2003; Landers et al. 2017). COPD patients may live reasonably well for many years or succumb quickly to early complications (Lynn and Adamson 2003). As a consequence, patients and relatives go through a rollercoaster of experiences and emotions, since they cannot predict when the fatal exacerbation is likely to happen (Elkington et al. 2005; Landers et al. 2017). This rollercoaster of emotions makes the concept of dying less clear, since at some point, a person was healthy, then sick, and either recovered or died quickly (Lynn and Adamson 2003). This unpredictable disease trajectory results in patients not discussing the topic of death and in important treatment decisions being made at the end of life, such as do not resuscitate orders (Landers et al. 2017). However, in recent years, the disease course seems to have become more difficult to predict, since most patients have multiple comorbidities (Cavaillès et al. 2013; Strauss et al. 2014; Luckett et al. 2018). Multiple comorbidities exacerbate morbidity and mortality in COPD, leading to increased hospitalisations and healthcare costs (Cavaillès et al. 2013). Moreover, multiple comorbidities require different approaches towards COPD management and care (Cavaillès et al. 2013; Franssen and Rochester 2014). Despite this, COPD patients with large

symptom burden, frequent exacerbations and high mortality risk should be identified (NICE 2011a). Palliative care should be offered to these patients, in order to address their physical, social and emotional needs (NICE 2011a).

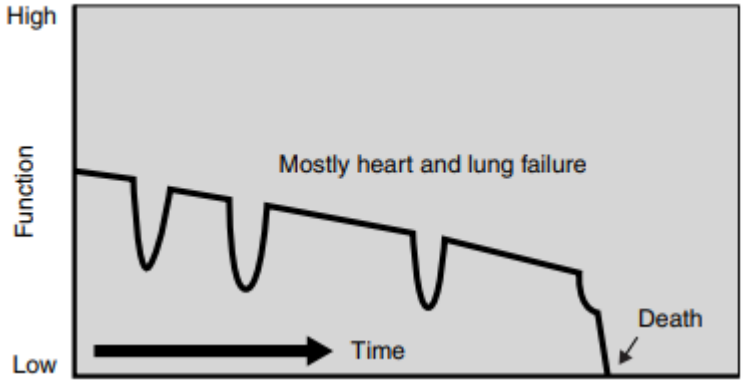


Figure 1 Disease trajectory in single organ failure (Lynn and Adamson 2003)

2.3 Palliative care and end of life care

Palliative care focuses on preventing and relieving suffering through early identification, holistic assessment and treatment of patients' and relatives' physical, psychosocial and spiritual concerns (Gore et al. 2000; NICE 2011b; WHO 2011; NCPC 2012; Public Health England 2014; WHO 2016). Thus, palliative care can defined as the total care provided to patients with progressive and advanced disease (NCPC 2012). The last phase of palliative care, in the last 12 months of life, is typically regarded as end of life care (NICE 2011b).

In England, approximately 165,000 people receive palliative care annually (NCPC 2012). However, current estimates suggest that 75% of people approaching the end of life would benefit from palliative care (Etkind et al. 2017a). This mismatch between the proportion of patients that receive palliative care and the number of patients that would benefit from it seems to suggest issues in palliative care delivery, either in patient identification or service provision. Palliative care delivery is likely to be further impacted, since the number of deaths will rise 25% by 2040 (Etkind et al. 2017a). Previous literature recommends referring patients to palliative care services when treatment is available to prolong life but prognosis is uncertain, which is commonly the case for patients with moderate to severe COPD (NCPC 2012). Traditionally, most patients receiving palliative care had advanced cancer, however patients with end-stage organ failure (such as COPD), neurodegenerative illnesses and advanced dementia also need comprehensive and timely access to palliative care (NCPC 2012). The steady increase of health care use and costs by patients with life-limiting conditions highlights the need for palliative care delivery (NCPC 2012). However,

at present, palliative care services for these patients are scarce, especially in the community (O'Brien et al. 1998; Davidson et al. 2004; Fitzsimons et al. 2007; Cochrane et al. 2008).

The last phase of life is often difficult to identify in patients with life-limiting conditions. This means that palliative care is often started late in the illness trajectory or only after the occurrence of a marked deterioration (NCPC 2012). As consequence, determining when treatments should move their focus from therapeutic to palliative care is often difficult (Fitzsimons et al. 2007; Whellan et al. 2014). In order to avoid this, it is recommended that palliative care should be started early in the disease trajectory and that hospital admissions can be used as an opportunity to integrate this care (Jorgenson et al. 2016). In fact, it has been shown that early integration of palliative care in the disease trajectory of patients with life-limiting illnesses can reduce hospital admissions and overall healthcare costs (NICE 2011b; NCPC 2012).

Patient involvement when planning and providing palliative care must be central (NCPC 2011; NICE 2011b; Department of Health 2012a). Thus, in order to provide high-quality palliative care, patients need to discuss their preferences and decide on their future care and treatments (Public Health England 2014). Communication and care co-ordination are fundamental to good patient-centred palliative care (NCPC 2011; NICE 2011b). The possibility of dying needs to be identified and discussed well ahead of time, so that patients have the opportunity to achieve their wishes or preferences (NICE 2011b; NCPC 2012). Palliative care works hand-in-hand with advance care planning to facilitate just that. Advance care planning is a voluntary process of discussion with the aim of helping someone to identify and record their preferences and wishes for future care (Department of Health 2012a). Palliative and advance care planning conversations should start at diagnosis and continue throughout the disease trajectory (Ford et al. 2013). General Practitioners (GPs) have a key role in initiating discussions about palliative care, however the proportion of GPs reporting palliative care conversations with patients decreased approximately 10% from 2012 to 2014 (Public Health England 2014). These conversations are difficult and sensitive, therefore clinicians need training on how to initiate conversations and carry out advance care planning with patients (NCPC 2011; NICE 2011b; Public Health England 2014).

Conversations about palliative and future care between patients and clinicians are important, since families may not be aware of their relative’s preferences for care. Previous literature suggested that most spouses were unaware of their relative’s end of life wishes, which highlighted the lack of open conversations amongst family members (Public Health England 2014). Thus, only one third of people have communicated their funeral wishes to someone and just 6% have their preferences for future care in writing (Public Health England 2014). The reluctance in talking about death, dying and bereavement can impact on the way people experience the end of

life (Public Health England 2014). According with the NCPC: *'People's choices are at the heart of good end of life care.'*[1]

2.3.1 Palliative care in COPD

COPD patients experience several severe symptoms such as debilitating breathlessness, anxiety and panic attacks (Gore et al. 2000; Guthrie et al. 2001; Curtis 2008; Lanken et al. 2008; Bausewein et al. 2010; Barnett 2012; Choudhuri 2012). These symptoms are at its highest level at the end of life, resulting in reduce quality of life for COPD patients (Guthrie et al. 2001; Elkington et al. 2004; Choudhuri 2012). As a consequence, previous literature has recommended that COPD management should focus on symptom relief, quality of life and patient comfort (Guthrie et al. 2001; Elkington et al. 2004; WHO 2011; Barnett 2012; Choudhuri 2012; WHO 2016). Thus, COPD patients benefit from palliative and advance care planning, since they experience several exacerbations throughout their disease trajectory, which can result in mechanical ventilation and premature death (European Respiratory Society and American Thoracic Society 2004; Scullion and Holmes 2009; Choudhuri 2012; Department of Health 2012a; NICE 2015). As a consequence, patients require care plans with information as to how to proceed in case of future deteriorations (European Respiratory Society and American Thoracic Society 2004; Scullion and Holmes 2009; Department of Health 2012a; NICE 2015).

Despite the fact that COPD patients have worse quality of life scores and increased symptoms than patients with lung cancer, the quantity of palliative care provided to COPD patients compares poorly to the care received by cancer patients (Gore et al. 2000; Curtis 2006; Roberts et al. 2008a; Prigmore and Pursey 2009; Barnett 2012). Discrepancies between palliative care provided to patients with cancer and COPD have been widely documented in previous studies. A recent study showed that most patients admitted to hospices had cancer, whilst the proportion of patients with non-malignant lung disease, including COPD, was only 0.5% (Etkind et al. 2017a). Thus, the findings from the SUPPORT study suggested that COPD patients were more likely to die in the intensive care unit (ITU) and to receive more aggressive treatments than lung cancer patients, despite also preferring comfort care (Curtis 2008). Another study has suggested that less than half of all NHS hospitals have formal palliative care arrangements for COPD patients and that only 11% of Trusts provided information about palliative care to patients with severe COPD (Roberts et al. 2008a; Prigmore and Pursey 2009). Lastly, a cross-national study highlighted that COPD patients were less likely to achieve their preferences, and to die at home or in a palliative

[1] NCPC (2011) Commissioning End of Life Care - Act early to avoid A&E. *The National Council for Palliative Care*: 4

care institution than cancer patients (Hunt et al. 2014; Cohen et al. 2017). A commonly reported cause for COPD patients' limited access to palliative care includes their unpredictable disease trajectory and prognosis (Yohannes 2007; Curtis 2008; Prigmore and Pursey 2009; Barnett 2012; Cohen et al. 2017). Moreover, wide variation in the care of these patients seems to be common suggesting that there is no consensus about the best approach to provide palliative care to COPD patients (Yohannes 2007; Curtis 2008).

Limited access to palliative care for COPD patients has several factors at its cause, which includes the difficulty in determining an accurate prognosis and in identifying the dying phase (O'Brien et al. 1998; Choudhuri 2012). In order to aid clinicians to identify when patients are approaching the dying phase, clinical indicators have been suggested as potential predictors, please refer to **Table 2** to find the full list (Barnett 2012). This uncertainty results in clinicians' avoiding starting palliative care discussions with patients (Prigmore and Pursey 2009). In fact, previous literature suggested that conversations about palliative care are infrequent and of poor quality (Seamark et al. 2007; Yohannes 2007; Curtis 2008). Another barrier for palliative care includes patients' and relatives' poor understanding about COPD, especially about the progressive and terminal character of this illness (Curtis 2008). This barrier reiterates the need for accessible and comprehensive patient information about COPD (Department of Health 2011a).

Table 2 Clinical indicators that help identify patients approaching the end of life **(CURTIS 2008; BARNETT 2012)**

1. Very severe COPD (FEV1 <30% predicted); 2. History of recurrent exacerbations of COPD and frequent hospital admissions; 3. Low body mass index and presence of other co-morbidities; 4. Severe breathlessness at rest; 5. Patient on maximal therapy and/or LTOT; 6. Patient unable to carry out activities of daily living; 7. Likelihood of dying within the next 12 months.

2.3.2 Palliative care in other conditions

Previous research has often drawn comparisons between the care provided to patients with COPD, lung cancer and other life-limiting conditions, since these patients share similar symptoms and disease trajectories (Gore et al. 2000; Curtis et al. 2002). Therefore, understanding the provision of palliative care in these conditions can help contextualize the care provided to COPD patients.

2.3.2.1 Palliative care in cancer

Non-small cell lung cancer has particularly high mortality rates, as over two-thirds of patients die within the first year of diagnosis (Numico et al. 2001). Symptoms in lung cancer are related to the local growth of the cancer (pain, breathlessness, wheezing, haemoptysis and cough) and to systemic effects (malaise, anorexia, asthenia and fever) (Numico et al. 2001; Kvale et al. 2007). Treatments for these symptoms are similar to the ones found in COPD, apart from radiotherapy and chemotherapy (Numico et al. 2001; Kvale et al. 2007).

Lung cancer has been often associated with a significant amount of suffering and a general decrease in the quality of life (Ford et al. 2013). Palliative care has traditionally been provided to these patients since it can help relieve their suffering (WHO 2007; Ford et al. 2013). In addition, combining palliative care with standard oncology care early in the disease course has numerous benefits, including increased quality of life and improved survival (Dahlin et al. 2010; Temel et al. 2010; Ford et al. 2013; Bade and Silvestri 2016). However, palliative care in lung cancer is both less common and often near the end of life, increasing the risk of patient suffering (Bade and Silvestri 2016). Misconceptions about palliative care, such as belief that palliative care is exclusive of curative care, often underlie delayed referrals to palliative care (Bade and Silvestri 2016). In order to prevent the late start of palliative care in lung cancer, previous literature suggests starting palliative care conversations at diagnosis and continuing them throughout the disease course (Ford et al. 2013).

2.3.2.2 Palliative care in non-malignant diseases

Individuals with chronic illness, such as heart failure and chronic kidney disease, often have longer illness trajectories than cancer patients (Davidson et al. 2004; Fitzsimons et al. 2007; Whellan et al. 2014; Wasylynuk and Davison 2015). This disease trajectory means that when therapeutic options are exhausted, patients experience a swift transition from a chronic illness phase to a terminal stage (Fitzsimons et al. 2007). However, due to unpredictable illness trajectories, it can be difficult to determine when care should move its focus from therapeutic to palliative care (Fitzsimons et al. 2007; Whellan et al. 2014).

Needs assessments in patients with non-malignant conditions have identified significant symptom burden and unmet physical and psychosocial needs, which justifies the need for palliative care (O'Brien et al. 1998; Davidson et al. 2004; Rosenwax et al. 2005; Solano et al. 2006a; Cochrane et al. 2008). Most patients with an advanced condition experience high symptom burden, decreased independence and quality of life, social isolation and family burden (Fitzsimons et al. 2007; Alston and Burns 2015; Wasylynuk and Davison 2015; Jorgenson et al. 2016). They also report feelings of depression and/or difficulty in accepting the inevitability of imminent death (Solano et al. 2006a;

Fitzsimons et al. 2007). Other common symptoms associated with non-malignant conditions include: pain, anxiety, confusion, fatigue, breathlessness insomnia, nausea, constipation and anorexia (Solano et al. 2006a). Application of many of the principles of palliative care can help optimise symptom management (O'Brien et al. 1998; Davidson et al. 2004). Therefore, it is recommended starting palliative care early and using hospitalizations as an opportunity to integrate palliative care (Jorgenson et al. 2016). The unpredictable illness trajectory found in these life-limiting conditions clearly demonstrates the importance of introducing advance care planning early and ensuring that conversations about future care between patients and clinicians are ongoing (Wasylynuk and Davison 2015; Raghavan and Holley 2016).

Although life-limiting conditions cause three out of four deaths in developed countries, specialist palliative care services have primarily focused on cancer patients, (Solano et al. 2006b; Cochrane et al. 2008; Martín-Lesende et al. 2016). When comparing with cancer, there are less palliative care services available for patients with non-malignant conditions, especially in the community (O'Brien et al. 1998; Davidson et al. 2004; Fitzsimons et al. 2007; Cochrane et al. 2008). In order to improve palliative care provision, research has suggested that palliative care should be provided on the basis of need, rather than diagnosis (Cochrane et al. 2008).

Patients with COPD, heart failure and chronic kidney disease face similar challenges when accessing palliative care. The unpredictable and complex disease trajectory coupled with clinicians' poor understanding about palliative care seem to prevent the early start of palliative care. In contrast, patients with lung cancer are able to access more palliative care services, although comfort care is also typically started late.

In summary, poor palliative care provision to COPD patients seems to be associated with the lack of palliative and future care discussions, the difficulty in accurately prognosticating, and the lack of resources available for specialist palliative care, especially in the community. The complex and individualized disease trajectory seen in COPD challenges prognostication, and results in palliative care and discussions being started late in the disease trajectory. Early discussions between COPD patients and clinicians can help ensure the timely start of palliative care and in patients' preferences being respected. Therefore, understating patients' preferences for discussions and clinicians' opinions and recommendations becomes a priority.

2.4 Conversations about palliative care in COPD

Good healthcare communication is seen as effective communication that enables patients to have meaningful dialogues with clinicians (NHS England Patient and Public Participation and Insight Group 2016). Therefore, to improve patients' experience, NICE recommends tailoring services to patients' needs and preferences through regular patient-clinician conversations (NICE 2012; NHS Finance and Operations - NHS Group 2016). Thus, people approaching the end of life should be able to discuss their preferences in an sensitive manner and clinicians should allow for changes in their wishes (NICE 2011b, 2012). The Royal College of Physicians produced a report encouraging clinicians to engage in early discussions about prognosis and palliative care, since these conversations were found to empower renal patients and to result in better experiences at the end of life for the wider public (Davison and Simpson 2006; Wright et al. 2008; Bailey and Cogle 2018; Dixon et al. 2019). These conversations enable patients and clinicians to plan care for the future (NICE 2005) and it has been shown that the provision of timely and relevant information about palliative care can positively enhance patients' hope (Davison and Simpson 2006). Despite these benefits, poor communication, especially at the end of life, is often found in clinical practice, which results in significant harm to patients (Dingley et al. 2008). Indeed, direct correlations between poor palliative care communication and inadequate care were highlighted in the Francis Report (Francis 2013). The issues identified in the Francis Report emphasize the importance of effective communication especially at the end of life.

In COPD, conversations enable patients and clinicians to understand, debate and agree on their preferences for palliative and future care (Curtis 2006). Patients' preferences should be respected when developing treatment escalation plans, emergency and resuscitation decisions, palliative care delivery and hospice care (Curtis 2006). As described above, poor prognostication in COPD prevents the discussion and delivery of palliative care, which results clinicians not knowing when and how to discuss palliative care with patients (Curtis 2006; Tavares et al. 2017). Research has shown that whilst more than half of patients shared a desire to discuss palliative care, only one third of patients had a conversations with a clinician (Au et al. 2012; Leung et al. 2012; Tavares et al. 2017). These conversations were started late in the disease trajectory, usually when the patient's condition was considered advanced and/or after a sudden deterioration (Sullivan et al. 1996; McNeely et al. 1997; Curtis 2000; Gaspar et al. 2014; Tavares et al. 2017). In addition, most conversations occurred in hospital wards and intensive care units (McNeely et al. 1997; Curtis 2000, 2008; Tavares et al. 2017). However, clinicians believed that conversations should have been started when patients were stable (Sullivan et al. 1996; McNeely et al. 1997). In comparison, patients with lung cancer had palliative care conversations generally earlier and with increased

frequency (Edmonds et al. 2001). More information about palliative care communication in other illnesses will be provided below.

The quality of discussions was rated as low by patients and quality remained low as they approached the end of life (Janssen et al. 2011a; Janssen et al. 2011b; Au et al. 2012; Houben et al. 2015). The low quality was related to the lack of topics covered in the discussion (Engelberg et al. 2006; Janssen et al. 2011a; Houben et al. 2015). Some clinicians claimed that conversations emotionally impacted patients, therefore some clinicians purposely withheld information related to prognosis (Curtis 2000; Curtis et al. 2004; Curtis et al. 2008; Crawford 2010; Philip et al. 2012). Despite this, the presence of previous palliative care discussions was associated with better health-related outcomes (Reinke et al. 2011c). Providing training to health professionals can improve the frequency and quality of palliative care discussions with patients (Seamark et al. 2007; Lanken et al. 2008; Spence et al. 2009; Barnett 2012; Department of Health 2012a).

2.4.1 Palliative care conversations in other illnesses

Information about palliative care conversations in other illnesses can help contextualize and inform decisions about why, when and how to initiate conversations in COPD. Similarities and divergences across different illnesses with similar disease pathways put into perspective the current landscape for palliative care conversations.

Early and ongoing discussions with heart failure patients about palliative and future care were seen as essential (Harding et al. 2008; Ben Gal and Jaarsma 2013; Hjelmfors et al. 2014; Whellan et al. 2014; Wordingham et al. 2016). The American Heart Association encourages regular discussions about preferences in the annual heart failure review (Dunlay et al. 2015; Wordingham et al. 2016). In agreement, heart failure patients called for timely and honest discussions with clinicians (Harding et al. 2008; Hjelmfors et al. 2014; Wordingham et al. 2016). However, a recent North American study showed that only 12% of healthcare professionals discussed palliative care with heart failure patients (Dunlay et al. 2015). These clinicians hesitated starting discussions and reported low levels of confidence in discussing palliative care, enrolling patients in hospices and providing end of life care (Dunlay et al. 2015). Another study suggested that clinicians found honest palliative and future care conversations difficult (Wordingham et al. 2016). Discussions in heart failure often occurred during highly emotional times and clinicians were rarely trained to conduct conversations (Hjelmfors et al. 2014; Wordingham et al. 2016). Despite this, the occurrence of discussions resulted in less aggressive care and in increased hospice referrals, however accurate prognostication was commonly highlighted as a barrier for palliative care (Wordingham et al. 2016).

The American Renal Physicians Association developed guidelines to facilitate conversations about advance care planning and prognosis (Koncicki and Swidler 2013; Rak et al. 2017). However, despite welcoming the opportunity to discuss their preferences, a recent study showed that none of the patients recruited had discussed palliative care with a clinician (Goff et al. 2015). Renal clinicians required education on how to communicate effectively and address patients' concerns, since poor communication skills can diminish the trust of patients in clinicians and adversely affect palliative care discussions (Rak et al. 2017). The lack of palliative care conversations seems to have contributed to dialysed patients receiving less support from hospice services than patients with other diagnoses (Murray et al. 2006; Schell and Holley 2013; Rak et al. 2017).

In cancer, early discussions about palliative care preferences are also recommended by experts (Ahluwalia et al. 2014). At present, most recommendations for palliative care communication in cancer are based on clinical wisdom and expert opinions, rather than empirical evidence (Thorne et al. 2014). Patients want to be able to discuss their concerns, receive information about the status of their illness and about the symptoms they are likely to experience in the future, but most importantly to be assured by clinicians that their painful symptoms will be appropriately managed (Umezawa et al. 2015). However, a recent study showed that only 47% of patients with advanced cancer had an early palliative care discussion with a healthcare professional (Ahluwalia et al. 2014). This lack of discussions may be related to clinicians finding conversations about bad news difficult, despite self-assessing their communication skills favourably (Back et al. 2008). Patients with previous discussions were less likely to be admitted to hospital and to receive aggressive treatments at the end of life (Wright et al. 2008; Ahluwalia et al. 2014). Thus, palliative care discussions were not associated with an increase in depression or anxiety scores (Wright et al. 2008).

Similarities between palliative care conversation in COPD and other non-malignant illnesses were found. However, cancer patients were more likely to discuss their preferences with clinicians and to receive less aggressive treatments at the end of life, than patients with long-term conditions.

Communication between COPD patients and healthcare professionals is seen as essential to ensure that patients can access palliative care timely and effectively. NICE, 2005 considered these discussions as the first step to ensure that patients received treatments and care based on their preferences. At present, palliative care discussions are uncommon and have poor quality, which require urgent improvement. Lack and late palliative care discussions are an important cause of COPD patients' limited access to palliative care. This lack of discussions seems to have resulted in the poor delivery of palliative care. Due to an unpredictable disease trajectory and prognosis,

healthcare professionals are uncertain as to when and how to initiate discussions with patients. Novel insight is required to inform and ultimately improve the frequency and quality of palliative care discussions in COPD.

Patients' preferences for palliative care conversations and clinicians' opinions and experiences when initiating and conducting discussions have not been previously investigated. Previous research has focused on improving clinicians' confidence and competence for discussions and seems to have ignored patient preferences. However, since patients are the most affected and interested party when discussing palliative care, their thoughts and preferences should be central in informing the planning of quality care. This study adds novel insight by using patient preferences gathered in interviews to inform and direct interviews with clinicians, with the aim of finding common ground and address some of the challenges and unknowns in palliative care communication. The approach used to investigate patient's preferences and clinicians' judgements for palliative care conversations in COPD are described in the next chapter.

Chapter 3 Study design

This chapter provides an overview of the research aim and question, and methods used in the study. Previously published and unpublished literature was reviewed and no studies were identified researching this specific topic.

3.1 Research aim and question

The overarching aim of this research study was to define the optimal timing and nature of palliative care conversations in COPD, by understanding patients' and clinicians' views and synthesizing the optimal approach. This aim was achieved by exploring patient preferences for palliative care conversations at different stages of their disease trajectory; and by understanding clinicians' recommendations and experiences when starting and conducting these conversations. Both parties participating in palliative care discussions were interviewed: patients and clinicians.

Considering the research aim, the primary research question was "How do COPD patients' preferences and clinicians' judgements shape the timing and nature of palliative care conversations?" A series of linked secondary research questions have also been explored and can be found in **Table 3**.

Table 3 Secondary research questions

- "What is the current state of evidence regarding palliative care conversations in COPD?"
- "What are the gaps in evidence that leads to the scarce number and quality of discussions?"
- "What are the preferences of COPD patients for the timing and nature of discussions?"
- "When, how, where and by whom should palliative care discussions be initiated?"
- "Does the timing and nature of discussions change throughout the disease trajectory?"
- "What are clinicians' perspectives on the timing and nature of palliative care discussions?"
- "What are the similarities and divergences between previously published literature, patients' preferences and clinicians' judgments about palliative care discussions?"

The research question was unpicked and the main keywords were identified and defined. These keywords included "Patient's preferences," "Clinicians' judgements," "Timing and Nature" and "Palliative Care conversations." The definitions of these keywords can be found in **Table 4**.

Table 4 Definition of keywords found in the research question	
Patients' Preferences	COPD patients' perspectives and choices as to when discussing palliative care with clinicians. The study aimed at understanding the opinion and thoughts of the people who ultimately benefit from the care agreed in palliative care discussions.
Clinicians' Judgements	Interpretation of COPD patients' clinical and social context by a healthcare professional based on their knowledge and experience leading to a conclusion. The study gathered clinicians' opinions, recommendations and experiences when initiating and conducting discussions with patients.
Timing and Nature	The ideal timing, healthcare professional, approach and place to initiate and conduct palliative care conversations with COPD patients.
Palliative Care Conversation	Palliative care is seen as a holistic, compassionate and comprehensive care that includes symptom control, conversations about future care, arrangements for the end of life, support throughout the end of life process, funeral arrangements and bereavement support. Therefore, palliative care conversations include a discussion between a COPD patient and a clinician about any component described above. These conversations may include education about palliative care, information regarding prognosis, and preferences for palliative, future care and the end of life.

3.2 Philosophical stance

The nature of the research question has directly influenced the methodology adopted in this study. Qualitative research is a form of social inquiry that focuses on the way that people make sense of their experiences and the world in which they live (Holloway and Galvin 2017). It offers methods to gain a deep understanding and investigate explanations for people's perceptions about a certain phenomenon (Holloway and Galvin 2017).

Qualitative enquiry is a valuable tool when researching decision-making around the areas of dying and potential interventions (Holloway and Galvin 2017). These areas of study are intimately related with the research question – patients and clinicians deciding on the timing and nature of palliative care conversations. Patients' preferences for discussions are based on the meaning that they attribute to their condition and to palliative care, their lived experience and their context/background. Understanding patients' and clinicians' thoughts and preferences requires

interpretation and an idiographic approach (Gray et al. 2017). As a consequence, the researcher's experiences, reflections and interpretation influence the data generated from the interaction with patients (Gray et al. 2017). Researchers from different clinical, professional and social backgrounds, and with different past experiences and world views may choose to focus on different aspects of data collection and analysis. In this case, my nursing background, my experience in looking after COPD patients and my white Portuguese background influenced my approach towards data collection and analysis throughout the study.

Research studies should focus on developing novel knowledge to the field of study, but most importantly in solving issues found in clinical practice. The research question focuses on a common issue found in clinical practice – the lack or late start of palliative care conversations with COPD patients. Therefore, a pragmatic stance needed to be considered when designing the study, and collecting and analysing data. The data generated from the interpretation of patients' and clinicians' thoughts needed to be relevant for clinical practice. Therefore, a large number of patients and a pragmatic approach was used to understand and explain patients' preferences for palliative care discussions. Similarly, clinicians from different professional backgrounds that look after COPD patients were interviewed.

3.3 Methods

As described in chapter one (page 2), this study was divided into 4 interconnected phases. These phases had a sequential order and followed an iterative process. Please refer to **Figure 2** for more information and to **Appendix A** to find a Gantt chart framing the different phases of the study. These phases had specific research aims and questions, methods, findings and conclusions. The different phases included:

- Phase 1: Systematic literature review on palliative care communication in COPD;
- Phase 2: Qualitative interviews with COPD patients;
- Phase 3: Qualitative interviews with clinicians.
- Phase 4: data integration

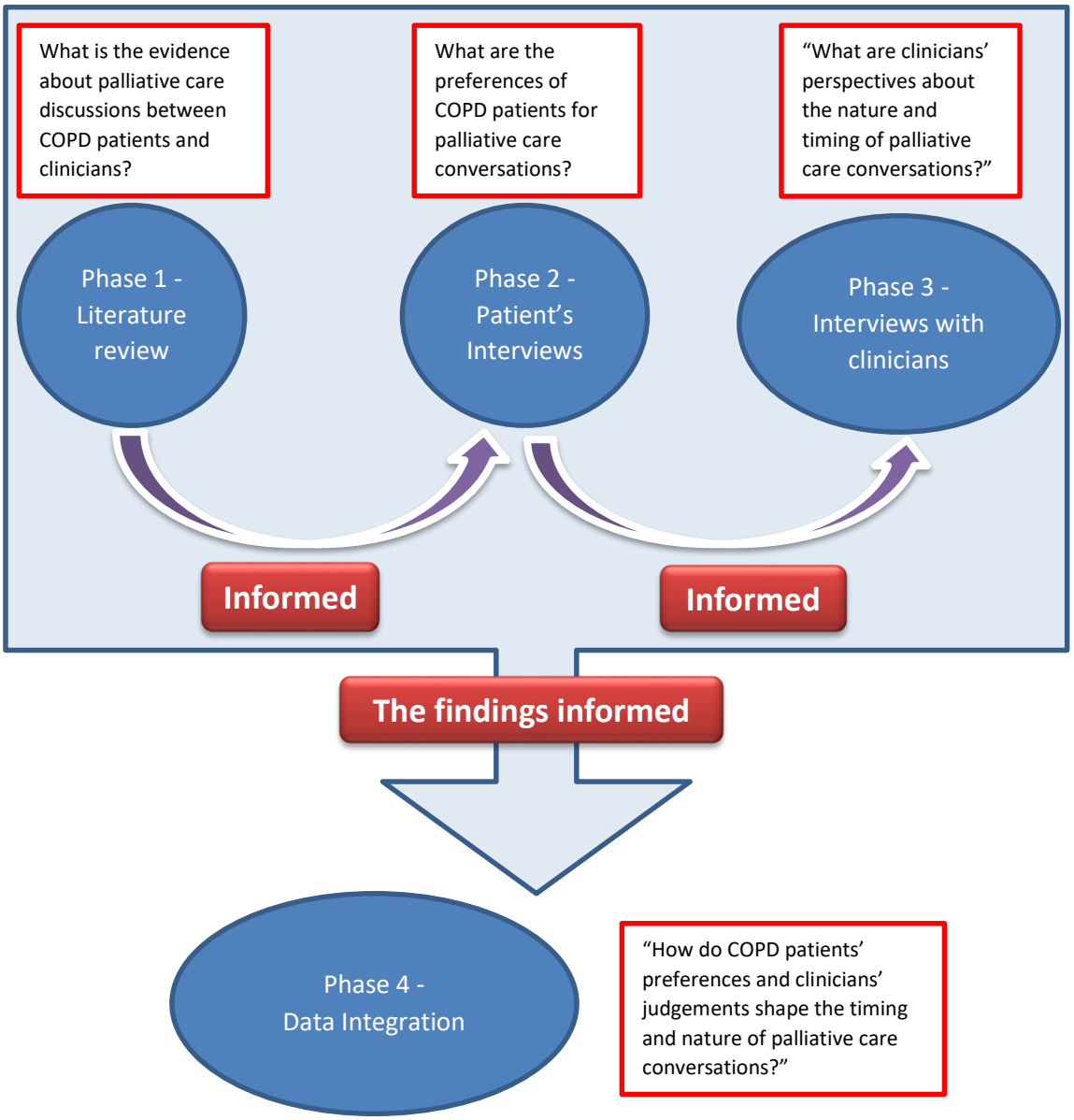
Phase 1 involved the systematic search and review of published and unpublished literature about palliative care discussions between COPD patients and clinicians. All major healthcare-related databases and websites were searched, and PRISMA guidelines were followed. The findings of this phase helped design phase 2 and provided a general picture about the current status of palliative care discussions. Please refer to chapter 4 and page 33 for more information about this phase.

Phase 2 looked at COPD patients' preferences for palliative care discussions with clinicians. Patients at different stages of disease severity were interviewed and their case-notes reviewed.

Interviews followed a semi-structure approach and data analysis was guided by principles of IPA. The findings generated in this phase were used to design the interview guide and to generate discussion with clinicians in phase 3. Please refer to chapter 5 and page 59 for more information about this phase.

The third phase of the study aimed at exploring clinicians' thoughts and experiences about palliative care conversations, considering patients' preferences. COPD-related clinicians from different professions and levels of experience were interviewed. Interviews followed a semi-structure approach and data analysis followed thematic analysis principles. Please refer to chapter 6 and page 79 for more information about this phase.

Figure 2 Connection between the different phases of the study



The information gathered in all the different phases was combined and integrated in phase 4, which resulted in the overall findings of this study. The integration method used in this case was the triangulation protocol, which allowed the capture of a more complete picture of palliative

care discussions in COPD (O'Cathain et al. 2010; Farquhar et al. 2011). Thus, this method allowed the analysis and integration of the different phases after each had been analysed separately. Please refer to chapter 7 and page 95 to find more information.

3.3.1 Methodology used in phase 2

The methodology used in phase 2 is discussed here, since this phase is a key component of the study and its conduct and analysis methods have indirectly shaped Phase 3 and 4. Phase 2 used a pragmatic approach towards Interpretative Phenomenological Analysis (IPA), which requires further justification.

The approach chosen to guide the design of phase 2 and help answer the research questions was IPA. IPA is rooted and derives from phenomenology (Smith 2008). Phenomenology has been frequently used as a method of inquiry by a wide range of disciplines, including health sciences (Holloway and Wheeler 2010). Phenomenology was applied when studying the experiences, perceptions and perspectives of people who use or used healthcare services (Holloway and Wheeler 2010; Gray et al. 2017). Phenomena are explored and interpreted when people discuss their experiences or thoughts about them (Gray et al. 2017). In an effort to explore a certain phenomenon, one tries to get closer to the participant's world by taking an emic perspective (Smith 2008). However, this approach is complicated by the researcher's own preconceptions (Smith 2008). Phenomenology has three major streams, which comprise descriptive, hermeneutic or interpretive, and existentialist approaches (Holloway and Wheeler 2010). IPA is intimately related with hermeneutic phenomenology, which entail the interpretation of participants' thoughts (Larkin and Thompson 2012).

Hermeneutic phenomenology describes and interprets the answers and perspectives of the participants involved in the study (Holloway and Wheeler 2010). Unlike descriptive phenomenology, hermeneutics does not aim for transcendental knowledge (Larkin and Thompson 2012). Participants are inseparably involved with the world and their body cannot be dissociated from their mind, which results in knowledge that is specific to the participants in question and situated in a place and time (Larkin and Thompson 2012). Hermeneutic phenomenology differs from IPA since it does not take into account the impact of the researcher in the findings generated from the interaction with patients and their interpretation of the data.

IPA aims to explore in detail how participants make sense of their lives and the world surrounding them (Smith 2008). IPA is also theoretically influenced by symbolic interactionism (Yardley 1997). Symbolic interactionism argues that the meanings that individuals ascribe to events should be of central concern and these meaning are only obtained by the process of interpretation (Yardley

1997; Pietkiewicz and Smith 2014). The researcher has an active role in the research process so their background and preconceptions influence how they understand and interpret the participant's personal world (Smith 2008). As a consequence, the researcher tries to make sense of how participants try to make sense of their world, resulting in a double hermeneutic approach (Smith 2008).

IPA helped to understand the factors that contribute and influence patients' preferences for palliative care conversations. This was achieved by means of interpretation and considering patients' clinical and social variables. The complexity surrounding a person with COPD requires more than mere description of their thoughts. Instead, understanding patients' thoughts involved the interpretation of their background, role in society, level of education, disease severity, the point in time of the interview and their social and clinical characteristics.

Despite the benefits associated with the strict the use of IPA, phase 2 used a pragmatic approach, which guided patient interviews and their analysis. The rationale for this was the necessity to explore the view of patients at different stages of disease severity, which resulted in a larger number of patients recruited than is customary in IPA. Another reason for using a pragmatic approach included the focus on future events for most patients (palliative care discussions), rather than past experiences. At the start of the study, it was anticipated that only a small number of patients would have had a palliative care discussion. Therefore, most patients would not be able to draw on previous experiences when discussing their preferences for these conversations. The focus on future events it is also not customary to IPA, which prevented the in-depth use of IPA. Despite this, IPA still offered the lens with which to explore, interpret and explain COPD patients' preferences. The IPA principle most affected by the use of a pragmatic approach was idiography, since the in-depth analysis and interpretation of individual interview extracts was not fully achieved at the level seen in other IPA studies. Other methodologies were considered when developing phase 2, however these approaches did not seem suitable, please see **Table 5**.

Table 5 Methodologies considered for phase 2 of this study

METHODOLOGY	Description	Reasons for exclusion
ETHNOGRAPHY	Studies the culture or subculture of certain organizations or groups of people (Holloway and Galvin 2017).	Unable to develop an ethnographic study, since this would require visiting consultations where people discuss palliative care. This would not be feasible due to lack of conversations and the difficulty in predicting when these discussion would take place. Moreover, this approach would not answer the research question that explores patients' preferences for conversations.
GROUNDED THEORY	Focuses on developing theory through interaction, interviewing and observation (Gray et al. 2017).	The use of this methodology did not seem appropriate, due to its theorizing aspect and the exploratory character of the study. In addition, the emic perspective required when collecting and analysing data, contrasts with one of the fundamental principles of this methodology. Lastly, a thorough review of the literature had been done before the start of phase 2.
NARRATIVE ANALYSIS	Focuses on understanding participants' insider experience about a certain illness or event (Holloway and Galvin 2017).	Phase 2 seeks to understand the thoughts of patients about a certain phenomenon that may not have happened for the majority them. Patients' their thoughts may have been influenced by their past experiences, but do not constitute the principal research aim.

3.4 Ethics

This research study was approved by the South Central – Hampshire B Research Ethics Committee (REC) on the 7th of February 2017. The ethical permission process required several amendments to the research proposal and research documents, which lasted approximately 1 year. The ethics application had a large impact on data collection, since it delayed it by several months and decreased the amount data collected during patient interviews. The amendments requested by the REC included:

- The REC requested further information about the topics discussed in the interviews; PPI involvement; options available for patients that required further support as a result of the interview; and about data governance.
- The research committee suggested removing time constraints on the diagnosis of COPD in the inclusion criteria (such as patients with severe COPD and a diagnosis for more than 10 years).
- The REC stated that palliative, end of life care and ACP should only be discussed with patients with severe or very severe COPD. The committee argued that these topics could unnecessarily distress patients with milder disease. As a consequence, the committee suggested excluding patients with mild/moderate disease from the study, or not discussing palliative care topics with these patients. The committee seemed to be

peremptory about this topic. After consideration and discussion amongst the supervisory team, it was agreed to interview patients with mild and moderate COPD, but without questioning them on palliative care or end of life. Excluding these patients from the study would exclude a large COPD population and prevent the in-depth investigation of their preferences for the timing and nature of palliative care discussions. Current evidence suggests that palliative care should be initiated early in the disease trajectory and this can only be researched if patients with milder COPD are recruited. Moreover, patients with mild/moderate COPD may not necessarily have a better health status when considering other comorbidities and age. The exclusion of these patients would deny them the opportunity to share and register their thoughts/preferences for discussions. Despite this, a sensitive approach was used in the interviews, the language was tailored to the patient and patients with milder forms of COPD were only asked about future care and treatments. Patients dictated the depth and language and interviews were paused/stopped if patients felt uncomfortable. Moreover, patients were assessed and monitored throughout the interview for signs of distress. Reassurance, a drink and tissues were provided as necessary [the impact of this decision is discussed in Chapter 8.4 and page 139].

- General amendments to the patient's and healthcare professionals' information sheet, consent form and invitation letter were also requested. Examples of these changes included: providing information in lay format; providing further information about the use of the recordings from interviews; changing layout of the forms; and differentiating between clinicians' and patients' forms.

3.5 Data governance

Information shared during all interviews was kept confidential, under the Data Protection Act 1998. The interview audiotapes were only accessed by the main researcher and the study's supervisors. Supervisors accessed anonymised audiotapes for learning and training purposes and to ensure the overall quality of the information gathered during the interviews. All interviews and personal information were kept securely. Personal information was only kept for the participants who asked to be contacted at the end of the study. Participants were informed that they could request the exclusion of their participation from the study up to 7 days after the interview.

Participants were made aware at the beginning of the interview that any information considered a criminal offence would be shared with legal authorities. This included sensitive information under the Criminal Law Act 1977. Depending on the type of information disclosed, different actions were taken to ensure the safety of anyone involved in the incident. If the information

shared posed a direct threat that involved the participant's immediate safety, the University's Data Protection Officer was contacted immediately. However, if the information shared did not pose an immediate threat to the individual, this information was firstly discussed with the study's supervisors and the University's Data Protection Officer was contacted at a later stage. Participants were made aware of any intentions to report information to legal authorities. If participants required further support about the study, they were advised to contact the Research Enterprise and Governance Office. No complaints nor incidents involving sensitive information occurred.

Data management followed the Data Protection Act 2018, Research Data Management 2018-19 and the General Data Protection Regulations 2018 approved by the University of Southampton. All data collected was kept securely. Non-digital data was labelled, indexed, categorized and locked away in cabinets, to which only the main researcher has access. These cabinets were kept behind code locked doors in the Research Department of a local NHS Trust. An anonymised ID was given to every participant, and only the main researcher had access to the list containing participants' details and their ID number. Participant information and their anonymised ID were kept in different cabinets. This ensured that participants cannot be identified if only one cabinet was accessed. Digital data was kept in password-protected computers and documents, to which only the main researcher had access.

Data was only kept for as long as necessary and was reviewed regularly to determine whether retention was still required. The following types of data were kept securely:

- Participants who wished to be informed of the results will be contacted at the conclusion of the study. This information was recorded in 2 different forms. The 1st form solely contained the participants' names whom wished to be contacted and the 2nd form contained their respective address of contact (being this email or postal address). Each patient was given an identification code which was used to identify the participants' names and their respective address. Both records were kept in different lockers, to which only the principal researcher had access. These lockers were kept in locked rooms at the Research Department of a local NHS trust.
- All interview transcripts, audiotapes, consent forms, data collection forms and the final thesis will be kept either in the University of Southampton ePrints Soton or in the Health Sciences repository for a minimum of 10 years. Data will be assessed by iSolutions and an allocation will be given depending on the exact type of data. Archiving will be done off-site according with the university's data management policy.

Once non-anonymised data was thought to be no longer necessary, it was destroyed following the university's guidelines. Data kept in a magnetic and/or solid state media was given to the

Serviceline service, so that the disk could be physically destroyed. Paper-based data and optical media, such as DVDs and CDs, were physically destroyed using a suitable shredder. The university's shredder and disposal services were used to securely destroy research data.

Data was only transferred to the supervisory team within the premises of the University of Southampton. Digital data was transferred to other researchers by using encrypted files, this prevented the access to sensitive information by people outside the research team. Only data that did not include participants' contact details was shared with other researchers. Documents' and computers' passwords were changed regularly to prevent access to information by external individuals to the study.

3.6 Data dissemination

The main findings and the conclusion of the study were disseminated in various different ways. The primary source of dissemination was through national and international research journals within the respiratory and palliative care specialty. This source of dissemination allowed the findings to reach largest number of people. A second form of dissemination was using academic and/or research conferences within and outside the University of Southampton. This included conferences sponsored or developed by other universities, by respiratory and/or palliative care societies, by NHS Trusts and other relevant research conferences. The last method of data dissemination consisted in presenting the results of the research study to respiratory and/or palliative care services, groups of MDTs working with COPD patients and groups of COPD patients.

The next chapter presents Phase 1 of the research study and outlines how it has informed Phase 2 and 3.

Chapter 4 Phase 1 - Palliative care conversations in COPD – a systematic literature review

4.1 Introduction

This chapter describes the methods and findings of a systematic literature review on palliative care discussions between healthcare professionals and COPD patients. This review pinpoints areas that require further research and suggests ways of improving palliative care communication. The findings of the review have informed the overall design and development of the next two study phases. The extent to which this review informed the interviews with patients is presented at the end of this chapter.

A systematic approach was chosen, which included the search of all major health-related databases, using key terms related to the topic. The findings were analysed and presented using a narrative synthesis as a guide. The review was published in the European Respiratory Journal – Open Research in April 2017 and is presented as it was published in the journal.

The last literature search was conducted in May 2015, another paper search was carried out in June 2019. This second search identified 6 new papers, of which 4 papers reported original research and 2 papers included literature reviews (please refer to chapter 4.7 and page 53 for more information). Original research focused on barriers for palliative care discussions; in developing interventions to improve conversations with patients; and in assessing the long-term impact of interventions in improving palliative care communication. These new findings were integrated with the findings resulting from all phases in Chapter 7 and page 95.

The full paper is presented in the next page as published in the European Respiratory Journal – Open Research.

Journal: European Respiratory Journal – Open Research

Title: Palliative and end-of-life care conversations in COPD: a systematic literature review

Authors: Nuno Tavares, Katherine Hunt, Nikki Jarrett and Tom Wilkinson

Reference: Tavares N, Jarrett N, Hunt K and Wilkinson T (2017) Palliative and end-of-life care conversations in COPD: a systematic literature review. *ERJ Open Research* 3(2)

Paper accepted for publication in December 2016 and published in April 2017

4.2 Introduction

Chronic obstructive pulmonary disease (COPD) is characterised as a chronic disorder with persistent airflow obstruction, progressive breathlessness and chronic productive cough (NICE 2011a). COPD is associated with anxiety, depression, lack of energy, anorexia and restricted mobility (Sullivan et al. 1996; Wilson et al. 2008; Department of Health 2011a; Halldórsdóttir and Svavarsdóttir 2012; Momen et al. 2012). In the UK, it is estimated that 3 million people have COPD (NICE 2010; Smith and Kirkpatrick 2013) and it is responsible for 30,000 deaths per annum (Scullion and Holmes 2009).

People suffering from life-threatening illnesses, such as advanced COPD, should receive palliative care in order to improve their and their families' quality of life (WHO 2011, 2016). Palliative care focuses on the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of all physical, psychosocial and spiritual issues affecting the patient and his/her relatives (WHO 2011, 2016). Any palliative care provided within the last 12 months of life is considered as end of life care, the last phase of palliative care (NICE 2011b).

The NHS End of Life Care strategy recommends open conversations between healthcare professionals and patients as the end of life approaches (Scullion and Holmes 2009; Department of Health 2012a). These discussions are the first step in ensuring that well planned care is delivered (NICE 2005). Indeed, awareness that death is approaching and what can be expected is seen as a prerequisite of a 'good death' (Momen et al. 2012).

Difficult prognostication in COPD and in identifying with confidence the patients who are likely to die within 6 months poses an important barrier for early palliative care delivery (Curtis 2006). Despite the development of different prognostic tools, the uncertainty regarding the start of

palliative care for COPD patients remains challenging (Curtis 2006). Gore and colleagues found in 2000, that patients with end stage COPD suffer from multiple severe symptoms, such as breathlessness, anxiety and depression; only a small proportion of patients receive palliative care and social support; and patients are likely to die whilst on aggressive treatments and in intensive care unit settings (Gore et al. 2000). Considering this and acknowledging the difficulties in prognosticating, it remains the physician's responsibility to educate patients about palliative care and to understand and respect their preferences (Curtis 2006). Professionals should consider patients' opinions and preferences when developing treatment escalation plans, emergency and resuscitation decisions, palliative care interventions and hospice care (Curtis 2006). Preferences can only be understood, debated and agreed in early conversations with COPD patients (Curtis 2006).

Despite sharing similar health status, care trajectories and symptom burden (Gore et al. 2000; White et al. 2011), the quality and the proportion of patients with COPD who receive palliative care compares poorly to the care received by patients with cancer (Curtis et al. 2004; Curtis et al. 2005; Crawford 2010; Leung et al. 2012). Patients with COPD receive less palliative care and die following more aggressive treatments at the end of life than patients with lung cancer, despite having the same preferences for palliative care (Curtis 2008). Although this suggests inequality in care provision based on diagnosis, it presents an opportunity to learn from practices in cancer care.

Given the importance of communication about palliative care between COPD patients and healthcare professionals, it was sought to systematically review the literature on palliative and end of life care discussions between healthcare professionals and patients with COPD in order to identify best practice, as well as the barriers, facilitators, challenges and meaning of these conversations.

Previous narrative and systematic reviews have been published in this subject (Curtis 2000; Kass-Bartelmes and Hughes 2004; Curtis et al. 2005; Curtis 2006; Curtis 2008; Momen et al. 2012; Stephen et al. 2013; You et al. 2014). However, a comprehensive, evidence-based and systematic review was thought to be necessary to contextualize newly developed research. Considering the limitations of previous reviews, a systematic literature review was developed. This review offers evidence gathered from virtually all relevant health-related databases and websites, presents evidence developed from the year 1996 to 2015 and places equal importance on all types of literature, includes only papers with moderate to high quality and systematically analyses the data gathered from all papers. Furthermore, this review highlights new information which previous reviews did not provide. The new topics consist of the following: place, frequency, quality, importance, and disease features that triggered palliative care communication; in-depth

information about barriers and facilitators; comparison of communication in COPD and cancer; and, finally, approaches to improve communication about palliative care in COPD. Healthcare professionals looking after COPD patients and researchers developing studies within this subject can use this review as an accurate reference for their day-to-day clinical practice.

4.3 Methods

4.3.1 Design

Prior to the development of the systematic literature review, a literature review protocol was outlined (for more information regarding the methods used please refer to **Appendix B**). Therefore, only a brief description of the protocol will be presented here. This review was conducted in accordance with: PRISMA guidelines; the guidance provided by the Centre for Reviews and Dissemination Guidelines; and was based in the systematic reviews included in this review (Centre for Reviews and Dissemination 2008; Liberati et al. 2009; Momen et al. 2012; Stephen et al. 2013). The SPICE framework was used to inform the literature search strategies outlined in the review (see **Table 6**).

Table 6 SPICE framework

SETTING	Primary and secondary care.
PERSPECTIVE	People with COPD and their family, regardless of demographics (apart from being 18 years or older) or health status, and healthcare professionals looking after these patients, such as nurses or doctors.
INTERVENTION	Discussions about palliative care between patients with a diagnosis of COPD and/or families, and healthcare professionals. Discussions between patients with COPD and family members or informal carers, and between healthcare professionals and patients' relatives alone were excluded. Discussions about palliative care were defined as a discussion where participants exchanged ideas and information about all aspects related with preferences for care that were not focused in a curative outcome, but, instead, in quality of life and symptom relief.
COMPARISON	A comparator was not found appropriate for inclusion due to the explanatory character of this review.
EVALUATION	To comprehend what is known about palliative care discussions between patients with COPD and healthcare professionals.

4.3.2 Search Strategy

In order to find a comprehensive number of studies and to ensure that no relevant articles were missed, all major healthcare-related databases and websites were included in the literature search (see **Table 7**). To reduce the number of non-relevant studies retrieved by the databases, the following limits were applied: to include only participants 18 years old or older, to include only studies in English and to include only papers from North America, Europe, Australia and New Zealand.

Table 7 Databases and websites searched

DATABASES SEARCHED	Medline; CINAHL; PsycINFO; HMIC; AMED; Web of Science; ASSIA;IBSS; Delphis; PubMed; ScienceDirect; Cochrane Library; EMBASE; BNI; AgeInfo and Scopus
WEBSITES	Thorax Website; British Thoracic Society (BTS); National Institute For Health And Care Excellence (NICE); Medical Research Council (MRC); Department Of Health (DoH); Economic And Social Research Council (ESRC); National Institute For Health Research (NIHR); American Thoracic Association (ATS); British Lung Foundation (BLS); The National Council For Palliative Care (NCPC); The European Association For Palliative Care (EAPC); Association For Palliative Medicine (APM).

The search strategy included the use of various terms related with the main topics of this review, “Communication”, “Palliative Care” and “COPD” (see **Table 8**). In the databases CINAHL and MEDLINE as well as keywords, Medical Subject Headings were also used. These two databases were thought to be the most important for this review, therefore were searched twice using the different strategies described above. All databases were lastly searched on the 29th of May of 2015.

After the selection of the papers included, the reference list of every paper was scanned. Browsing the reference list of papers helped to identify further studies of interest that would have not been identified otherwise (Centre for Reviews and Dissemination 2008). The inclusion and exclusion criteria were defined in the literature review protocol, before commencing the literature search. The inclusion criteria is presented in **Table 9** (please refer to **Appendix B** for further information about the inclusion and exclusion criteria).

Table 8 Keywords used to search the literature

“COPD”,	"Pulmonary Emphysema",
“Chronic Obstructive Pulmonary Dis*",	“Chronic Disease”,
“Chronic Obstructive Airway Dis*”,	“Lung Disease”,
“Chronic Lung Dis*”,	“Critical Illness”,
“Chronic Lung Illness”,	“Advanc* Illness”,
“Chronic Pulmonary Illness”,	“Obstructive Lung Dis*”,
“Chronic Pulmonary Dis*”,	“Pulmonary Dis*”,
"Chronic Bronchitis",	“Hospice”,
"Palliative Car*",	“Advance Care Planning”,
“End-Of-Life”,	“Advance Directives”,
"End Of Life",	“Prognosis”,
“Terminal Care”,	“Family”,
“Terminally Ill*”,	“Patient”,
“Hospice Care”,	“Patient Care Conferenc*”,
“End-Stage Care”,	“Patient-Family Conferenc*”,
“Care Of The Dying”,	“Psychology”,
“Dying Care”,	“Attitude Of Health Personnel”,
“Death”,	“Patient Satisfaction”,
“Dying”,	“Physician-Patient Relations”,
“Discuss*”,	“Physician-Patient Communicat*”,
“Conversat*”,	“Nurse-Patient Relations”,
“Communicat*”,	“Professional-Patient Relations”,
“Inform*”,	“Health Professional”,
“Barriers”,	“Nurses”,
“Facilitators”,	“Physicians”,
“Therapeutic”,	“Hospital”,
“Disclos*”,	“Medical Staff”
“Decision Making”,	

4.3.3 Quality appraisal

Research studies can vary considerably in methodological rigour and to avoid biased results, all papers were assessed regarding their quality (Centre for Reviews and Dissemination 2008). This assessment helped to ascertain if the studies were robust enough to be included in the review (Centre for Reviews and Dissemination 2008). Papers were assessed according with their nature, qualitative or quantitative. All papers were assessed prior to inclusion and a quality assessment form was kept for each paper.

The quality assessment forms for qualitative and quantitative studies were adapted from widely used forms developed by the Quality Research and Health Working Group and the McMaster University, respectively (Thomas et al. 1998; Bromley et al. 2002). These forms were developed by expert researchers of both qualitative and quantitative research and were found reliable and valid tools for assessment. The qualitative and quantitative forms are presented in **Appendix C** and **D**, respectively.

Table 9 Inclusion criteria of papers selected for review

PAPER LANGUAGE	Papers were included if written in English.
PARTICIPANTS	The participants included were people with COPD and healthcare professionals aged 18 years old or above. Patients should have been diagnosed according with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines. Papers were included if the sample represented 50% or more of patients with COPD, except if the papers were purposely comparing COPD with other diseases.
STUDY DESIGN	All study designs were included in the review.
STUDY QUALITY	Papers were included if presented high or moderate quality.
COUNTRY RESTRICTION	Only papers from North America, Europe, Australia and New Zealand were included.
INFORMATION IN PAPERS	Papers were included if more than 50% of the information included was about palliative care conversations with COPD patients.
INTERVENTION	The discussions included were conversations about the topic – palliative care –between a person with COPD or a relative and a healthcare professional.

4.3.4 Data extraction and data analysis

The data contained in each paper was extracted into a Data Extraction Form (see **Appendix E**). The form was adapted specifically to fulfil the objective and questions of the review from three other data extraction forms (Dr Tracy Long-Sutehall, University of Southampton; (Saks and Allsop 2007; Centre for Reviews and Dissemination 2008)).

Data analysis and data synthesis was carried out using a narrative synthesis approach. A narrative synthesis is an approach used to synthesise the findings of multiple studies, primarily focusing on words and text, however a synthesis can involve the manipulation of some statistical data (Popay et al. 2006). The findings all papers will be presented in different themes. A flow diagram of the steps taken to develop a narrative synthesis can be found in **Appendix F**.

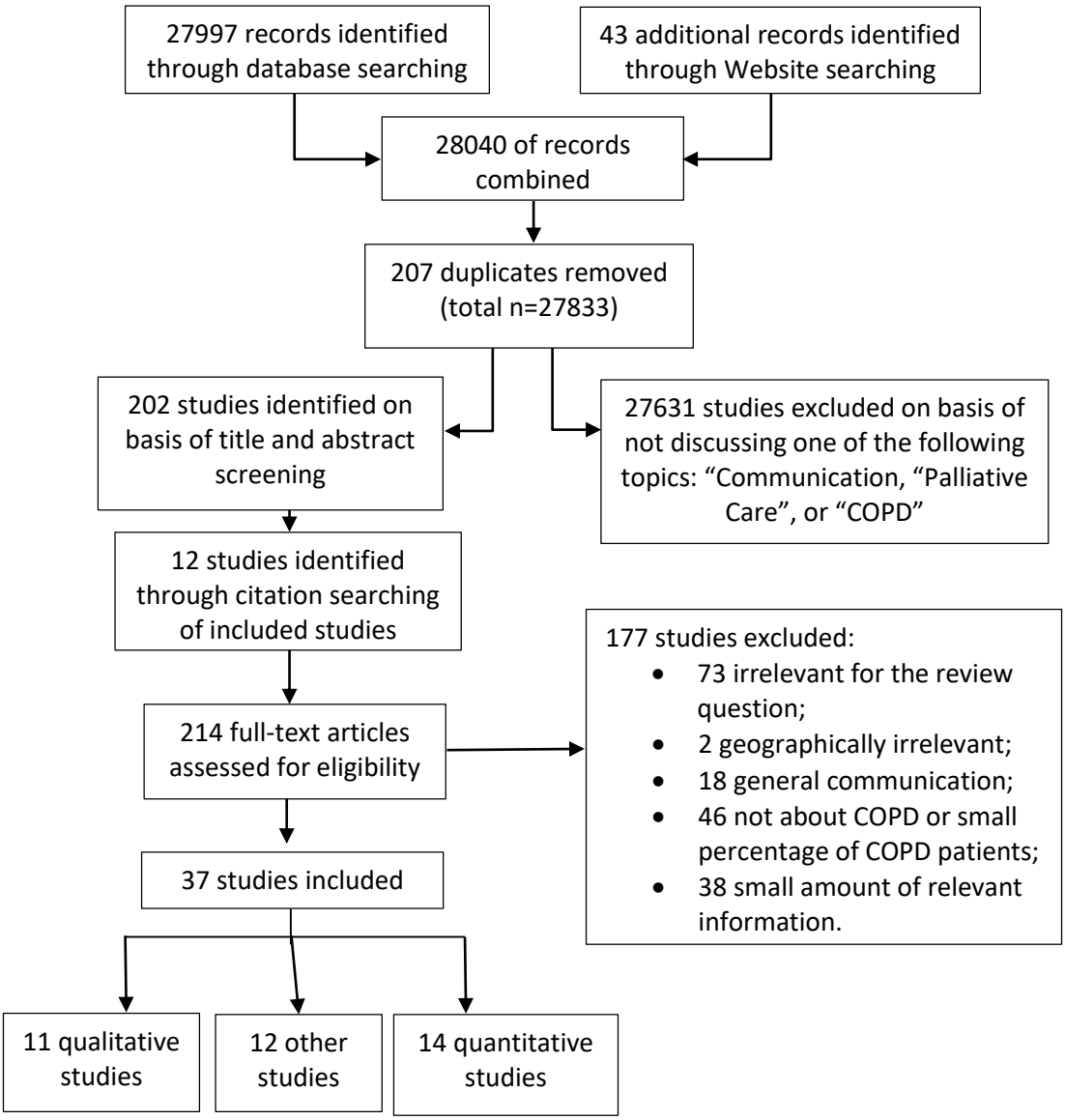
4.4 Findings

4.4.1 Papers included

The initial search retrieved 28040 papers, after which all papers were scanned for eligibility criteria. The total number of studies included in this review was 37 (for an extended analysis of all papers see **Appendix G**). Fourteen papers were quantitative studies, 11 were qualitative studies and 12 were diverse including narrative and systematic reviews, and comparative studies. The

majority of papers were originated from the Unites States of America (n=20), 7 from the UK, 4 papers from 3 European countries, and the remaining 6 from other countries. A flow diagram describing the steps undertaken until the final number of papers was reached can be found in **Figure 3**.

Figure 3 Literature Search Flow Diagram



Most papers studied patients aged above 65 years old, with severe to very severe airflow obstruction, who were oxygen dependent, had previous exacerbations of COPD and an estimated prognosis of death of more than one year. The most studied group of healthcare professionals were respiratory physicians. Outpatient clinics were the most common setting where conversations were studied. The majority of the papers generated from the USA (a total of 14/20) were from the geographic area of Seattle. Finally, some of these studies used the same sample, but analysed the data using different approaches and/or developed cross-sectional studies with the same participants.

Quantitative methods were most frequently employed and a lack of good quality in-depth qualitative research was noted. This was especially noted in the following themes: barriers for palliative care conversations; time, place and person to hold discussions; quality of communication; and importance and impact of conversations in COPD patients.

4.4.2 Quality of evidence

All papers included in this review were quality assessed as described earlier. Fifty-eight percent of the qualitative papers included in the review were rated as high quality, whilst 42% were rated as being of moderate quality. The reasons for which papers scored moderate quality included: lack of comprehensive information regarding the methods chosen, recruitment process, exclusion and inclusion criteria; language used during interviews, the use of somehow leading questions was noted; and lack of discussion or limitations section. Quantitative papers had their quality evenly distributed, 47% of papers were rated as high quality, whilst 53% of papers showed moderate quality. Some reasons for rating papers with moderate quality were: the small percentage of participants that agreed to be included in the study; lack of representativeness of the sample chosen; and lack of control for cofounders. For more information regarding the specific weak and strong points of each paper, please refer to **Appendix I**.

4.4.3 Frequency of discussions

The majority of studies showed that only a small percentage of COPD patients had discussed palliative care topics, this ranged from 0% to 56%, (Dexter et al. 1998; Curtis 2000; Elkington et al. 2001; Halliwell et al. 2004; Kass-Bartelmes and Hughes 2004; Curtis et al. 2005; Knauft et al. 2005; Janssen et al. 2011b; Au et al. 2012; Leung et al. 2012; Momen et al. 2012; Philip et al. 2012; Seamark et al. 2012; Fahim and Kastelik 2014; Gaspar et al. 2014; Schmidt et al. 2014; Houben et al. 2015). The majority of studies reported percentages equal or lower than 30% (Dexter et al. 1998; Halliwell et al. 2004; Knauft et al. 2005; Janssen et al. 2011b; Au et al. 2012; Leung et al. 2012; Philip et al. 2012; Seamark et al. 2012; Houben et al. 2015).

In a primary care study 41% of GPs reported that they discussed prognosis often or always with their patients, while 15% reported discussing the subject rarely or never (Elkington et al. 2001). Moreover, 30% of GPs left it for patients or their relatives to raise the subject (Elkington et al. 2001).

The desire to discuss palliative care topics was reported by more than half of the patients (Au et al. 2012; Leung et al. 2012). This desire was acknowledged by half of GPs, who stated that some patients who would like to discuss prognosis did not get the opportunity (Elkington et al. 2001).

Despite this, almost three quarters of patients thought that their doctor probably or definitely knew the type of care they would want if they were too sick to speak for themselves (Knauft et al. 2005).

When comparing GPs from Auckland and London, Auckland GPs reported to discuss prognosis more often with severe COPD patients (Mulcahy et al. 2005). London GPs were more likely to agree that patients with severe COPD who would like to discuss prognosis did not get a chance (Mulcahy et al. 2005). Interestingly, two-thirds of both groups agreed that they were more likely to discuss prognosis with cancer than COPD patients (Mulcahy et al. 2005). Furthermore, Dutch patients reported having these conversations significantly less frequently and with less quality than US patients, despite the fact that they had severe disease (Janssen et al. 2011a).

4.4.4 Time, place and person discussing palliative care

Discussions about treatment preferences were reported to occur when the patient's COPD was advanced or when a serious decline was noted (Sullivan et al. 1996; McNeely et al. 1997; Curtis 2000; Gaspar et al. 2014). Furthermore, the majority of physicians chose to initiate conversations when the FEV1 was <30% (Sullivan et al. 1996; McNeely et al. 1997). In contrast, all physicians agreed that this should ideally be initiated when a patient was in a stable condition (Sullivan et al. 1996). The right time to discuss these topics were more defined in cancer than in COPD, where cancer specialist nurses were involved from diagnosis until the patient's deterioration (Curtis 2008; Crawford 2010). Cancer specialist nurses provided personalized holistic care to cancer patients from the breaking of bad news, through their clinical treatment until the inevitable deterioration (Crawford 2010).

The disease features that most commonly triggered palliative care discussions according with clinicians were: FEV1<30% of the predicted value; on or prior to an intensive care unit (ICU/ITU) admission; when a sudden event had happened, such as the introduction of LTOT and/or non-invasive ventilation (NIV); when maximum therapy was achieved; and when all curative treatments were exhausted (Sullivan et al. 1996; McNeely et al. 1997; Curtis 2000; Gaspar et al. 2014). These features were chosen by clinicians as these mark an important point in the deterioration of the overall health status of the patient (Sullivan et al. 1996; McNeely et al. 1997; Curtis 2000; Gaspar et al. 2014).

When considering the place of discussion, it was reported to occur more often in hospital wards and intensive care units than in primary care (McNeely et al. 1997; Curtis 2000, 2008). Furthermore, this study reported that only 23% of all palliative care conversations occurred during outpatients' clinics, when compared with 77% in intensive care units and respiratory wards

(McNeely et al. 1997). Hospital admissions for COPD exacerbations were considered chaotic experiences and were not seen as an appropriate place to discuss palliative care (Seamark et al. 2012).

A small qualitative study conducted in secondary care reported that patients desire someone they knew and who knew them when discussing palliative care (Seamark et al. 2012). This usually translated to the person being their GP, whereas a respiratory physician or a specialist nurse was seen as someone with the clinical knowledge but not necessarily the personal relationship (Seamark et al. 2012).

4.4.5 Quality of communication

Patients have identified communication as one of the most important skills of physicians in providing adequate end of life care (Janssen et al. 2011b). However, the majority of studies that assessed the quality of end of life care communication, reported that COPD patients rated the quality as low (Janssen et al. 2011a; Janssen et al. 2011b; Au et al. 2012; Houben et al. 2015). Only a single study showed that communication was perceived as satisfactory by patients (Schmidt et al. 2014). Quality of communication appeared to remain poor as patients approached their end of lives, even after the use of interventions to improve the frequency and quality of these discussions (Au et al. 2012; Houben et al. 2015). Interventional studies demonstrated potential for improvement the quality of conversations, but only in two domains: patients' feelings about deterioration and spiritual beliefs (Au et al. 2012; Houben et al. 2015).

The quality of end of life care communication was rated low, mainly because most end of life care topics were not discussed (Engelberg et al. 2006; Janssen et al. 2011a; Houben et al. 2015). These topics included, talking about spiritual and religious beliefs, what dying might be like and prognosis (Houben et al. 2015). When discussed, however, the quality was rated moderate to good (Houben et al. 2015).

When comparing Dutch with US patients both groups reported very low scores for quality of communication about end of life care, however the Dutch group reported lower quality of general and end of life care communication (Janssen et al. 2011a)[2].

[2] The tool used was the Quality of Communication Questionnaire [48]. Rating of quality of communication varies from 0 (very worst quality) to 10 (very best quality).

4.4.6 Content of discussions

Patients and families varied in the way they viewed the relationship between their desires for prognostic information and their need to maintain hope (Curtis et al. 2008). Patients and healthcare professionals reported tension between remaining hopeful and the reality of the patients' healthcare status, as this could create barriers for discussions and have an emotional impact on them (Crawford 2010; Philip et al. 2012). When patients were asked "how much information do you want?", the initial answer was "all information", though simply asking this was not adequately enough to elicit informational needs (Curtis et al. 2008).

Some patients believed that frank prognostic information might negatively impact their hope and increase anxiety and depression, therefore some physicians purposely withheld information to avoid this (Curtis 2000; Curtis et al. 2004; Curtis et al. 2008). However, while suggesting it may be harmful for some patients, none considered it harmful for themselves (Philip et al. 2012). Finally, many patients expressed the importance of individualising the clinician's approach for hope and prognosis, and of longstanding relationships with physicians (Curtis et al. 2008).

The topics frequently covered when discussing treatment preferences were: the possibility of an ICU admission; the intubation procedure; the patient's inability to speak or to eat while being ventilated; the likelihood of death if mechanical ventilation was not performed; and the death rate associated with mechanical ventilation (Sullivan et al. 1996; McNeely et al. 1997; Schmidt et al. 2014). Most physicians stated that they framed information to influence the patient's decision according to their clinical judgment about the potential for a successful outcome and a return to a suitable quality of life (Sullivan et al. 1996; McNeely et al. 1997; Curtis et al. 2004).

Interestingly, participants often reported the use of the terms "emphysema" and "respiratory insufficiency" by physicians, but very rarely the use of "COPD"; and patients used "asthma" and "allergy" to describe their disease (Schmidt et al. 2014). In contrast, "death" was not stressed by name, but it was the implied alternative if the patient chose not to be intubated (Sullivan et al. 1996). Patients and their families rated emotional support as the skill they most prized in physicians (Ahia and Blais 2014). The most rarely discussed topics and the information/education desired by patients can be found in **Table 10**.

Table 10 Missed topics in discussions and information desired by patients

Most frequently missed topics during discussions (CURTIS ET AL. 2004; CURTIS ET AL. 2005; CURTIS 2006; ENGELBERG ET AL. 2006; JANSSEN ET AL. 2011A; JANSSEN ET AL. 2011B; REINKE ET AL. 2011A; MORRIS ET AL. 2012; GASPAR ET AL. 2014; SCHMIDT ET AL. 2014; HOUBEN ET AL. 2015)	• The process of dying and prognosis; • Spiritual or religious beliefs; • What dying might be like; • How long the patient has live; • Getting sicker; • Future treatment decisions; • Preferences for life sustaining treatments, such as intubation, ICU admission, intubation and tracheotomy.
Information or education desired by patients (CURTIS ET AL. 2002; REINKE ET AL. 2011A)	• Oxygen; • Tube feeding; • Intravascular fluids; • Hospice and hospital care; • Insurance and out-of-pocket expenses.

Overall, patient education about end of life care was ranked as one of the most important domains by patients with COPD (Curtis et al. 2002). This suggested that for patients with end-stage COPD, education was an especially important domain in which physicians may fall short (Curtis et al. 2002; Curtis 2006; Fahim and Kastelik 2014). The vast majority of patients did not recognise palliative care as an option for COPD and some did not understand the meaning of cardiopulmonary resuscitation and of NIV (Fahim and Kastelik 2014). Furthermore, one of the most important educational areas for end-stage COPD patients was the progressive and irreversible nature of severe COPD (Curtis et al. 2002).

4.4.7 Barriers and facilitators

The identification and overcome of barriers for palliative care communication will thereby promote high-quality palliative care for COPD patients (Knauft et al. 2005). Most studies showed that patients and physicians identify several barriers and few facilitators when discussing palliative care (**Table 11**). Patients who reported having had discussions identified fewer barriers and more facilitators than patients who did not have any discussions (Knauft et al. 2005).

Table 11 Most common barriers and facilitators cited by patients and physicians

	PATIENTS	PHYSICIANS
BARRIERS	1. Patients focused on staying alive (Curtis et al. 2005; Knauft et al. 2005; Crawford 2010) 2. Patients not certain of which doctor would be taking care of them (Curtis et al. 2005; Knauft et al. 2005); 3. Patients do not know what kind of care they would want in the future (Curtis et al. 2005; Knauft et al. 2005); 4. Limited understanding of palliative care and COPD (Momen et al. 2012; Philip et al. 2012) 5. Denial of health status and of the possibility of dying (Kass-Bartelmes and Hughes 2004; Curtis 2006; Crawford 2010) 6. Emotional distress of discussions and of palliative care (Crawford 2010; Philip et al. 2012; Seamark et al. 2012) 7. Patients' readiness to discuss palliative care (Knauft et al. 2005);	1. Lack of time in appointments to discuss all topics (Knauft et al. 2005; Crawford 2010); 2. Discussions may take way patients' hope (Knauft et al. 2005); 3. Lack of feedback and documentation (Elkington et al. 2001; Halliwell et al. 2004; Mulcahy et al. 2005; Crawford 2010) 4. Lack of thorough knowledge of the patient (Sullivan et al. 1996; Crawford 2010) 5. Difficulty to start discussions and to choose the right time (Sullivan et al. 1996; Elkington et al. 2001; Halliwell et al. 2004; Mulcahy et al. 2005; Curtis 2008; Crawford 2010; Gaspar et al. 2014; You et al. 2014; Houben et al. 2015) 6. Difficulty for patients to understand and accept information in short periods of time (Sullivan et al. 1996; Reinke et al. 2011a; Philip et al. 2012); 7. Vision of palliative care as confined to the last days of life and exclusive of life sustaining treatments (Halliwell et al. 2004; Philip et al. 2012) 8. Uncertainty to prognose in COPD (Elkington et al. 2001; Mulcahy et al. 2005; Curtis 2008; Crawford 2010; Momen et al. 2012; Houben et al. 2015) 9. Reluctance of palliative care services to care for patients with COPD (Philip et al. 2012) 10. Complex discharge planning for COPD (Crawford 2010)
FACILITATORS	1. Patients who had relatives or friends who had died (Knauft et al. 2005); 2. Patients' trust in their physician (Knauft et al. 2005); 3. Patients interpret physicians' skills as very good (Knauft et al. 2005); 4. Patients' belief that physicians truly care about the patient (Knauft et al. 2005).	1. Good patient-physician relationship (Knauft et (Philip et al. 2012)al. 2005); 2. Physicians who cared for many patients with lung disease (Knauft et al. 2005); 3. Physicians who care for patients with previous acute episodes (Knauft et al. 2005).

4.4.8 Importance of palliative care discussions in COPD and the comparison with cancer

It may be useful for physicians to know whether the conversation about end of life care can reflect on a patient's perceived quality of care and whether these conversations can lead to perceptions of worse overall health status (Leung et al. 2012). The majority of GPs and physicians reported that discussions about prognosis were essential in management of severe COPD and that they had an important role in facilitating these discussions (Elkington et al. 2001; Mulcahy et al. 2005; Gaspar et al. 2014). The occurrence of discussions was associated with higher quality of health status, of dying and death. Patients were also more likely to report having received the best possible care, to acknowledge that their provider knew their wishes and to state that their doctor provided a very good explanation of their breathing problems (Reinke et al. 2011c).

Several differences between patients with COPD and patients with cancer were found in the included papers. When comparing COPD and cancer patients, open awareness of death and dying was the norm for cancer patients (Curtis 2008; Crawford 2010; Leung et al. 2012). Patients with cancer were more likely to specifically state their diagnosis by name than COPD patients, whereas COPD patients were more likely to express little or no understanding of their illness and of having less education (Morris et al. 2012). In contrast, patients with cancer were more likely to introduce prognosis in discussions regarding their disease (Morris et al. 2012). Interestingly, even when referencing general mortality, both groups of patients often emphasized living with rather than dying from incurable illness (Curtis 2008; Morris et al. 2012).

4.4.9 Improving palliative care communication

When patients asked their physicians for every possible treatment, physicians often concluded that patients wanted all imaginable treatments, regardless of benefit and invasiveness (Quill et al. 2009). However, the most appropriate response was to discuss the patient's underlying treatment values and non-medical concerns and to provide accurate information about the patient's illness, prognosis and possible outcomes of life-sustaining treatments (Quill et al. 2009).

In order to improve the quality and frequency of palliative care discussions, five studies reported the use of an intervention to facilitate conversations (Dexter et al. 1998; Szmuilowicz et al. 2010; Reinke et al. 2011a; Simpson 2011; Au et al. 2012). These interventions were widely accepted and considered meaningful by the majority of participants. The interventions tested in these studies included: the use of computer-based reminders by physicians to improve frequency of conversations and completion of advance directives; the use of a short retreat to provide training to medical residents about communication skills; the use of feedback forms containing information about patients' preferences for future care; the use of home sessions to provide care,

education and discussions about advance care planning and palliative care; and finally, the use of a computer program to provide education and training regarding palliative care for patients, in order to facilitate conversations with their clinicians (Dexter et al. 1998; Szmuilowicz et al. 2010; Reinke et al. 2011a; Simpson 2011; Au et al. 2012). The studies used different approaches to improve palliative care communication and used patients and/or clinicians as the main targets.

Despite the fact that all interventions were designed to improve frequency and/or quality of communication, only a modest impact in improving the characteristics of palliative care communication was noted (Dexter et al. 1998; Szmuilowicz et al. 2010; Reinke et al. 2011a; Simpson 2011; Au et al. 2012). One of the reasons why these interventions may have had little impact was that the interventions may have made the patients feel uncomfortable (Au et al. 2012).

4.4.10 Suggestions to improve palliative care conversations

A series of recommendations for palliative care conversations with COPD patients resulted from the data analysis and synthesis of the papers included in the review. These suggestions may provide some help to clinicians when approaching patients with COPD. The different suggestions are as follows:

- Conversations should be started early in the disease course or opportunities to start discussions should be identified (Halliwell et al. 2004). This will help to build a therapeutic relationship with the patient (Halliwell et al. 2004). These opportunities/triggers can be:
    - The presence of *cor pulmonale* (Curtis 2008);
    - The need for ventilation in the previous year (Curtis 2008);
    - Arterial partial pressure of carbon dioxide >45mmHg or FEV1 <30% (Curtis 2008);
    - Recent hospital admission or consultation (Halliwell et al. 2004; Ahia and Blais 2014; You et al. 2014; Houben et al. 2015);
    - Oxygen dependency or weight loss (Curtis 2008);
    - Observed deterioration in the patient's condition (Halliwell et al. 2004; Curtis 2008; Ahia and Blais 2014; Houben et al. 2015);
    - Age above 70 years (Curtis 2008; Crawford 2010);
    - Assessment of therapy options (Halliwell et al. 2004; Ahia and Blais 2014).
- Discussions should be prepared and include the implications of diagnosis and of possible outcomes of life-sustaining treatments (Halliwell et al. 2004; Quill et al. 2009; Ahia and Blais 2014). Patient's understanding about his/her condition and his/her desired informational needs should be sought (Ahia and Blais 2014). Patient's relatives should be included in discussions, if the patient so desires (Curtis et al. 2008; Schmidt et al. 2014). In

agreement with this, clinicians should identify and acknowledge patient's preferences (Quill et al. 2009; Crawford 2010);

- Clinician should share his/her medical opinion and propose a philosophy and plan of treatment, considering the patient's needs and wishes (Quill et al. 2009; Ahia and Blais 2014). During this, patients may feel upset or emotional, therefore, support should be provided (Halliwell et al. 2004; Ahia and Blais 2014). Any disagreements identified should be negotiated with the patient, to come to a shared decision (Kass-Bartelmes and Hughes 2004; Quill et al. 2009; Ahia and Blais 2014);
- Patients may request burdensome treatments, in this case harm-reduction strategies should be chosen (Quill et al. 2009). Considering this, all patients should set goals and plan for the future with their clinicians (Ahia and Blais 2014);
- Clinicians should document all the information discussed and agreed, and should work closely with other professionals to ensure that the patient's wishes are fulfilled (Ahia and Blais 2014; You et al. 2014). Conversations should be restarted when new triggers arise or whenever the patient requires. (Halliwell et al. 2004; Ahia and Blais 2014).

4.5 Discussion

The small proportion of COPD patients who receive palliative care may be a reflection of the lack of conversations between patients and clinicians. One reason for this may be the lack of accurate prognostic tools in COPD. This makes it difficult for clinicians to recognise when the ideal time to initiate palliative care discussions is. Various tools have been suggested, but most have inadequate prognostic ability. For example, the tools used during the SUPPORT study showed that, at 5 days prior to death, patients with COPD were predicted to have >50% chance of surviving for 6 months (Curtis 2008). Other tools with little prognostic value include BODE, DECAF and DOSE score. DOSE score can be used as a prognostic instrument for mortality in COPD, however only 57.1% of patients with the highest score died within 5 years of follow-up (Sundh et al. 2012). When looking at the BODE score, 63.2% of patients with the highest BODE score were still alive at 3 years (Esteban et al. 2010). This shows the unpredictability and complexity of COPD, and makes it challenging to predict with certainty when a patient is approaching the end of life. Therefore, early conversations about all aspects of the disease should be held and these should include discussions about palliative care interventions, as well as preferences for end of life care.

Another important factor when communicating palliative care with COPD patients was the patient's willingness to discuss this with a clinician. Most of the papers highlighted the importance of patients' willingness to discuss palliative care as a key factor to a successful discussion. Two studies showed that 33% of patients did not wish to discuss palliative care, however further

research looking into patients' willingness to discuss palliative care was not found. The recruitment of patients not willing to discuss this topic may have posed very difficult, hence, the lack of research in this area. The hypothetical explanation that led these patients to participate in the studies was that the studies targeted mainly healthcare professionals, instead of patients themselves. Despite this, several actions can be taken to reduce the impact of the unwillingness to discuss palliative care, including: picking up cues about patients' readiness/willingness to discuss palliative care, slowly titrating the amount of information provided to patients about palliative and waiting for patients/relatives to raise this subject on their own.

The quality of end of life care communication was found to be poor and this was mainly because most topics were not discussed. However, when they were discussed the quality was found to be moderate to good. This suggests that the problem resided in the initiation of conversations and not in the clinicians' skills (Houben et al. 2015). A lack of detailed information about the frequency and quality of conversations was also noted. If important topics were not discussed, the quality of communication related to these topics cannot be correctly assessed. This leaves a large proportion of the conversation with unknown quality.

Patients who had palliative care discussions with clinicians were found to rate their medical care and their clinicians' skills higher than patients who did not. This suggests that because they had a discussion about preferences for care with their clinicians, they may have had their wishes respected and the care adjusted to their preferences. Thus, this suggests an important link between palliative care discussions and patient assessments of care quality, and should be explored in future work. However, it was noted a paucity of in-depth information about the impact and the importance of conversations for patients. Further qualitative research is required to explore the importance and impact of conversations, and to understand with certainty which factors of discussions have greater impact for patients.

Participants stated that the preferred clinician with whom to have the discussion was their GP and the best place was within outpatient clinics or during GP appointments. Participants reported that the best time to start discussions was early in the disease trajectory. However, the majority happened very late in the disease trajectory, usually when patients were admitted to high dependency wards and were unable to speak for themselves. Families were left to have discussions with clinicians who had little knowledge about the patient. Most of this data was generated from quantitative research, yet much could be gained from in-depth qualitative research specifically collecting information from patients describing the most appropriate timing, place and person to discuss palliative care, describing the reasons behind their choices and suggesting ways to achieve their preferences.

Several studies tested the effect of interventions in improving the frequency and/or quality of palliative care discussions, however, all studies had a small impact on discussions. . Only one study focused on improving and measuring physicians' skills at the end of the study (Szmuilowicz et al. 2010). This study concluded that only "responding to emotion" improved in clinicians' skills and that clinicians tended to lose their skills with time, especially when considering emotional empathy. Another study showed that when clinicians do discuss palliative care their discussions are rated as moderate to good by patients (Houben et al. 2015). This suggests that the quality and frequency of conversations were not linked with lack of skills of clinicians, but with the high number of barriers for conversations and the difficulty in initiating them (Szmuilowicz et al. 2010; Simpson 2011; Au et al. 2012). Hence, the little impact of interventions in improving discussions. Minimizing the barriers for discussions about palliative care will greatly enhance their frequency and quality.

The frequency of end of life care conversations in cancer is remarkably similar to the frequency seen in COPD, 21-37% (Wright et al. 2008; Zhang et al. 2009). However, several differences between patients with COPD and cancer were highlighted when considering these discussions. The majority of these differences are thought to be disease-related and due to the awareness that the general public has of both diseases. Cancer brings the expectation of death and hence people expect conversations regarding ultimate prognosis and its impact on treatment and care. In COPD the progression over time is variable and difficult to predict, consequently these aspects of care planning are not expected or requested (Crawford 2010). Patients and healthcare professionals need further education regarding all illness-related aspects, including the inevitable life-limiting character of COPD.

4.5.1 Strengths and limitations

This review has several strengths and limitations. A strong point is that because of the design used, a systematic review, the review shows the results of a comprehensive literature search. This design ensured that most health-related databases and websites were searched. Another positive point is the quality of the papers presented. The quality assessment process guaranteed that only moderate-high quality studies were included, enriching the quality of the information presented. Finally, the last strength is the use of the narrative approach to process, analyse and synthesize data. The methodical approach made this crucial process systematic and valid.

A limitation of this review is the language in which the studies were written. Only papers written in English were included in the review. This may have excluded important information from the review, especially information about cultural variables and demographics. A second limitation is the small number of studies, especially the lack of qualitative studies, controlled trials and

objective comparisons of approaches and their influence on outcomes for patients. The third limitation found is the origin of the studies. Studies from Africa, South America and Asia were excluded. The exclusion of these papers may have decreased the amount and quality of multicultural information. However, only two papers fell into this category and their quality was poor. The last limitation is the number of COPD patients contained in the studies. The review only included studies that contained at least 50% of COPD patients. This may have excluded information that only arose in those studies, however this is thought to be unlikely.

4.6 Conclusion

In conclusion, the current state of the literature shows that:

- Frequency and quality of palliative care discussions was poor;
- Patients and physicians endorsed too many barriers;
- Most topics were not discussed;
- When discussions happened they occurred in an advanced stage of disease, in an acute and stressful environment and with clinicians who did not thoroughly know the patients.

Moreover, remarkable differences were found between patients with cancer and COPD. The above description of the findings shows that the current panorama of palliative care discussions does not favour the fulfilment of patients' wishes and preferences.

Given the relationship between palliative care conversations and the application of patients' preferences, the lack of optimal communication between clinicians and patients is likely to impact upon care quality, patient satisfaction, and ultimately, the likelihood of a "good death." Therefore, the development of further qualitative and quantitative research in this field of study in the UK is crucial. Further research is necessary specifically to explore the perceptions and understanding of patients regarding palliative care discussions with clinicians. Undertaking research in this area will ultimately help in the development of new pathways and practices, which in turn will improve outcomes for COPD patients by ensuring timely and appropriate care planning through open discussions.

The paper was fully presented above and the second literature review is presented in the next page.

4.7 Second literature review

A second literature review was undertaken to search for newly published literature from the date of the last search – May 2015. The same methods and databases were used as in the first search. These methods can be found in Chapter 4.3 and page 36. A total of 658 papers were screened across all databases. After removing duplicates, this resulted in 281 papers. After screening for title and abstract, 12 papers were thought to fulfil the criteria, so their full text was analysed. From the full text analysis, 6 papers met the inclusion criteria and were included in this second review. This paper search was conducted on the 24th of June 2019.

This review reports the findings of 4 original research papers and 2 reviews of the literature. The original research papers included 2 randomized control trials, 1 retrospective study and 1 qualitative study (3 papers recruited COPD patients). These papers reported original research exploring the barriers and the impact of different interventions in the frequency and quality of palliative and future care discussions in COPD. The reviews include one systematic and one critical review of the literature. Most findings from these reviews have been reported in the systematic literature review conducted in phase one. Therefore, only new findings identified in these reviews will be reported below.

4.7.1 Findings

Palliative and future care discussions in COPD were rare, despite being welcomed by most patients (68-99% of patients) (Jabbarian et al. 2018). However, rates of discussions in COPD were comparable to discussions in other illnesses (general medicine and cancer patients) (Jabbarian et al. 2018). Sense making, emotional impact, readiness and the nature and timing of discussions impacted patients' perspective about them (Wong and Gottwald 2015). Providing training to clinicians, especially about the triggers for discussions, and service-related changes seemed to result in more discussions with patients (Wong and Gottwald 2015; Jabbarian et al. 2018). Early and gradual discussions enabled patients to express their concerns, wishes and life values (Wong and Gottwald 2015; Jabbarian et al. 2018). Honest information seemed to promote hope, if hope was redirected to quality of life, rather than duration of life (Jabbarian et al. 2018). An individualised approach was recommended, where clinicians consider individual patient's needs and readiness (Wong and Gottwald 2015).

4.7.1.1 Barriers for discussions

Barriers for discussions were identified by clinicians who participated in a focus group study (Gott et al. 2009). Healthcare professionals reported that COPD patients were provided with inadequate

information about the likely course of their condition at diagnosis and throughout the disease trajectory (Gott et al. 2009). However, clinicians identified the lack of agreement as to who was responsible to initiate discussions as a barrier (Gott et al. 2009). Ambivalence between primary and secondary care clinicians was identified when discussing the clinician responsible for starting discussions (Gott et al. 2009). Moreover, clinicians found it difficult to define and identify end of life for COPD patients, resulting in uncertainty as to when to start discussions with patients and refer to palliative care services (Gott et al. 2009; Jabbarian et al. 2018). Lack of time and lack of training were highlighted as factors that prevented the start of discussions (Gott et al. 2009). An ethos of "cure at all costs" was also highlighted as a barrier for palliative care discussions, since this meant "giving up on the patient" (Gott et al. 2009). Clinicians saw end of life as terminal care and confined to the last weeks of life (Gott et al. 2009). Lastly, starting discussions could result in a reduced adherence to self-management activities (Gott et al. 2009), which can be exacerbated by patients' avoidance in help-seeking behaviours (Wong and Gottwald 2015). Instead, patients adapt their life to the COPD diagnosis (Wong and Gottwald 2015).

4.7.1.2 Interventions to improve palliative and future care communication COPD

One study focused on understating the long-term impact of a randomised control trial to improve the frequency and quality of palliative care discussions in COPD (Reinke et al. 2017). The records of patients who had died at follow up were screened for documentation of palliative care discussions with clinicians (Reinke et al. 2017). The study showed that 73% of these patients had at least one discussion about palliative care with a clinician (Reinke et al. 2017). The average number of discussions per patient was 3 and the most common topic of discussion was hospice care (52% of all discussions) (Reinke et al. 2017). Interestingly, the intervention to improve the frequency of discussions was not associated with a long-term effect when compared with the control group (Reinke et al. 2017). Moreover, poorer general health status or poorer disease-specific health status were not associated with increased discussions, as hypothesised before the study (Reinke et al. 2017). The study concluded that all patient should be given the opportunity to discuss it, whilst nearly 25% of patients did not (Reinke et al. 2017). Moreover, the intervention did not seem to change long-term clinician behaviour towards discussions (Reinke et al. 2017).

Two studies used a nurse-led intervention to facilitate discussions between patients and clinicians (Sinclair et al. 2017; Houben et al. 2019). These randomized controlled trials used different approaches in their nurse-led session and were developed in different countries - Australia and The Netherlands (Sinclair et al. 2017; Houben et al. 2019). Both studies showed an improvement in quality and frequency communication about advance care planning (Sinclair et al. 2017; Houben et al. 2019). Moreover, the combined findings showed that discussions led to more relaxed relatives, more advance directives completed and in the appointment of more decision

makers (Sinclair et al. 2017; Houben et al. 2019). Higher symptom burden and patients' strong preferences for the intervention led to greater uptake for discussions with clinicians (Sinclair et al. 2017). Despite this, the intervention did not improve quality of death and dying, depression or anxiety levels (Houben et al. 2019). Preferences for discussing palliative care with clinicians was the most predicting factor for patients to accept participating in conversations (Sinclair et al. 2017). Interestingly, the proportion of COPD patients that preferred to participate in advance care planning was similar to the proportion found in cancer (Sinclair et al. 2017). These interventions were well accepted and patients did not find these discussions difficult (Wong and Gottwald 2015; Sinclair et al. 2017; Houben et al. 2019).

4.7.2 Conclusion

Palliative care discussions in COPD remain uncommon, despite most patients preferring them. These discussions can lead to the development of care plans based on patients' preferences, resulting in positive outcome for patients. Barriers for discussions are well known and continue to be identified in the literature. Interventions improve the frequency of discussions and the quality of life for patients, however they do not seem to be sustainable at long-term. Patients' preferences for palliative care discussions is the strongest predictor for their occurrence.

4.8 How the literature review informed the research study

The literature review highlighted gaps in knowledge, which helped steer the research study. In particular, the review highlighted that there is very little understanding about patients' preferences for the timing and nature of palliative care conversations and about clinicians' experiences and opinions when starting and conducting these discussions with patients. The lack of evidence on patients' preferences for discussions seems to have contributed to the late or non-occurrence of these conversations. The review suggested that clinicians found it difficult to engage in conversations with patients, since they were uncertain as to when and how to discuss palliative care with patients. By understanding patients' preferences, clinicians may feel more confident in starting and conducting conversations with patients. The gaps in knowledge identified in the review formed the interview topics discussed with patients. These topics included:

- Preferred timing for palliative care conversations;
- Preferred clinician with whom to discuss palliative care;
- Preferred approach when discussing palliative care;
- Preferred place for discussions.

The review also suggested that patients' understanding about the current status of their condition and the progressive nature of COPD; their disease severity, as well as symptom and treatment burden may influence their preferences for palliative care discussions. The depth of knowledge about COPD and palliative care seems to impact patients' ability to rationalise and plan for the future (Giacomini et al. 2012). Patients with less healthcare-related knowledge may underestimate the impact of COPD in their lives and the inevitable progress of their condition (Giacomini et al. 2012; O'Hare et al. 2019). Another finding was that the impact of treatment and symptom burden on patients may influence their preferences for future care and treatments (Pinnock et al. 2011; Harb et al. 2017; Reinke et al. 2017). Patients with an increased treatment and symptom burden may decline aggressive treatments and prefer care that promotes quality of life (Goncalves et al. 2017).

These factors, which were highlighted in the review, were also integrated into Phase 2. Patients' understanding about palliative care and COPD formed interview topics, whilst disease severity formed the recruitment strategy. This was because patients at different stages of their disease trajectory were likely to have different levels of symptom and treatment burden, and for this burden to increase with disease severity.

The review suggested that patients and clinicians had different perspectives about the timing and nature of palliative care conversations. These divergences seem to be an important element of late and/or lack of palliative care discussions in COPD. For instance, patients and clinicians have different understandings and expectations of COPD, palliative care, the disease trajectory and treatment priorities and goals. These divergences need to be identified and further understood. As described in Chapter 3 and page 23, the interviews with clinicians explored these divergences using patients' preferences collected in phase 2.

The review has also highlighted that current prognosticating tools and indicators are inaccurate when attempting to predict the end of life and the start of future care discussions. As a consequence, clinicians found it difficult to identify when to start discussions with patients. Clinicians were only able to identify patients in their last days of life, which resulted in discussions being started late in the disease trajectory. At present, there is limited evidence on how clinicians understand, manage and incorporate prognostication uncertainty into the timing and nature of palliative care discussions with patients. Consequently, the investigation of clinicians' thoughts and experiences about the timing and nature of palliative care conversations comprises phase 3 of this study. Timing and nature of discussions formed the four main interview topics with clinicians: timing, person, place and approach for palliative care conversations with patients.

The systematic review suggests that there is a clear link between the lack of palliative care conversations and the proportion of COPD patients that receive palliative care. The lack of in-depth information about patients' preferences and clinicians' thoughts about the timing and nature of palliative care discussions is a leading cause for their non-occurrence. As a consequence, understanding the thoughts and preferences of both parties made the design and conduct of this study essential. An important way to improve the provision of palliative care for COPD patients is to ensure that patients have the opportunity to discuss their care preferences in appropriately timed and regular discussions. Please refer to **Figure 4** to understand how discussions can impact in the delivery of palliative care.

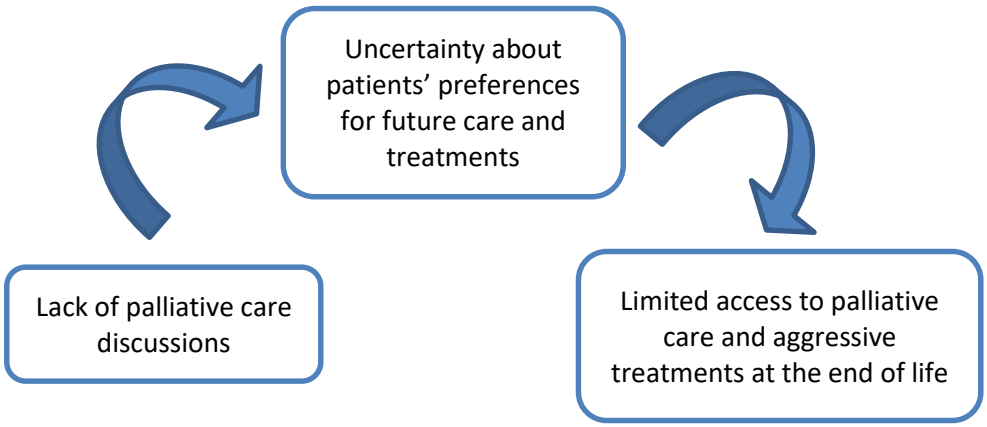


Figure 4 Impact of conversations in the delivery of palliative care in COPD

The literature review identified other areas within palliative care communication that require further research, such as understanding the impact of discussions in patients' psychological wellbeing, quality of life and in the type and quantity of care received at the end of life. However, since, at present, most patients do not discuss palliative care, recruiting patients to explore the impact of discussions would be difficult. Thus, understanding their thoughts and preferences for discussions was thought to provide novel knowledge that could help design and develop future research about the impact of discussions in patients.

Phase 2 and 3 integrate the gaps in knowledge found in the literature, in an effort to address the research question described in this Chapter 3.1 and page 23. Phase 2 of the study is described in-depth in the next chapter.

Chapter 5 Phase 2 – COPD patients' preferences for palliative care discussions

5.1 Introduction

This chapter presents phase 2 of this research study. This phase aimed at exploring and explaining the preferences of COPD patients for palliative care conversations. Patients at different stages of their disease trajectory were recruited and interviewed. The interviews focused on palliative care discussions with healthcare professionals and used a semi-structured approach. Phase 2 is presented as a journal paper in the format, word count and style of the "Palliative Medicine" Journal where it is currently undergoing peer review (Tavares et al. 2019 [under review]-a). This paper format includes: background; methods; findings; discussion and conclusion. Please refer to chapter 3.3 and page 25 to find more information about the methods used in this phase. The paper has been edited with the first comments from the Journal peer-review.

The paper is presented in full in the next page.

Journal: Palliative Medicine Journal

Title: COPD patients' preferences are to discuss palliative care plans with their known respiratory clinicians, but to delay conversations until their condition deteriorates: a qualitative study

Authors: Nuno Tavares, Katherine Hunt, Nikki Jarrett, Tom Wilkinson

Reference: Tavares N, Hunt K, Jarrett N and Wilkinson T (2019 [under review]-a) COPD patients' preferences are to discuss palliative care plans with their known respiratory clinicians, but to delay conversations until their condition deteriorates: a qualitative study [under review]. *Palliative Medicine*

Paper submitted for Journal review on the 5th of June 2019. Revisions have been completed following peer review, currently waiting Journal response.

5.2 Background

Chronic obstructive pulmonary disease (COPD) is a life-limiting illness characterised by progressive breathlessness and chronic productive cough (Department of Health 2011b; NICE 2011a). Worldwide, it is estimated that 250 million people have COPD and it is responsible for 5% of all deaths (World Health Organization 2017). COPD symptoms severely impact patients' lives, as they are associated with a decline in quality of life, overall health status and prognosis (NICE 2010; Miravitlles and Ribera 2017). These patients should be identified and offered palliative care, in order to address their physical, social and emotional needs (NICE 2011a; WHO 2011, 2016). Palliative care can reduce symptom burden and invasive treatments, and provide further psychosocial support to COPD patients (Curtis 2008). However at present, only a small proportion of patients receive palliative care, increasing the likelihood of patients dying whilst on aggressive treatments (Gore et al. 2000). Difficulty in prognosticating in COPD, in predicting individual mortality risk, and in moving the focus from therapeutic to palliative care are significant barriers (Curtis 2006; Fitzsimons et al. 2007). Therefore, prognosticating in COPD requires a different approach than the traditional cancer model, which may include the early and progressive integration of palliative care in current COPD care (Donnelly 1996; Claessens et al. 2000; Curtis 2008; Johnston et al. 2016; den Herder-van der Eerden et al. 2017; Gardener et al. 2019). As a result, the recommendation is to start palliative and advance care planning early, using hospital admissions as an opportunity to integrate it with standard COPD care (Jorgenson et al. 2016).

Regular and early discussions allow patients to express their preferences and ensure that well planned care based on patients' preferences is delivered (NICE 2005; Curtis 2006; NICE 2011b; NCPC 2012; Ford et al. 2013). A recent systematic literature review highlighted that only one third of COPD patients at different disease stages had discussed palliative care with a clinician (Tavares et al. 2017). Palliative care conversations usually occurred in hospital wards and intensive care units, when the patient's condition was considered advanced and after a sudden deterioration (Sullivan et al. 1996; McNeely et al. 1997; Curtis 2000, 2008; Gaspar et al. 2014; Tavares et al. 2017). The current lack of discussions seems to have restricted the access of COPD patients to palliative care, since clinicians are uncertain as to when and how to initiate discussions with COPD patients. A possible explanation for this uncertainty may be the lack of understanding regarding COPD patients' preferences for palliative care discussions, especially as their disease progresses (Tavares et al. 2017). Therefore, this study aimed at exploring COPD patients' preferences for conversations about palliative care and future treatments with clinicians. Further understanding regarding patients' preferences can result in more discussions, since clinicians can tailor the timing and nature of discussions to these preferences.

5.3 Method

5.3.1 Design

Patients' preferences for discussions with clinicians seem to be influenced by a multitude of factors, including the meaning that they attribute to the discussions, their perception about their condition, previous healthcare-related experiences, and their social background. As a consequence, understanding patients' preferences not only requires interpretation, but also an idiographic approach (Gray et al. 2017). Therefore, a pragmatic approach of Interpretative Phenomenological Approach (IPA) was used in this study.

5.3.2 Sample

The disease severity and symptom and treatment burden may influence patients' preferences for palliative care discussions (Reinke et al. 2017). Therefore, the study used a purposive sample, where COPD patients at different stages of their disease trajectory were recruited. Patients diagnosed with COPD according to GOLD guidelines were allocated to one of 3 groups based on airflow obstruction (obtained from the result of their Forced expiratory volume at 1 second (FEV1)): mild (FEV1 >80% predicted); moderate (79% >FEV1> 50% predicted) and severe/very severe (FEV1< 50%) (Global Initiative for Chronic Obstructive Lung Disease 2018). Patients were recruited by letter or were signposted from General Practioner surgeries, respiratory outpatient

clinics and the research department in the UK in 2017. Portsmouth Hospitals NHS Trust as a sponsor of the study allowed the recruitment of patients in their research department and the respiratory outpatient service[3]. Whilst, GP practices were approached and recruited through the Clinical Research Network Wessex. Informed written consent was obtained for all patients. See Table 12 for inclusion and exclusion criteria.

Table 12 **Inclusion and exclusion criteria**

Criteria **Patients with COPD**	**Inclusion Criteria**	**Exclusion Criteria**
Criteria common to all COPD patients recruited	• Older than 18 years of age; • Patients with a diagnosis of COPD according with NICE or GOLD guidelines; • Solely receiving active standard treatment;	• No formal diagnosis of COPD; • Recent hospital admission (less than 2 weeks), since patients were likely to feel unwell and be recovering from their admission, which could impact their ability to articulate their preferences; • Unable to fully express himself/herself in English; • Patients with a diagnosis of a severe mental health condition (such as extreme anxiety, agitation and/or depression), which could prevent data collection or cause further emotional distress. Healthcare professionals were advised not to signpost these patients, as per the information contained in their medical records.

5.3.3 Data collection[4]

Interviews were audiotaped, lasted 45-90 minutes and followed a semi-structured approach. Interviews were piloted with respiratory patients and conducted by the first author (NT[5]), who had no clinical involvement in the care of participants at any time. The questions followed a topic guide that focused on exploring patients' preferences for the timing, clinician, approach and site of palliative care discussions. The construction of the topic guide was based on the findings of previously conducted systematic literature review (Tavares et al. 2017). This review highlighted

[3] Please refer to **Appendix H** to find the Patient Information Sheet.
[4] Please refer to **Appendix I** to find detailed information about the data collection process.
[5] Training completed in qualitative interviewing. No previous relationships any patients.

that further understanding was required about patient's preferred clinician, timing, place and approach for palliative care discussions, which formed the basis of the interview guide (Tavares et al. 2017). However, due to a specific request from the ethics committee, only patients in the severe COPD group were asked about palliative care. Patients with mild and moderate disease were only asked about preferences for future care/treatments, since, according with the committee, discussing palliative care and end of life would potentially cause unnecessary distress in patients. Palliative care and end of life were only discussed with patients with milder disease when raised by themselves. This guide was piloted and developed with the assistance of respiratory patients. Questions were personalised to every participant, using participants' own words to describe certain concepts where appropriate, following the direction set out by participants and discussing topics as far as patients were willing to discuss them. Since palliative care discussions could emotional distress patients, support and reassurance was provided during the interviews and participants were able take breaks or stop the interview if they became distressed in any way. Moreover, patients were signposted to their GP if there was concern about their physical or psychological health.

Interviews took place in the most convenient place for the participant, such as patient's homes and local hospital. Data was collected from April-September 2017 and was stopped at data saturation point. This was achieved at different points - no new themes emerged after the 6th interview in the mild, 11th interview in the moderate and 7th interview in the severe group. Three more interviews were conducted to ensure that data saturation had been achieved. The lack of new emerging themes in the last interviews was discussed within the authorial team that agreed to stop data collection. Social and clinical data were collected either at the interview or through case-note review. Patients were consented for case-note review and their records were accessed in order to obtain information on the results of their pulmonary function tests, 6-minute walk test and the presence of other comorbidities.

5.3.4 Data analysis[6]

All interviews were transcribed verbatim and managed using qualitative software Nvivo 11. The study followed the analytical approach provided by JA Smith, M Larkin and A Thompson (Smith 1996; Smith 2008; Smith et al. 2009; Smith 2011; Larkin and Thompson 2012; Pietkiewicz and Smith 2014). The transcripts were analysed by the first author (NT). However, all co-authors checked and discussed the agreement of codes, themes and interpretations and monitored the coding process. Ten percent of interview transcripts were coded by at least two co-authors, the

[6] Please refer to **Appendix I** to find in-depth information about the data analysis process.

resulting thoughts from coding were discussed and authors' interpretations of data compared. Lastly, co-authors participated in the development of categories of codes and in the final list of themes. The involvement of all co-authors in all steps of data analysis ensured trustworthiness of the research findings. All interviews were anonymised and only the first author had access to participant identifiable data. The study was reported using the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007).

5.4 Results

A total of 33 patients with COPD were recruited and interviewed. Patients' characteristics can be found in Table 13. The analysis of the interview transcripts yielded a total of 117 deductive codes and 42 inductive codes. The deductive codes focused on addressing the aim of the study, whereas inductive codes provided context and further information to patients' preferences and thoughts. All deductive codes originated 15 categories. These categories and relevant inductive codes originated 5 superordinate themes (SOT) and 16 lower-order themes (LOT).

Table 13 **Patient characteristics**

Characteristics	Number
Gender (Male/Female patients (total))	**22/11 (33 out of 254 invited patients)**
Age in years (mean (SD))	**72.5 (7.5)**
Background	
White British – number of patients (%)	33 (100%)
Education	
Did not complete secondary school (%)	18%
Completed secondary school (%)	46%
Further education (%)	36%
Smoking status	
Smoker (%)	5 (15%)
Ex-smoker (%)	26 (79%)
Non-smoker (%)	2 (6%)
Smoking pack years (mean (SD))[7]	**44.5 (34)**
Disease severity	
Mild disease (number (mean FEV1 % predicted[8]))	8 (90%)
Moderate disease (number (mean FEV1 % predicted))	15 (65%)
Severe or very severe disease (number (mean FEV1 % predicted))	10 (33%)
Years after diagnosis (mean (SD))	**7 (4.1)**

[7] Higher scores indicate an increased exposure to smoke
[8] Lower FEV1 % predicted suggests increased airflow obstruction and disease severity

Patients who had attended a respiratory consultant clinic (%)	**16 (48%)**
Exacerbations in the last year (mean (SD))	**2.4 (1.7)**
Hospital admissions (patients admitted (mean number of admissions))	**13 (1.6)**
Long-term oxygen therapy (%)	**4 (12%)**
Medical Research Council Dyspnoea Scale (mean score (SD))[9]	**3.3 (0.9)**
Recruitment Site	
Primary Care	5
Respiratory Outpatient Clinics	7
Research Department	21

From the in-depth analysis of the interviews with COPD patients, 5 overarching themes were found, (see **Table 14**). Quotes were selected purposively and edited to illustrate the interpretation of patients' thoughts. Therefore, unnecessary information or irrelevant pauses were removed.

Table 14 **List of themes**

Super-ordinate themes	Lower-order themes
SOT 1 – Preferred person to discuss palliative care	LOT A1 – Assessment of competency LOT A2 – Building of a trusted relationship LOT A3 – Practicalities of discussions LOT A4 - Care authority
SOT 2 – Preferred timing for palliative care discussions	LOT B1 - In the future: "Becoming unwell" LOT B2 - Present moment: "Ready now" LOT B3 – COPD reviews and future uncertainty
SOT 3 – Initiating and conducting palliative care conversations	LOT C1 – Initiating discussions with clinicians LOT C2 – Content of palliative care discussions LOT C3 – Sharing the decision-making process
SOT 4 – Palliative care and the end of life	LOT D1 – Previous discussions and next steps LOT D2 – Barriers and effects of discussions LOT D3 – Comfort care when approaching the dying moment
SOT 5 – Future with COPD	LOT E1 – Inevitable progression of COPD LOT E2 – "I accept all treatments, if they are beneficial" LOT E3 – Care and treatment options

5.4.1 Preferred person to discuss palliative care

A third of patients viewed General Practitioners (GPs) as a potential ideal clinician due to familiarity and easy access, however some of these patients found that GPs lacked time and

[9] Higher scores suggest increased breathlessness – range 1-5

expertise to start conversations. Respiratory consultants and practice nurses with respiratory background/training were also viewed as ideal clinicians with whom patients could discuss palliative care. Patients reported a tension between preferring discussions with familiar and expert clinicians. However, patients acknowledged that GPs lacked the required knowledge, time and patient-relationship to have these discussions. In contrast, practice nurses who undertook respiratory reviews were seen as more knowledgeable and as *"COPD nurses"*.

> *"A general practitioner is exactly what is it says on the tin, a general practitioner. He (GP) doesn't know everything about every subject and paid to. Whereas if I'm in trouble with my COPD, I would like to think that a COPD specialist would be prepared to discuss my treatment."*
>
> *(P12, moderate COPD)*

The lack of continuity of care was often mentioned, which impacted the patient-clinician relationship and the likelihood of patients feeling they could discuss future treatments and preferences. A large proportion of patients could not see their designated GP, even if they had booked appointments in advance. GPs had little knowledge about patients and some patients saw different doctors for the same episode of illness (such as a chest infection). Poor continuity of care and difficulty in building a relationship were also found with practice nurses.

> *"I think probably the GP, assuming that you've got the one GP that you regularly go to… Who (GP) knows your history and you have a relationship over the last few years."* *(P2, mild COPD)*

Despite the fact that GPs were difficult to access, they were seen as the *"front line"* or the *"first point of call"* for patients. Some patients highlighted practicalities that prevented discussions, including GP's lack of time to discuss patients' concerns and short appointments. Moreover, patients waited long periods of time for appointments with GPs. As a consequence, patients only booked GP appointments in emergency situations as they felt that booking appointments to discuss future preferences would prevent other people from accessing urgent care.

> *"I mean I would hate to take somebody else's urgent appointment, for me to go and discuss what might happen in 10-20 years' time. (…) I don't think the GP has got time for that, they see you when you're ill. They don't see you when you ask those types of questions I don't think."*
>
> *(P20, moderate COPD)*

Some patients believed GPs had the power to start the process of *"referring to the hospital"* or to *"authorize"* their preferences for care. However, other patients believed that GPs lacked the

required power to materialize their preferences for future care. In contrast, respiratory consultants were seen as clinicians with more power.

> *"I'd rather go as far the up ladder as I could. (…) Dr XYZ (GP) would have to go through various stages to get to that power. I mean I could talk to her (GP) very easily, she's (GP) smashing. (…) But I think when it comes to this you want someone (clinician) who's got [pause] both knowledgeable and can put into action what they are saying (respiratory consultant)."*
>
> *(P27, severe COPD)*

5.4.2 Timing for palliative care discussions

The most commonly preferred timing for discussions was somewhere in the future. Most patients believed they were not "that bad yet" to engage in conversations with clinicians. Some patients preferred to have the discussion "*now*", whilst others preferred to have this at the annual review.

> *"Well, if my health was to deteriorate, say within the next 5-10 years. Then that might be a good time to discuss it."* *(P29, severe COPD)*

Preferences for the timing of discussions with clinicians was related to self-prognosis, as patients assessed their condition when considering initiating conversations. Patients that preferred to initiate discussions in the future perceived their condition to be "*good*" and did not foresee an imminent deterioration. *"Becoming unwell"* or a deterioration in COPD was frequently mentioned as an ideal time to start discussions (see Table 15).

> *"I don't know (what unwell looks like). If I was constantly ...hum... having exacerbations and, even if I got over it. My breathing deteriorated to such a degree that I could hardly move around. Then, I would think "well if anything happens again that's the end for me." I don't think I would want to struggle on, because I know that I wouldn't be able to alter that situation."* *(P17, moderate COPD)*

Palliative care discussions were seen as difficult and some patients only wanted to start them if absolutely necessary. Since to patients, it felt that the initiation of these discussions meant that their condition was effectively deteriorating and that the end of life was approaching.

> *"When I was in hospital they told me that, there was a chance that I wasn't going to get better. If I go down again, I probably wouldn't get better. Then, when I went to see Dr XYZ (respiratory consultant) the other*

(day).... And he started talking about do I want to go into hospital or …hum... would I want to be resuscitated, would I want to go on a …hum... Ventilator. You don't get asked those questions unless it's... Do you? In all honesty you don't. Unless it's close to the time you're going."

(P24, very severe COPD)

Table 15 **Patients' definition of what "becoming unwell" is in the context of starting a palliative care discussion**
○ Recurrent, increased and/or severe breathlessness (7); ○ Increased hospital admissions and/or COPD exacerbations (3); ○ Continued decline of their condition (4); ○ Little treatment effectiveness or exhaustion of treatments (1); ○ Thoughts around "I had enough" (3); ○ Limited or reduced mobility caused by from breathlessness (3); ○ Sudden and severe deterioration in condition, such as cardiac arrest (1).

Previous experiences of severe exacerbations provided context and raised patients' awareness about discussions with clinicians. Discussions during exacerbations were not seen as appropriate by some patients, however conversations could be initiated after these difficult periods.

"I suppose once you've been through a bad time with your breathing and you've actually, well not necessarily been admitted to hospital, but you've had a really bad infection. Just after that, when you've about recovered, it would be a good time for you to sort out what you want to do. Once you've been close to it (death), you can focus your mind a bit more on it."

(P9, moderate COPD)

Patients that preferred to discuss palliative care *"now"* had a clear idea of the care that they did not want to receive in the future. When considering their condition, patients preferred to have the discussion while their condition was stable, since this allowed them to fully engage in the discussion. Despite this, not all patients that preferred to start discussions *"now"* seemed prepared to initiate them.

"Well, anytime (now). Whenever it's convenient with anyone like… You know? Because at the moment I'm in good health. So I would really like to, I suppose, talk to someone about i. e. if I did get really bad and everything else, you know?" *(P4, mild COPD)*

A smaller group of patients preferred to discuss their preferences at the time of their annual COPD review. The annual review was seen as important to plan the care and debate future care. Despite this, not all patients had access to regular reviews.

"When the review comes up and the medication (review), it would be a good time, wouldn't it? Because by then they (clinicians) would be up to date of what the problems are." *(P6, mild COPD)*

5.4.3 Initiating and conducting palliative care conversations

Most patients preferred that clinicians started the discussion, whilst a smaller number of patients stated that they would prefer to initiate the conversation themselves. Interestingly, patients that preferred to initiate conversations themselves, also preferred to have the discussion somewhere in the future.

"Yeah. I'd rather they (clinicians) (start discussions), obviously. They (clinicians) are the ...hum... the experts. They (clinicians) know what's happening, I don't know what's happening to me half the time, do I?"

(P24, very severe COPD)

The majority of patients would like to receive detailed, honest and truthful information about disease progression; treatment options and their outcomes. The lack of illness-related information and the long waits for information was regularly highlighted by patients. Other patients preferred gradual and digestible information, since they felt that negative information or information provided too early could have a negative psychological impact.

"Oh yeah, I mean I believe you should know everything, because you can make an informed decision if you know everything. If someone is going to hold something back, then it's not going to be beneficial. I wouldn't like to make a decision, having kept this back and the treatment was going wrong because I didn't know the full story." *(P29, severe COPD)*

Sharing decision making was seen as important and further information should be provided, so that patients can participate in this process. Despite this, some patients preferred to follow their clinicians' recommendations, rather than participate in the decision-making process.

"I don't (choose treatments/care), I'm that sort of person. If the doctor thinks I should have it, then I say yes. If that's what the doctor thinks, I'll go for it. I can't imagine me saying "No, I don't think I'll have that." I think it would be unwise, I would just go with what the professional said."

(P8, mild COPD)

5.4.4 Palliative care and end of life

In general, patients had little knowledge about the concept of 'palliative care', even for the patient who had received palliative care in the past. Only two patients had previously discussed palliative care with clinicians and both patients had very severe COPD. These discussions focused on continuing or stopping medical treatments, such as hospital admissions.

> *"I spoke to her (community respiratory nurse) the other day and she said "well, if Dr XYZ (consultant) asked you this, then there's nothing we can do, he can't... if you go into hospital they will resuscitate you, they will do everything they can, unless you get your doctor to... You get a... form." Because I told Dr XYZ (consultant) I don't want any of that. If it's time, then it's time. So, yeah, I'll have to be, we'll have to phone the doctor and sort that out. (P24, very severe COPD)*

> "I said (to the COPD consultant) "okay, what happens now?" He (COPD consultant) says "Well, along the way we might have to do an operation (lung volume reduction surgery)." I said "that ain't never going to happen, full stop, end of." (The COPD consultant said) "Okay I can put that down, we're not going down that route." (…) *Yeah (I understand palliative), my brother in law had it, of sorts. (Hum) I think it was palliative care, I'm sure it was. He had people coming in 4 times a day, to make sure he had something to eat, something to drink, he's had a wash and things like that. Is that palliative care?" (P25, very severe COPD)*

> *"It's a little bit of a shame really. I heard about palliative care and on Monday, the person that would have been doing the talk (for the Breathe Easy group) would have been from palliative (care). Unfortunately I won't be there, because I'm on holiday. So I'm going to miss out on that one. [Laughs] But I'm sure, Er*** (colleague), will tell me all about it. (Do you know what palliative care is?) Well, not really. I don't pre guess. I'm not 100 percentage certain of what it is. It's a little bit like exacerbations, it took me months to realised exacerbations were actually chest infections." (P28, severe COPD)*

As a result of the research interview, patients mentioned that they felt ready to engage in discussions with clinicians. Research interviews were seen as useful and helpful and no patients found them distressing.

Actually speaking to you has been quite helpful, actually. You've explained quite a lot of things, I know I have been rambling on. I can talk to my GP and (I) got things that I can mention to the GP about different things. *There's things I haven't thought of, maybe I should investigate a little bit further. So you planted the seed, if you know what I mean, in my mind to explore different things in different avenues. That's been most enlightening.*

(P7, mild COPD)

"It's (the interview has) been quite useful for me, because it has forced me to try and find a measured response, which you have made me think more deeply about things that I might not have gulled to think about. So, I thank you for that." *(P26, severe COPD)*

"I mean I can talk to my doctor as well it doesn't matter. In fact, I think I will speak with him better after having spoken with you. [Laughs] There's lot of thing that you don't even put into words normally. You might think about them, but..." *(P9, moderate COPD)*

"(After this interview) I'm going to talk to my husband, especially about what I want to happen at the end (of life) and about how I don't want to be left, you know, in a wheelchair with oxygen, etc." *(P13, moderate COPD)*

5.4.5 Future with COPD

Most patients had not thought about the future with COPD, since they focused on "*living the moment*" and on positive experiences/things. The future was associated with concerns related to disease progression and the impact of symptoms and exacerbations. Patients preferred to receive all available care *"for now"*, however there was a consensus in declining care/treatments if their condition deteriorated in the distant future. Declined care/treatments included invasive treatments, such as mechanical ventilation and cardiorespiratory resuscitation. All patients had little understanding about the care available for their condition.

"No, no (thoughts about the future). I guess because I take each day as it comes. Hum… Maybe I should be concerned that… Hum… Maybe one day I wake up and be unable to breathe. But then I wake up and find I'm dead. Why should I be concerned? Ain't nothing I can do about it. There ain't nothing doctors can do about it that they are not doing. So, what's the point?" *(P26, severe COPD)*

5.5 Discussion

5.5.1 Summary of the findings

This study has identified COPD patients' preferences for conversations with clinicians. Patients preferred to discuss palliative care and future treatments with COPD-expert clinicians with whom they had an established relationship. They felt that discussions should be started once their condition deteriorated, as they found it difficult to access care and perceived these conversations as death discussions. Conversations should be initiated by clinicians and include detailed information about the patient's condition and future care/treatments. As highlighted in previous studies (Hofmann et al. 1997; Janssen et al. 2011b; Leung et al. 2011; Seamark et al. 2012), most COPD patients had not discussed palliative care with clinicians. This emphasises the need for research interventions in order to improve the frequency of discussions, which may in turn help increase patients' access to palliative care delivery.

5.5.2 Discussion of findings

A recurrent theme from interviews was the challenges faced by primary care. The increasingly large workload, related to increasing number of patients with multiple chronic illnesses, and staff shortages has led to a loss in trust in these services (The King's Fund 2018; Buchan et al. 2019; World Health Organization 2019). Patients reported short appointments, lack in continuity of care and clinicians with little knowledge about COPD in primary care. This contrasted with patients' preferences for discussions with clinicians with increased familiarity and expertise. Since services were not able to meet patients' needs/preferences, they would only see clinicians when they were unwell and avoided booking appointments to discuss their preferences. As a consequence, patients felt they lacked permission to start these discussions, since clinicians focused on treating acutely ill patients. The lack of time in appointments was highlighted by most clinicians in other studies (Knauft et al. 2005; Aslakson et al. 2012). Insufficient time for direct patient care is a concern frequently reported in healthcare (Dugdale et al. 1999; Erickson et al. 2017) and priority is often given to acute care so palliative care is not routinely offered, even when it can provide psychological support and symptom relief. Lack of time and a large workload seems to impact continuity of care. Patients preferred to see a COPD clinician with whom they had an established relationship and saw continuity of care as important. Continuity of care has been associated with more palliative care discussions and patient satisfaction (Hjortdahl and Laerum 1992; Knauft et al. 2005). However, poor continuity of care was primarily felt in primary care, which is interesting since continuity of care is a core value and traditionally provided by general practice (Guthrie and Wyke 2006). Continuity of care is in decline in the UK and the US, which may affect clinicians'

ability in providing care for patients with COPD and other long term conditions (Adler et al. 2010; Barker et al. 2017). General practices and teams have become larger and have been managing an increasingly bigger patient list, which can result increase consultation times, but reduce continuity of care (Adler et al. 2010; Barker et al. 2017). The issues reported by patients seem to prevent discussions between patients and clinicians in primary care and are significant barriers in accessing palliative care.

The ideal timing for palliative care discussions was the future, after sudden and considerable deterioration in the patient's condition. Preferences for later discussions seem to contradict the evidence that advocates earlier palliative care conversations in COPD (WHO 2011; Tavares et al. 2017). However, these preferences are underpinned by several factors that include service rationing and patient's perceptions about their condition and the healthcare system. At present, conversations are rushed, held when patients are unwell and in hospital, and with clinicians who do not know the patient (Tavares et al. 2017).

The first factor for patients preferring late discussions is related to patients' poor understanding about COPD, palliative care, future care/treatments and the discussion of these topics with clinicians. Lower health literacy is a challenge in COPD care as patients often lack knowledge about their condition and their perception about future expectations is often poor (Roberts et al. 2008b; Gauronskaite et al. 2016). Moreover, a large proportion of patients with COPD have a lower socioeconomic status which negatively impacts their participation in palliative care discussions (Prescott and Vestbo 1999). The combination of poor understanding, socioeconomic factors and lack of previous discussions seems to reduce patients' willingness to discuss these topics. Patients need knowledge and power when participating in shared decision making and palliative care discussions (Joseph-Williams et al. 2014), both of which are in short supply in this population. Moreover, patients have a paternalistic understanding of the clinician-patient relationship, where patients allocate the expertise and decision power to clinicians (Simon 2013; Laue et al. 2017). Despite preferring to be involved in decision making, patients leave the final choice of treatment for clinicians, since they lack the knowledge and experience to develop informed preferences, and are afraid of making the wrong decision (Say and Thomson 2003). Stigma is commonly reported by patients and can affect their self-esteem, access to healthcare and discussions about their preferences (Johnson et al. 2007; Berger et al. 2010). Patients who feel stigmatized may hesitate to seek care which can result in patients avoiding discussions about refusing or requesting specific treatments that they believe could help their condition (Johnson et al. 2007; Berger et al. 2010).

Another factor highlighted by patients and the literature is the lack of information provided by clinicians about their condition, especially about their progress over time (Gardener et al. 2018).

In contrast to current practice, patients favoured detailed information about the progress of their condition and the different treatment options. The lack of information meat that patients with advanced COPD did not seem to recognize the decline in their condition and preferred discussions somewhere in the future. The inability to envision the end of life and death suggests that patients do not see the progressive decline in their condition (Giacomini et al. 2012). Instead, patients adapt to their condition and hope to recover from exacerbations, which they do not necessarily see as potentially fatal (Giacomini et al. 2012).

Currently, clinicians only initiate discussions about palliative care and future care/treatments when patients are approaching the end of life (Tavares et al. 2017). Discussions focus on withdrawing aggressive treatments and in initiating end of life care (Sullivan et al. 1996). As a consequence, patients believed that these discussions should only be initiated when they approach the end of life and perceived discussions as death conversations. This was highlighted by participant number 24 (page 69) and by the large amount of patients that discussed death and dying in the interview (15). Patients believed that starting end of life discussions too soon would reduce their hope and have a negative impact on their well-being. These discussions seemed to be related to patient's attitudes towards death and death anxiety, since the latter decreases end of life care communication between patients and clinicians (Brown et al. 2014). In fact, death anxiety is associated with lower quality of life (Cella and Tross 1987; Sherman et al. 2010), which is commonly found in COPD (Zamzam et al. 2012; Wacker et al. 2016). As patients believed they were discussing end of life, they were faced with discussing death, dying and their mortality. This can potentially be distressing and deter patients from discussing their preferences. Despite recognizing the importance of discussions about the introduction of comfort care/treatments, patients to postpone discussions to the end of their life. The probable causes for delaying discussions include patients' low health literacy levels caused by the lack of information/education provided by clinicians, a practice culture that avoids discussing palliative care with patients, and patients' perception that discussing palliative care means discussing death. Lack of information/education seems to have a large impact on how patients construct their perception about their condition and about conversations with clinicians (Gardener et al. 2018). As a consequence, patients seemed to be in conflict between wanting palliative care discussions, but only in the future. This conflict was clearly demonstrated in some patients that preferred to discuss their preferences "now," but stated that they did not feel ready. The factors highlighted above seem to be the cause of this lack of readiness. If patients were given the opportunity to discuss their preferences while they were well with a COPD clinician they knew well, in an adequate environment and in a sensitive manner, patients would potentially endorse these conversations at a much earlier stage. Moreover, offering regular conversations about the future from the point of diagnosis could potentially change patients' perceptions about these

conversations and help them see them for what they are - not a conversation about death (NICE 2005; Ford et al. 2013). This approach reinforces the model that integrates palliative with curative care, rather than an abrupt transition from chronic to end of life care (Hardin et al. 2008).

The difficulties in prognosticating with accuracy in life-limiting illnesses, especially in COPD, affects the start of palliative care and emphasises the need to support clinicians in recognizing when patients are approaching the end of life (Shipman et al. 2008; Goff et al. 2015). As a consequence, it has been suggested the use of triggers for palliative care discussions, such as a FEV1 of less than 30%; starting long-term oxygen therapy; the need for ventilation; or recent hospital admission (Halliwell et al. 2004; Curtis 2008). Whilst, these triggers may be useful in identifying patients with advanced disease, they also lack prognostic accuracy. Tools and indexes have also been developed to increase the predicting reliability of these triggers, such as the BODE and DOSE scores, however they have also been ineffective (Powrie 2004; Sundh et al. 2012). Since, over half of patients studied with the highest BODE score were still alive after 3 years (Esteban et al. 2010). The lack of prognostic accuracy seems to be a contributing factor for the lack of palliative care delivery (Shipman et al. 2008; Goff et al. 2015), therefore a holistic and coordinated approach towards palliative care may be required. Moreover, to reduce the impact of prognosis uncertainty and increase patient support, a change in current model of care, where palliative care is integrated into COPD care from diagnosis, is required (den Herder-van der Eerden et al. 2017; Scheerens et al. 2018; Siouta et al. 2018). The study recruited patients at different stages of their disease trajectory, since it was expected that the proportion of patients that favoured palliative care discussions increased as their condition progressed (Pinnock et al. 2011; Harb et al. 2017). However, this was not the case. Disease severity, symptom and treatment burden seemed to have little impact in patients' preferences. Despite this, patients continued to accept all treatments as their disease deteriorated and only declined treatments that had little benefit (Harb et al. 2017). Interestingly, even at the end of life most patients opted for aggressive treatments, such as cardiopulmonary resuscitation and ventilation (Bereza et al. 2015). This seems to be related to patients' limited understanding of their condition, especially about the life-limiting character of COPD (Gauronskaite et al. 2016).

5.5.3 Strengths and Limitations

One limitation of the study is that it only includes people with a British and white background. The preferences of this group of COPD patients may not be generalized to people from other ethnic groups or countries. Despite this, most findings echo what national and international literature had previously published about palliative care discussions. Another limitation is related to the Ethics Committee ruling that prevented discussing the terms "palliative care" and "end of life"

with patients with mild and moderate COPD and instead calling it “future care and treatments”. The Ethics committee justified this request upon the basis that discussing these terms with patients would provoke unnecessary distress to patients. This may have resulted in altered perceptions and preferences for discussions with clinicians, since patients with milder COPD may not have fully grasped the content of the discussion. Despite this, most patients seemed to associate these conversations with end of life conversations, in the same way as those with severe COPD. Lastly, one of the strengths of this study was the use of IPA principles, which enabled the interpretation of patients’ thoughts using an idiographic approach. This resulted in in-depth understanding of every patients’ thoughts and preferences for conversations.

5.6 Conclusion

Patients prefer clinicians with a strong COPD knowledge-base and with whom they have an established relationship to start discussions about palliative care and future treatments, but only once their condition severely deteriorates. Preferences for timing are largely related to constraints in clinical practice, which act as a barrier for early and open discussions between patients and clinicians. Early discussions can only be initiated, if the current model of care shifts from stand-alone conversations at and about the end of life, to regular conversations that allow the integration of palliative care at a much earlier stage. Ongoing research is needed to help determine how palliative care can be integrated effectively and routinely in the care of COPD patients.

The paper has been fully presented above. The ways in which phase 2 informed phase 3 are described in the next page.

5.7 How did this phase inform phase 3

As described in Chapter 3.3 and page 25, the three phases of this study complement and inform each other in different ways. Phase 1 highlighted that clinicians were uncertain as to how and when to start palliative care discussions with patients (Tavares et al. 2017). Thus, the review suggested that clinicians and patients had dissonant perspectives about the timing and nature of these discussions. Therefore, the discussion of patients' preferences for palliative care conversations formed a key part of the interviews with clinicians. These preferences were gathered from patient interviews conducted in phase 2. As an example, the interview topic "ideal clinician to initiate discussions about palliative care with patients" included several prompts that resulted directly from patient interviews, such as their thoughts and experiences (please refer to **Appendix S** for more information). Some of these topics included:

- Patients preferred to have discussions with clinicians that had increased COPD-related knowledge and authority;
- Patients preferred to discuss palliative care with COPD specialist clinicians;
- Patients stated that most GPs lacked knowledge, care authority and time to discuss palliative care;

These prompts were used to generate discussion with clinicians, since they were asked to comment on these preferences. This discussion was held alongside discussing clinician's experiences and opinions for the appropriate timing and nature of palliative care discussions. Relevant information found in Phase 1 was also incorporated in the interview guide and used as prompts.

Requesting clinicians to reflect on patients' preferences was a novel approach that added considerable knowledge to the current literature, since it provided their interpretation of patients' thoughts. This approach was thought to highlight divergences and convergences between patients' and clinicians' perspectives, which may have prevent the start and conduct of discussions. Previous research conducted with healthcare professionals has focused on their recommendations and experiences when discussing palliative care, but were not directly linked with patient preferences.

Lastly, in Phase 2, patients' identified healthcare professionals with whom they preferred to discuss palliative and future care. Therefore, the recruitment strategy in phase 3 focused on these preferred clinicians, which included GPs, practice nurses, COPD specialist nurses and COPD consultants. Discussing palliative and future care with healthcare professionals that patients find more appropriate, may result in them having a better experience and in fully sharing their preferences.

Chapter 5

The next chapter describes phase 3 of the research study.

Chapter 6 Phase 3 – Clinicians' judgments when discussing palliative care with COPD patients

6.1 Introduction

The systematic literature review highlighted that healthcare professionals and COPD patients often have divergent perspectives about the timing and nature of palliative care discussions. Therefore, the purpose of this phase was to understand clinicians' thoughts about the nature and timing of palliative care conversations and to discuss this in the context of the patients' preferences generated from phase 2. In addition, clinicians were questioned about the impact of patient's clinical and social context when starting and conducting palliative care conversations. Similar to phase 2 of this study, phase 3 is presented here in the format and word count of the BMJ Supportive and Palliative Care Journal, where it is currently under peer review (Tavares et al. 2019 [under review]-b).

The paper is presented in full in the next page.

Journal: BMJ Supportive and Palliative Care Journal

Title: Timing and nature of palliative care discussions are patient-specific according to clinicians: a qualitative study

Authors: Nuno Tavares, Katherine Hunt, Nikki Jarrett, Tom Wilkinson

Reference: Tavares N, Hunt K, Jarrett N and Wilkinson T (2019 [under review]-b) Timing and nature of palliative care discussions are patient-specific according to clinicians: a qualitative study *BMJ Supportive and Palliative Care*

Paper submitted for journal peer review on the 28th of September

6.2 Background

Chronic obstructive pulmonary disease (COPD) is a progressive and life-limiting illness that causes breathlessness and chronic cough (Department of Health 2011b; NICE 2011a). COPD patients have a high symptom burden (NICE 2010; Miravitlles and Ribera 2017) and these symptoms are managed by means of aggressive and invasive treatments, especially as they approach the end of life (Curtis 2008; Beernaert et al. 2013). Palliative care can support these patients holistically and provide care that focuses on quality of life and effective symptom relief (WHO 2016). In order to offer care focused on patients' preferences, conversations about future care need to take place (Curtis 2006; NICE 2011b). However, the unpredictability and complexity of COPD prevents the early identification of patients in need of palliative care (Curtis 2006; Fitzsimons et al. 2007; Whellan et al. 2014). This means that there is often no obvious 'right time' to initiate conversations about end of life and palliative care.

Discussing preferences and creating end of life care plans can ultimately result in improved experiences at the end of life while reducing patients' symptom burden (Gott et al. 2009; Sinclair et al. 2017; Houben et al. 2019). Despite this, most COPD patients do not get the chance to discuss their preferences until they approach the end of life (Houben et al. 2015; Tavares et al. 2017). A recent paper has focused on understanding COPD patients' preferences for palliative and future care discussions with patients (Tavares et al. 2019 [under review]-a). Clinicians' opinions about COPD patient preferences for discussions are currently unknown (Tavares et al. 2017), so this study aimed to explore clinicians' perspectives on when and how to initiate and conduct palliative care discussions with COPD patients.

6.3 Method

6.3.1 Design

This paper reports on the third component of a larger study looking at how and when to start discussions about palliative and end of life care planning in COPD. A systematic literature review (Tavares et al. 2017) and a qualitative study of patients' preferences and opinions for the timing and nature of discussions (Tavares et al. 2019 [under review]-a) formed the first components of the study. These two components informed the design of this study, the recruitment strategy and the interview topic guide (such as patient perceptions about the lack of expertise in primary care and their preference in delaying these discussions). Recruitment focused on health professions cited by patients as the preferred person to discuss palliative care (Tavares et al. 2019 [under review]-a).

6.3.2 Sample

The study used a purposive sample and recruited clinicians who provided direct care to COPD patients at different stages of their condition. This included practice nurses; general practitioners (GPs); COPD consultants and COPD specialist nurses. It was postulated that these clinicians worked in environments where discussions could be held sensitively; had some training or knowledge about palliative care discussions; and/or were in a position to build relationships with patients. The inclusion criteria can be found in **Table 16**.

Table 16 **Inclusion criteria for healthcare professionals**

Professional background	Practice nurses, GPs, COPD consultants and COPD specialist nurses
Age	Aged 18 or over
Clinical practice	Clinicians providing direct care to COPD patients
Language	English speaking clinicians
Location	Clinicians working in geographical area of Hampshire

Clinicians were recruited by email or by letter[10]. The NIHR Clinical Research Network (CRN) signposted primary care clinicians to the study. The CRN informed GP practices about the research study and requested that clinicians willing to participate contacted the first author. Secondary care clinicians were signposted to the study by the research department of the hospital where they worked. Clinicians were sent information about the study and were requested to

[10] Please refer to Appendix U to find the Participant Information Sheet and to Appendix V to find the Consent form.

contact the researcher if willing to participate. Written informed consent was obtained for all participants.

6.3.3 Data collection

Interviews were audiotaped, lasted 20-45 minutes and followed a semi-structured approach. The interviews were conducted by the first author (NT), who had no previous relationship with the participants. The questions followed a topic guide[11] that focused on exploring clinicians' understanding about the nature and timing of palliative care discussions and in debating patient's preferences for these discussions. The exact phrasing of the questions and the scope and depth of the interview varied on an individual basis.

Interviews were undertaken at a time and place convenient to the participant, usually GP practices and hospital. Data collection[12] was carried out between December 2018 and March 2019 and stopped at data saturation point. Data saturation was judged achieved when no new themes/topics were emerging from the interviews with clinicians. The decision to stop data collection was discussed and agreed within the authorial team.

6.3.4 Data analysis

All interviews were transcribed verbatim and anonymised. Data was managed using qualitative software Nvivo 11 and analysed using thematic analysis (Tuckett 2005; Braun and Clarke 2006). Transcripts were read several times and coded. Codes were developed, defined, reviewed and grouped into larger categories of codes and final themes. All transcripts were analysed by the first author (NT), whilst all the authors monitored and supervised the transcript analysis, participated in the development of the codes and themes, contributing to the trustworthiness and methodological quality of the study. The consolidated criteria for reporting qualitative research (COREQ) were used to report the research findings (Tong et al. 2007).

6.4 Results

Fourteen clinicians, out of 22 clinicians contacted, participated in the study and their characteristics are summarised in **Table 17**.

[11] Please refer to Appendix S to find the interview topic guide.
[12] Please refer to Appendix T to find the Data Collection Form where clinicians' information was collated.

Table 17 **Clinicians' characteristics**	
Gender – Male (%)	4 (29%)
Mean age in years (SD)	50 (8.5)
Years in practice (SD)	22 (12.5)
Number of COPD patients seen a week (SD)	17 (8)
Number of discussions a monthly (SD)	3 (5)
Special interest or training palliative care (%)	6 (43%)
Professional background:	
• **COPD consultants**	3 (23%)
• **COPD specialist nurses**	3 (23%)
• **Practice nurses**	4 (27%)
• **General practitioners**	4 (27%)

The analyses yielded 59 deductive codes and 50 inductive codes. The deductive codes focused on addressing the aim of the study, whereas inductive codes provided context and further information on clinicians' thoughts. The combination of the different codes originated 7 categories of which 4 themes emerged, please refer to table 18.

Table 18 **Categories and themes generated from interviews with clinicians**	
Categories	**Themes**
• Approaches when discussing palliative care; • End of life and end of life care; • Future with COPD; • Palliative care; • Clinicians starting and conducting discussions; • Timing for discussions with patients; • Previous discussions with patients	• Established relationship; • Timing informed by prognosis; • Individualized approach; • Readiness for discussions.

Quotes were selected purposively and unnecessary information or irrelevant pauses were edited out for clarity and anonymity.

6.4.1 Established relationship and clinician expertise

Healthcare professionals could not pinpoint specific clinicians that should have palliative care discussions with patients. Instead, most clinicians believed that patients should discuss this with a well-known clinician, since this was thought to increase trust and familiarity. Participants believed that some clinicians felt less comfortable when discussing palliative care with patients, since some

patients became emotionally distressed. Despite this, no participant found discussions particularly difficult for themselves.

When analysing interdisciplinary differences, more medics considered themselves suitable clinicians to initiate discussion than nurses. Some primary care clinicians believed that hospital clinicians should take ownership of discussions, since care plans developed in primary care were not always respected in hospital. Most participants believed that communication skills and knowledge about COPD, palliative care and services available were essential. Participants' knowledge and skills differed across and within professional backgrounds. However, most participants seemed to have little understanding about palliative care, since they viewed it as end of life care and exclusive of acute treatments.

6.4.1.1 Secondary care

Consultants reported regular palliative care discussions with patients in outpatient clinics, especially on hospital wards. Participants believed that consultants' medical background; expertise; patient-relationship; and regular contact with end-stage patients made them suitable clinicians to start discussions with patients. COPD specialist nurses had daily discussions with patients and provided palliative care to patients in the community. Moreover, these clinicians seemed to have a large knowledge base, the opportunity to build relationships with patients, and offer longer appointments. However, these clinicians did not always have the confidence to initiate discussions.

> *I've just been doing that (patient support sessions) depending on the patients. But it definitely gives me a better amount of time and relationship with patients. (…) I think in consultant clinics you get to develop a good relationship with patients if you do the same clinic, which I do. Because you get a caseload of patients and you get to know them.* *(P5, COPD Nurse)*

6.4.1.2 Primary care

Participants stated that increasingly higher pressure in primary care resulted in shorter appointments, longer waits and reduced continuity of care. In fact, one practice nurse noted the variation in GP surgery management, which meant that patients were left in a '*postcode lottery*' for their care. Some nurses and GPs were *"thrown in"* to COPD clinics with little to no training, so clinician skill and competency varied greatly across surgeries. Since primary care clinicians managed patients with different health conditions, some participants believed they possessed a less in-depth knowledge about COPD.

> *You can get one practice where the practice nurses are specialists in their own rights. Because they've done courses, they've done the spirometry course and all of that, and a COPD course. But then there are COPD nurses out there that have done very little courses that pick it up as they go along.* *(P9, Practice nurse)*

GPs felt that their overview of the patient's medical history provided them with the required tools to start discussions. However, in contrast to practice nurses, GPs felt less able to build relationships with patients and had less time for discussions. Despite this, most practice nurses did not discuss palliative care, since they lacked the necessary training and knowledge. Moreover, practice nurses only saw patients with milder COPD, who nurses believed did not require palliative care discussions.

> *I mean it's harder for me now (to build relationships with patients), because I'm only doing one day a week here. I don't think it's difficult (to build relationships). I mean I think things have changed in general practice. In that we don't see those patients as often, as I say the practice nurses do the respiratory reviews and stuff. So they are more likely to have those conversations.* *(P12, GP)*

6.4.2 Timing informed by prognosis

Clinicians had conflicting thoughts about the ideal timing for discussions with patients. Timing was based on the individual patient and on poor prognosis. Participants found prognostication complex, so looked for factors that signalled poor prognosis when timing discussions, such starting long-term oxygen. In general, participants started discussions with patients with an advanced and deteriorating condition, usually at the end of life.

> *You can be now very severe (COPD), end stage (COPD), but that end stage could be weeks, months, could be years. We don't tackle or approach it (palliative care discussions) with patients, because the trajectory is so unknown and varied. You could be saying we're going to do this end of life stuff, but they might still be here in 18 months. We've got loads of them (patients) that you're surprised they're still going, but I wouldn't be surprised if somebody said "they died". I'd be like "okay it's sad, but not unexpected."* *(P4, COPD nurse)*

In contrast to current practice, most participants believed all patients should be given the opportunity to start early discussions and that early discussions could reduce the emotional impact of a late discussion, allowing patients to plan ahead. In fact, due to the complex nature of COPD, one consultant believed that care should steadily transition from aggressive to more comfortable treatments/care as disease severity progressed. Moreover, participants

recommended regular discussions with digestible information that increased in depth as the patient's condition deteriorated. Annual reviews and pulmonary rehabilitation were considered ideal opportunities to start discussions and offer education about palliative care.

> *If it's someone I know well, that's something (palliative care) I like to broach early on if I can. If it's someone you can see declining just over a period of time. At least having it mentioned once or twice, then when you really want to discuss it, it doesn't feel unusual to the patient. It feels like it was something you were naturally coming to.*
>
> *(P13, GP)*

6.4.3 Individualized approach

Although, participants reported that both parties started the discussion, they started discussions much more often than patients. Participants highlighted that patients and families rarely started discussions in a direct way, instead they provided cues about their readiness to start discussions. The lack of discussions started by patients was attributed to their poor understanding about the severity and progressive nature of their condition, and in differentiating between exacerbations and chronic decline.

> *I usually start it (the discussion), very rarely you get a patient (to start it). Actually, I suppose I've had one or two that talked about it in a roundabout way, because a family member had died of COPD and that sometimes leads to conversations at the start, "I don't want to be like that person, because they were so breathless at the end." But it's a minority.* *(P3, Respiratory consultant)*

Many factors influenced the approach chosen by clinicians when starting discussions with patients, including their anxiety levels and understanding about their disease severity. Participants' approach to starting and conducting discussions varied between direct and indirect. These approaches can be found in **Table 19**.

Table 19 **Methods used/recommended when discussing palliative care with patients**

Before the discussion	Starting the discussion	Conducting the discussion	Concluding the discussion
Get to know the patient – establish a healthy and long relationship	Ask patients to reflect on the advanced stage of their condition and implications for the future	Early and gradual, discussion with patients as disease severity worsens	Allow final questions
	Explain the severity of the patient's condition and implication for the future at the start of the discussion		
	Start discussions in a *"roundabout way"* to reduce anxiety	Discuss and explain treatment options and goals of care	Document discussion in patient's records and complete required forms
	Pick up cues on patients' readiness for discussions	Discuss preferences from generalities to specifics from place of care to specific treatments	
	Unpick patients' concerns or fears about treatments, future or severity of their illness	Ask open questions about patients' preferences for information about treatments and care	Feedback outcome of discussions to other members of the MDT
	Acknowledge unpredictability of their condition when starting discussion		
	Direct or indirect start of discussions – open and honest discussion versus hope fostering discussion	Frame discussion positively – focusing on what the services can offer and on symptom management	In order to limit the emotional impact of discussions, conclude the discussion on a positive note or with something cheery.
	Primary care continues discussion if started in secondary care	Patient-led discussion – picking up cues throughout discussion	
	Primary can start discussion if patient was being seen for another issue – stable COPD	Explore and unpick fears and concerns about deteriorating and end of life; and discuss an action plan	Provide written information that supports discussion
	Offer patients the opportunity to discuss it	Discuss future care using a framework – AACP or UCP	

Some participants felt that starting discussions in a *"roundabout way*" (indirect approach) reduced anxiety levels and made discussions more acceptable. This approach was especially used in patients with increased anxiety and depression levels. The use of strong words, such as "palliative care," "death" and "end of life," were avoided, since these were seen to cause distress and reduced hope. In contrast, a small proportion of participants believed they should have an open and honest discussion with patients (direct approach), by providing accurate and direct information about their advanced condition.

> *I don't think I would be talking about palliative care with them. I would be talking to them as an individual and how they feel about what's going to happen? And how do they feel about dying? I wouldn't probably mention the word palliative, because they wouldn't understand what that means. But it might come when you're talking about introducing the palliative care team.* *(P9, Practice nurse)*

Participants recommended focusing on understating patients' preferences and in agreeing on a care plan. However, most discussions focused on treatment withdrawal and symptom management at the end of life. Sharing the decision making with patients was seen as important, but participants felt that some patients had unrealistic expectations leading to challenges in maintaining balance between patients' wishes and clinicians' medical decisions.

> *I think what I struggle with in some discussions around escalation and stuff, is that there's the whole how much is the patient's decision and how much is the medical professional's decision. You have to be quite careful in terms of giving people the idea about what they can accept. You don't want to create an expectation that they can demand a treatment and I think there's a group of people with COPD who very much want to fight for every last hour and day of life they can have.*
>
> *(P1, Respiratory consultant)*

6.4.4 Readiness for discussions

Participants looked for prompts that could help them identify when patients were ready to initiate discussions. They suggested that patient readiness to discuss palliative care depended on various factors (**Table 20**). However, participants' perception of patients' readiness also seemed to impact their own readiness to initiate discussions.

Table 20 **Factors associated with readiness for discussions**
• Patient's older age; • Patient's understanding about COPD and current status of their condition; • Patient's perception about palliative and future care discussions; • Patient's attitude towards death; • Patient's personality; • Patient's or other people's experiences regarding healthcare; • Clinicians' approach when starting and conducting discussions; • Focus of discussion.

Clinicians believed that patients' understanding about the progressive nature of COPD and their disease severity impacted patients' readiness to discuss palliative care and was related to insufficient information provided to patients throughout their disease trajectory. In fact, some participants had purposely withheld information about the progressive nature of COPD, for fear that this would emotionally impact patients. However, providing education about the progressive character of COPD was seen as very important.

> *I did (talk to patients about palliative care) when they were first diagnosed in a sense. Because I talked to them about what COPD was and I'd give them the booklet. I tried to avoid it being an aggressive or progressive disease. I didn't say anything about palliative care. I would say if you carry on smoking things might worsen, you might end up on oxygen and things like that. (P9, practice nurse)*

Some participants highlighted that patients were surprised/distressed when discussions were started, but believed that patients felt appreciative some time later. Whilst, other participants reported that patients felt relieved from the start. Moreover, clinicians suggested that patients were not ready to start end of life discussions early in their disease, or during acute exacerbations as this was interpreted as death being imminent.

> *I think I just said to him (a patient) "I'm going to put the cards on the table here. These are our options. I'm not saying you're going to drop down dead today. I don't see you dying imminently, but we need to discuss how we're going to support you." I remember him initially being like "what, what, what?" And then when he realised we were actually looking at how we could support him and keep him at home, he was fine. (P4, COPD nurse)*

6.5 Discussion

6.5.1 Summary of the findings

This study explored clinicians' experiences of discussing palliative care with patients. Clinicians felt that those with a relationship with the patient should start the discussion. Discussions were started when the end of life was identified, through the recognition of key clinical red flags. In contrast to current practice, early, gradual and regular discussions with patients were seen as best practice. Direct or indirect approaches were used when starting and conducting discussions. Whether discussions came late or early in the relationship or took a direct or indirect approach, the discussion was tempered by the need to maintain hope and a good relationship, but also to avoid raising false expectations on what resources were available for patients and what medicine could achieve for them.

6.5.2 Discussion of findings

Clinicians believed that discussions should ideally be started clinicians with increased expertise and good relationships with patients. Therefore, there was no agreement on which clinicians were the most suitable to discuss this. Previous research has also highlighted a lack of clarity on who's responsible for initiating discussing with patients (Gott et al. 2009). Although clinical expertise and patient-relationships are paramount when discussing palliative care (Back et al. 2007; Coyle et al. 2015), the lack of a designated clinician responsible for initiating discussions with patients can lead to nobody starting them. However, there seems to be a general lack of research exploring the lack of an explicit clinician responsible for discussing palliative care. The concern of nobody initiating/conducting discussions was also raised during interviews by a COPD consultant.

The absence of a designated clinician who is responsible to start and conduct palliative care conversations with patients may result in discussions not being started or being poorly conducted. A possible explanation for this includes the lack of training and experience on starting and conducting these discussions. Previous research suggested that clinicians with less expertise are less likely to start and conduct palliative are discussions, since expertise is dependent on training and in discussions taking place on a regular basis (Back et al. 2007). Specific guidance on who is responsible to start discussion, and on the timing and approach for palliative care conversations may facilitate the development and implementation of interventions that can help improve the frequency and quality of discussions (Gott et al. 2009). Thus, guidance may reduce clinicians' uncertainty regarding the timing and nature of discussions, increase clinicians' confidence, which

could result in increased willingness and reduced emotional impact of discussions on patients (Gott et al. 2009).

A recurrent theme from interviews was the challenges faced by primary care. The increasingly large workload and staff shortages has led to a reduction in the amount and quality of care provided to patients (The King's Fund 2018; Buchan et al. 2019; World Health Organization 2019). Short appointments have also been highlighted in previous studies (Knauft et al. 2005; Aslakson et al. 2012), which led to a reduction in direct patient care (Dugdale et al. 1999; Erickson et al. 2017). GPs found it particularly difficult to build patient-relationships and to find time for discussions, whilst practice nurses lacked the time and knowledge. Consequently, patients managed in primary care had little access to palliative care discussions, since these clinicians did not seem suitable to start them. Little access to discussions was further exacerbated by clinicians' confusion between palliative and advance care planning and end of life. Moreover, the barriers found in primary care prevented the integration of early palliative care discussions with patients (Hardin et al. 2008). As a result, patients had to wait until they engaged with secondary care and their condition deteriorated considerably, before having the opportunity to start discussions. The integration of discussions could start while a patient's condition is stable and shortly after diagnosis (Hardin et al. 2008; Higginson et al. 2014a). Primary care clinicians felt able to start early conversations if time and training was provided.

Throughout the interviews there was conflicting opinions about best and current practice for the timing of discussions. Most participants had a one-off discussion with patients usually at the end of life, whilst they believed discussions should be started earlier and be held regularly with patients. Late or lack of discussions have also been reported in other life-limiting conditions, such as heart failure and chronic kidney disease (Barclay et al. 2011; Mandel et al. 2017). Starting discussions late in the disease trajectory seems to be related to clinicians' poor understanding of palliative care (confined to the end of life) and to the difficulty of prognosticating in COPD (Sullivan et al. 1996; O'Neil et al. 2008; Shipman et al. 2008; Spathis and Booth 2008; Crawford 2010; Landers et al. 2017; Luckett et al. 2018). As an example, the practice nurses interviewed reported a lack of training and confidence to start discussions. Despite this, a previous study showed that a proportion of patients would like to discuss palliative care with practice nurses (Tavares et al. 2019 [under review]-a). These differences in patients' and clinicians' perceptions about the timing and nature of palliative care seem to seriously limit their occurrence. Service rationing, clinician and patient-specific barriers, such as unpredictable disease trajectory and lack of time (Spathis and Booth 2008; Landers et al. 2017), were also barriers for early discussions with patients. A change in the current model of care, from stand-alone discussions at the end of life, to

early, gradual and brief discussions throughout the disease trajectory could minimize these barriers (Hardin et al. 2008; Higginson et al. 2014a).

Interestingly, the importance of social determinants was seldom mentioned by clinicians, despite being commonly reported in previous research (Prescott and Vestbo 1999; Pleasants et al. 2016). In fact, clinicians seemed to dismiss the impact importance of social determinants in patients' health status, in their ability to self-manage and in their ability to participate in discussions (Prescott and Vestbo 1999). Low socioeconomic status can negatively impact patients' understanding and perception of their condition, reduce their ability to self-manage and decrease their ability and willingness to discuss palliative care (Prescott and Vestbo 1999; Roberts et al. 2008b; Gauronskaite et al. 2016). Further, low socioeconomic status were associated with reduced knowledge and power, which are important factors when accessing and negotiating care (Prescott and Vestbo 1999; Roberts et al. 2008b; Joseph-Williams et al. 2014; Gauronskaite et al. 2016; Pleasants et al. 2016). Lack of power and knowledge can lead patients to devolve all expertise and decision power to clinicians, which limits their participation in palliative care discussions (Simon 2013; Laue et al. 2017). Poor understanding and low health literacy seems to be related to a lack of information provided by clinicians about patients' condition, especially about their progress over time (Gott et al. 2009; Gardiner et al. 2010; Siouta et al. 2016; Gardener et al. 2018; Tavares et al. 2019 [under review]-a). In order to improve access to healthcare, and palliative care in particular, patients need education, through early and informative discussions about all aspects of COPD, palliative care and future treatments. Late discussions further reduce patients' power, since they will often be at their most vulnerable at the point at which they require palliative care.

6.5.3 Limitations

The first limitation of the study is that most clinicians expressed some interest in palliative care discussions. This was not the case for two nurses – one practice nurse and one COPD specialist nurse. Clinicians interested in the topic may feel more confident and comfortable in discussing palliative care. Interviewing clinicians less interested in discussing palliative care or that found discussions particularly difficult, could have generated different data. Another limitation of the study is the lack of ethnic diversity in the sample which prevented any exploration of the impact of ethnicity on palliative care discussions. This may have been especially important when considering the spiritually attached to palliative care discussions.

6.6 Conclusion

Clinicians believed that a person with increased expertise and an established relationship with the patient should start palliative care discussions. Various clinician-specific barriers mean that there is no designated clinician that should start discussions. Current stand-alone discussions are difficult to time and to conduct appropriately and sensitively, resulting in the non-occurrence or in late discussions with patients. Instead, discussions should be started from diagnosis, develop over time and information should be provided gradually. The discussion should be patient-led and patient-centred, focused on patients' preferences for immediate care and held in a comfortable and private environment. A shift in the model of care, from stand-alone end of life care conversations to integrating palliative care early in the disease trajectory, is required.

The integration and synthesis of the findings from Phases 1, 2 and 3 is presented in the next chapter.

Chapter 7 Phase 4 - Data integration of Phases 1, 2 and 3

7.1 Introduction

Phase 4 integrates the findings from the previous 3 research phases culminating in the overall findings of this study. This data integration results in a more complete picture of palliative care discussions in COPD and seeks to highlight as well as understand discrepancies between patients and clinicians' perspectives. As suggested in previous research, the integration of different qualitative methods assists researchers in actively seeking diversity and divergent cases, in order to present phenomena in all their different facets (Parahoo 2014). This phase is presented in the format of the COPD: Journal of Chronic Obstructive pulmonary disease, where it will be submitted for review by the end of 2019.

The paper is fully displayed in the next page.

Journal: COPD: Journal of Chronic Obstructive Pulmonary Disease

Title: Late end of life care discussions are the norm in COPD, but early and gradual discussions are recommended: patients' preferences and clinicians' recommendations

Authors: Nuno Tavares, Nikki Jarrett, Tom Wilkinson, Katherine Hunt

Paper will be submitted for journal peer review by the end of 2019

7.2 Background

Patients with chronic obstructive pulmonary disease (COPD) have a high symptom burden, which is typically managed by means of aggressive and invasive treatments as patients approach the end of life (Curtis 2008; NICE 2010; Beernaert et al. 2013; Miravitlles and Ribera 2017). Providing more aggressive and invasive treatments throughout the disease trajectory increases the burden of treatment for patients, which reduces quality of life and is associated with poor experiences at the end of life (Gore et al. 2000; Nava et al. 2007; May et al. 2014; Gautschi and Franzen 2016). Whilst this increase in burden of treatment is inadvertent as it results from efforts to manage deterioration and reduce the increasing symptom burden, it nonetheless contradicts the ethos of palliative care. Palliative care aims at alleviating symptoms and in supporting patients holistically by means of minimally invasive treatments and patient-centred care (WHO 2016).

Access to palliative care for COPD patients is impacted by several barriers, including challenges accurate prognostication, clinicians' limited understanding of palliative care and COPD, organizational barriers and a lack of discussions about palliative care (Curtis 2006; Mousing et al. 2018). Despite the presence of various prognostic tools, there is still uncertainty regarding when to start palliative care for COPD patients (Curtis 2006).

Access to person-centred palliative care in COPD is dependent on clinicians and patients initiating conversations about these topics (NICE 2005; Crawford et al. 2013). However, most patients do not get the opportunity to discuss their preferences for palliative and future care with clinicians (Tavares et al. 2017). As a consequence, previous research has suggested that using interventions targeting clinicians and patients increases the frequency of palliative and future care discussions[13] between patients and clinicians (Tavares et al. 2017). However, the long-term effect of these

[13] For brevity, this paper will refer to palliative and future care discussions as palliative care discussions.

interventions was not sustained overtime (Reinke et al. 2017; Tavares et al. 2017). Due to the complexity of palliative care discussions in COPD, a multiphasic research study was developed to explore: 1) published evidence, 2) patients' preferences, and 3) clinicians' opinions about these discussions. This paper reports the integration of the three phases to inform how palliative care discussions should be embedded within COPD care.

7.3 Method

7.3.1 Design

This paper combines and integrates the findings from a research study conducted over 3 phases that, although different, complemented and informed each other. The first phase was a systematic literature review looking at published evidence about the timing and nature of palliative care discussions in COPD (Tavares et al. 2017). The literature search was conducted in February 2016 (updated in June 2019 with new data incorporated). This review suggested that there are several barriers to palliative care discussions and that understanding of patients' preferences for these discussions was limited (Tavares et al. 2017). As a consequence, the second phase of the study looked at patients' preferences for the timing and nature of palliative care discussions with clinicians (Tavares et al. 2019 [under review]-a). Patients preferred to discuss palliative care with clinicians that had greater expertise and an established patient-relationship, usually once their condition had deteriorated significantly (Tavares et al. 2019 [under review]-a). Patients favoured large amounts of information about care and disease progression, but reported that clinicians' lack of time and focus in acute care, and absence of a patient-relationship prevented the provision of timely and in-depth information (Tavares et al. 2019 [under review]-a). Patients' preferences identified in phase 2 were used to generate discussion with clinicians in phase 3 and their recommendations for discussions were sought (Tavares et al. 2019 [under review]-b). Only clinicians cited by patients as suitable professionals with whom to discuss palliative care were interviewed in phase 3 (Tavares et al. 2019 [under review]-b). A total of 47 participants were interviewed in both phases – 33 COPD patients and 14 healthcare professionals. Patients' interviews were analysed using an interpretative phenomenological analysis, whilst clinicians' interviews used a thematic analysis approach (Tuckett 2005; Braun and Clarke 2006; Smith et al. 2009; Pietkiewicz and Smith 2014).

7.3.2 Data analysis

The integration and analysis of studies that used different methods of data collection and analysis requires the use of an approach often found in mixed methods research (Farquhar et al. 2011).

Methods used in mixed-methods studies are driven by the epistemological underpinnings of the study, as well as the type of data generated (O'Cathain et al. 2010; Farquhar et al. 2011). The integration method in this case was the triangulation protocol. This method involves studying a problem using different methods, which results in a more complete picture about a phenomenon (O'Cathain et al. 2010). Moreover, the triangulation protocol facilitates the integration and combination of data after the separate analysis of each phase of the study (O'Cathain et al. 2010). The triangulation framework used for data analysis can be found in **Table 21.**

Table 21 **Triangulation framework (O'Cathain et al. 2010)**
• Analysing the different phases of the study separately; • Listing and comparing findings from all phases side by side; • Looking for convergence, complementarity, dissonance and silence across phases; • Identifying and describing divergences and complementarities; • Developing a coding matrix that included similarities and divergences between phases. Please refer to Appendix W to find the coding matrix. • Developing meta-themes from the coding matrix – themes across findings.

The findings from the different research phases were combined in a single table using the themes of the initial research phase. After this, data were compared across phases and the integrated results were entered in a fourth column. The findings from data integration were analysed and relationships between them explored. As a consequence, recurrent themes were identified, which focused on current practices and best practices when discussing palliative care in COPD and on the factors that impacted/influenced the start and conduct of these discussions. The origin of the information provided in the findings section of this chapter is reported within brackets, for example data from phase 1 is displayed as (1).

7.4 Findings

The systematic literature review provided less targeted data to inform the research subject, when compared with the other phases. However, it had an important role in identifying gaps in knowledge which were then explored in the interviews with patients and clinicians. In contrast, phases 2 and 3 provided in-depth knowledge about the timing and nature of palliative care discussions.

7.4.1 Current practice in discussing palliative care – end of life conversations

The frequency and quality of palliative care discussions in COPD is poor with only 30% of patients reporting a previous discussion with clinicians (1). In fact, only 2 (6%) patients that participated in the interviews reported having had a previous palliative and future care discussion (2). In contrast, previous studies have shown that most patients want to have the opportunity to discuss their preferences with clinicians (1). When discussions did occur, they were more likely to take place in secondary care than primary care (3).

The majority of palliative care discussions were started in hospital, when patients were unwell and approaching the end of life (1, 2 and 3). The timing for palliative care discussions was related to patients' poor prognosis and since it was difficult to ascertain this with accuracy, clinicians focused on specific patient milestones when starting discussions (1 and 3). These included hospital admissions or the start of long-term oxygen therapy (1 and 3). These discussions were difficult and most focused on end of life care and in withdrawing medical treatments (1 and 3).

> *Conversations about treatment preferences were reported to occur when the patient's COPD was advanced or when a serious decline was noted. Furthermore, the majority of physicians chose to initiate conversations when the forced expiratory volume in 1 s (FEV1) was <30%. - Systematic literature review (Tavares et al. 2017) – (Phase 1)*

> *So those conversations, I usually think in terms of if somebody is having frequent exacerbations that come to hospital. And by that they're into hospital 2 to 3 times a year, they are taking a bad trajectory and that's when I have the conversation. I will have discussions with them pretty routinely either when they're in hospital or when they've come back to their follow-up clinic to be seen.*
>
> *(P3, respiratory consultant) – (Phase 3)*

The current timing and type of discussion, which focused on treatment withdrawal, led most patients to prefer future discussions when their condition had severely deteriorated (2). Patients perceived discussions as focused on terminal care and they associated discussions with imminent death, negative emotional impact and clinicians giving up on them (2). Therefore, patients delayed discussions to a distant future.

> *At the moment, I would always be optimistic that I'm going to improve sufficiently to have decent quality of life subsequent treatment. But obviously, if it got to the situation where it might not, then I'd have to think again. But I don't want to face it (discussing preferences with clinicians) until that time comes.*
>
> *(P11, patient with moderate COPD) – (Phase 2)*

Most discussions were started by clinicians rather than patients, which concords with patients' preferences (2 and 3).

> *I'd rather they (clinicians) (start discussions), obviously. They (clinicians) are the experts. They (clinicians) know what's happening, I don't know what's happening to me half the time, do I?* *(P24, patient with severe COPD) – (Phase 2)*

Since most discussions happened in hospital wards, these were usually started abruptly, in a cold manner and were generally brief discussions (3). Moreover, patients were found to be more vulnerable at this time, feeling unwell and closer to death (3). This was believed to lead patients to think that death was imminent and to see discussions as a threatening event (3). As a consequence, clinicians reported tension between damaging hope and discussing the reality of the patient's condition (1 and 3).

> *I know I find it (discussions) a bit harder on the wards. If I just met somebody and when I know they're in a vulnerable situation and it all seems much more real if you see what I mean? Particularly, if it's something (palliative care) that they never kind of considered before. And also, you're much more likely to go in much faster and more cold, because you're not in a clinic room, you know? And it's not all kind of more theoretical, it's actually... That is less comfortable.*
>
> *(P2, respiratory consultant) – (Phase 3)*

In contrast, a smaller proportion of patients preferred to initiate discussions themselves (2). When patients did start discussions they did so in an indirect manner, by providing cues about their readiness to clinicians (3). Patients with advanced disease that preferred to start discussions themselves, also preferred to delay the start of these discussions (2). These patients felt this helped them maintain control of the start of discussions, since they were the ones initiating them (2).

> *I think it will become apparent to me, that I need additional help, before it becomes apparent to anybody else. So, I guess the ball would have to be on my court to seek further advice. Barring a near catastrophe.*
>
> *(P26, patient with severe COPD) – (Phase 2)*

> *I usually start it (the discussion), very rarely you get a patient. Sometimes you get families don't you? I suppose I've had one or two (patients) that talked about it in a roundabout way, because a family member had died of COPD and that sometimes leads to conversations at the start, "I don't want to be like that person, because they*

were so breathless at the end." But it's a minority.

(P3, respiratory consultant) – (Phase 3)

Clinicians and patients seemed to expect different outcomes from palliative care discussions. Clinicians focused on reducing the amount and type of unnecessary treatments provided to patients and, when possible, in gathering patients' preferences for care (3). Therefore, discussions had a practical and well defined outcome, such as producing a DNACPR order (1 and 3). Whilst patients preferred to gather information about their condition and about the different treatments available for their condition (2). This mismatch between patients' and clinicians' perspectives meant that clinicians focused on the negative side of discussions, whilst patients' focused on hope-fostering topics. These differences can impact patients' willingness to start discussions and result in emotional distress for patients.

The quality of end-of-life care communication was rated low, mainly because most end-of-life care topics were not discussed. These topics included talking about spiritual and religious beliefs, what dying might be like and prognosis.

Systematic literature review (Tavares et al. 2017) – (Phase 1)

I think I would ask, what's available if I got that bad. Yeah, what's the best plan and that would come under the palliative care and etc, etc. I'd like to know the details (of my condition), the (treatments) options. I'd like to know if I was going to get better or not. Or if I was going to stay the same or not.

(P31, patient with severe COPD) – (Phase 2)

I can think back to a specific case where the lady in question was housebound and she had very severe COPD, home oxygen and nebulisers. She was needing increasing hospital admissions and we were slowly starting to talk about the fact that perhaps we need to start choosing the time when we don't give antibiotics and we don't admit her to hospital. And sort of accept it's the end of life really. (P13, GP) – (Phase 3)

The impact of discussions in patients' wellbeing varied on an individual basis, some patients were relieved, whilst others were upset and distressed (2 and 3). In clinicians' experience, patients were surprised and upset when the discussion was first started, but appreciative and reassured after some time (3). This may in part be due to the method of starting and conducting the discussion, as well as the type of information shared with patients, as these seemed to influence the impact of discussions (2 and 3). For instance, framing discussions in a negative way (3) or providing negative information about the patients' condition (2) could result in emotional distress for some patients. Nonetheless, the occurrence of discussions was associated with a better perception about death and dying, the care provided and clinicians' skills (1).

The occurrence of discussions was associated with higher health status, and of a higher quality of dying and death. Patients were also more likely to report having received the best possible care, to acknowledge that their provider knew the treatments they wanted and to state that their doctor provided a very good explanation of their breathing problems if they engaged in conversations.

- Systematic literature review (Tavares et al. 2017) – (Phase 1)

I think it would (give me peace of mind), yes. Because I could see them (children) arguing. So, yeah. 'Cause we don't see much of my older son at all. And I can imagine him bulldozing in. Hum... He tried it with my youngest son.

(P18, patient with moderate COPD) – (Phase 2)

I remember once I raised it (palliative care discussion) with someone that was obviously deteriorating and he now had NIV started. I think we actually had a chat with and actually I think I just said to him "I'm going to lay it on line, I'm putting the cards on the table here. These are our options. I'm not saying you're going to drop down dead today, you know? I don't see you dying imminently, but we need to discuss how we're going to support you and your wife." I remember him initially being like "what, what, what?" And then when he realised we were actually looking at how we could support him or keep him at home and stop the pinging in/out he was fine. And actually he had a really nice death in the end and he actually did die in hospital I think, which was his preferred place of death. (P4, COPD nurse) – (Phase 3)

7.4.2 Factors that impact the start and conduct of discussions

Barriers for palliative care discussions delayed and prevented the start of discussions between patients and clinicians (1). The presence of these factors negatively impacted patients' psychological wellbeing when discussions did occur (1, 2 and 3). Therefore, overcoming these barriers could help increase the frequency and quality of discussions (1). Interestingly, patients only identified external barriers that were service- or clinician-related (2). **Table 22** combines the factors that prevented discussions or that resulted in a negative experience for patients when they were present at the start of discussions. These factors were collated from the different phases of the study.

Table 22 **Factors that prevent discussions or result in negative experiences when discussing palliative care**	
Service-related barriers	• Staff shortages (3); • Long waits for appointments (2 and 3); • Poor environment – such as hospital setting (3); • Palliative care services not tailored for COPD patients (3); • GP surgeries amalgamating, creating bigger and impersonal centres (2); • Reluctance of palliative care services to care for patients with COPD (1); • Complex discharge planning for COPD patients (1); • Lack of time (1, 2 and 3); • Lack of continuity of care (1, 2 and 3); • Large workload (2 and 3); • Little or inconsistent training about COPD and palliative care, especially in primary care (2 and 3).
Patient-related barriers	• Severe anxiety (3); • Unpredictable disease trajectory (1 and 3); • Communication impairment or barrier (3); • Cognitive impairment (3); • Negative perception about discussion and emotional distress (1 and 3); • Difficulty in accepting disease severity, future disease progression and death (1 and 3); • Unrealistic expectations about treatments and condition (2 and 3); • Poor understanding about COPD, treatment options and palliative care (1, 2 and 3); • Not wanting to take other people's appointments to discuss a non-urgent problem (2); • Not wanting to engage in discussions (1 and 3); • Unsure about preferences for care (1); • Focused on staying alive (1); • Difficulty in grasping and accepting complex information (about their health status, prognosis and future treatments) in short periods of time (1); • Lack of trust in their physician (1); • Lack of healthcare-related past experiences (3); • Avoidance in upsetting family by starting discussions (3).

Clinicians-related barriers	• Little knowledge about COPD and palliative care (2 and 3); • Difficulty in starting discussions in first encounter (3); • Difficulty in combining active treatment with palliative care (3); • Inconsistent message across different clinicians or settings (3); • Lack of knowledge about the patient's condition (2); • Discussion with non-native English speaking clinicians – difficult to convey the message (2); • Belief that discussions may take away patients' hope (1); • Perceptions that clinical priority is to treat ill people (2); • Lack of feedback and documentation from previous discussions (1); • Difficulty in starting conversations and choosing the right time (1); • Belief that palliative care is only confined to the last days of life and exclusive of life sustaining treatments (1); • Little education and information provided to patients (1); • Uncertainty as to who's responsible to start discussions (1); • Ethos of care: *"cure at all costs"* (1).

7.4.2.1 Patient-related factors

Patient-related barriers for discussing palliative care with clinicians were individual-dependent and were influenced by past experiences (2 and 3). Patients only had basic knowledge about COPD, were unaware of the progressive nature of their condition and the severity of their condition (2). As a consequence, clinicians believed that education about COPD, specifically about the progressive character of COPD was essential, since lack of understanding in both parties prevented the start of discussions (3). Moreover, patients had little to no knowledge about palliative care and saw this as terminal care, exclusive of acute treatments (1, 2 and 3). Little contact with death and lack of discussions about death was seen as a cultural barrier that reduced patients' understanding about palliative care and prevented discussions with clinicians (2 and 3).

> *The vast majority of patients did not recognise palliative care as an option for COPD and some did not understand the meaning of cardiopulmonary resuscitation and of non-invasive ventilation. Overall, patient education about palliative care was ranked as one of the most important topics by patients with COPD.*
>
> *- Systematic literature review (Tavares et al. 2017) – (Phase 1)*

> *People get too carried away about death, don't they? As if it is a taboo subject. You know, I can understand someone about incest, because it might affect them personally, but death you going to get anyway.*
>
> *(P9, patient with moderate COPD) – (Phase 2)*

> *Sometimes you're there trying to explain what intensive care will be like and what HDU would involve and "I'm not really sure you're (patient) understanding, I don't know how much of this you're (patient) really understanding."*

(P2, respiratory consultant) – (Phase 3)

Clinicians found that patients' attitudes towards death and dying also affected their willingness to discuss palliative care (3). These attitudes were individual-specific and included fear, death anxiety and/or non-acceptance of death and dying (1 and 3). In general, relatives and younger patients or clinicians were less acceptant of death, whilst some patients approaching the end of life felt increasingly threatened by the notion of death (3).

> *People avoid these conversations (about palliative care), because nobody wants to die [Laughs]. Just they (patients) thinking to themselves actually, "I'm going to die over the next few months and I can't face that and I don't want my trusted GP to tell me that. I don't want to upset my family." I think there are cultural issues as well. I think in this country people find it very difficult to talk about death and dying, unlike some other countries. And I think there is a culture, I think there is a sociological aspect to all those as well. So from a pure GP medical point of view, I think patients are frightened to talk about it. (P14, GP) – (Phase 3)*

7.4.2.2 Clinician-related factors

Clinicians' characteristics varied on an individual basis, but especially on a professional background basis (3). The presence of COPD expertise was identified as an important factor when starting and conducting discussions with patients (1, 2 and 3), yet most clinicians had only basic knowledge about palliative care (1 and 3). In general, patients preferred COPD-expert clinicians with whom they had an established relationship, regardless of professional background (2).

GPs were considered *"generalist"* clinicians who saw patients with a wide range of conditions, which limited their COPD-specific knowledge and their ability to start discussions (2 and 3). In contrast, COPD consultants and COPD nurses had a larger COPD-related knowledge base and were considered skilled clinicians (2 and 3). Patients saw practices nurses as clinicians with a large knowledge base, however practice nurses did not feel confident in starting discussions and believed they lacked knowledge and training (2 and 3). The labelling of practice nurses as *"COPD nurses"* or *"respiratory nurses"* and the delegation of most COPD management to these clinicians seemed to create an expectation by patients that practice nurses were highly trained and COPD experts (2 and 3). Whilst, practice nurses deferred discussions to GPs, they felt they would be able to initiate palliative care discussions if appropriate training was provided (3).

> *The GP is okay, he's lovely. But he doesn't know a lot about it. He'll say "I'll have to refer you to the practice nurse who deals with it. Because she knows more than I do." He admits those sorts of things. (P16, patient with moderate COPD) – (Phase 2)*

I think it's a bit like the postcode lottery. You can get one practice where the practice nurses are specialists in their own rights. Because they've done courses, they've done the spirometry course and a COPD course. But then there are COPD nurses out there that have done very little courses that pick it up as they go along or they've been like: "See it and do it" from their previous practice nurses.

(P9, practice nurse) – (Phase 2)

Limited access to healthcare professionals was frequently highlighted by COPD patients (2). GPs were particularly difficult to access, especially when patients required longer appointments to discuss palliative care (2 and 3). Secondary care clinicians were also difficult to access by some patients, since patients had to meet certain criteria for referral to secondary care or else they would only see these clinicians when admitted to hospital (2 and 3). COPD nurses were particularly difficult to access, due to their limited geographical availability (2 and 3). On the other hand, practice nurses were considered approachable clinicians and easy to talk to (2).

My GP is terrific, she's absolutely terrific. There is only one thing wrong with her (GP), she's just too terrific. You can't get to see her (GP), hardly ever.

(P27, patient with severe COPD) – (Phase 2)

I had good relationships with patients (when I worked as practice nurse). I had a caseload that I knew really well, that trusted me and probably (patients) were able to see me more. I was more accessible than the GP. They (patients) wouldn't always see the same GP. But if you have a designated COPD nurse (practice nurse), then you've got a caseload of patients. That you will see and review on a routine basis.

(P5, COPD nurse) – (Phase 3)

7.4.2.3 Service-related factors

The lack of time was the most common factor associated with not discussing palliative care with patients (1, 2 and 3). This was primarily reported in primary care by GPs and practice nurses (2 and 3) who described a battle for time and the need to readjust services to be able to cope with increasing demand, compromising patient care (3). Short appointments affected COPD management, but especially palliative care discussions (2 and 3). In addition, patients struggled to access primary care, which led them to only seek medical advice when their condition had acutely deteriorated (2). Since patients did not view palliative care conversations as a priority, they feared taking appointments that could be given to ill people if they wanted to discuss their preferences (2). As a consequence, patients deferred discussions until their condition had significantly deteriorated and they found it difficult to manage on their own (2).

I mean I would hate to take somebody else's urgent appointment, for me to go and discuss what might happen in 10-20 years' time. (…) I don't think the GP has got time for that, they see you when you're ill. They don't see you when you ask those types of questions I don't think. (Patient with moderate COPD, female) – (Phase 2)

We have a very heavy workload. It's not as if we can usually see these people (end-stage COPD patients) every week. These people (end-stage COPD patients) often when they're terminal stage, they need home visits and home visits take a lot of time. There's really not enough time and it's much easier to try and avoid the (palliative care) conversation and get on with your notes. (P14, GP) – (Phase 3)

Patient-clinician relationships were seen as a key factor by both parties when considering starting palliative care discussions (1, 2 and 3). However, service rationing severely reduced clinicians' ability to build and maintain therapeutic relationships with patients (2 and 3). GPs were the clinicians most affected by the lack of a relationship with patients (2 and 3). Since patients struggled to build relationships in primary care, they expected to build a relationship with consultants when they were admitted to hospital (2). However, due to an increased workload and lack of time, consultants found it difficult to build relationships with hospitalised patients (3). Instead, consultants were able to build relationships if patients were followed-up in outpatient clinics (2 and 3). The mismatch between patients' expectations and consultants' capacity in building relationships in hospital seemed to contribute to the reported emotional distress associated with discussions (2 and 3).

I think probably the GP, assuming that you've got the one GP that you regularly go to… Who (GP) knows your history and you have a relationship over the last few years. (P1, patient with mild COPD) – (Phase 2)

I mean a lot of the patients you get to know, so you can see their trajectory and you can see them declining. I mean there are people who've done PR (pulmonary rehabilitation) in the past. May have come through to (exercise) maintenance, been in consultant clinics, you know? You can see what's happening. You can see their admissions become more frequent, their infections become more frequent. So you can see what's happening. But also, through discussions at MDT (multidisciplinary team meetings). It all helps to sort of understand what's going on with that specific patient. (P5, COPD nurse) – (Phase 3)

7.4.3 Best practice when discussing palliative and future care in COPD – patients' preferences and clinicians' recommendations

When starting and conducting palliative care discussions, patients and clinicians placed less relevance on professional background, than in the healthcare professionals' COPD expertise and the existence of a patient-relationship (1, 2 and 3). However, both parties differed on the importance of the healthcare professional characteristics. Clinicians cited the patient-clinician relationship as the most important factor (3), whilst patients preferred to discuss palliative care with COPD expert clinicians with good communication skills and with the ability to assure the achievement of their preferences in the future (2).

> *"A small qualitative study conducted in secondary care, reported that patients desire someone they knew and who knew them when discussing palliative care."*
>
> *- Systematic literature review (Tavares et al. 2017) – (Phase 1)*

> *I'd rather go as far the ladder as I could. (…) Dr XYZ (GP) would have to go through various stages to get to that power. I mean I could talk to her (GP) very easily, she's (GP) smashing. (…) But I think when it comes to this you want someone who's got [pause] both knowledgeable and can put into action what they are saying.*
>
> *(P27, patient with severe COPD) – (Phase 2)*

> *I think that knowing the patient, continuity, does help those conversations. And I think that often when those conversations are clumsy done it is not because of skill of the doctor or nurse who's having the conversation, it's about the knowledge of the background of the patient. So, it does help to know the patient, to build the trust.*
>
> *(P1, respiratory consultant) – (Phase 3)*

Previous studies and clinicians recommended the start of early, regular and gradual discussions throughout the disease trajectory (2 and 3). According to clinicians, early discussions could improve patients' understanding about the progressive nature of COPD and reduce the emotional impact of a future end of life discussion (3). However, only a small proportion of COPD patients preferred early discussions with clinicians (2). Patients that had a better awareness of the progressive nature of their illness seemed to be more likely to prefer earlier discussions (2). These patients were more likely to have clearer preferences on treatments, to prefer planning ahead and to be able to fully share their preferences with clinicians, than patients with preferences for late discussions (2). In addition, patients worried about not being able to discuss their preferences if conversations were started in the distant future (2). Previous literature has shown that palliative care discussions could be anticipated and started earlier, and that early discussions were generally well accepted by patients (1).

In contrast, all respiratory physicians agreed that this should ideally be initiated when a patient was in a stable condition. Conversations should be started early in the disease course or opportunities to start discussions should be identified. This will help to build a therapeutic relationship with the patient.

- Systematic literature review (Tavares et al. 2017) – (Phase 1)

Well, I think I'm coming to that age now and I've got those health conditions. And it's being fair of what possibly could happen and face up to it now. I'm not sure I want to (face it). (P21, patient with moderate COPD) – (Phase 2)

If it's someone I know well, it's something (palliative care) I like to broach early on if I can. As I say even mentioned it, just initiating the discussion. If it's someone you can see declining just over a period of time. At least having it mentioned once or twice, then when you really want to discuss it then it doesn't feel unusual to the patient. It feels like it was something you were naturally coming to. So, I like to be proactive if possible. (P13, GP) – (Phase 3)

The annual review and pulmonary rehabilitation were considered suitable timings for starting or providing information about palliative care discussions (2 and 3). Patients saw these appointments as an opportunity to gather accurate and up to date information about the status of their condition, which could enable them to plan ahead and prepare for the future (2). Practice nurses had good patient-relationships that could facilitate discussions (2 and 3). However, annual reviews were very time limited, which according to clinicians, prevented the initiation of discussions during these appointments (3).

When the review comes up and the medication (review), it would be a good time, wouldn't it? Because by then they (clinicians) would be up to date of what the problems are. (P6, patient with mild COPD) – (Phase 2)

(A regular discussion) could then flag up to patients that things might happen to them, including if you're getting recurrent illnesses or you're really struggling. Then the end of life bit will come up as part of that. Having worked in cystic fibrosis, which I admit it's a very different illness. It's (cystic fibrosis is) clearly life-limiting and public are very aware of that. But that's part of their annual review, so when people (with cystic fibrosis) come to that (review) each year, there is a section that is just set aside for that kind of planning. "What would you expect to happen in the next year?" That would mirror people with moderate and severe COPD, who could start having those conversations. (P1, respiratory consultant) – (Phase 3)

When discussing palliative care, patients preferred to receive honest information about their condition, treatments options and outcomes (1 and 2). In contrast, a small proportion of patients preferred gradual and sensitive information that was not upsetting or that would not reduce their hope (2). Therefore, patients and clinicians recommended that clinicians tailor approaches to address patients' needs and preferences (2 and 3). Indeed, both parties agreed that discussions should be patient-centred and patient-led (3). In line with previous literature, clinicians recommended avoiding the use of strong and death-related words in an effort to limit the emotional impact of discussions on patients (1 and 3).

> *Patients and healthcare professionals reported tension between remaining hopeful and the reality of the patients' condition, as this could pose a barrier for conversations and have an emotional impact on them. Some patients believed that frank prognostic information might negatively impact their hope and increase symptoms of anxiety and depression; therefore, some physicians purposely withheld information to avoid this. Finally, many patients expressed the importance of individualising the clinician's approach for hope and prognosis, and of longstanding relationships with physicians.*
>
> *- Systematic literature review (Tavares et al. 2017) – (Phase 1)*

> *(I expect) honesty from the doctors, and that means talking to me. Obviously compassion, but I don't want to be poked, prodded, blood tests every day and "we try this and we try that." (…) Straight forward and honest (information). That's what I want the doctors to be with me. Hum... I can't put it in any other way.*
>
> *(P17, patient with moderate COPD) – (Phase 2)*

> *I don't think I would be talking about palliative care with them. I would be talking to them as an individual and how they feel about what's going to happen? And how do they feel about dying? Where do they want to be at that stage of their life? I wouldn't probably mention the word palliative, because they wouldn't understand what that means.* *(P10, practice nurse) – (Phase 3)*

In line with previous studies, patients preferred to receive in-depth information about the severity of their condition, the future and about the different treatments available (1 and 2). Patients believed that this information could help them make informed decisions and in sharing the decision making process with clinicians (1 and 2). However, clinicians recommended providing small amounts of information over time, since they believed patients struggled to retain and grasp large amounts of information (3). This difference in perspective may have caused the general lack and delay in information reported by patients, since clinicians struggled to provide information overtime (2 and 3).

When patients were asked how much information they wanted, the initial answer was "all information"; however, simply asking this was not adequately enough to elicit informational needs.

- Systematic literature review (Tavares et al. 2017) – (Phase 1)

Oh yeah, I mean I believe you should know everything, because you can make an informed decision if you know everything. If someone is going to hold something back, then it's not going to be beneficial. I wouldn't like to make a decision, having kept this back and the treatment was going wrong because I didn't know the full story.

(P29, patient with severe COPD) – (Phase 2)

I think they just want enough information. One reason I like to have these discussions over a few meetings is because there's just so much you can focus on potentially. And you just need to break it down a bit, so that they can chew it over themselves and decide what's best for them. I think it's just the case of anything in primary care, but if you go and give them lots of information, whether it's verbal or written information. I think it's overwhelming for them if it's all delivered at once. (P13, GP) – (Phase 3)

7.5 Discussion

Summary of the findings

Current and best practices when starting and conducting palliative care discussions in COPD varied greatly. Discussions in COPD are uncommon, but when discussions did occur they were generally brief and abrupt, started by unfamiliar clinicians and with hospitalised patients with advanced COPD. In contrast, evidence from the literature, as well as from our interviews with patients and clinicians suggests that discussions should be started early, occur regularly and develop overtime. Moreover, patients should be able to discuss palliative care with well-known and competent clinicians. Many factors prevented clinicians from having early and regular discussions with patients though service rationing was the largest barrier.

Discussions of the findings

In line with previous research, current conversations were started when patients had advanced COPD or when a significant deterioration was noted (Sullivan et al. 1996; McNeely et al. 1997; Gott et al. 2009; Gaspar et al. 2014). Consequently, late discussions may result in negative experiences for patients and clinicians. One consequence of late discussions is that they occur during hospitalizations (Tavares et al. 2017; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). In general, hospitalised patients have a brief and abrupt discussion about

end of life with a clinician that they had never met before (Tavares et al. 2017; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). As a result, clinicians reported that most patients were *"shocked"* and *"distressed"* when discussions were started (Tavares et al. 2019 [under review]-b). Discussions were rushed since clinicians' lacked time for in-depth discussions and patients were close to death (Clayton et al. 2005). Hospital admissions were experienced as chaotic events with poor continuity of care, where patients were too unwell to be able to fully participate in discussions (Say and Thomson 2003; Seamark et al. 2012; Luckett et al. 2018). A previous study has suggested that patients were only able to marginally participate in discussions during hospital admissions, since they had reduced mental faculties (Seamark et al. 2012). In addition, since current discussions occurred when patients were approaching the end of life, clinicians' and services' struggled to plan, coordinate and implement care (Epiphaniou et al. 2014; Faes et al. 2016). The lack of time associated with late discussions leaves little room for preferred care to be implemented effectively, which can result in patients receiving less care and support, and in negative experiences at the end of life (Johnson and Booth 2010; Epiphaniou et al. 2014; Mathews and Johnston 2017).

Patients and clinicians often confused palliative and future care discussions with end of life and death conversations. This was illustrated by clinicians' focus on treatment withdrawal and in starting discussion when patients had end-stage COPD, such as during an acute hospital admission. Moreover, clinicians believed that offering palliative care meant a cessation of hope and giving up on patients, rather than providing care that focused on reducing symptom and treatment burden (WHO 2016). In fact, previous studies have noted healthcare professionals ' poor understanding of palliative care, as it is viewed as a failure of acute care (Hanratty et al. 2006; Prem et al. 2012). Indeed, we found that clinicians' poor understanding about palliative care contrasted with patients' preferences for discussions with clinicians expect in COPD and palliative care (Tavares et al. 2019 [under review]-a). The root of misunderstandings about palliative care seems to be multifactorial, arising from an *ethos* of care focused on "cure at all costs," lack of training about palliative care and a belief that palliative care is a nurses' job (Hanratty et al. 2006; Gott et al. 2009). Consequently, we found that clinicians avoided or framed discussions in a negative way, which resulted in emotional distress for patients. The combination of avoiding discussions and in framing them negatively largely impacted patients' perception about palliative care discussions, which often resulted in patients avoiding discussions. Providing training to clinicians about the *ethos* and meaning of palliative care is paramount (Duenk et al. 2017; Smallwood et al. 2018a).

Patients' preferences for late palliative care discussions with clinicians was related to their understating about palliative care and COPD. Previous studies have shown that COPD patients

have extremely limited awareness about palliative care (Fahim and Kastelik 2014; Carlucci et al. 2016). Patients often drew on their own and/or other people's experiences to construct their understanding about palliative and advance care planning (Simon et al. 2008). This means that patients saw palliative care discussions as terminal discussions that aimed at stopping their treatments and care (Tavares et al. 2019 [under review]-a). This poor understanding led patients to delay discussions to the distant future as they thought this would allow them to continue receiving treatments and care (Tavares et al. 2019 [under review]-a). Another adjuvant for late discussions was the little understanding about the progressive character of COPD, especially about the current status of their condition (Fahim and Kastelik 2014; Tavares et al. 2019 [under review]-a). In line with other studies, patients often reported a lack of information about the progress of their condition and called for frequent, honest and in-depth information from clinicians (Tavares et al. 2017; Tavares et al. 2019 [under review]-a). Poor understanding about COPD has been associated with patients' being less able to start and participate in discussions, and with less preferences for discussions with clinicians (Clayton et al. 2005; Siouta et al. 2016). Thus, previous studies have found that COPD understanding significantly impacted patients' ability to access healthcare services, and reduced their quality of life and ability to self-manage (Giacomini et al. 2012; Georgopoulou 2014; Etkind et al. 2017b). However, in line with previous research, clinicians feared that providing negative information about disease severity would damage patient hope, and this led them to withhold information (Knauft et al. 2005; Curtis et al. 2008). In order to improve understanding, clinicians recommended further information at diagnosis about the progressive nature of COPD and about the need for regular and gradual discussions with patients (Tavares et al. 2019 [under review]-b).

The accumulated evidence suggests that a viable solution to reduce distressing and late palliative care discussions in COPD includes early discussions between patients and clinicians. Early, regular and gradual discussions between patients and clinicians about how patients experience their condition and its treatments and offering less burdensome treatments that fit their preferences may avoid the concerns highlighted above (Tavares et al. 2019 [under review]-b). Instead of emotionally loaded and negative conversations at and about end of life, time-evolving and regular discussions from diagnosis that evolve over time from generic and brief to specific and in-depth discussions may prove more beneficial. Incorporating these discussions during the annual review was suggested by clinicians as a potential approach. Embedding patient-centre discussions throughout the disease trajectory may provide an opportunity for patients to share concerns about their condition and their preferences for future care, which may result in patients receiving less aggressive treatments (May et al. 2014; Scheerens et al. 2018). Previous research has suggested that early palliative care discussions were associated with better experiences and reduced treatment burden at the end of life, resulting in greater quality of life for patients (Gomes

et al. 2014; Higginson et al. 2014a). Reducing treatment burden can be achieved by a change into a culture of care that uses regular discussions about how patients are coping with their condition and the support they need to self-manage (Higginson et al. 2014b; May et al. 2014). Despite this, further research is required to understand how early discussions about palliative care are accepted by patients and how to integrate palliative care discussions effectively in current care.

7.6 Conclusion

The current approach towards palliative care discussions results in a lack of conversations between patients and clinicians, distressed patients, and overuse of burdensome treatments at the end of life. Regular and gradual discussions that focus on patients' illness and treatments experiences and in offering treatments based on patients' preferences and coping mechanisms might avoid the emotional impact of late discussions. These discussions ensure that care is patient-centred and increase patients' and clinicians' understating about the benefits of palliative care. Early discussions promote a culture of open awareness about the progressive nature of COPD and of shared decision making, by empowering patients.

Chapter 8 Discussion

8.1 Introduction

This chapter reviews the research questions that directed the research study and the findings generated from the 4 different research phases. These findings have been integrated in the previous chapter, in an effort to answer the research questions. The research phases were designed, developed and analysed using a pragmatic approach and aimed to provide novel insight that could help solve a clinical issue, by shaping clinical practice. Consequently, the discussion of findings in this chapter has also been achieved using a pragmatic and clinically orientated approach. Here, findings are contextualised using literature that focuses primarily on COPD, but also on patients with other long-term and life-limiting conditions. Literature related to other conditions has offered insights where there is insufficient research in COPD populations and facilitated comparisons between care practices for COPD and other conditions.

The second part of this chapter discusses the implications of the findings for clinical practice and the need for further research. This includes considerations about integrating the research findings into clinical practice and pinpointing areas that require further investigation and understanding. Lastly, the chapter provides a critical appraisal of the research phases and highlights the overall limitations of the study.

8.1.1 Purpose of the study and research questions

The overarching aim of the study was to understand the timing and nature of palliative care discussions between COPD patients and clinicians. This was achieved through exploring previously published literature, patients' preferences for palliative care discussions and clinicians' opinions regarding the start and conduct of these discussions. Interviews were conducted with COPD patients at different stages of the illness trajectory and clinicians from a range of professions involved in the care of people with COPD. Considering the purpose of the study, the following research question was developed - "How do COPD patients' preferences and clinicians' judgements shape the timing and nature of palliative care conversations?" Answering this question may help understand the barriers for conversations and how these could be addressed, in order to increase the likelihood of palliative care conversations. This understanding may assist clinicians to initiate and conduct discussions with patients, based on patients' preferences; and assist commissioners and managers to develop and tailor services to patients' needs. Secondary research questions were developed and can be found in Chapter 3.1 and page 23.

8.2 Summary of the findings

Most patients favoured an opportunity to discuss palliative care, however only less than a third of COPD patients reported having a discussion with a clinician. When discussions did occur, they took place with end-stage COPD patients and were rated by patients as having poor quality. Moreover, patients were acutely unwell at the time of the conversation and discussed their preferences with clinicians that did not know them. Noisy and busy hospital wards were a common place for discussions and topics focused on treatment withdrawal and end of life care. As a consequence, discussions were seen as negative events that most patients' avoided or deferred to the distant future.

In contrast to current clinical practice, patients reported a preference for conversations with a competent, skilful and well-known clinician. However, service-related barriers limited clinicians' availability to see patients and to build long-term relationships with them. Clinicians recommended early discussions, whilst patients preferred to delay them until their condition severely deteriorated. Patients' preferences for late discussions seemed to be related to their poor understanding about the progressive character of COPD and about palliative care; and to healthcare-related barriers that prevented them from accessing services/clinicians with whom they could have these conversations sensitively and appropriately. Patients wanted to discuss their preferences for treatments and care with clinicians, but not at the present time. Patients with mild and moderate forms of COPD preferred to wait for clinicians to start the conversations, whilst patients with advanced COPD preferred the opposite. In general, patients preferred large amounts of information about disease progression and treatments. However, clinicians argued that an individual-based approach should be chosen when starting and conducting discussions with patients. This approach was thought to limit the impact of discussions on patients' hope and in upsetting the patient when starting discussions.

The results suggest that starting early and gradual discussions with patients can reduce the impact of discussions on patients, increase their willingness to engage in conversations about future care and treatments, and prepare them for in-depth palliative care discussions with clinicians later in life. At diagnosis, discussions should focus on managing mild exacerbations and establishing action plans for the immediate future. Overtime, conversations can evolve to discussing patients' preferences and capacity to cope with complex inhaler and medication regimens, and aggressive treatments, such as hospitalizations, ventilatory support and lung volume reduction surgery. These cumulative discussions can offer an opportunity for disease severity and prognosis information to be provided. As a result of these cumulative and gradual discussions, specific burdensome treatments, such as ITU admissions with mechanical ventilation, can be transitioned

to more comfortable care, such home-based care with increased support/monitoring. In addition, discussions can focus on disentangling treatment burden and in deciding which and how to tackle conditions, in an effort to reduce the patient workload and suffering associated with treatments (such as severe pain caused by repeated arterial blood gas tests). The natural occurrence of future care discussions throughout the disease trajectory, can ensure that symptom and treatment burden is reduced, rather than increased.

Patient, clinician and service-related barriers prevented the start of early discussions in COPD. The focus on reducing avoidable barriers, such as poor knowledge about COPD and palliative care in patients and clinicians, may facilitate and enable the integration of palliative care discussions early in the disease trajectory. However, further research is required to explore the impact of reducing these barriers on early palliative care discussions.

8.3 Discussion of the findings

The discussion of the research findings in relation to previous literature has been divided into four themes. These themes follow the structure and approach used in the Phase 4 – Chapter 7 and page 95. This resulted in the following themes:

- Late discussions at and about end of life care;
- Early, regular and gradual discussion with patients;
- Clinicians factors that impact palliative care discussions;
- Service related factors that prevent discussions with patients.

At the end of this chapter, a critical appraisal of the research study is discussed and recommendations for clinical practice and future research are presented.

8.3.1 Late discussions at and about end of life care

This study highlighted that palliative care discussions were started very late in the disease trajectory and that most patients did not have an opportunity to discuss their preferences. Only two patients had ever discussed palliative care and both had very severe COPD, several COPD-related hospital admissions and were at a high risk of deterioration and death (Tavares et al. 2019 [under review]-a). Similarly, clinicians reported that they usually initiated discussions when patients had advanced disease and were approaching the end of life (Tavares et al. 2019 [under review]-b). However, clinicians stated that earlier discussions could take place if they were started by patients (Tavares et al. 2019 [under review]-b). Previous studies have shown similar findings, in that conversations were only started when patients had advanced COPD or when a sudden and severe decline was noted (Sullivan et al. 1996; McNeely et al. 1997; Gott et al. 2009; Street and

Haidet 2011; Gaspar et al. 2014). Clinicians focused on specific triggers when starting discussions with patients (Tavares et al. 2019 [under review]-b). These triggers, which have also been reported in the literature, included the presence of other comorbidities, the start of long-term oxygen therapy and severe anxiety or depression (Sullivan et al. 1996; McNeely et al. 1997; Tavares et al. 2019 [under review]-b). Novel insight from this study has shown that patients preferred to discuss palliative care in the future, even as their disease severity increased. In fact, patients used "self-prognosis" to determine when to start discussions with clinicians (Tavares et al. 2019 [under review]-a). Patients' preferences for late discussions seemed to contradict clinicians and literature recommendations for early and gradual discussions with patients (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b).

Late palliative care discussions were started when patients with advanced disease were acutely unwell and admitted to hospital (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). In fact, one out of the two patients had his first discussion as an inpatient (please refer to Chapter 5.4 and page 64 for more information). This gentleman had very severe COPD and was acutely unwell in hospital receiving aggressive treatments, such as NIV. This gentleman was told that his chances of survival were low, especially if he developed another chest infection. In this case, discussions about treatment withdrawal and preferences for care were continued in outpatient consultant clinics, after hospital discharge (Tavares et al. 2019 [under review]-a). Similarly, secondary care clinicians reported that most discussions occurred when patients were unwell and admitted to hospital (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Discussions during respiratory outpatient appointments and in primary care were uncommon (Tavares et al. 2019 [under review]-a). The causes of patients' preferences for late discussions and their disadvantages are considered and discussed below.

Late and hospital discussions were associated with several disadvantages that had a large impact on clinicians, but especially on COPD patients. The first disadvantage was associated with discussions started during hospital admissions and included lack of continuity of care. Previous research has suggested that patients never know who will be looking after them when admitted to hospital (Curtis et al. 2005; Knauft et al. 2005). Despite this, some of the patients interviewed believed that they were able to develop "instant" relationships with clinicians, while admitted to hospital and expected compassionate discussions with these clinicians (Tavares et al. 2019 [under review]-a). However, at present, most ward-based discussions were started with clinicians that had never met the patients and in the first encounter (Tavares et al. 2017). In agreement with previous research conducted in advance cancer, clinicians reported starting hospital-based discussions using a cold and abrupt approach (Clayton et al. 2005; Tavares et al. 2019 [under review]-b). This approach seemed to be related with patient's very severe condition and the

imminence of death, lack of time and lack of patient-clinician relationship (Clayton et al. 2005; Tavares et al. 2019 [under review]-b). Late and abrupt discussions seemed to have a negative emotional impact, since clinicians reported that patients were *"shocked and distressed"* when discussions were started (Tavares et al. 2019 [under review]-b). This suggests that patients were either not expecting or ill-prepared when discussions were started; or that the approach used when discussing palliative care was not the most appropriate. Other disadvantages and consequences of late palliative care discussions are discussed below.

8.3.1.1 Patient participation in the conversation

This study and previous research indicate that clinicians and patients strongly believe that discussions should not be started during acute exacerbations of illness (Seamark et al. 2012; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). These preferences contrast with clinical practice, where it is routine for discussions to occur when patients are acutely unwell and in hospital. Seamark and colleagues (2012) have shown that patients admitted to hospital do not recall palliative care discussions with clinicians. This may be because, hospital admissions were chaotic and patients reported lack in continuity of care (Say and Thomson 2003; Seamark et al. 2012). Hospitalised patients were too ill to engage in conversations and some inpatients even experienced hallucinations (Seamark et al. 2012; Luckett et al. 2018). Starting discussions at this time prevented patients from fully engaging with clinicians, since they were too ill to participate (Seamark et al. 2012; Luckett et al. 2018). It is perhaps for these reasons that patients considered a discussion about current status and near future more tangible than in-depth discussions about care/treatments preferences for a distant future (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). In-depth palliative care discussions require patients to understand the severity of their condition, to understand the treatments available and their likely outcomes and to think and share their preferences for care with clinicians (Scheerens et al. 2018). Since patients' cognitive abilities may be temporarily compromised at this time, patients cannot fully participate in discussions and in sharing the decision making process with clinicians (Seamark et al. 2012; Jerpseth et al. 2018; Kayyali et al. 2018).

Patients' compromised ability to participate in palliative and future care discussions can result in relatives acting as their care advocates (White et al. 2019). However, previous research has highlighted mismatches in patients' and relatives' preferences for care/treatments, with families favouring more aggressive treatments (Chen et al. 2019; White et al. 2019). In fact, patients' preferences for care at the end of life seems to contradict their preferences for late discussions with clinicians, since they preferred a natural death at home with little suffering and no medical intervention (Curtis 2008; Beernaert et al. 2013; Bereza et al. 2015; Tavares et al. 2019 [under

review]-a). Instead, late palliative care discussions can result in patients receiving more aggressive treatments and in “comfort care” only being started at the end of life (Lilly and Senderovich 2016). This study found that conflict between patients’ preferences for future care and discussions with clinicians seems to be associated with their poor understanding about the aim and meaning of palliative care. Patient’s understanding about palliative care will be discussed later in this chapter.

Patient participation in palliative and future care discussions can lead to a reduction in symptom burden as their condition deteriorates, whilst also reducing the treatment burden (Lilly and Senderovich 2016). Burden of treatment is a published theory that encompasses patients’ perceptions of the workload and resources that they devote to healthcare-related activities and its direct effect on patient functioning and wellbeing (Boyd et al. 2014; May et al. 2014; Dobler et al. 2018). Patients with life-limiting conditions, such as COPD, experience growing demands when organizing and co-ordinating their care and when complying with complex treatment regimens (May et al. 2014). Patients need to organize and comply with treatment regimens in order to effectively self-manage (May et al. 2014). However, treatment burden can be overwhelming for patients, especially as disease trajectory advances, treatments become increasingly morecomplex and patients develop other co-morbidities (May et al. 2014; Dobler et al. 2018). Patients require capacity to deal and manage the treatment burden associated with their various health conditions (Shippee et al. 2012; May et al. 2014; Dobler et al. 2018) Burden of treatment and capacity to cope with treatments are intertwined, and imbalances in any of the two can result in increased strain on patients and caregivers, poor adherence to therapies and poor healthcare outcomes for patients, such as little quality of life (May et al. 2009; Shippee et al. 2012; May et al. 2014). In order to reduce workload and increase patient’s capacity to cope with treatments, a different approach towards healthcare has been proposed – minimally disruptive medicine (May et al. 2009). This approach seeks to tailor treatment regimens to the realities of patients’ lives and in providing patient-centred care (May et al. 2009). Caregivers can also prevent imbalances between workload and capacity, since they support patients and substantially contribute with practical work around illness management (Vassilev et al. 2013; Lippiett et al. 2018).

Since COPD patients often have multiple chronic comorbidities, they need to cope with increasingly morecomplex treatment regimens from several different healthcare professionals and work to normalise these in their daily lives (May et al. 2009; Shippee et al. 2012). In order to avoid this, patient involvement through discussions must be a central part of disentangling treatment burden and in deciding which and how to tackle conditions, in an effort to follow principles of minimally disruptive medicine (May et al. 2009). Thus, these discussions allow clinicians to provide holistic care to patients with multiple morbidities resulting in structured and

coordinated care (May et al. 2009; Shippee et al. 2012). This model of care seems to concord with patients' preferences for comfort care at the end of life and a minimally medicalised death (Tavares et al. 2019 [under review]-a). Therefore, palliative care discussions in COPD need to make principles of Burden of Treatment Theory a central component of their focus.

8.3.1.2 Perceptions about COPD and palliative care discussions

Because current practice involves late palliative care discussions, often during periods of rapid deterioration, patients interpreted these discussions as about end of life care and treatment withdrawal. As a consequence, discussions were associated with imminent death and a sense of *"giving up,"* which, according to health professionals, seemed to result in reduced hope and lower mood for patients (Tavares et al. 2019 [under review]-b; Tavares et al. 2019 [under review]-a). Similar findings have been reported in previous research which has suggested that whilst patients wanted to discuss their views about future care, they felt uncomfortable with the traditional model of binding "advance directives" (MacPherson et al. 2013). This discomfort was related to future uncertainty, which will be discussed later this chapter (MacPherson et al. 2013). Since patients did not self-assess their condition as terminal and misunderstood the purpose and benefits of palliative care, patients delayed discussions for the distant future, when they believed they were likely to be approaching the end of life (Tavares et al. 2019 [under review]-a). As a result, palliative care discussions were only started when they became almost impossible to avoid, at the end of life.

Patients continued to delay discussions with clinicians as their disease advanced (Tavares et al. 2019 [under review]-a). No difference in preferences for the timing of palliative care discussions was found between patients with mild, moderate or severe/very disease COPD (Tavares et al. 2019 [under review]-a). Preferences for timing of discussions were expected to change as patients' symptom and treatment burden, and disease severity increased (Pinnock et al. 2011; Harb et al. 2017; Reinke et al. 2017). The lack of change in patients' preferences for late discussions as their disease severity increased may suggest that the issues reside in clinicians' approaches when starting and conducting discussions and/or in patients' poor understanding of the overall progress of their condition. These conversations were started late in the disease trajectory and focused on treatment withdrawal. In fact, understanding how patients' preferences changed throughout the disease trajectory was one of the reasons why patients at different stages of disease severity were recruited (Tavares et al. 2019 [under review]-a). This type of study allowed the measurements of patients' preferences for discussions at different points of the COPD disease trajectory (Sinclair et al. 2017). However, patient interviews and a recent study have shown that the presence of an increased symptom and treatment burden, or an increased disease severity were not associated with an increase in engagement nor with an increase in

preferences for palliative care discussions (Reinke et al. 2017). Thus, patients' preferences for aggressive treatments, such as resuscitation, could not be predicted simply based on their disease severity (Gaber et al. 2004; Tavares et al. 2019 [under review]-a).

Another reason for avoiding discussions is future uncertainty inherently related to their unpredictable disease trajectory. Future uncertainty frequently distresses patients, which results in poor adaptation to their condition, adverse coping strategies, and in pursuing unrealistic treatments and care (Etkind et al. 2017b). Patient uncertainty seems to be caused by disease complexity, poor information provision and the unpredictability or ambiguity of events (Etkind et al. 2017b). Furthermore, patients may feel insecure if clinicians appear to be in doubt about which treatments are best (Say and Thomson 2003). Uncertainty influences patient experience by affecting their information needs, preferences and future priorities for care (Etkind et al. 2017b). This uncertainty can result in unreasonable patient expectation, which makes consensus more difficult to achieve during palliative care discussions (Montgomery and Fahey 2001; Say and Thomson 2003). Whilst clinicians can be reluctant to raise uncertainty with patients, research suggests that responding and sharing uncertainty with patients may decrease their anxiety (Say and Thomson 2003; Etkind et al. 2017b). Further, better understanding and communication around uncertainty in the clinical setting can improve information provision, help to engage and empower patients and facilitate patient-centred care (Say and Thomson 2003; Etkind et al. 2017b).

Patients' limited and misconstrued understanding about palliative care seemed to act as a contributing factor for late discussions. Patients' perceptions about palliative and advance care planning was largely grounded in current practices for palliative care discussions (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Since patients were only offered discussions at and about end of life care that focused on treatment withdrawal, patients constructed their understanding based on this (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Instead, palliative care should be seen as a philosophy that aims at helping people to focus on 'living with' rather than 'dying from' an advanced illness (Luckett et al. 2018). As a consequence, patients adopted a defensive stance towards end of life discussions viewing it as removing treatments from them and possibly shortening their life (Tavares et al. 2019 [under review]-a). Since patients perceived these discussions as death conversations their attitude towards death impacted discussions with clinicians (Tavares et al. 2019 [under review]-a). In agreement with previous studies, clinicians reported that patients often experienced death anxiety, which led them to avoid or delay discussions with patients that they believed required palliative care (Brown et al. 2014; Tavares et al. 2019 [under review]-b). This may explain why

death anxiety has been shown to result in lower quality of life and poor experiences at the end of life (Cella and Tross 1987; Sherman et al. 2010).

Clinicians and policymakers also share a poor understanding about palliative care with patients. This poor understanding about palliative care may be related to the lack of clarification and standardization of these terms, which can result in limited access to palliative care for patients (Lynn and Adamson 2003; O'Neil et al. 2008; Shipman et al. 2008; Luckett et al. 2018; Tavares et al. 2019 [under review]-b). The language typically associated with palliative care often assumes that it means turning away from conventional/curative care (Lynn and Adamson 2003). However, chronically ill patients routinely blur this distinction, since they need a mix of both types of care (Lynn and Adamson 2003). Previous literature has suggested that patients and clinicians may favour the term supportive care rather than palliative care, since supportive care is associated with managing problems associated with active treatments (Luckett et al. 2018).

The need for standardizing and clarifying terms goes beyond COPD and involves other life-limiting conditions, such as heart and kidney failure. In heart failure, clinicians mistakenly believe that palliative care should only be provided to end of life patients facing death (Okumura et al. 2018). Thus, recent research has shown that clinicians had limited comprehension on how palliative care could complement medical therapies and the value of palliative care for heart failure patients (Okumura et al. 2018). Poor understanding seemed to be related to the prognostic uncertainty in heart failure, which makes it difficult to plan towards fulfilling patients' end-of-life wishes (Okumura et al. 2018). Similar findings were reported in chronic kidney disease, where clinicians lacked understanding about palliative care, due to the unpredictable disease trajectory and the lack of training (Sturgill and Bear 2019). The clarification of these terms in life-limiting conditions - palliative care and end of life - may reduce confusion for patients and clinicians, improve access to care and increase discussions about palliative care (Shipman et al. 2008).

Another cause for late discussions includes patients' poor understanding about the progressive nature of COPD, the severity of their condition and the treatments available. Poor understanding resulted in patients' inability to envision end of life and to recognize the need to plan ahead (Roberts et al. 2008b; Giacomini et al. 2012; Gauronskaite et al. 2016; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). As a result, patients adapted to their new condition and hoped to recover from exacerbations, which they did not necessarily see as potentially fatal (Giacomini et al. 2012). In fact, patients' distorted illness perceptions were significantly associated with limited healthcare access and poor quality of life (Georgopoulou 2014). As a consequence and in line with previous research, patients found it difficult to start discussions themselves and were less likely to participate in conversations (Clayton et al. 2005; Siouta et al. 2016; Tavares et al. 2019 [under review]-a). Although patients wanted to be involved

in decision making, they did not wish to make the final treatment choice, since they lacked knowledge and experience, and were afraid of making the wrong decision (Say and Thomson 2003). In line with previous research, this study suggests that poor understanding about COPD seems to be related to a lack of information provided by clinicians about the severity of the patient condition, especially about their progress over time, and about the treatments available (Gott et al. 2009; Gardiner et al. 2010; Siouta et al. 2016; Gardener et al. 2018; Tavares et al. 2019 [under review]-a). Patients had little knowledge about the treatments available for their condition and inhaler therapy was often mentioned as their sole COPD treatment (Tavares et al. 2019 [under review]-a). As a result of patients' poor understanding about the different treatments available, they may voluntarily or involuntarily choose burdensome treatments and in unnecessary suffering. This contrasts with patients' pursuit for treatments with a negligible burden associated (Tavares et al. 2019 [under review]-a).

In an effort to improve patients' understanding of COPD, palliative care and treatments available, it has been suggested that clinicians must provide technical information that is clear and unbiased to ensure that patients' preferences for care are based on facts and not misconceptions (Say and Thomson 2003). Lack of awareness and future uncertainty about COPD may have led patients to believe that discussions were not a priority, which supported a tendency to avoid them.

8.3.1.3 Social determinants and their impact on healthcare access

Another contributing factor for late discussions is patients' lower socioeconomic status, since health inequalities are inextricably linked with social inequalities (Prescott and Vestbo 1999; Collins et al. 2018). Interestingly, the importance of social determinants and their impact in patients' healthcare choices was barely mentioned during the clinician interviews (Tavares et al. 2019 [under review]-b). Socioeconomic deprivation is common in COPD and has been associated with limited healthcare access, reduced quality of life and a higher number of comorbidities (May et al. 2009; Georgopoulou 2014; Strauss et al. 2014). Furthermore, deprivation reduces patients' ability to self-manage and to seek timely support, which results in common COPD patterns of increased emergency care use, worsened health outcomes and increased mortality (Pleasants et al. 2016; Collins et al. 2018). Lower socioeconomic status limits patients' power and participation in discussions, since a lower status has been associated with reduced understanding and perception of their condition (Prescott and Vestbo 1999; Roberts et al. 2008b; Gauronskaite et al. 2016; Cole et al. 2017). Indeed, patient education is an important factor when improving disease knowledge and eliminating health inequalities (Lisspers et al. 2014). COPD patients need knowledge and power when sharing the decision making process or discussing palliative care (Fahim and Kastelik 2014; Joseph-Williams et al. 2014). However, patient knowledge alone is

insufficient and power to participate in discussion can be difficult to attain (Joseph-Williams et al. 2014).

Lower socioeconomic and its inherent impact on patients' ability to seek and participate in healthcare activities may have been a contributing factor for patients preferring late palliative care discussions (Korpershoek et al. 2016). In this study, low socioeconomic status seems to have contributed to patients' feeling that they lacked permission and capacity to raise palliative care discussions with clinicians or steer the consultation in that direction (Tavares et al. 2019 [under review]-a). This lack of permission/ability to raise discussions was highlighted in interviews where patients reporting only seeking care at times of crisis and in avoiding "bothering" healthcare professionals with "less pertinent" issues, such as their preferences for future care (Tavares et al. 2019 [under review]-a). In order to increase patients' confidence and self-efficacy in seeking help and in participating in healthcare related activities, previous research has suggested empowering patients through patient education (Disler et al. 2016; Luckett et al. 2018; Yadav et al. 2018). Thus, patients should be supported as collaborative decision makers in discussions and in challenging clinicians to relinquish the authoritative role in place of an equal partnership (Disler et al. 2016). Collaborative decision making can be difficult to achieve and decision-making models have not been particularly successful in evening out the power deferential between patients and professionals (Sullivan et al. 1996; Makoul and Clayman 2006).

As describe above, limited access to healthcare can result in patients only seeking support at times of crisis and in delaying palliative care discussions with clinicians. In line with previous evidence, this study found that some patients avoided bothering healthcare professionals and did not actively express a wish for help, which delayed seeking help even in acute exacerbations (Habraken et al. 2008; Shipman et al. 2009; Tavares et al. 2019 [under review]-a). In addition, help-seeking behaviours have been found to be influenced by perceptions of ease of access, quality of relationship with their GP, and perceived disease severity and threat (Shipman et al. 2009; Tavares et al. 2019 [under review]-a).

Limited access to healthcare, a common theme in patient interviews, was likely to prevent the start palliative care discussions (Tavares et al. 2019 [under review]-a). COPD patients reported long waits for appointments, even when seeking treatment for acute exacerbations, and a general lack in continuity of care (Tavares et al. 2019 [under review]-a). Previous research has clearly suggested a link between limited access to care and increased hospitalizations, decreased access to respiratory specialists and patients' needs not being met (Lisspers et al. 2014; Kim et al. 2016). In contrast, good access to healthcare services may enable patients and clinicians to openly discuss care needs and develop action plans (Shipman et al. 2009). In addition, limited healthcare

access seems to affect patient willingness and readiness to discuss palliative care (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b).

8.3.1.4 Readiness for discussions

Patients' willingness and readiness were highlighted by clinicians as important factors when starting discussions with patients (Tavares et al. 2019 [under review]-b). The review conducted in Phase 1 highlighted the importance of patients' willingness when discussing palliative care and that about a third of patients that participated in two studies did not wish to discuss palliative care (Au et al. 2012; Leung et al. 2012). As a consequence, starting conversations or giving healthcare information to patients who do not want them can cause undue anxiety and distress (Barnes et al. 2012). Previous research suggested that patients were reluctant for clinicians to initiate discussions for fear of harming themselves, if they were not ready to think about those issues (Clayton et al. 2005). A recent study has suggested that readiness was associated with patients' and other people's previous experiences, social support and proactive interventions from clinicians (Sinclair et al. 2017). Previous research has explored ways that helped predict changes in COPD patients' readiness. However, current communication models in healthcare are based on health behaviour change (Westley and Briggs 2004). The Transtheoretical model of change and the stages of mental work model have been studied in COPD and have demonstrated some efficacy in informing clinicians about patients' readiness (Westley and Briggs 2004; Nguyen et al. 2013). These models could help clinicians tailor information and their approaches when considering the patients' readiness stage in these models (Westley and Briggs 2004; Fried et al. 2009). However, these models can be difficult to use and are time-consuming when used in clinical practice (Westley and Briggs 2004; Fried et al. 2009). Instead, using the Burden of Treatment Theory to guide consultations from diagnosis may increase patients' readiness and willingness for discussions. These discussions could focus on patients' capacity to cope with treatments, rather than limiting the focus of discussion on death and treatment withdrawal. Starting early and regular discussions about palliative and future care will be discussed in the section 8.3.2 – page 128.

8.3.1.5 Current model of care

A contributing factor for late palliative care discussions in COPD is the current model of care which focuses on managing acute events, such as exacerbations, rather than a proactive approach, which encompasses regular discussions about patient care preferences (Spence et al. 2009). The current healthcare model is designed to engineer dramatic rescues from injury or illness by means of surgery and medication (Lynn and Adamson 2003; Luckett et al. 2018). However, increased service rationing has largely limited the amount of direct care provided to

patients (Dugdale et al. 1999; Spence et al. 2009; Erickson et al. 2017). Consequently, the current model of care does not fully meet patients' needs and preferences as disease progresses and they approach the end of life (Crawford et al. 2013). At present, there is minimal care co-ordination, which results in episodic, reactive, and fragmented care, with poor communication between the acute, primary, and community care sectors (Lynn and Adamson 2003; Crawford et al. 2013; Luckett et al. 2018; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). In fact, none of the current chronic disease management, palliative care, or specialist palliative care models meet the needs of patients with advanced COPD (Crawford et al. 2013). The latter models meet the needs of people that have a relatively short and predictable disease trajectory, and an associated functional decline, which is commonly found in cancer (Spathis and Booth 2008; Crawford et al. 2013). Although there has been an increase in palliative care provision for COPD patients and other long-term conditions, services lack adequate resourcing and infrastructure (Crawford et al. 2013).

The insufficiencies of the current model are further aggravated by recent changes in the patient population, but especially in the COPD population. Recent studies have shown that most of the elderly population have multiple chronic conditions and that more people are living with a physical disability (Lynn and Adamson 2003; Johnston et al. 2016; Payne et al. 2017; Luckett et al. 2018). These changes are likely to increase the demand on healthcare services, since people will increasingly require more care and support (Lynn and Adamson 2003; Johnston et al. 2016; Payne et al. 2017; Luckett et al. 2018). The presence of multiple comorbidities in COPD increases complexity and uncertainty and mean that patients can live reasonably well for many years or succumb quickly to early complications (Lynn and Adamson 2003). These changes have also made the concept of dying become less clear (Lynn and Adamson 2003). At one time, a person was healthy, then sick, and either recovered or died quickly (Lynn and Adamson 2003). Unpredictable prognosis and daily fluctuations mean that the optimal timing to shift from chronic management to palliative care is difficult to identify (Luckett et al. 2018). As a consequence and as suggested by this study, an unpredictable prognosis can result in patients creating unrealistic expectations and hoping for a cure, whilst clinicians manage the challenges of distinguishing gravely ill from dying patients (O'Neil et al. 2008; Etkind et al. 2017b; Luckett et al. 2018; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Unpredictable prognosis in COPD can result in services not being prepared to accommodate these patients, especially in primary and hospice care. In line with previous research, some clinicians interviewed suggested that hospices and palliative care services were not prepared to accommodate patients with non-malignant conditions, since these services continue to expect sharp and predictable transitions from terminally ill to dying patients (Lynn and Adamson 2003). Recent research has suggested multidisciplinary approaches towards assessing and supporting patients with complex COPD and

some local trusts are beginning to accommodate these recommendations (Rathinam et al. 2014). However, most patients still struggle to access health care and receive poor and little supportive and holistic care at the end of life (Etkind et al. 2017b; Tavares et al. 2017; Luckett et al. 2018).

The aforementioned inadequacies in the current model of care seem to have contributed to clinicians only starting discussions when patients were acutely deteriorating or unwell (Tavares et al. 2019 [under review]-b). A change in the current model of care is required to ensure that the needs and preferences of patients are adequately met (Lynn and Adamson 2003; Luckett et al. 2018). As an example, end-of-life care services need to take into account the pressures of an ageing population that is living longer with increasingly complex diseases and comorbidities (Johnston et al. 2016). New models of care that integrate respiratory and palliative care and focus on patient-centre care have been proposed in COPD (Philip et al. 2018; Smallwood et al. 2018a). Models of care that enable early discussions between patients and clinicians will be further discussed in the next subchapter.

8.3.2 Early, regular, cumulative and gradual discussions with patients

Advance care planning is a core tenet of palliative care discussions and ensures that patients' preferences for care and treatments are registered with clinicians (Gott et al. 2009). However due to the reasons discussed in the previous chapters, only a small proportion of patients preferred to discuss palliative care "now" or regularly with clinicians, (Tavares et al. 2019 [under review]-a). In contrast, the clinicians interviewed and the literature advocate early discussions with COPD patients (Sullivan et al. 1996; Tavares et al. 2017; Tavares et al. 2019 [under review]-b). Clinicians in this study surmised that early discussions may have a smaller emotional impact and be more acceptable to patients than late discussions, since they evolve over time from the generic to the specific and from brief to in-depth discussions (Tavares et al. 2019 [under review]-b). Indeed, discussions about how patients are experiencing their illness and about the treatments that would best suit patients are likely to be more accepted by patients. This can ensure that discussions are patient-centre and patient-led, since they consider patients' capacity to cope with treatments, treatment burden and the suffering associated with invasive and demanding treatments (Shippee et al. 2012; May et al. 2014).

Clinicians suggested that early and regular discussions may become routine for patients, such as having vital signs taken at consultations (Tavares et al. 2019 [under review]-b). Previous research would agree and reports that early discussions about palliative care, through different interventions, were well accepted and received by patients (Gaber et al. 2004; Detering et al. 2010; Wong and Gottwald 2015; Sinclair et al. 2017; Houben et al. 2019). Early discussions with patients have been associated with more relaxed relatives, greater use of advance directives and

Lasting Power of Attorney declarations (Sinclair et al. 2017; Houben et al. 2019). Early and continuous conversations that offer elderly patients (of which, COPD patients) the opportunity to share their preferences can improve their experience at the end of life and lead to greater satisfaction with the care provided (Gott et al. 2009; Detering et al. 2010). This can result in earlier palliative care provision, which has been demonstrated to improve the quality of life and survival in patients with cancer and non-malignant conditions (Temel et al. 2010; Siouta et al. 2016; Luckett et al. 2018). Offering regular conversations about the future from the point of diagnosis might also change patients' perceptions about these conversations, helping them see them for what they are, not a conversation about death (NICE 2005; Ford et al. 2013).

It has been suggested that the End of Life Care Strategy should provide clear guidance about the timing and nature of discussions, which could help embed regular discussions in clinical practice (Gott et al. 2009). Moreover, European and American guidelines/pathways from government and respiratory societies have suggested that palliative care discussions should be an integral part of medicine and have encouraged regular discussions between patients and clinicians (Siouta et al. 2016; Jabbarian et al. 2018; Scheerens et al. 2018). However, due to the unpredictable COPD trajectory, these guidelines/pathways have greatly varied in their recommended timing for palliative care discussions and referrals (Siouta et al. 2016). Clear guidance on how, who and when to start discussions may result in clinicians feeling more empowered and confident when discussing palliative care with patients. In line with previous research, this study suggested that healthcare professionals need to understand the implications of the diagnosis and build a good relationship with the patients, in order to integrate early palliative care discussions in COPD care (Scheerens et al. 2018; Tavares et al. 2019 [under review]-b). However, until early discussions are considered an essential part of COPD management by services and healthcare professionals, palliative care discussions will continue to be seen as best practice by clinicians but unattainable (Spence et al. 2009; Jabbarian et al. 2018).

8.3.2.1 Patient-centred discussions

Encouraging open and honest communication about palliative and future care can foster patients' feelings of participation, control, and shared responsibility in "co-producing" their own healthcare and health (Luckett et al. 2018). Using a partnership approach can allow healthcare professionals to share decision making and allow patients to fully participate in discussions (Luckett et al. 2018). Open and honest discussions about care needs can result in individualized patient-centred plans considering patients' preferences for future care (Barnes et al. 2012; Johnston et al. 2016; Jabbarian et al. 2018; Luckett et al. 2018). Moreover, previous literature and clinicians interviewed recommended a slow and iterative approach to discussions, which focuses on anticipating, identifying, and providing support for patients, especially at the end of life (Luckett

et al. 2018; Tavares et al. 2019 [under review]-b). However, these discussions also need to focus on how patients are coping with their condition and its treatments, and in developing action plans that include minimally disruptive treatments. These conversations can be embedded in current COPD consultations and be used to provide patient information about disease progress, treatments available and what to expect from the future. In addition, conversations may enable a gradual transition from burdensome treatments, such as regular appointment, hospital admissions and ventilatory support, to comfort care, such as GP follow-up and home-based care with oral antibiotics.

Previous research has recommended that clinicians should respond empathetically to the emotional content of the discussion, which can empower patients rather than damage their hope (Barnes et al. 2012). In addition, ensuring that conversations are guided by principles of Burden of Treatment Theory (May et al. 2014) can result in the power being transferred from clinicians to patients during consultations. Therefore, these conversations can focus on patients' coping mechanisms and in adjusting care and treatments accordingly.

Clinicians have suggested starting discussions with patients from diagnosis and the annual COPD review was considered a potential option for discussions (Tavares et al. 2019 [under review]-b). In line with previous research, clinicians interviewed have also suggested developing education sessions during pulmonary rehabilitation sessions that focus on educating patients about COPD, advance care planning and palliative care (Habraken et al. 2008; Burge et al. 2013; Packer et al. 2015; Tavares et al. 2019 [under review]-b). These education sessions can help raise patients' awareness and readiness for discussions and seemed to be well accepted by patients (Heffner et al. 1997; Burge et al. 2013). As an example, early and gradual discussions may be brief, focused on how patients are coping with their illness and on what is required of them to manage their condition and its treatments, and be part of current chronic disease management (Tavares et al. 2019 [under review]-a). Moreover, discussions may need to focus on the immediate future, such as managing a mild exacerbation with oral antibiotics or a severe exacerbation with a hospital admission, since in-depth discussions about a distant future and end of life seemed difficult for patients to understand and led patients to avoid them until they became absolutely necessary (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Therefore, the complexity involved with current palliative care conversations and their impact on patients reinforces the need for early and regular discussions guided by burden of treatment theory.

In order to support patients and clinicians when discussing future care and treatments, the National Institute for Health and Care Excellence and the Department of Health advocate the use of tools that enable patient involvement in identifying their needs and preferences (Gardener et al. 2019). Examples of these tools include SNAP, PEPSI COLA Aide Memoire, Holistic Common

Assessment tool, Respecting Choices and Five Wishes (Detering et al. 2010; Reinke et al. 2017; Gardener et al. 2019). However, these tools have limited utility for patients with advanced COPD, since they are clinician-led, rather than patient-led, and fail to identify all areas where patients need more support (Gardener et al. 2019). Discussing the net benefits of continuing or discontinuing treatments as goals of care change may help frame discussions as positive choices rather than "giving up" on patients (Barnes et al. 2012; Luckett et al. 2018; Tavares et al. 2019 [under review]-b). Moreover, discussing goals of care and the associated treatment burden, rather than specific treatments, can increase patient participation in discussions and reduce patient's difficulty in grasping them (Barnes et al. 2012; MacPherson et al. 2013; May et al. 2014). The model of integration palliative care in the chronic management of COPD patients could enable the start of early palliative care discussions and ensure the provision of patient-centre care (Lynn and Adamson 2003; Hardin et al. 2008; den Herder-van der Eerden et al. 2017). Integrated palliative care will be discussed in the next subchapter.

8.3.2.2 Integrated palliative care

There is a widely recognised need to deliver holistic, supportive, needs-led, person-centred care to COPD patients, which requires involving patients in identifying and addressing their support needs (Johnston et al. 2016; den Herder-van der Eerden et al. 2017; Gardener et al. 2019). As such, early and integrated palliative care focuses on coordinating care around physical and psychological needs of patients with advanced illnesses, which can result in a positive impact on patients (den Herder-van der Eerden et al. 2017; Scheerens et al. 2018; Siouta et al. 2018). In fact, patients with end-stage COPD have expressed the need for integrated palliative home care as an addition to standard care (Scheerens et al. 2018). Integrated palliative care can be defined as:

> *"Bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid."* (Ewert et al. 2016)

Previous research in different patient groups suggests that integrated palliative care is associated with increased continuity of care, quality of life, survival rates, less hospital admissions and cost-effectiveness (Higginson et al. 2014a; Thorsteinsdottir et al. 2016; den Herder-van der Eerden et al. 2017; Payne et al. 2017; Scheerens et al. 2018; Siouta et al. 2018; Smallwood et al. 2018b). In addition, patients with early completed advance directives were found to be less likely to die in the intensive care unit, to receive mechanical ventilation and to have a long hospital (Fu et al. 2018). The benefits provide robust evidence to support early integration of palliative care for patients with chronic conditions, especially COPD (Higginson et al. 2014a; Smallwood et al.

2018b). Early palliative care could avoid burdensome treatments, such as unnecessary hospital visits and admissions, and aggressive care, especially at the end of life (Scheerens et al. 2018). Despite the use of the term "early palliative care," most of the interventions in these studies were designed and initiated when patients had end-stage or advanced COPD or when patients were thought to be in their last year of life. Two interpretations can be drawn from the use of term "early palliative care" in these studies: at present palliative care is provided very late in the disease trajectory; and the term "early" seems to have different meaning for different clinicians. This variation is likely to lead to poor delivery of palliative care to COPD patients and lack of discussions.

There is a tendency in clinical and policy level to compartmentalise chronic disease management and palliative care, whilst these should be provided to patients alongside and integrated (Gott et al. 2009). This tendency prevents the start of palliative care from the point of diagnosis in COPD and the implementation of continuous palliation for older people (Ahmedzai and Walsh 2000; Gott et al. 2009). In order to avoid this, it has been suggested that palliative care should become a life-long component of healthcare, starting at a low base and rising overtime until it become the predominant theme, rather than an abrupt shift (Lynn and Adamson 2003; Hardin et al. 2008; O'Neil et al. 2008). Early in the illness trajectory, patients may need both curative treatment and palliative care aimed at treating symptoms and preventing disease progression; whilst late in life treatments should focus on relieving symptoms, providing support and reducing treatment burden (Lynn and Adamson 2003; Luckett et al. 2018). Moreover, the early and continuous introduction of palliative care is central in improving the experience of patients with chronic conditions at the end of life (Gott et al. 2009). This would ensure that care gradually transitioned from aggressive and invasive treatments to a comfort and patient-centred care (Lynn and Adamson 2003; Crawford et al. 2013). This gradual transition in care could be assisted by discussions about how patients are experiencing their condition and about treatments that most suit patients' coping mechanisms (May et al. 2009). The early integration of palliative care could reduce symptom burden, whilst also decreasing treatment burden for patients (May et al. 2009). A reduction in treatment burden would allow patients with limited capacity to cope with the required workload (Shippee et al. 2012). In fact, providing information and combining palliative care and chronic disease management can be highly appropriate at the end of life (Lowton 2008; Luckett et al. 2018).

This new paradigm in healthcare requires that care for patients with multiple comorbidities shifts from single disease practices to a patient-centred framework that recognizes the different services that patients may need, the symptom and treatment burden, and the duration of time that people live with the illness (Strauss et al. 2014; Luckett et al. 2018). However, service

rationing in primary care, which has been thoroughly reported in this and previous studies, can undermine patient-centred care, since reactive medicine can lead to reduced contact with patients and poor continuity of care (Lynn and Adamson 2003; Crawford et al. 2013; Luckett et al. 2018; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). In an effort to respond to patient needs, a model of concurrent chronic disease and palliative care has been suggested (Luckett et al. 2018). The WHO has proposed a Framework for Innovative Care for Chronic Conditions that identifies people with chronic illness requiring support from formal healthcare services, communities and the wider policy environment (Luckett et al. 2018). This framework highlights how the integration of community services with healthcare services can support patients and families with chronic conditions (Luckett et al. 2018). Moreover, service elements from case management, especially when considering care coordination and improving outcomes, can be transferred and used when planning and providing care in COPD (Luckett et al. 2018). However, poor understanding about palliative care and COPD, and current service rationing prevent the use of this model in COPD care.

In order to ensure early and integrated palliative care, a cumulative stepped model of integration between hospices and local health and social care providers has been recommended (Payne et al. 2017). At present, most hospices operate in ways that support and supplement other providers and only a small proportion of hospices supplant local provision by providing in-patient facilities, especially to non-cancer patients (Payne et al. 2017). A previous study suggested five components for early integrated palliative home care that include: (1) training on symptom recognition and physical therapy exercises for clinicians; (2) regular home visits; (3) information leaflets on self-management; (4) semi-structured protocol to record the outcomes of home visits and (5) integration of care by encouraging collaboration and communication between involved clinicians in primary and secondary care (Scheerens et al. 2018).

Despite the benefits of integrating palliative care, at present, integrated palliative care is not fully achieved due to funding constraints, lack of clear clinicians' responsibilities and the unpredictable illness trajectory (Payne et al. 2017; Scheerens et al. 2018). As a consequence, clinicians describe difficulties in integrating palliative care with acute care when there are many other competing priorities (Shipman et al. 2008). Moreover, relational, informational and management continuity was often deficient in integrated palliative care, especially if provided or coordinated by GPs (den Herder-van der Eerden et al. 2017). Another issue is that it can be difficult for patients to navigate the wide range of services available, reducing their access to care (Johnston et al. 2016). Indeed, further integration of palliative care initiatives with clinicians involved in patients' care networks, such as community nursing services, can result in improved service effectiveness and in better service navigation for patients (Johnston et al. 2016; den Herder-van der Eerden et al. 2017).

Greater integration by hospices is required to work with local providers, with more clarity in managing cross organisational information and sharing and allocation of co-ordination roles and responsibilities (Payne et al. 2017).

8.3.3 Clinician factors that impact palliative care discussions

Patients and clinicians often highlighted the importance of expertise, sensitivity and of the patient-clinician relationship in palliative care discussions (Clayton et al. 2005; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). However, this study and previous research suggested that patients and clinicians do not always agree in the timing and nature of discussions, which can result in disparate views (Clayton et al. 2005; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Disparate views may prevent the start of discussions between patients and clinicians, which may result in late discussions. These different views included:

- Patients preferred late discussions, whilst clinicians believed discussions should be initiated early in the disease trajectory and evolve overtime. The factors that led patients to prefer late discussions have been discussed in the first section of this chapter, refer to page 117;
- Patients placed more importance on clinicians' expertise when discussing palliative care, whilst clinicians believed patients preferred to discuss their preferences with clinicians with whom they have an established relationship;
- Patients and clinicians seemed to have different agendas for palliative care discussions. Clinicians viewed discussions as opportunities to discuss treatment withdrawal, whilst patients used discussions to gather information about the severity of their condition and the treatments available;
- Patients preferred open, honest and detailed information about all aspects of care, but especially about the severity their condition. However, clinicians believed patients preferred brief and hope-fostering information throughout the disease trajectory;
- Patients had different perceptions about clinicians' competencies, when compared with clinicians' self-assessment of their competencies. As an example, practice nurses that carried out annual reviews were seen by patients as COPD experts, whilst nurses reported a lack of expertise and confidence.

This mismatch in expectations and perceptions about palliative care discussions suggests that clinicians have limited understanding about patients' preferences and is a contributing factor for the current delay in, and lack of, palliative care discussions. Previous research has also highlighted a similar mismatch between clinicians' and patients' desire for information, interest in life-

sustaining treatments, beliefs about treatment effectiveness and prognosis, level of health literacy and emotional state (Strull et al. 1984; Say and Thomson 2003; Street and Haidet 2011). In fact, evidence suggests that clinicians thought patient beliefs were more aligned with their own, and an even greater dissonance was found between clinicians and patients of different ethnic backgrounds (Street and Haidet 2011). Patient satisfaction, commitment to treatment, and perceived outcomes of care are higher when healthcare professionals and patients achieve a shared understanding on issues, such as the patient's role in the decision making process (Street and Haidet 2011).

As discussed in the subchapter 8.3.1 and page 117, clinicians' understanding about palliative care impacts upon discussions with patients. In agreement with previous research, most clinicians interviewed had a poor understanding about palliative care, since this was essentially seen as end of life care (O'Neil et al. 2008; Shipman et al. 2008; Luckett et al. 2018; Tavares et al. 2019 [under review]-b). In fact, clinicians with little understanding about palliative care and COPD were more likely to defer or avoid palliative care discussions altogether (Tavares et al. 2019 [under review]-b). Previous research has also reported a great variance in clinicians' understanding about palliative and end of life care, suggesting that specialist palliative care was largely concerned with cancer and care of the dying (Shipman et al. 2008; Luckett et al. 2018). Furthermore, some clinicians believed that palliative care conflicted with chronic disease, whilst others believed that discussions would reduce patients' willingness to participate in self-management activities (Halliwell et al. 2004; Gott et al. 2009; Tavares et al. 2017; Tavares et al. 2019 [under review]-a). Despite this, there is no evidence that starting discussions affects patient willingness to self-manage (Gott et al. 2009).

Clinicians poor understanding about palliative care may be related to the complexity and unpredictability of the disease trajectory in COPD (Spathis and Booth 2008; Tavares et al. 2017). This unpredictability leads to clinicians' uncertainty as to when to start of palliative care and discussions (Sullivan et al. 1996; Spathis and Booth 2008; Crawford 2010; Landers et al. 2017; Tavares et al. 2017). Dying trajectories in conditions other than cancer are less predictable, leaving professionals unwilling to enter into prognostic discussions. (Barnes et al. 2012). Patients' individuality and differing rates of disease progression acts as a barrier and adds to the difficulty of timing discussions (Sullivan et al. 1996; Tavares et al. 2017). Various tools have been suggested as aids for prognosticating in COPD or to identify when patients are approaching the end of life, however most tools have inadequate prognostic ability. The prognostic models used in the SUPPORT study have showed that at 5 days prior to death, patients with COPD were predicted to have >50% chance of surviving for 6 months (Donnelly 1996; Claessens et al. 2000; Curtis 2008). The DOSE score is another tool that aims at prognosticating COPD patients' mortality (Sundh et al.

2012). The use of the DOSE score showed that only 57% of patients in the highest scored (an overall score of 8) died within 5 years of follow up (Sundh et al. 2012). Furthermore, the BODE index is a multidimensional grading system for COPD that is used to predict mortality. It has been suggested that this index can be a better predictor of mortality that FEV1 alone (Powrie 2004). However, a recent study has suggested that over half of the patients studied with the highest BODE score were still alive at 3 years (Esteban et al. 2010). Lastly, previous research has suggested using the question "would you be surprised if this patient died in the next 12 months?" to identify when to start palliative care, but this question has proven to be inaccurate in determining prognosis (Luckett et al. 2018). The patients interviewed in Phase 2 of the study presented on average higher DOSE and BODE scores as their disease severity increased (Tavares et al. 2019 [under review]-a). However, due to the ineffectiveness of these tools, these scores provided little indication of mortality, instead these scores provided information about disease severity and symptom and treatment burden (Tavares et al. 2019 [under review]-a), Because of this, clinicians preferred to wait for the "slippery slope" before initiating palliative care or discussions with patients (Tavares et al. 2019 [under review]-b).

The difficulty in prognostication was frequently mentioned by the clinicians and they compared prognostication in COPD with other conditions (Tavares et al. 2019 [under review]-b). Difficulties in prognostication affect the start of palliative care, which emphasises the need for supporting clinicians in recognizing when end of life care should begin (Shipman et al. 2008; Goff et al. 2015). This challenge is not confined to COPD care but found in other life-limiting conditions, such as heart failure and chronic kidney disease (Pocock et al. 2005). Due to variable rates of disease progression in heart failure and chronic kidney disease, predicting mortality risk and disease progression is often difficult (Lee et al. 2003; Pocock et al. 2005; Tonelli et al. 2006). There are no widely accepted predictive tools in these conditions, which means that clinicians make *ad hoc* decisions about which patients to treat, risking delays in treatment or unnecessary treatment (Lee et al. 2003; Tangri et al. 2011). In contrast, the clinicians interviewed reported that predicting the mortality risk and disease progression with accuracy in cancer was achieved more easily, than in non-malignant conditions (Tavares et al. 2019 [under review]-b).

The use of a holistic approach where multiple factors are taken into account in a multi-variable model may help refine and quantify clinicians' predictive ability in COPD (Pocock et al. 2005). However, the constant search for the appropriate timing to start discussions may prevent discussions the start of palliative care discussions with patients. Instead, prognostic uncertainty could be circumnavigated if early and patient-centred discussions were embedded into COPD care and future care planning became the norm.

8.3.4 Service-related factors that prevent discussions with patients

Patients and clinicians thoroughly discussed service rationing in healthcare, especially in primary care, and its impact on patient care (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). The increase in economic pressures and reduction in local philanthropy have resulted in a decrease in the national resources available for the NHS and social services (Payne et al. 2017). Moreover, increased time pressure, workload, number of patients with multiple chronic conditions and staff shortage have been previously documented, and have led patients to lose trust in healthcare services (Street and Haidet 2011; The King's Fund 2018; Buchan et al. 2019). As a result, patients and clinicians reported short appointments and lack of care continuity (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). The lack of time in appointments and the reduction in direct patient care have also been thoroughly documented in previous research studies (Dugdale et al. 1999; Knauft et al. 2005; Aslakson et al. 2012; Erickson et al. 2017). This reduction in patient care seems to contribute to delayed patient help seeking, as discussed in Chapter 8.3.1 and page 117 (Tavares et al. 2019 [under review]-a). Moreover, reduced time for patient care results in priority being given to acute care so palliative care may not be routinely offered to patients, even when it can provide psychological support and symptom relief (Tavares et al. 2019 [under review]-a).

A reduction in direct patient contact seems to have a direct impact on continuity of care (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Patients and clinicians believed that continuity of care was important, especially when considering discussing palliative care (Clayton et al. 2005; Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). Previous research has suggested that continuity of care increases patient satisfaction in healthcare and their quality of life, and is a key facilitator for palliative care discussions (Hjortdahl and Laerum 1992; Knauft et al. 2005; Barker et al. 2017). Continuity of care helps clinicians' to accumulate knowledge about patients and gives them a sense of responsibility towards their patients (Hjortdahl and Laerum 1992). However due to service rationing, there is insufficient time for consultations to be dedicated to conversations about patients' views, which prevents the development of patient-clinician relationships (Street and Haidet 2011). As a result, most clinicians, especially GPs, reported an increasing difficulty in building long-term therapeutic relationships with their patients (Tavares et al. 2019 [under review]-b). Continuity of care, traditionally a core value of general practice, seems to be in jeopardy (Guthrie and Wyke 2006). In fact, continuity of care is in decline in the UK and concerns have been raised regarding clinicians' ability to providing care for the increasing number of patients with long term conditions (Adler et al. 2010; Barker et al. 2017). The lack of time available for discussions and little organisational

commitment and policy support for clinicians pose as barriers for palliative care discussions and patient-centred care (Detering et al. 2010).

Established patient-clinician relationships, clinical expertise and effective communication skills are paramount when discussing palliative care and end of life with patients (Back et al. 2007; Coyle et al. 2015). Patients and clinicians interviewed believed that conversations should be started and conducted by clinicians with appropriate expertise and a good relationship with the patient (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). However, patients and clinicians did not agree on a specific healthcare professional that was best equipped to take charge of palliative care discussions (Tavares et al. 2019 [under review]-a; Tavares et al. 2019 [under review]-b). The lack of a designated clinician responsible for initiating discussions with patients can often result in nobody taking responsibility for discussions, and none taking place (Tavares et al. 2019 [under review]-b). this may also make clinicians less likely to make palliative care conversations a priority in their daily practice, and less likely to undertake training on COPD and palliative care or accumulate clinical experience by carrying out discussions (Back et al. 2007). Further guidance and research regarding who is responsible for carrying out discussions and on how discussions can be integrated in the care of patients can minimize these effects. Increased guidance might result in clinicians knowing with clarity their role in palliative and future care discussions, which can include embedding discussions in their consultations or delivering patient education sessions about these topics (Tavares et al. 2019 [under review]-b). However, whilst communication training for healthcare professionals can optimize palliative care discussions with patients, it must be focused, relevant, and tailored to their individual needs (Clayton et al. 2005; Barnes et al. 2012).

8.4 Strengths and limitations of the study

Critical analysis of research allows the assessment of findings within a context of validity, rigour, and ethical appropriateness. This section critically evaluates the impact of the researcher in all aspects of the study, the methods used for data collection and data analysis, the recruitment strategy and the impact of the ethics committee review and approval of the study. Lastly, a consideration of the dilemmas posed by undertaking clinical research whilst working clinically as a nurse in the clinical area explored in the study will be presented.

My input as a researcher influenced all aspects of the research study, which is both a limitation and a strength. As discussed in Appendix I, my world views, opinions and understanding about the topic under investigation informed and shaped of the study, from the design to the findings. My professional, social and ethnic background have also influenced the focus and methods of the

study. As an example, my professional background and clinical experience allowed me to have an insider perspective of the current care provided to COPD patients. In fact, my clinical observations allowed me to understand not only the issues faced by patients, such as receiving late palliative care, but also the difficulties that clinicians face when timing the start of palliative and end of life care. On the other hand, my middle class background differed from some participants' background, which may have resulted in slightly different interpretations of their thoughts. In order to mitigate against this limitation, the study supervisors closely monitored all stages of the study, in an effort to ensure the trustworthiness of the findings. In fact, data collection and analysis were especially reviewed and regularly monitored, through supervisors' access to interview transcripts and audiotapes, to the different steps of data analysis and to the reported findings.

Participants were not invited to read transcripts or to participate in data analysis, since this was thought to be fraught with challenges. Since all phases of the study were carried out by myself, especially participant interviews and data analysis, the overall findings of the study include participants' thoughts and preferences influenced by my input as a researcher. As a result, the research findings are a collaborative work between the researcher's interpretation of all relevant facts and participants' thoughts (Smith 2011; Larkin and Thompson 2012). Inviting patients to read interview transcripts or to participate in data analysis, seemed to undermine this collaborative work, by interfering in data interpretation. In addition, the impact of reading transcripts – and of the written word - could lead patients to "clean" transcripts, which could have led to less open and honest opinions about the topic area (Mero-Jaffe 2011).

Another limitation of the study was the recruitment and interview of participants from a British and white background. Although, participants from different ethnic backgrounds were approached, only white British participants accepted to participate in the study. Issues in recruiting participants from different ethnic minority groups have been widely documented in previous research, which seem to highlight that common recruitment approaches fail to attract or capture these population groups (Redwood and Gill 2013). The non-participation of participants from different ethnic minorities results in a lack of understanding about their preferences and thoughts. However, since this was an exploratory study, the recruitment of patients from different minorities was not prioritized. Further research should explore the understanding and preferences of participants from ethnic minority backgrounds, in order to build a complete picture of the needs and experiences of this population. The need for further research is especially important, since people from different ethnic backgrounds have different practices and approaches towards end of life, and less access to care (Szczepura 2005).

A third limitation of the study included the discussion of the research topic with COPD patients – palliative care discussions. The vast majority of patients included in the study had not discussed palliative or future care with healthcare professionals. Consequently, patients discussed their thoughts and preferences about something that they had never experienced and which they had little understanding about. Interviewing more patients with previous palliative care discussions could have provided further understanding to their thoughts and preferences. However, the findings of this study are in tandem with previous research that reported a general lack of discussions and a difficulty in recruiting patients that had discussions with clinicians.

A fourth limitation included the use of the terms “palliative care” and “end of life” solely with patients with severe to very severe COPD. This was a specific request from the Research Ethics Committee that feared distressing/upsetting patients with milder COPD by asking them to comment on these topics. Instead, patients with mild to moderate COPD were asked about preferences for future care and treatments, and were only asked about palliative care or end of life if they raised the topics. This request limited the scope and nature of the questions asked to patients with mild to moderate COPD and the understanding their preferences and thoughts about these fundamental aspects of care. Moreover, the request resulted in altered perceptions about discussions, since patients with mild to moderate COPD may have not fully grasped the content of the discussion. Future research should explore the preferences of patients with mild disease for palliative care, since this study demonstrated that interviews did not cause undue distress to participants.

My role as a clinical academic healthcare professional can be seen as both a limitation and a strength. The clinical academic role had many benefits, including the transfer of knowledge/research to clinical practice and the insider perspective towards COPD care, but also some disadvantages. The shift between clinical nurse and a nurse researcher was especially challenging when interviewing COPD patients. The necessity to wear different “hats” in different days of the week required some adaption. Due to the nature of the nursing role and in my focus in helping people, I struggled in being a passive recipient of information and in not providing advice to patients. Moreover, since the patient information sheet displayed information about my clinical duties, most patients seemed to have an agenda for the interview and tried to steer the conversation into self-management activities and in accessing further care, such as new inhalers and medications. The initial interviews were the most challenging with regards to this role dilemma. The support provided by my supervisors helped me overcome this problem, whilst taking my ethical responsibility towards patients into account. Overtime, I felt more comfortable within this new role and I was able to improve my approach when collecting data from COPD patients.

A strong point of this study was using a novel approach when looking at patient's preferences. Qualitative interviews were carried out with COPD patients at different stages of their condition and with different levels of healthcare-related experience. The use of this new approach allowed:

- The study of changes in patient preferences throughout the disease trajectory;
- Understanding the preferences of patients with mild disease, who, sooner or later, may wish to participate in discussions;
- The investigation of when to start palliative care discussions when considering the complex and unpredictable disease trajectory.

The systematic literature review suggested that previous studies recommended starting palliative care discussions early in the disease trajectory (Tavares et al. 2017). However, these studies did not identify a specific timing when conservations should be started (Tavares et al. 2017). Thus, recent research has suggested exploring changes in patients' preferences throughout the disease trajectory (Sinclair et al. 2017). Therefore, the use of this approach seems to have provided further understanding to these research queries.

Another strength of this study included the interview of both parties involved in palliative care discussions, patients and healthcare professionals. This study used a novel approach, which included discussing patients' preferences for palliative care discussions with clinicians. The interview of both patients and clinicians provided in-depth understanding regarding the timing and nature of palliative care discussions. This approach highlighted similarities and divergences between patients' and clinicians' thoughts, which helped contextualize the current landscape of palliative care discussions. As an example, healthcare professionals were asked to comment on patients' preferences for the timing of conversations. Clinicians' answers provided relevant information as to why patients preferred late discussions, which included clinicians' focus on treating ill patients, lack of continuity of care and patients' death awareness.

The last strength of this study included the approach adopted to complete the PhD candidature – thesis by publication. Although presenting the different phases of the study in paper format may have reduced the word count available for each paper, it resulted in papers being thoroughly reviewed by journal peer review. The first 2 phases of this study have been through Journal peer-review. As a result of this peer review, phase 1 was published in an international journal, and Phase 2 was edited with the feedback provided by Palliative Medicine Journal. Journal peer-review helped mitigate against the lone researcher analysis and interpretation of these phases, ensuring the trustworthiness and accuracy of the research findings.

8.5 Recommendations for clinical practice and future research

Discussing the implications of this study for clinical practice is fraught with challenges, especially when considering the small sample of participants recruited and the locality of the study. Recommendations for practice from findings as they sit within the extant literature are identified below. These recommendations may help reduce the number of issues related to the lack or poor discussion of palliative care in COPD.

A novel approach towards palliative care conversations is recommended for clinical practice. This recommendation requires a fundamental shift in the organisation of COPD care, since it promotes the integration of palliative care conversations in everyday practice. Healthcare professionals should regularly discuss how patients are coping with their condition and its treatments and offer treatments based on patient' preferences, whilst considering the burden associated with them. Discussions should start at diagnosis and be relevant for patients, by considering their position in the disease trajectory, previous healthcare-related experiences and capacity to cope with and manage specific treatments, such as medication regimen, hospital appointments and admissions and ventilatory support. Moreover, clinicians should use an honest and open approach, share up-to-date information about patients' health conditions and develop action care plans based on their preferences. These plans should be based on patients' preferences and values, and be mindful of and attend to issues related to burden of treatment, in order to ensure that treatments continue to be the most appropriate for the individual patient throughout their disease trajectory. This would ensure that patients receive treatments that effectively relieve their symptoms, but that have little burden for patients. At first, discussions may focus on preparing and managing mild exacerbations. However as discussions evolve and the illness progresses, patients gain further understanding about the severity of their condition, which may lead them to prefer less burdensome treatments, to accept alternative methods to manage their condition and to receive increased support for their needs. This approach - patient-centred care - ensures that care is provided according with the *ethos* of palliative care, but without the emotional charge of "palliative care or end of life care discussions," whilst attending to issues related to the burden of treatment and a person's capacity to manage their condition(s). Patient-centred discussions can be incorporated into the care of patients regardless of diagnosis, comorbidities and disease trajectory, since conversations focus on patients' experiences and preferences for managing symptom and treatment burden. As an example, these discussions could be integrated into the care of patients with other life-limiting illnesses, such as heart failure and chronic kidney disease.

Embedding this new approach towards palliative and future care discussions into clinical practice cannot be fully achieved without its challenges. Of note, this new approach will require significant

training for healthcare professionals looking after people with COPD, the use of additional human and monetary resources, the integration of recommendations for discussions in clinical guidelines and of further research. The pathway that facilitates the integration of palliative care discussions into current clinical practice and our recommendations for further research are described below.

The first step and recommendation to ensure that palliative care discussions are kept at the core of standard COPD care is to understand how to effectively integrate/embed them. This can be achieved by exploring best methods to integrate discussions in daily practice, such as understanding which and how consultations should accommodate discussions and what support clinicians need to effectively and sensitively discuss palliative care with patients. In addition to this research, it is important to understand the impact of discussions in patients' psychological wellbeing (such as developing mixed methods research exploring the effects of early and gradual palliative care discussions on patients' emotional wellbeing) and care (such as exploring whether discussions result in patients' preferences being achieved and in less burdensome treatments provided at the end of life). The ultimate aim of this recommended research is to ensure that palliative care discussions are fit for purpose, time and cost-effective and that clinicians can carry out these conversations according with patients' preferences. The results of this research will allow the development of cost-effective training resources on when and how to carry out discussions with patients. These training sessions should also include additional education about the different aspects of COPD care, including palliative and end of life care.

Some local COPD services have now recognized the need to support primary care and are providing education sessions to nursing and medical teams. These education sessions target undertaking and interpreting pulmonary function tests and in managing inhaled therapies. However, much could be gained from providing in-depth education about the progressive nature of COPD, palliative care in COPD, about patient information needs and the impact of treatment burden on patients. This additional education would provide the foundation for embedding discussions into their clinical practice, which could result in discussions being integrated in routine COPD care. Educating healthcare professionals is essential since they provide most patient information and support to patients in healthcare-related decision making. Education sessions that result in the effective and efficient delivery of COPD-related information to healthcare professionals at a minimum cost would be ideal. As an example, future research should develop brief education sessions (2-4 hour sessions) focused on palliative care discussions and COPD management, whilst using real-patient scenarios. These sessions could be integrated into clinicians' continuous professional development, in an effort to improve their commination skills and COPD care management. In addition, it would be interesting to understand the impact of these sessions on patient care, quality of life and overall healthcare costs. This research would

demonstrate whether discussions result in a reduced treatment and symptom burden and in better experiences for COPD patients, especially at the end of life.

A third step to ensure that palliative care discussions are embedded into clinical practice include the development of clear guidelines on the timing and nature of these conversations. The combination of this research study with the research recommended in the previous page will result in clear evidence as to when and how to effective and sensitively discuss patients' preferences for future care and treatments. Commissioners, service managers and clinicians are mandated by guidelines and policies launched by public and governmental regulatory bodies. Guidelines and policies need to provide clear guidance on how palliative care discussions should be integrated in current COPD care, and define all terms related to palliative care conversations, such as palliative care and end of life. Clear guidance is likely to result in patients' and clinicians' having full and similar understanding about the timing and nature of discussions, preventing mismatches between the two parties and the integration of discussions in COPD care.

The last recommendation for embedding patient-centre discussions in COPD care complements all previous steps, since it increases the likelihood of patient participation in palliative care discussions through providing patient education. This study identified an urgent need for patient education about palliative care, advance care planning, treatments available, and COPD, especially about the progressive nature of their condition. Embedding discussions into current COPD care may enable patients to gain more understanding about the status of their condition, however this needs to be coupled with thorough knowledge about COPD. As an example additional patient education can be provided during pulmonary rehabilitation sessions; COPD-related consultations or clinics with primary and secondary care healthcare professionals; in stand-alone education sessions about COPD and self-management – similar to the sessions offered to patients with Diabetes Mellitus; and through written information. Patient education sessions need to include information about the nature and progressive character of COPD, self-management, what to expect from healthcare services, and about palliative care and advance care planning. Future research should explore the use of stand-alone or integrated education sessions (such as, education sessions to newly diagnosed patients or sessions integrated in pulmonary rehabilitation programmes) in improving patients' knowledge and perception about the progressive nature of COPD, palliative care and advance care planning; and understand how education sessions can be widely implemented in clinical practice, considering cost-benefit, effectiveness and long-term sustainability. Once education sessions have been widely implemented, research should explore the impact of additional education on self-management, patient empowerment, quality of life (by considering their impact on treatment and symptom burden), willingness to participate in discussions and disease progression.

Chapter 9 Conclusion

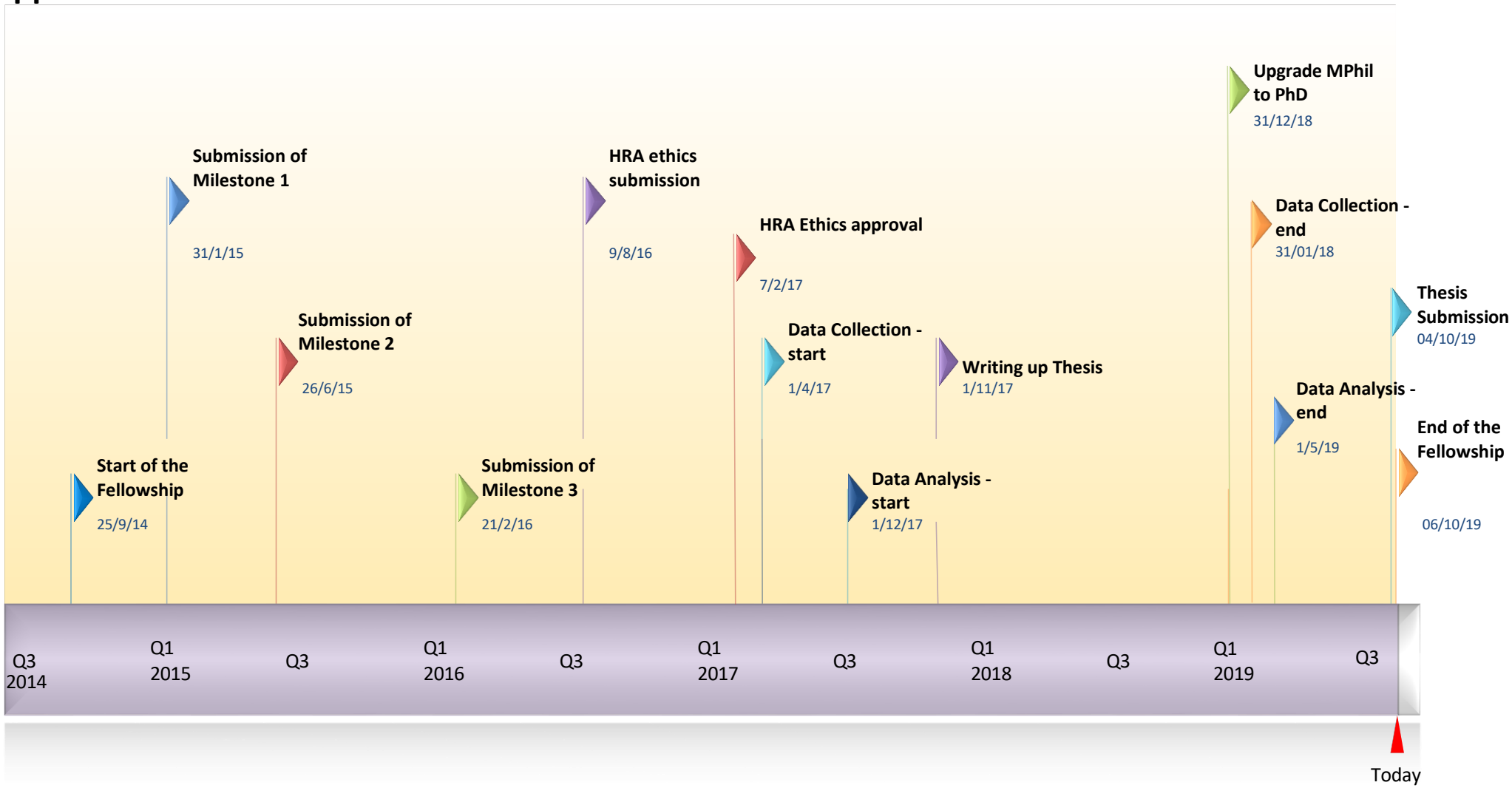
This research study explored the timing and nature of palliative care conversations in COPD when considering previous research, patients' preferences and clinicians' judgments.

The study identified a new approach towards palliative care conversations in COPD. As such, the recommendation is for early, gradual and cumulative discussions that are sensitively started and conducted by familiar COPD-expert clinicians, and that draw on patients' care preferences, in order to develop minimally disruptive care plans throughout the disease trajectory. This new paradigm means that care is focused on what patients can manage and on their own illness experience and trajectory, by adopting less burdensome treatments.

It is clear from this study that the current approach to discuss palliative care advocates a sudden change from aggressive treatments to end of life care and does not meet patients' needs or match the deterioration present in progressive illness. Conversations about palliative care are complex, require considerable time in consultations and require significant patient and clinician expertise about COPD and palliative care. Thus, the current model of care does not support the early and continuous discussions with patients that this study advocates. Giving patients the opportunity to discuss their preferences while they are well with a COPD-expert clinician that they know well, in an adequate environment and in a sensitive manner, can lead patients to support these conversations at a much earlier stage. In addition, starting discussions about current and future care options from the point of diagnosis could ensure that patients receive less burdensome treatments based on their preferences. It is essential to resolve the current absence of palliative care discussions, so that palliative care services can provide effective care to more COPD patients.

Appendices

Appendix A Gantt Chart



Appendix B Literature review protocol

B.1 Introduction

The literature review aims to explore the current knowledge published about the topic – palliative care conversations in COPD. Literature reviews are categorized according with the methods used to search and analyse the data. They can be narrative, systematic, meta-analysis or meta-synthesis literature reviews. The approach chosen to review the literature was the systematic review due to its comprehensive methods of data search and analysis. As part of systematic literature review, before starting the literature search, a protocol should be developed stating all the aspects related with the literature review.

The main question of this literature review is: **"What is known about palliative care discussions between patients with COPD and healthcare professionals?"** In this review will search for evidence in the form of papers, journals, policy documents and clinical guidelines. The search will identify published and unpublished evidence about palliative care discussions between patients with COPD and healthcare professionals. The research topic is considered to be one important factor for little provision of palliative care for patients with COPD in the UK. Furthermore, the frequency and quality of these discussions were found to be generally poor leading to poor delivery of palliative care in clinical practice and the nonfulfillment patients' wishes and preferences for the end of life.

B.2 Methods

This protocol will be developed using the guidance for undertaking reviews in healthcare by the Centre for Reviews and Dissemination Guidelines of the University of York, PRISMA guidelines and informed in previous systematic reviews related with the topic (Centre for Reviews and Dissemination 2008; Liberati et al. 2009; Momen et al. 2012; Stephen et al. 2013). The SPICE framework was used to frame the literature search strategies outlined in this review (see **Table 1**).

TABLE 1 Spice framework

SETTING	Primary and secondary care, such as hospital wards, outpatient clinics, GP practices, residential or nursing homes and hospices.
PERSPECTIVE	People with COPD and healthcare professionals directly involved in the care of these patients, including nurses, physiotherapists and doctors. COPD patients included in the review should be 18 years of age or older. Disease severity, gender, co-morbidities, number of exacerbations, amount and type of medication, socio-economic status, ethnicity and geographical area will not be considered an exclusion criterion.
INTERVENTION	Discussions about palliative care between patients with a diagnosis of COPD and healthcare professionals. Discussions between patients with COPD and family members or informal carers were excluded. Discussions about palliative care were defined as a discussion where participants exchanged ideas and information about all the aspects related with preferences of care that were not focused in a curative outcome, but instead in quality of life and symptom relief. These discussions can be held over a period of time and more than once so that participants can reach an agreement for the best suitable care.
COMPARISON	A comparator was not found appropriate for inclusion because of the explanatory character of this review.
EVALUATION	To comprehend what is known about palliative care discussions between patients with COPD and healthcare professionals. To explore what is known about the frequency, quality, content, time, place, importance, barriers and facilitators of palliative care discussions with COPD patients.

Due to the explanatory character of the review, all study designs will be included, such as quantitative, qualitative and mixed-methods. The complexity and the individual characteristics of the disease being studied and the people affected by it, all types of studies have to be included.

B.2.1 Search Strategy

In order to undertake a systematic searching approach of the literature, keywords will be used to search through databases and websites, experienced professionals will be contacted about relevant literature within this subject and the reference lists of the papers included will be searched. All major health-related databases will be selected. Refer to **Table 2** to find the databases and websites included.

Appendix B

Table 2 Databases and websites searched	
Databases Searched	Medline; CINAHL; PsycINFO; HMIC; AMED; Web of Science; ASSIA; IBSS; Delphis; PubMed; ScienceDirect; Cochrane Library; EMBASE; BNI; AgeInfo and Scopus
Websites	Thorax Website; British Thoracic Society (BTS); National Institute For Health And Care Excellence (Nice); Medical Research Council (MRC); Department Of Health (DoH); Economic And Social Research Council (ESRC); National Institute For Health Research (NIHR); American Thoracic Association (ATS); British Lung Foundation (BLS); The National Council For Palliative Care (NCPC); The European Association For Palliative Care (EAPC); Association For Palliative Medicine (APM).

The search will included a large variety of terms related with the main topics of this review, “Communication”, “Palliative Care” and “COPD” (see **Table 3** to find all keywords used). In the databases CINAHL and MEDLINE as well as keywords, Medical Subject Headings will also be used. These two databases are thought to be the most relevant for this review as they are dedicated to Medical and Nursing Sciences. These 2 databases will be searched twice using keywords and Medical Subject Headings to ensure a comprehensive search.

TABLE 3 Keywords used to search the literature

“COPD”,
“Chronic Obstructive Pulmonary Dis*",
“Chronic Obstructive Airway Dis*”,
“Chronic Lung Dis*”,
“Chronic Lung Illness”,
“Chronic Pulmonary Illness”,
“Chronic Pulmonary Dis*”,
"Chronic Bronchitis",
"Palliative Car*",
“End-Of-Life”,
"End Of Life",
“Terminal Care”,
“Terminally Ill*”,
“Hospice Care”,
“End-Stage Care”,
“Care Of The Dying”,
“Dying Care”,
“Death”,
“Dying”,
“Discuss*”,
“Conversat*”,
“Communicat*”,
“Inform*”,
“Barriers”,
“Facilitators”,
“Therapeutic”,
“Disclos*”,
“Decision Making”,
"Pulmonary Emphysema",
“Chronic Disease”,
“Lung Disease”,
“Critical Illness”,
“Advanc* Illness”,
“Obstructive Lung Dis*”,
“Pulmonary Dis*”,
“Hospice”,
“Advance Care Planning”,
“Advance Directives”,
“Prognosis”,
“Family”,
“Patient”,
“Patient Care Conferenc*”,
“Patient-Family Conferenc*”,
“Psychology”,
“Attitude Of Health Personnel”,
“Patient Satisfaction”,
“Physician-Patient Relations”,
“Physician-Patient Communicat*”,
“Nurse-Patient Relations”,
“Professional-Patient Relations”,
“Health Professional”,
“Nurses”,
“Physicians”,
“Hospital”,
“Medical Staff”

Another way of identifying papers is by looking at the reference lists of all the included papers and of any other relevant papers. The experts in the field, identified from the literature, will be contacted in order to find any missing papers, unpublished work and ongoing research. Whenever a relevant conference abstract is found, the authors will be contacted via email or via Research Gate in order to obtain the full-text version of the study.

The inclusion criteria is defined prior to the search in order to include only the relevant and suitable papers and to reduce the risk of bias. The quality of all papers will be assessed and their inclusion in the study will be done according with their quality. Furthermore, papers will be screened by one researcher at first, in which the papers will be identified by their title and abstract, and then papers will have their full text screened to confirm eligibility. If during this process uncertainty arises regarding the eligibility of any paper, agreement will be sought after discussion of all the researchers involved. Thirty percent of all the selected papers will be assessed according with the inclusion and exclusion criteria and quality guidance by all researchers to ensure validity and reliability in the methods used. Inclusion criteria is presented in **Table 4**.

Table 4 Inclusion Criteria of papers selected for review	
PAPER LANGUAGE	Papers will be included if written in English. The first language of all researchers is English, therefore the inclusion of papers written in any other language would pose a barrier to thoroughly analyse the papers.
PARTICIPANTS	The participants included were people with COPD and healthcare professionals aged above 18 years old. The COPD diagnosis should be done according with the Global Initiative for Chronic Obstructive Lung Disease (GOLD), in which a spirometry is performed showing a FEV1/FVC lower than 70%. Papers were included if the sample represented 50% or more of patients with COPD, except if the papers were purposely comparing COPD with other diseases. Papers had to include approximately the same amount of COPD patients and patients with other conditions. A 10% margin was used to include or exclude papers. However, the 10% margin was only applied to the larger categories of patients with other diseases.
STUDY DESIGN	All study designs were included in the review. The main purpose of the review was to identify and analyse all data published regarding this subject. Therefore, all study designs were included.
STUDY QUALITY	Papers were included if presented high or moderate quality. The inclusion of papers with low quality would contaminate the overall findings and conclusion of the review, leading to inaccurate and unreliable data.
COUNTRY RESTRICTION	Only papers from North America, Europe, Australia and New Zealand were included. This is thought relevant as literature from countries with different cultural believes towards health and from countries with small healthcare resources would not provide relevant and usable data for a European and North American society.

INFORMATION IN PAPER	All papers must contain in their abstract, title or full text a combination of 2 or more keywords as defined above, i. e. "Discussions" and "End of Life Care", or "COPD" and "Palliative Care" or any other combination that is relevant enough for the topic. Papers were included if more than 50% of the information included was about palliative care conversations with COPD patients. This was done using word count. The papers excluded using this approach contained 30% or less of relevant information. Furthermore, the information contained in these papers did not present new information about the topic discussed. Papers were excluded from the literature review if there wasn't enough information to assess their quality, reliability and validity. This was applied to Conference and Poster Abstracts and Audits.
INTERVENTION	Conversations included were conversations about the topic – palliative care –between a person with COPD and a healthcare professional.
DISCUSSION TOPICS	The palliative care discussions addressed at least one of the following topics: • "What are the patient's wishes and preferences for palliative and end of life care?" • "What is the patient's and clinician's understanding of palliative care?" • "What care can be offered to the dying patient?" • "What may the end of life care and/or death look like?" • "What may the future be like?" • "What are the patient's preferences for life-sustaining treatments?" • "How long does the patient have to live?" • "What is the desired place of death?" • "Who would the patient like to be present in the time of death?" • "What are the arrangements for after death?"

B.2.2 Quality appraisal of studies

The quality assessment of qualitative studies will be done using a checklist developed by the Qualitative Research and Health Working Group in 2002. This specific checklist looks at the theoretical and epistemological issues, the study design, the sampling and data collection, the analysis, the findings/interpretation/trustworthiness, and the implications/limitations. This checklist was chosen due to:

- The easy though comprehensive approach of assessment;
- Defined questions for the respective part of the qualitative paper ensuring the entire paper is thoroughly assessed;
- Specific information on how to grade each section of the paper.

Although, this checklist is somehow old, it is thought that it is the most complete and easy to use checklist, and also it seems to fit very well within the papers piloted.

To assess quantitative studies, it was chosen the tool "Quality assessment tool for quantitative studies". This tool was developed by the Effective Public Health Practice Project (EPHPP), 1998. The assessment tool has been widely used in systematic reviews by the EPHPP, the McMaster

University and the National Collaboration Centre for Methods and Tools in Canada. This tool has a structured assessment criteria, it is very comprehensive and has been widely used internationally in multiple systematic review studies.

B.2.3 Data extraction and analysis

The analysis will be done, at first using descriptive coding, to identify relevant information about the topic and then using axial coding, to find repetitive themes in the papers. After this process data will be divided into themes and then analysed and presented as such. It is impossible to predict what the themes are in the literature, so this will not be described here. The data found in the papers will then be extracted into a "Data Extraction Sheet". Therefore, every paper included in the review will have one data extraction sheet and one quality assessment form. The data extraction sheet will be constructed considering the purpose and needs of the study. Three main sources were used to construct the data extraction sheet, the "Guidance for undertaking reviews in healthcare" by the Centre for Review and Dissemination of the University of York in 2008; the Data Extraction Sheet developed by Long-Sutehall, 2015; and the guidance suggested by Jones in 2007.

The data synthesis approach chosen was a **narrative synthesis.** This follows what has been said above about the heterogeneity of study designs and paradigms included in the study and the complexity and individual characteristics of the disease and population in study. The narrative synthesis will be used according with the guidance and framework suggested by Popay, 2006. The framework has 4 main elements:

1. Developing a theory;
2. Developing a preliminary synthesis;
3. Exploring relationships within and between studies;
4. Assessing the robustness of the synthesis.

Although as acknowledge by Popay, this guidance is not prescriptive, the use of the framework should be according with the types of research included, such as qualitative, quantitative or mixed-methods, and the study characteristics. In this particular review not all the tools contained within each element will be used to synthesise the data. Due to the unpredictability of the research findings it not is possible to define *a priori* which tools will be used throughout the review. Conclusions will be drawn from the synthesis and recommendations made.

B.3 Limitations of the review

According with the protocol a few limitations of the literature review have been identified. The first limitation will be the language of the papers, since only papers written in English will be

included in the review. This may reduce the number of retrieved papers and, therefore, reduce the number of papers included in the review. Some information may not be included because of the linguistic barrier. Another limitation that may pose in the literature review is that it doesn't include COPD participants in the end of life care pathway. This limitation may exclude interesting information about discussions in this particular group of patients. However, it has been noted in previous research studies that when patients in the end of life care pathway, they tend to have different opinions from when they were in a stable condition and in a stress-free environment.

B.4 Conclusion

In summary, with the development of this literature review protocol it is thought that major risks of bias have been solved. After the final approval of this literature protocol by the study's supervisors, the literature search and review will be commenced following the steps and guidance mentioned above.

Appendix C Quality assessment form for qualitative research

Article No:	**Review date:**
Title:	
Authors:	**Type of Publication:**
Publication Date:	**Country of Origin:**
Citation:	

1. Theoretical/Epistemological Issues	**Assessment (circle most appropriate)**	**Comments**
• Is a qualitative approach appropriate to answer the research question?	Appropriate Unclear Inappropriate	
• Is a qualitative approach justified by the author? Hints: Does the research methodology seek to understand or illuminate the subjective experiences or views of those being researched? Does the research methodology seek to understand WHAT is happening and the reasons WHY observed situations, outcomes or discourses occur?	Justified Unclear Not Justified	
• Is the purpose of conducting the research adequately described and justified? Hints: Was a review of the secondary data conducted and is presented? Is the research linked to policy or practice development processes?	Justified Unclear Not Justified	
TOTAL:	Adequate	

	Unclear Inadequate	

2. **Study Design**	**Assessment (circle most appropriate)**	**Comments**
• Is the context of the research adequately described?	Adequate Unclear Inadequate	
• Is the research question relevant to the context described?	Relevant Unclear Not Relevant	
• Are the research aims/objectives/questions clearly defined and focused?	Adequately Defined Unclear Poorly Defined	
• Are the methods used appropriate to the research question? Hints: Is a range of methods for triangulation, or is use of a single method justified? Do the methods investigate what they claim to? Have the best methods been chosen to address the research question?	Appropriate Unclear Inappropriate	
TOTAL:	Adequate	

	Unclear Inadequate	

3. Sampling and Data Collection	Assessment (circle most appropriate)	Comments
• Is the sampling strategy appropriate to the research question? Hints: Usually purposive or theoretical NOT random or representative. Is the sample sufficient to understand the study context and population? Was the sampling pre-determined or did it evolve as the fieldwork progressed?	Appropriate Unclear Inappropriate	
• Is the choice of sampling strategy justified? Hints: Are the reasons for this choice discussed/compared to other strategies? Who was selected and why? (consider gender, age, ethnicity, marital status) How were participants selected and why? Is it clear why some participants were not selected?	Adequately Justified Unclear Not Justified	
• Are data collection procedures clearly described? Hints: How was data collected? (topic guides, checklists) Were data collection tools pilot tested? Where was the data collected and why was this location chosen? (privacy, confidentiality, familiarity)	Clear Unclear	

How was the data recorded and why? (tape recorded, notes)		
• Are the roles of researchers clearly described? Hints: Who conducted the research, how were they selected? Are the researchers skills, motives, background, position in terms of power-relations (gender, age, ethnicity, employment relations, etc.) and perspective described and discussed?	Clear Unclear	
• Are ethical issues addressed in data collection and adequately discussed? Hints: How was the research explained to the participants? What consent procedures were used? How were confidentiality and privacy assured?	Adequate Unclear Inadequate	
TOTAL:	Adequate Unclear Inadequate	

4. Analyses	**Assessment (circle most appropriate)**	**Comments**
• Are the data analysis procedures explicit? Hints: Is it clear how the researcher processed the raw data to arrive at the stated results? Were the categories and themes identified in advance, or derived from the data? Are all data taken into account in the analysis?	Explicit Unclear Vague	

Are responses/experiences compared and contrasted across different groups/individuals/study sites?		
• Is the data analysis procedure reliable/dependable? Hints: Who was involved in the analysis and at what stage? Did more than one person (including researchers and other stakeholders) identify themes and code transcripts?	Reliable Unclear Potential Bias	
TOTAL:	Adequate Unclear Inadequate	

5. Findings, Interpretations and Trustworthiness	**Assessment (circle most appropriate)**	**Comments**
• Are the findings valid/internally coherent/trustworthy? Hints: Are the findings drawn from analysis of collected data rather than the researcher's preconceptions? Is there adequate critical discussion for and against the researcher's arguments? E.g. Are negative and divergent views adequately discussed? Are quotes used to substantiate the researchers' conclusions form the analysis? Is triangulation or data cross-checking used? Have findings been validated by respondents? Has the researcher critically reflected on his/her own bias, role and influence? Has the research critically reflected on the quality of the data collected and skills of the research team?	Valid Unclear Invalid or Potential Bias	
• Are the findings relevant? Hints:	Relevant	

Are the findings relevant to the study aim/objectives/questions? Do they contribute new knowledge or understanding? How important are the findings in local context? (geographical, cultural, political, socio-economic)	Unclear Limited Relevance	
TOTAL:	Adequate Unclear Inadequate	

6. Implications and Limitations	**Assessment (circle most appropriate)**	**Comments**
• Are the implications of the study clearly defined? Hints: Are the findings placed in local context? (geographical, cultural, political, socio-economic) Have findings been disseminated to key stakeholder including participants? Are the findings discussed in wider context? (in relation to other studies on the same topic) Are recommendations made for policy and practice?	Clear Unclear	
• Is there adequate discussion of the study limitations? Hints: Are study limitations described and accounted for? (cost, time and resources) Are the weaknesses of the study designed discussed?	Adequate Unclear Inadequate	
TOTAL:	Adequate Unclear	

	Inadequate	

TOTAL of all 6 points:	Adequate	
	Unclear	
	Inadequate	

Note: This Quality Assessment form of Qualitative Research was developed by the Qualitative Research and Health Working Group, LSTM in 2002. To the original criteria was only added the rows stating "TOTAL". These rows were added to the initial tables in order to have a final overall scoring when the paper was being assessed.

Appendix D Quality assessment tool for quantitative studies

Article No:	Review date:
Title:	
Authors:	Type of Publication:
Publication Date:	Country of Origin:
Citation:	

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely
3. Not likely
4. Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1. 80 - 100% agreement
2. 60 – 79% agreement
3. less than 60% agreement
4. Not applicable
5. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

1. Randomized controlled trial
2. Controlled clinical trial
3. Cohort analytic (two group pre + post)
4. Case-control
5. Cohort (one group pre + post (before and after))
6. Interrupted time series
7. Other specify _____
8. Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If yes, was the method of randomization described? (See dictionary)

No Yes

If yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1. Yes
2. No
3. Can't tell

The following are examples of confounders:

1. Race
2. Sex
3. Marital status/family
4. Age
5. SES (income or class)
6. Education
7. Health status
8. Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1. 80 – 100% (most)
2. 60 – 79% (some)
3. Less than 60% (few or none)
4. Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1. Yes
2. No
3. Can't tell

(Q2) Were the study participants aware of the research question?

1. Yes
2. No
3. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1. Yes
2. No
3. Can't tell

(Q2) Were data collection tools shown to be reliable?

1. Yes
2. No
3. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1. Yes
2. No
3. Can't tell
4. Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1. 80 -100%
2. 60 - 79%
3. less than 60%
4. Can't tell
5. Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3
Not applicable			

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1. 80 -100%
2. 60 - 79%
3. less than 60%
4. Can't tell

(Q2) Was the consistency of the intervention measured?

1. Yes
2. No
3. Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

1. Yes
2. No
3. Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

Community Organization/Institution Practice/Office Individual

(Q2) Indicate the unit of analysis (circle one)

Community Organization/Institution Practice/Office Individual

(Q3) Are the statistical methods appropriate for the study design?

1. Yes
2. No
3. Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1. Yes
2. No
3. Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the grey boxes onto the following table.

Appendix D

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**
		1	2	3

Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1. STRONG (no WEAK ratings)
2. MODERATE (one WEAK rating)
3. WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1. Oversight
2. Differences in interpretation of criteria
3. Differences in interpretation of study

Final decision of both reviewers (circle one):

1. **STRONG**
2. **MODERATE**
3. **WEAK**

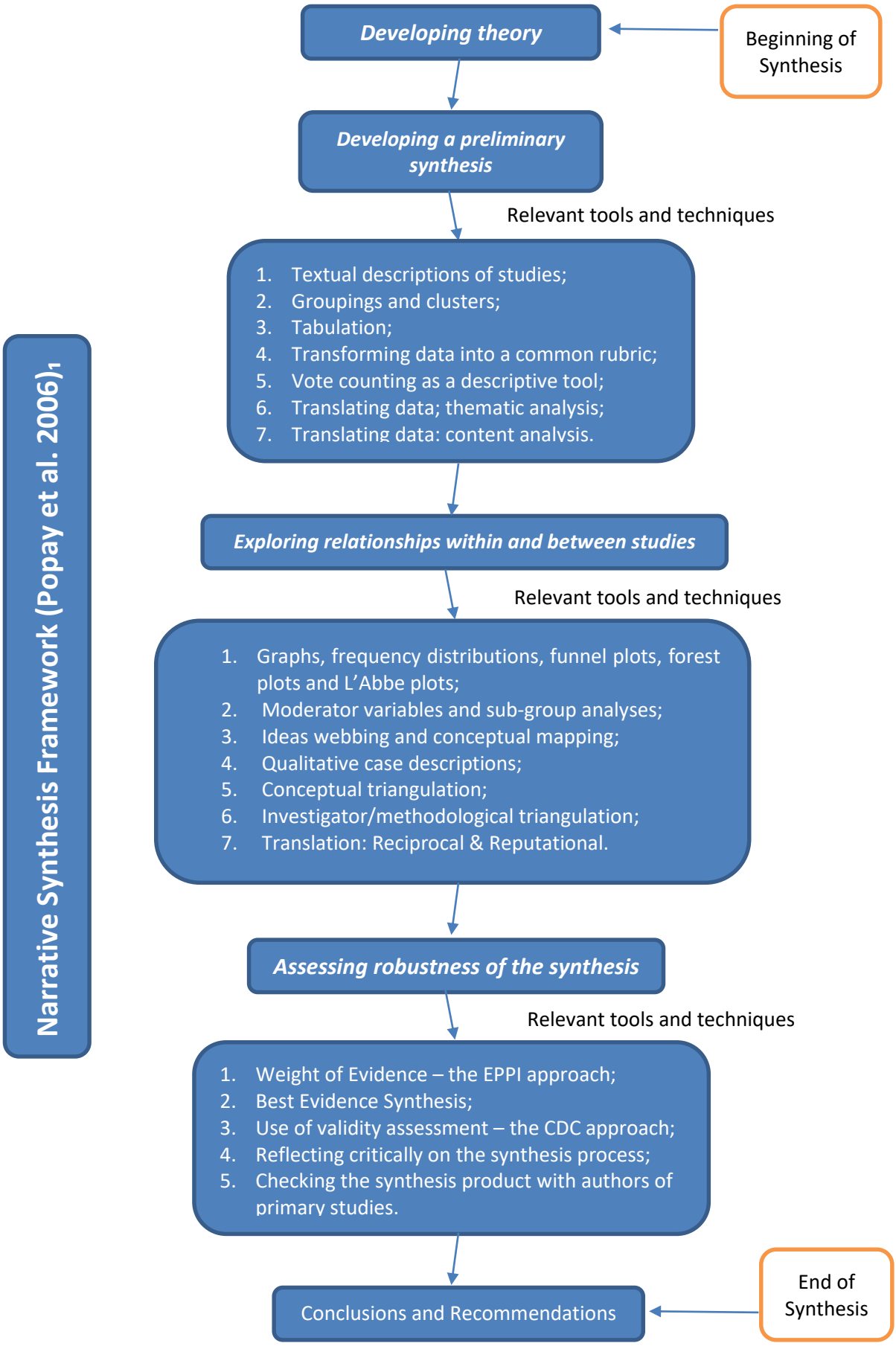
Appendix E Data extraction form

Article No:	**Review date:**
Title:	
Authors:	**Type of Publication:**
Publication Date:	**Country of Origin:**
Citation:	
Keywords/Definitions:	
Objectives:	
Study design:	
Methods:	
Inclusion/exclusion criteria:	
Recruitment Process and Setting:	
Intervention:	
Participants characteristics:	
Statistical Techniques:	
Main Findings:	
Type of analysis:	
Additional Outcomes:	
Conclusions:	
Suggestions made:	
Future Research:	
Strengths:	
Limitations:	
Own Notes:	

Methodological/Theoretical/Contextual Relevance:					
Rating: Quality of Research:			**Rating: Relevance of Study:**		
A	**High Quality**		**1**	**Extremely Relevant**	
B	**Medium Quality**		**2**	**Quite Relevant**	
C	**Low Quality**		**3**	**Marginal Relevant**	

Note: The Data Extraction Form was developed by combining the guidance and advice taken from several authors (Saks and Allsop 2007; Centre for Reviews and Dissemination 2008) and the Data Extraction Sheet facilitated by Dr Tracy Long-Sutehall. This form uses most of the criteria advised by the authors, however, only the relevant topics were included in order to be a comprehensive and thorough form, but at the same time easy to use and efficient for mixed-methods data.

Appendix F Narrative synthesis framework



Appendix G Studies included in the literature review

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(AHIA AND BLAIS 2014), USA	To model pertinent end of life care communication and discuss practical tips to incorporate goals of care and ACP into a primary care practice.	Case Report • 71-year-old male patient with chronic obstructive pulmonary disease.	• General internists and family medicine practitioners in primary care are central to eliciting patients' goals of care and achieving optimal end of life outcomes for their patients.	• The method chosen in the study – case report; • Prevents generalization for other patients/cases; • Approach suggested to establish goals of care was not tested before and does not include patients' opinions.	• Describes feelings, concerns and thoughts of one COPD patient and his relative about palliative care conversations.
(AU ET AL. 2012), USA	To improve the occurrence and quality of end of life communication with a simple communication intervention using a patient-specific feedback.	Cluster randomized trial • 92 respiratory physicians; • 182 COPD patients in the control group and 194 in the intervention group.	• The baseline quality of communication in both treatment and control groups was poor. • Participants frequently reported that they would like to discuss end of life care preferences.	• Does not provide in-depth information about patients' and clinicians' opinions, feelings and thoughts; • Study developed in one healthcare facility, generalization may be difficult; • Small percentage of women in the study; • Patients and clinicians approached during only one clinic to assess the conduction of conversations.	• Clustered randomized controlled trial – robust findings; • Included clinicians and patients across all backgrounds and disease stages.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(CRAWFORD 2010), UK	To explore the experiences of respiratory healthcare professionals in their conversations with COPD patients.	Qualitative phenomenology – Interviews • 2 respiratory physicians; • 3 respiratory nurse specialists; • 2 lung cancer nurse specialists.	• The timing of discussions is crucially dependent on the patient's illness pathway. • Picking up on subtle visual and verbal cues were highlighted. • Moral and ethical dilemmas, as well as the futility of treatment, were raised.	• Small sample of clinicians used; • No patients were included in the study; • Lack of details regarding the methods used, exclusion/inclusion criteria, recruitment process and data collection; • Results cannot be generalized; • Clinicians interviewed regarding interviews that they recalled having had in the past.	• Description of clinicians' experiences and concerns regarding palliative care conversations with patients; • Comparison of discussions between patients with cancer and COPD; • Description of the 5 most frequent themes regarding conversations with patients.
(CURTIS 2000), USA	To review what is known about communicating with patients and their families about end of life care in ITU settings.	Narrative Review Sample - Not Applicable	• Discussing dying with patients and their families is an extremely important part of providing good quality care for patients with chronic pulmonary diseases and families of patients in the ITU. • Providing sensitive and effective communication about end of life care requires training and practice as well as planning.	• Narrative review – which does not comprehend all studies published; • Includes data regarding all critical respiratory diseases; • Old review – published by the end of 2000; • No description of methods of data collection, analysis and synthesis; • No description of the limitations of the study.	• Comprehensive paper about palliative care and ACP in the intensive care unit; • Clinically orientated review;
(CURTIS 2008), USA	To examine problems in the delivery of high-	Narrative Review	• Improving communication represents an important opportunity for the	• Small section dedicated to palliative care discussions;	• Study very much focused in patients with severe COPD;

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	quality palliative care to patients with severe COPD and to identify ways in which to address these problems.	Sample - Not Applicable	improvement of the quality of palliative and end of life care received by these patients. • Poor palliative care in COPD was linked to poor communication.	• No description of methods of data collection, analysis and synthesis; • No description of the limitations of the study; • Narrative review – which does not comprehend all studies regarding the subject being reviewed.	• Describes practice focused recommendations for clinicians and patients.
(CURTIS ET AL. 2008), USA	To examine the interaction between the desire to have hope supported and the need to receive explicit prognostic information on the part of patients and family members.	In-depth longitudinal qualitative interviews • 55 patients (25 with COPD); • 36 family members; • 31 physicians; • 25 nurses.	• Asking patients directly how much information they wanted was not useful to identify informational needs. • Respondents identified two approaches to communicate prognosis: the direct and indirect approach.	• Sample chosen may have affected overall findings of study, as only physicians with good communication skills were chosen to recruit their patients into the study; • Findings are generated from participants in their last year of life, therefore conclusions can only be drawn for this specific group of COPD patients; • Difficult to generalize due to the type of study; • Small participation rate of physicians.	• Interesting study looking at desire for hopeful versus prognostic information; • Lack of comparison between COPD and cancer; • In-depth information about the views of patients with COPD and cancer about 4 diagrams describing communication in the last year of life.
(CURTIS ET AL. 2004), USA	To identify specific areas of communication about end of life	Questionnaires and Interviews • 115 COPD patients;	• Poorly discussed topics: talking about how long the patient has to live, talking about what dying might be	• Somehow old study, with data collected from 1999-2002; • Authors chosen a sample of patients with severe/advanced	• In-depth information about palliative care communication with patients with severe COPD;

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	care that patients report are not occurring and to identify specific areas of good and poor quality communication.	• 55 respiratory physicians.	like, talking with loved ones about what dying might be like and asking about the patient's spiritual or religious beliefs. • Depression symptoms was associated with quality of communication scores.	disease, therefore data can only be compared with patients in the same disease severity stage; • Lack of fully detailed description of inclusion criteria; • Difficult to generalize, due to type of study; • Small participation rate of patients; • Questionnaire used to ascertain the quality of communication; • Small interaction between qualitative and quantitative research.	• Large participation rate of physicians; • Thorough description of the quality of palliative care communication, however one cannot understand the true quality of discussions as most items were not discussed with patients.
(CURTIS ET AL. 2005), USA	To provide a narrative review of recent research regarding patient-physician communication about palliative care for COPD patients and to summarize the authors'	Narrative Review Sample - Not Applicable	• One reason for poor palliative care delivery in COPD was the lack of patient-physician communication about end of life care. • Patients and physicians identify many barriers to start conversations. • Depression has an important impact in end of life care communication.	• Lack of descriptions of the methods used to complete the narrative review; • Lack of discussion, limitations and strengths sections in the review; • Some information is based in studies done with patients with different conditions.	• Comprehensive review about palliative care communication with COPD patients; • Offers several recommendations to healthcare professionals; • Focused in the development of further research in this area.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	perspective on the research agenda.				
(CURTIS ET AL. 2002), USA	To elucidate the important aspects of physician skill at providing end of life care.	Focus Groups and Content Analysis • 24 COPD patients; • 36 AIDS patients; • 19 Cancer patients.	• Remarkable similarities were found in the perspectives of all patients including the importance of emotional support, communication, and accessibility and continuity. • For patients with COPD, the most concerning domain was the physicians' ability to provide patient education. • Patients with COPD desired education in: diagnosis and disease process, treatment, prognosis, what dying might be like, and ACP.	• Somehow old study using data from 2001; • Difficult to generalize the findings due to the type of study; • Findings are generated from patients with severe/terminal disease.	• Interesting study looking at the skills of healthcare professionals discussing palliative care; • In-depth information gathered using interviews with patients; • Thorough description of methods used in the study.
(DEXTER ET AL. 1998), USA	To test the hypothesis that reminding primary care physicians to discuss advance directives would stimulate such conversations and lead to the	Randomized Controlled Trial • 1009 patients (46% with a COPD diagnosis); • 147 primary care physicians.	• Physicians who did not receive reminders discussed advance directives with 4% of the patients compared with 24% for physicians who received both types of reminders. • Physicians who did not receive reminders completed	• Old study, used data from 1997; • Computer literacy may have changed the overall results if the study was to be repeated nowadays; • Physicians were encouraged to discuss advance directives with patients prior the study, this may have influenced the final results;	• Robust study, which used a randomized controlled trial; • Used an innovative computer-based programme to encourage palliative care conversations with patients; • Large participation rate in study; • Comprehensive description of the methods used in the study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	establishment of more advance directives.		advance directive forms with only 4% of their patients compared with 15% for physicians who received both types of reminders. • Overall, 45% of patients with whom advance directives were discussed completed at least one type of advance directive.	• Majority of participating physicians were faculty members who had larger knowledge about research and physiopathology, which may have influenced results; • Lack of data concerning patients' thoughts about discussions and about the appropriateness of the methods used.	
(ELKINGTON ET AL. 2001), UK	To investigate the role that conversations of prognosis play in GPs' management of patients with severe COPD and the factors that influence those discussions.	Survey • 214 GPs	• 72.5% thought that conversations of prognosis were often necessary or essential in severe COPD. • 82% felt that GPs have an important role in these discussions. • 50% of GPs were undecided as to whether patients with COPD wanted to know about their prognosis. • The majority of GPs that reported not discussing end of life with patients stated several reasons.	• Old study, which used information from 1999; • Lack of in-depth information of GPs regarding conversations about prognosis; • Small participations rate; • Lack of thorough information regarding the development of the survey.	• Robust study with a large sample of participants; • Survey piloted with small sample and based in previous interviews and literature review.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(ENGELBERG ET AL. 2006), USA	To describe the domain structure and the construct validity of the Quality of Communication Questionnaire.	Questionnaire • 113 COPD patients; • 83 hospice patients.	• Findings support the construction of two scales: a "general communication skills" scale and a "communication about end of life care" scale; • The two scales met standards of scale measurement; • This questionnaire represents an important step towards providing a measure of the quality of end of life communication.	• Small amount of information regarding the quality of discussions in clinical practice; • Somehow old study, used findings from 1998-2002; • Sample only included patients with very severe disease; • Questionnaire not used before, therefore may have not generated accurate results; • Lack of information from patients and physicians regarding their perspectives about the use of the questionnaire.	• Comprehensive description of the development of the Quality of Communication Questionnaire; • Large sample of patients; • Hypothesis were supported by findings.
(FAHIM AND KASTELIK 2014), UK	To evaluate the understanding of palliative care as an option in COPD and to identify any barriers to resuscitation conversations in this group of patients.	Questionnaire • 30 COPD patients.	• Thirteen patients understood the term NIV, and 11 of those would consider it again if needed. • Only 13% of patients knew that palliative care is an option in COPD. • Eleven patients understood the term cardiopulmonary resuscitation, and only five ever had a conversation regarding resuscitation.	• Questionnaire developed by the study authors without previous piloting; • Lack of description of the methods and data used to develop the questionnaire; • Lack of information stating the validity and reliability of the questionnaire, which may have biased the results;	• Study developed in the UK; • Several different assessment tools were used and their results were compared with the results of questionnaires.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
				• Lack of clinicians and patients' feedback regarding the use and feasibility of the study; • Small sample size; • Recruitment process may have influenced results, due to the recruitment of patients immediately after an acute exacerbation of their disease.	
(GASPARET AL. 2014), PORTUGAL	To evaluate the practice of Portuguese respiratory physicians in end of life communication and palliative care in COPD.	On-line Survey • 136 respiratory physicians.	• 48.5% of physicians reported that they have rarely introduced end of life care conversations. • 68% had never/rarely suggested decision-making on the use of invasive mechanical ventilation; • Discussions were described as occurring mostly during/after a major exacerbation. • Most participants perceive the discussion of end of life issues as being difficult/very difficult. • The most common reasons given were the feeling that	• Lack of detailed information about the perspectives of the participants included in the study; • Small participation rate; • Lack of information regarding the patients' opinions about these discussions.	• Robust study, showing data from another European country; • Comprehensive descriptions of the methods used in the study; • Only clinicians who looked after patients with COPD were included; • Recent study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			patients were not prepared for this conversation, fear of taking away the patient's hope and lack of training.		
(HALLIWELL ET AL. 2004), NEW ZEALAND	To identify strategies that GPs can use to facilitate conversation of prognosis with patients who have COPD.	Telephone interviews • 15 GPs; • 5 Respiratory Consultants.	• Seven strategies were identified to facilitate discussion of prognosis: be aware of implications of diagnosis; use uncertainty to ease conversation; build relationship with patients; be caring and respectful; begin conversation early in disease course; identify and use opportunities to discuss prognosis; and work as a team.	• Somehow old study, done in 2003; • Telephonic interviews used; • Exclusion of patients with COPD and other healthcare professionals; • Small sample of respiratory physicians; • Criteria of the questionnaire/questions of interview may have confused the participants.	• Showed in-depth perspectives of clinicians looking after COPD patents; • Data analysis and data synthesis.
(HOUBEN ET AL. 2015), THE NTHERLANDS	To examine the quality of end of life care communication during one year follow-up of patients with advanced chronic organ failure.	Questionnaires during home visits • 265 patients, of whom 105 had COPD.	• Quality of end of life care communication was rated low at baseline and did not change over one year. • Quality of end of life care communication was comparable for patients who completed two-year follow-	• Lack of detailed information about the quality of communication; • Inclusion only of patients with advanced/terminal disease; • Questionnaire used to assess quality of communication was not piloted or tested before, therefore the validity and reliability of the tool remains unknown;	• Very recent study; • Inclusion and comparison of patients with COPD with patients with other chronic illnesses; • Longitudinal study of a cohort of patients; • Large sample size.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			up and patients who died during the study. • The correlation between quality of end of life care communication and satisfaction with medical treatment was weak.	• Lack of detailed information about the perspectives of clinicians.	
(JANSSEN ET AL. 2011A), USA AND THE NETHERLANDS	To compare quality of patient–clinician communication about end of life care, and endorsement of barriers and facilitators to this communication in the Netherlands and the USA.	Comparison Study • 122 Dutch patients with COPD; • 391 North American patients with COPD.	• Dutch patients reported lower quality of communication about end of life care. • Clinicians in both countries rarely discussed life-sustaining treatment preferences, prognoses, dying processes or spiritual issues.	• Data gathered from patients in different time periods, using different methods, and patients with different disease stages and comorbidities; • Difficult to generalize due to regional differences; • Lack of objective measures to assess the quality of communication.	• Interesting comparison between patients with COPD living in the US and in The Netherlands; • Comprehensive description of the methods used to compare the two cohort of patients.
(JANSSEN ET AL. 2011B), THE NETHERLANDS	To assess life-sustaining treatment preferences, ACP, and the quality of end of life care communication in Dutch outpatients	Prospective and Observational study • 105 patients with severe COPD; • 80 patients with severe CHF.	• Advance directives were discussed with the physician specialist by 5.9% of patients with COPD and 3.9% of patients with CHF. • Patients rated quality of patient-physician end of life care communication as poor.	• Small amount of information dedicated to communication about end of life care; • Large differences between the two cohorts of patients; • Small participation rate; • Exclusion of clinicians from the study;	• Comprehensive description of the methods used in the study; • Comparison between patients with COPD and patients with heart failure.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	with clinically stable but severe COPD or Chronic Heart Failure (CHF).		• Physicians rarely discussed prognosis, dying and palliative care.	• Use of cross-sectional study; • Inclusion of patients with severe disease, may have prevented future comparisons with patients in different stages.	
(KASS-BARTELMES AND HUGHES 2004), USA	To show how physicians and other health care professionals can help their patients with ACP and assess patient preferences for care at the end of life.	Narrative Review Sample - Not Applicable	• Most patients did not participate in ACP, yet many were willing to discuss end of life care. • One way to determine patients' preferences for end of life care was to discuss hypothetical situations.	• Lack of information regarding the methods used in the report; • Lack of the discussion and limitations sections; • Somehow old study; • Report generated for the general patient regardless of their disease, therefore there is a lack of specific guidance for COPD.	• Report focused in clinical practice and in clinicians; • Presentation of a practical guide to discuss palliative care with patients.
(KNAUFT ET AL. 2005), USA	To identify the barriers and facilitators to end of life care communication as a first step to overcoming barriers and capitalizing on facilitators.	Focus groups and Cross Sectional Study • 115 oxygen-dependent COPD patients; • 56 respiratory physicians.	• 32% of patients reported having had a discussion about end of life care. • The most commonly endorsed barriers were "I'd rather concentrate on staying alive," and "I'm not sure which doctor will be taking care of me". • The greater the number of barriers endorsed by patients,	• Somehow old study, used findings collected in 1999-2002; • Inclusion of patients with only severe disease; • Small information regarding the development of the questionnaire used in the study; • Prospective cross-sectional study; • Lack of detailed information regarding the barriers and	• Robust study with large number of participants; • Large participation rate of patients; • First study considering the barriers and facilitators of palliative care discussions with patients with COPD; • Comprehensive study detailing the methods used in the study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			the less likely they were to have discussed end of life care with physicians.	facilitators of the conversations collected; • Small participation rate of physicians.	
(LEUNG ET AL. 2012), USA	To determine whether patients who reported having end of life conversations also reported higher perceived markers of quality of care and health status.	Cross-sectional study • 376 patients with COPD	• 14.6% of patients reported having end of life discussions. • Individuals who reported having end of life conversations with their physicians were significantly more likely to rate their quality of care as the best imaginable and to be very satisfied with their medical care. • Discussions were more likely to have occurred among patients with worse health status.	• Cross-sectional study; • Patients may have been excluded, if they did not acknowledge a discussion about palliative care that they actually had in the past; • Lack of detailed information about the effects of conversations in the patients' healthcare delivery and in their condition; • Exclusion of clinicians; • Lack of information regarding the content of conversations with patients and its consequent effect; • Somehow old, used data collected from 2004-2007; • Small number of women included in the study.	• Comprehensive description of the methods used during the study; • First study looking at the effects of discussions in the lives and wellbeing of patients with COPD; • Large sample size.
(MCNEELY ET AL. 1997), CANADA	To determine when respiratory physicians approach patients with end-stage	Questionnaire • 279 respiratory physicians	• Conversations were reported to occur most often at advanced stages of COPD. • 43% stated that they discuss mechanical ventilation with	• Old study, used data collected in 1996 or before; • Lack of detailed information regarding the topic from patients or physicians;	• Large sample size and large participation rate; • Comprehensive description of the methods used during the study;

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	COPD to decide about the use of mechanical ventilation, what information they provide to patients and how they provide it.		40% or less of their COPD patients before an exacerbation necessitates ventilatory support. • 55.2% described the decision-making process as a collaboration between patient and physician. • 53% of the respondents indicated that they occasionally, often or always modify the information provided to patients in order to influence their decision.	• Exclusion of patients; • Only respiratory physicians were included in the study.	• Detailed information regarding the development, piloting and administration of the survey.
(MOMENT AL. 2012), UK	To show the results of a literature review about end of life care conversations COPD.	Systematic Literature Review Sample - Not Applicable	• Most patients reported that they have not had end of life conversations with healthcare professionals. • Many patients would like these conversations, a potentially large minority would not. • Healthcare professionals find these discussions difficult and many prefer patients to initiate them.	• Lack of detailed methods used in the development of the review; • Small overall review, more details would benefit review; • Small number of databases searched; • Exclusion of grey and unpublished literature.	• Robust systematic review, which used a large and diverse number of references; • Recent review; • Presentation and synthesis of the review when compared with the large number of papers included.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(MORRIS ET AL. 2012), USA	To explore the responses of patients living with serious illness to the question "what is your understanding of your illness?" and to identify similarities and differences in themes and language used by cancer and non-cancer patients to discuss their illness.	Qualitative Analysis • 209 patients, of whom 70 had a diagnosis of COPD.	• 5 major themes were identified: naming the diagnosis or describing the pathophysiology, illness history, prognosis, symptoms, and causality. • Responses varied by diagnosis. Cancer patients' responses more often included specific diagnostic details and prognosis, while non-cancer patients referenced symptoms and causality.	• Difficult to generalize findings because of the heterogeneity of the participants included; • Exclusion of clinicians; • Inclusion of patients with only severe disease; • Somehow old study, findings from 2004-2007; • Lack of detailed information from patients and clinicians.	• Inclusion and comparison of patients with different diseases and demographics; • Evenly distribution of patients with different diseases; • Comprehensive description of the methods used in the study.
(MULCAHY ET AL. 2005), NEW ZEALAND AND UK	To compare the views of GPs in Auckland, New Zealand and London, UK on conversations of prognosis in severe COPD.	Questionnaire • GPs from London; • GPs from New Zealand.	• Most GPs in both samples stated that discussions on prognosis are necessary in severe COPD and that GPs have an important role in discussing prognosis. • Smaller proportions of both samples reported usually having such conversations, although Auckland GPs	• Somehow old study, used data gathered in 2003; • Comparison study; • May not be representative and generalizations may not be possible because of the heterogeneity of the sample; • Small response rate.	• Interesting comparison between 2 different groups of GPs in London and New Zealand; • Identical questions were asked to the two groups of GPs.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			(55.6%) were more likely to hold the discussions. • Auckland GPs were more likely to agree that patients with severe COPD wanted to discuss prognosis and that patients valued these conversations. • One-third of the Auckland GPs and nearly half the London GPs believe that some patients with severe COPD who want to discuss prognosis are not given the opportunity to do so.		
(PHILIP ET AL. 2012), AUSTRALIA	To explore the views of patients with COPD and healthcare professionals, focusing upon information needs and treatment preferences.	Interviews and focus groups • 10 COPD patients; • 18 nurses; • 7 respiratory doctors; • 6 allied healthcare professionals.	• The theme underpinning all discussions was of tension between maintaining hope and negotiating the reality of the illness and its consequences. • Patients tended to be optimistic, viewed acute exacerbations as separate from their underlying chronic	• Difficult to generalize due to the type of study – qualitative study; • Small participation rate and small sample size; • Particular inclusion criteria for the recruitment of patients, patients included if severe disease.	• In-depth perspectives of patients and clinicians regarding the information needs and end of life decisions; • Presentation of most discussed themes during interviews and focus groups; • Recent study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			illness, and were keen for intensive treatments, including intubation if acutely unwell. • Both patients and healthcare workers believed that information around end of life should be offered routinely.		
(QUILL ET AL. 2009), USA	To review the approach to requests for "everything" and to provide examples of how physicians can manage some aspects of the conversation.	Narrative Review/Expert Opinion • 75-year–old man with oxygen dependent COPD	• Clinicians should not take the request for "everything" at face value, but should instead use it as a basis for broader conversation. • The clinician should propose a philosophy of treatment and make recommendations that capture the patient's values. • Clinicians should respond to emotional reactions, negotiate disagreements, and use harm-reduction strategies.	• Methodology and methods of study not presented; • Study used as an example a COPD patients, however the language and general information is dedicated to patients with all sorts of diseases; • Lack of description of the discussion and limitations/strengths sections.	• Comprehensive information focused in clinical practice, with practical information given to clinicians; • Step-by-step approach to hold conversations with patients/relatives who want everything.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(CURTIS 2006), USA	To provide a brief narrative review of recent research regarding patient–physician communication about palliative care for patients with COPD.	Narrative Review Sample - Not Applicable	• One reason these patients may receive poor quality palliative care is that patient–physician communication about palliative and end of life care is unlikely to occur. • Understanding the barriers to this communication may be an important step to improve communication about end of life care and improve patient-centred outcomes.	• Lack of the following sections: methods, discussion and limitations/strengths; • May have missed important studies due to narrative review character; • Somehow old review; • Unable to understand the criteria, databases, data analysis and data synthesis methods used.	• Succinct and focused review in discussions about palliative care.
(REINKE ET AL. 2011A), USA	To explore whether educating patients via web conferencing would equip them with knowledge and skills to engage in conversations about end of life care.	Feasibility Study • 7 patients with severe to very severe COPD.	• 6 patients had completed advanced care planning forms but only half had shared these with their clinicians. • Most patients felt confident about discussing end of life care preferences. • Five felt the webinar was an acceptable option. • At 3 months, all participants had taken further action on end of life planning.	• Small sample size and sample not representative of the majority of the COPD population; • Very difficult to generalize and to draw conclusions from the sample used; • Lack of a control group; • Intervention presented in the study cannot be used with the general COPD patient due to high technology and education skills required.	• Interventional research study to improve conversations about end of life care wishes; • Comprehensive description of methods and of steps used during the study; • Description of implications of the study in future research.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(REINKE ET AL. 2011C), USA	To describe patient-clinician communication practices about end of life care in patients with COPD using self-reported questionnaires.	Cross-Sectional Study • 376 patients with COPD	• All end of life care topics were under-addressed. • Four topics were not addressed 77-94% of the time. • None of the quality of communication items varied significantly by clinician type.	• Lack of in-depth information regarding end of life care topics; • Use of a cross-sectional study of data collected previously; • Small number of female patients included.	• Comprehensive description of the methods and steps used during the study; • Medium-large participation rate in the study; • Novel study comparing clinicians' characteristics with the non- conversation of end of life care topics; • All types of clinicians included.
(SCHMIDT ET AL. 2014), FRANCE	To provide a description of the information provided by respiratory physicians to their COPD patients at regular follow-up visits and of the information received by COPD patients and their relative about COPD-related ICU stays.	Interviews • 126 COPD patients; • 102 relatives; • 173 respiratory physicians; • 135 ICU physicians.	• For 41% of patients and 54% of relatives, ITU admission had never been expected prior to admission. • One half of patients were not routinely informed by their respiratory physicians about possible ITU admission. • Treatment options were not explained to COPD patients during regular respiratory visits. • Respiratory physicians and ITU physicians have different perceptions of the decision-	• Lack of in-depth information about the perspectives of patients and clinicians; • Lack of information regarding the patients who died during their stay in the intensive care unit; • Clinicians who participated in the study did not look after the patients who were also included.	• Very recent study; • Large participation rate in the study; • Large number of intensive care units included in the study; • Comprehensive description of methods and steps taken in the study; • Data may be generalized to other areas of France, country of origin of the study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			making process pertaining to ITU admission and intubation.		
(SEAMARK ET AL. 2012), UK	To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for ACP and to understand, from the patient perspective, the optimum circumstances for ACP.	Interviews • 16 COPD patients; • 15 Relatives.	• No patients recalled conversations about resuscitation or planning for the future. • Hospital admission and discharge was seen as chaotic and lacking in continuity. • Some patients welcomed the opportunity to discuss ACP and felt that their GP would be the best person for this. • Others wished to avoid end of life care conversations but there was evidence that, with empathetic and knowledgeable support, these discussions could be initiated.	• Small number of female participants; • Difficult to generalize information due to qualitative character of the study; • Exclusion of clinicians in the study.	• Somehow recent Study; • Comprehensive and thematic description of the patients' perspectives regarding the use of hospital admissions to initiate conversations about resuscitation, ventilation and ACP; • Inclusion of patients in different stages of their disease.
(SIMPSON 2011), CANADA	To offer some preliminary observations from a qualitative doctoral study to explore the question: What is	Interventional Study • 8 patients with COPD; • 7 informal carers.	• Despite initial resistance on the part of six out of eight patients, all were able to discuss end of life care concerns and appreciate some aspects of doing so.	• May have included some leading questions, which may have biased some of the findings; • Lack of details regarding exclusion and inclusion criteria, limitations and strengths and final conclusion;	• Comprehensive description of methods used in the study; • Very much focused on the patient with COPD; • Well-structured interventional study.

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
	required for meaningful, acceptable ACP in the context of advanced COPD?		• The sessions were an opportunity to: (1) learn more about end of life care options; (2) consider/document end of life care preferences; (3) counter the silence around the subject; and/or (4) have their illness concerns and experiences heard.	• Only patients with severe disease were included; • Small sample size.	
(STEPHENET AL. 2013), UK	To highlight the key components and challenges for patients and health professionals discussing end of life care in non-malignant respiratory disease.	Systematic Literature Review Sample - Not Applicable	• Three themes involving components and challenges in end of life conversations were identified: the conversation, the health professional/patient relationship, and patient perceptions.	• Inclusion of patients with several non-malignant respiratory diseases; • Small number of databases and papers included; • 11-year window for the publication of papers; • Exclusion of other reviews in the study; • PICO framework used, therefore it led into a quantitative based review.	• Comprehensive description of the methods used during the review; • Well-structured systematic review; • Succinct, yet comprehensive review; • Somehow recent review, used data published from 1999 to 2010.
(SULLIVAN ET AL. 1996), CANADA	To examine how the physician perceives the decision-making process.	Interviews • 15 respiratory physicians.	• Narratives were very similar in content and seemed well rehearsed. • Fourteen respiratory physicians emphasized the	• Old study, findings dating from 1995; • Exclusion of patients from the study;	• In-depth details of the physicians' thoughts regarding communication about intubation and ventilation;

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
			importance of knowing patients as individuals prior to initiating this conversation. • Individual physician comfort also appeared to affect the timing of the conversation. • Physicians discussed the many elements that make the mechanical ventilation discussion difficult for physicians and patients.	• Difficult to generalize due to qualitative and regional character of the study; • Small number of female participants included; • Findings may only reflect what physicians perceive as ideal communication and not what physicians actually perform in practice.	• Large participation rate in the study; • Majority of clinicians included had large clinical experience; • Comprehensive description of the methods used during the study.
(SZMUILOWICZ ET AL. 2010), USA	To study whether a day-long communication skills training retreat would lead to enhanced performance of and confidence with specific end of life care conversations.	Randomized Controlled Trial • 23 medical residents in retreat group; • 26 medical residents in control group.	• Retreat participants demonstrated higher T2 scores for breaking bad news, discussing direction of care, and responding to emotion. • Comparing T2 to T1, the retreat group's improvement in responding to emotion was statistically significant. • The retreat group's confidence improved significantly only for the breaking bad news construct.	• May have included medical trainees who do not provide care to patients with COPD; • Lack of in-depth information about the communication skills of clinicians; • Exclusion of patients from the study; • Small sample size; • Results may have been biased somehow, because control group received feedback about their communication skills after being assessed.	• Robust information from a randomized controlled trial; • Large response rate; • Comprehensive description of the methods used during the study.

Appendix G

REFERENCE AND COUNTRY	AIM	STUDY DESIGN PATIENT GROUP AND SAMPLE	FINDINGS	WEAK POINTS	STRONG POINTS
(YOU ET AL. 2014), CANADA	To provide guidance for ACP as it pertains to the inpatient setting.	Narrative Review Sample - Not Applicable	• Clinicians can use the "surprise" question or more detailed clinical criteria to identify high-risk patients. • When discussing goals of care with patients, clinicians should ask patients which family members they would like present and involve them. • Discussions about goals of care and any decisions made should be clearly documented in the patient's medical record.	• Lack of methods, discussion and limitations sections in the study; • Inclusion of information and suggestion for patients with serious illnesses, therefore information was not specific tailored for patients with COPD.	• Recent Study; • Practical review, very much focused in clinical practice; • Important and interesting suggestions made by the authors.

Appendix H Participant Information Sheet – COPD Patients

Study Title: Preferences of people with respiratory problems for conversations about future care with doctors and nurses.

Researcher: Nuno Tavares **Ethics number**: 203444

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Most people who have COPD (a disease which causes narrowing of the breathing pipes) do not discuss the care they would like to receive in the future with their doctor. This makes it very difficult for doctors and nurses to provide the best care and treatments when people become too sick to speak for themselves.

I'm interviewing people with COPD to understand their preferences for conversations about care and decisions for future care and treatments. These conversations between healthcare professionals and patients include:

A) The treatments that patients would like to receive;

B) The treatments that patients would not like to receive;

C) The ideal person to speak for that person, if he/she becomes too sick.

My name is Nuno Tavares and I'm a nurse in Queen Alexandra Hospital in Portsmouth. In the hospital I work as a respiratory nurse and I look after very sick people with breathing difficulties. I'm also a student in the University of Southampton.

During the interview I will ask you:

A) What does COPD mean to you?

B) What is the sort of treatments and care that you would like to receive in the future?

C) When, with who and how would you like to discuss the treatments and care you want and do not want to receive in the future?

This research study is part of a PhD degree in the University of Southampton. The sponsor of the study is the University of Southampton.

Why have I been invited?

You were invited, because as a person who has COPD, we would like to know your opinion and to understand your preferences for conversations with doctors and nurses.

What will happen to me if I take part?

If you take part, I will meet you at a place of your choice so that I can interview you for about 1 hour. Our interview will be audiotape recorded and the recording will be kept at the University for a minimum of 10 years. After the interview, I will analyse your answers and use some of them as part of the results of the study. They will not contain any information that may identify you. I will also look at your case notes to collect details about your illness.

Are there any benefits in my taking part?

There are no immediate benefits. However, it may be that this research will influence nurses and doctors in the future when they are caring for people with COPD.

Are there any risks involved?

There are no obvious known risks. However, during the interview you may become upset in some way. I will support you in any way possible and/or pause or stop the interview altogether. If you find the interview very upsetting and would like to receive further support, we can suggest you the following options:

A) If you feel very low and sad please contact your GP or the respiratory team. You can call the respiratory team at Portsmouth on – Telephone: 02392 286000 Extension – 1350/6665; or the team at Southampton on – Telephone: 02381 204325-;

B) If you would like to talk about COPD with other people who also have COPD please contact the British Lung Foundation support groups. You can find more information on the British Lung Foundation website: https://www.blf.org.uk/support-for-you/breathe-easy; call their helpline on: 03000 030 555; or send them an email using their website. You can find very useful information in the British Lung Foundation website - https://www.blf.org.uk/

Will my participation be confidential?

Your participation will be confidential and all your information will be protected under the Data Protection Act. This means that all the information that you provide will be given a code and I will keep it securely in a password protected computer and/or in a lock cabinet closed behind code-locked doors kept in the Research and Innovation Department in Queen Alexandra Hospital, Portsmouth.

What happens if I change my mind?

If you change your mind, I will immediately stop the interview or prevent it from happening. If you change your mind after the interview, I can exclude you interview from the study up to 7 days after the interview. After this point, I will not be able to exclude it from the study.

What happens if something goes wrong?

In the unlikely case of concern or complaint, I advise you to contact the University of Southampton – **Research Governance Office** using the following methods:

1. **Address:** University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ
2. **Tel:** +44 (0)23 8059 5058
3. **Fax:** +44 (0)23 8059 5781
4. **Email:** rgoinfo@soton.ac.uk

Where can I get more information?

If you would like to receive more information and/or participate in the study, you can contact me directly using the following methods:

By Telephone: — 07514741881

By Email: nct1g14@soton.ac.uk

Appendix I Data collection and analysis of Phase 2

I.1 Data collection

The interview topic guide, as well as the participant information sheet, were co-developed with COPD and Asthma patients, please refer to **Appendix J** to find the guide. Patients were asked to comment on these documents/topics before research participants were approached. Before starting the interviews with COPD patients, a mock interview was held with a PPI champion, who was also a respiratory patient. This aimed at seeking feedback regarding the language and depth of questions asked throughout the interview. Moreover, regular meetings with the study supervisors were held in an effort to improve the quality of data collection and to improve the student's interview skills. As an example, the supervisors reviewed the transcripts of the first 3 interviews with patients and recommended a change in the structure of the interviews and the use of more open questions. As a consequence, the collection of clinical and social data was moved to the end of interview, rather than the beginning. The latter structure seemed to medicalise the interview, since it focused on history taking. Lastly, to ensure trustworthiness, supervisors were able to access and feedback on all transcripts and interviews throughout the data collection process.

I.1.1 Patient support

Conversations about palliative care were thought to be potentially distressing for patients, therefore information about the content of the interview was included in the PIS. Moreover, participants were made aware that discussions could distress or upset them in some way. Support and reassurance was provided and participants had the opportunity to take breaks or stop the interview at any time. If patients became upset during the interviews, reassurance was provided and the interview was paused or stopped if patients wished or became increasingly upset. Participants were signposted to their GP or respiratory doctor if there was concern about their physical or psychological health; to visit the Breathe Easy support groups if they wished to meet other patients; and to contact the British Lung Foundation for further support/information regarding their condition. There were no incidents where patients became upset or distressed by the content of the interview.

I.1.2 Clinical and social data

Another form of data collection included gathering social and clinical data, please refer to **Table 1**. All data was collected into a Data Collection Form that can be found in **Appendix K**. This data was

collected at the time of the interview, by direct questioning. However, if patients were uncertain or did not possess this information, case-notes were review. Social and clinical data provided further context to patients' thoughts and were used during interviews with healthcare professionals. These data are commonly used in clinical practice and provide further understanding about the patients' disease severity. As an example, the Hospital Anxiety and Depression Score scale (HADS) assessed the level of anxiety and/or depression. This tool was chosen since it had been widely used in previous COPD research, seemed simple and required little time to complete, and it had been previously proven sensitive (Pochard et al. 2001). Please refer to **Appendix L** to find the HADS scale. The main purpose of using this scale is to understand whether depression or anxiety influences patients' preferences for palliative care discussions. Previous research showed that patients who suffer from anxiety and/or depression have more thoughts about palliative care and/or death (Stapleton et al. 2005), however variation was found in different studies (Reinke et al. 2011b).

Table 1 Clinical and social data

SOCIAL DATA	Age;	
	Gender;	
	Level of education;	
	Smoking status;	
	Smoking pack-year;	This tool reflects the amount of tobacco smoked over the years. Higher score indicates heavier smoking.
	Social network.	
CLINICAL DATA	Lung function test results;	Also known as spirometry, this test assesses the amount of air contained in a forced and relaxed out-breath. The test is used to diagnose and monitor COPD patients and assess airflow obstruction.
	Arterial blood gas results (if available);	This test measures the acidity and levels of oxygen and carbon dioxide of arterial blood. The test aims at identifying the ability of the lungs in transferring oxygen and carbon dioxide in and out of the lungs.
	Medical Research Council Breathlessness scale (MRC breathlessness scale);	The scale grades the effect of breathlessness on the daily activities of COPD patients. Higher scores reflect a greater impact of dyspnoea in the lives of patients.
	Hospital Anxiety and Depression Scale (HADS);	The scale assesses levels of anxiety and depression experienced by COPD patients. Higher scores suggest greater levels of anxiety and depression.
	Dyspnoea, Obstruction, Smoking, Exacerbation (DOSE) index;	The index assesses disease severity and aids clinical management of COPD patients. The index combines relevant measures found in COPD – MRC Breathlessness scale, airflow obstruction, smoking status and the

		number of exacerbations in the last year. Higher scores are associated with an increased risk of mortality.
	Body Mass Index, Airflow Obstruction, Dyspnoea and Exercise capacity (BODE) index;	This index aims at predicting mortality in patients with COPD. The index combines relevant factors found in COPD – modified MRC Breathlessness scale, airflow obstruction, 6-minute walk distance and the body mass index. Higher scores suggest an increased risk of mortality
	Number of previous hospital admissions and exacerbations;	
	Previous or current use of LTOT and/or NIV;	

I.1.3 Practicalities of patient interviews

Interviews took place in the most convenient location for the participant, including patient's homes. The lone researcher policy in place at the University of Southampton was reviewed and guidance for the research process in such circumstances was developed (please refer to **Appendix M** for more information). Interviews started with the introduction of both the researcher and participant, a full explanation of the research study and of the interview was provided. The consent form was explained and signed before starting the interviews (refer to **Appendix N** to find the consent form).

I.1.4 Data analysis

As described in chapter 3.3 and page 25, data analysis was guided by principles of IPA. The use of IPA in research studies has been widely documented (Smith 1996; Smith 2008; Smith et al. 2009; Smith 2011; Pietkiewicz and Smith 2014). IPA is not considered a prescriptive method, so researchers can adapt it to their method of working and study type (Smith 2008). As a consequence, an analytical approach was developed for this study, please refer to **Appendix O**. Despite the acknowledged importance of the idiographic character of IPA, this could not be fully achieved due to the large sample of patients and the study's time and resource constraints. Despite this, patients' preferences and thoughts were looked at individually and considering potentially impacting factors, but oriented towards the themes that informed the research question. Since an IPA approach was not strictly followed, the analytical approach on how to develop an IPA study was adapted accordingly. A detailed account of the different analytical stages is provided below.

I.1.4.1 Step 1. Looking for themes in each participant

Data analysis used the assistance of the Nvivo software, which helped categorize, organize and structure the research study. This software has been widely used in the analysis of qualitative data and is well established within the academic community. The software uses “nodes” that are used for taking notes and summarizing participants’ thoughts; “annotations” to comment on transcripts; and “memos” to take longer notes. Therefore, the language used by the software is the same language used in this document.

Data analysis started with the construction of a list of deductive nodes. This step was done prior to reading the transcripts and focused on answering the research questions. Deductive nodes were developed considering the primary and secondary research questions and the interview schedule. These nodes provided a guide of orientation when reading, taking notes and summarizing the information contained in the transcripts. Information related to deductive nodes was sure to be found in the transcripts, since these were the main topics of the interviews and the research question. Other relevant nodes to the research question and to participants were labelled as inductive. These nodes derived from the transcripts and were not thought *a priori* as topics that answered the research questions in particular. Despite this, inductive nodes were seen as important as deductive nodes, since they provided invaluable information which helped contextualize and interpret participants’ thoughts/preferences. The list of the first deductive nodes can be found in **Appendix P** and **Table 1.**

I.1.4.2 Reading transcripts, line-by-line analysis, emerging and refining themes

The analysis of each transcript started with a careful read of all the document. Field notes were taken during interviews and contained thoughts about the interview and the patients interviewed. All interviews were transcribed verbatim and included communication shared by the interviewer and the interviewee. In order to structure data analysis, transcripts were analysed individually according with participants’ disease severity and started with participants 101-113 (mild disease), then 201-216 (moderate disease), and finally 301-312 (severe disease). The process of analysis for each transcript included: reading transcripts carefully; then the text was analysed line-by-line looking for information relevant to the research question. The text was analysed using the deductive nodes described above, using inductive nodes (nodes that resulted from new topics) and annotations (containing comments, notes and summaries). This analytical step generated a list of inductive nodes, please refer to **Appendix P and Table 2.**

At the end of this analytical step, deductive nodes contained large amounts of information. Therefore, these nodes were categorized into smaller nodes and more specific nodes - secondary

and tertiary nodes. Secondary and tertiary nodes organized and structured data in smaller headings, which made it easier to manage and analyse. The full list of inductive and deductive nodes were further refined. The reasons for this included: overlapping themes, little information contained in the nodes and/or less relevance of nodes for the research study. The information contained in the deleted/dropped nodes was transferred to existing nodes. The new list of inductive and deductive nodes can be found in **Appendix P and Table 3.**

I.1.4.3 Supervision and collaboration

The supervisory team met throughout the data analysis process. As an example, at some point the team discussed the progress of data analysis and reviewed the information identified in the steps described above. Three interview transcripts were analysed individually by the whole team and data analysis was discussed. The feedback from the supervisory meeting included:

- Nodes had to include larger parts of the transcript. The strategy used previously resulted in nodes only including very specific information related to the topic. Therefore, the team recommended the inclusion of larger parts of the transcript in the nodes, in order to provide further context and understanding to patient's choices and thoughts.
- Parts of the transcripts were excluded in nodes, leaving larger parts of the transcripts with no nodes attributed. The team recommended further analysis of these excluded areas. Again, this new information could provide further understanding of patient's preferences.

After this particular meeting, all transcripts were re-analysed, specifically targeting areas of the transcript that had not been previously coded. The final list of nodes, the number of participants that had nodes attributed to their thoughts (sources) and the number of instances in which participants talked about certain topics (references), can be found below in **Appendix P and Table 4.** As an example, of the different analytical steps one transcript can be found in **Appendix Q.**

I.1.4.4 Super-ordinate theme analysis

The following phase of the data analysis process included looking at each primary node. This analysis had the purpose of understanding participants' thoughts in relation to the topic described by the node. Primary nodes contained parts of transcript of several participants and the first step focused on gathering and analysing this information as a whole. Next, this information was looked at individually (patient by patient). The step of analysing information individually provided further clarification to patients' preferences and thoughts.

The steps taken when analysing the different primary nodes included:

1. The primary node was read as a whole before analysis;

2. The thoughts of patients contained in the node were summarized into a table. The summary included main thoughts, nuances, ambivalences, reasons for preferences or other relevant information;
3. The thoughts of patients were then grouped, if similar, and divergences noted and separated.
4. The groups of opinions, divergences and nuances were transferred to a word document. The number of patients with similar and divergent opinions and preferences were noted and recorded in a separate table.
5. Quotes from patients were retrieved and presented in the findings section to illustrate their thoughts. The entire transcript of patients that provided quotes was reviewed in order to further inform their choices.

I.1.4.5 Transforming nodes into themes

Nodes were analysed considering the information provided in them and themes emerged from the combination of these nodes. The research question focused on patients' preferences for the person, time, site and approach for palliative care discussions. Therefore, nodes that provided relevant information that helped answer the research questions were combined and integrated forming themes and subthemes. As an example, the theme *"Preferred timing for palliative care discussions"* includes the primary deductive node *"Timing"* and the inductive node *"Understanding of becoming unwell."* When discussing the ideal timing for discussions with clinicians, patients often stated that this depended on self-prognosis – their health condition - rather than a specific point in time. Therefore, this inductive node provided further understanding as to when patients believed palliative care preferences should be started, by exploring patients' perceptions about future deteriorations and the process of "becoming unwell." Subthemes emerged from the combination and integration of the different secondary nodes under the primary node "Timing". Please refer to **Appendix P and Table 4** to find these nodes and to Chapter 5.4 and page 64 to find the full list of themes.

From data analysis pen portraits with patient information were developed and a small proportion of these portraits can be found in **Appendix R.** These portraits were created in line with the idiographic approach used in IPA. Moreover, pen portraits provide further context to the thoughts shared by patients in the different themes, allowing one to have a closer view of their reality.

I.1.5 Reflexivity

Reflexivity is defined for the purposes of IPA as a deliberate and controlled reflection (Smith et al. 2009; Larkin and Thompson 2012). Personal preconceptions influenced all aspects of this research

study, especially the data analysis process (Larkin and Thompson 2012). IPA promotes the reflection of these underpinnings and their impact on the different stages of the research study (Larkin and Thompson 2012). This process is ongoing, starting before the design of the study and finishing after the research findings were presented (Smith et al. 2009; Larkin and Thompson 2012). A general reflexive account can be found in **Table 2**. This account reflects on the impact of personal preconceptions in this phase of the research work.

Table 2 Reflexive account

I'm a 28-year old middle class white Portuguese male. I consider myself to be well spoken and I usually try to present myself in a smart and tidy manner. I consider myself to be discreet, logical, deliberate and methodical. I feel more comfortable in a formal manner and I try to be as professional as I can when meeting patients. My cultural and social background thoroughly influenced my personality and my world views. These views are concentric with the ideals found in a developed society located in Western Europe. Moreover, my world views are specific to the 2010 decade and have evolved and changed overtime. *From a professional standpoint, I have a nursing background, therefore I tend to instinctively prioritize accounts from a clinical nature. I'm a clinically orientated person and clinical and social data have a large role in my clinical decisions. In the last 4 years, I've worked with COPD patients in hospital and community settings. Since august 2017, I've been assessing and delivering pulmonary rehabilitations sessions to COPD patients. This work has enabled me to learn the community pathway experienced by patients and to construct a different perspective about their healthcare needs. My clinical background has provided an insider's perspective from a clinician point of view. This has led to the construction of several beliefs about the care and treatments that patients receive or should receive. These underpinnings are based on the type, frequency and quality of care that patients should receive at different stages of their illness. These beliefs are likely to differ from patients' preferences, since I have no personal experience in living with COPD nor in requiring acute or chronic healthcare. Lastly, my perspective is at the opposite end of the spectrum when compared with patients' perspectives, since I have the healthcare provider standpoint, whilst patients are at the receiving end of the spectrum.* *My beliefs about the research topic have evolved over time, not only because of the development of the research study, but also due to the insider's perspective. This perspective provided further understanding about organizational and professional practicalities. This experience has impacted the way I understand and interpret the thoughts shared by patients. When considering palliative care conversations in COPD, I believe in early discussions with patients and that every patient should have the opportunity to discuss their preferences and concerns about the future with a clinician. I believe these discussions provide valuable*

information to clinicians and may direct their approaches towards care and treatments. Moreover, conversations provide illness-related information to patients, such as prognosis and treatment options. Conversations can result in lower levels of anxiety and depression, as patients know what to expect from the future and from clinicians. Thus, patients can see their preferences respected and their symptom burden reduced. Moreover, conversations are likely to reduce futile and aggressive treatments and to improve patients' quality of life. I am a person who plans the future and feels reassured to know what to expect. Despite this, I understand that people have different approaches to life and the future. These approaches may diverge further when considering our own mortality. Conversations about palliative care are inevitably associated with patients' mortality.

My clinical experience contrasts well with my research experience. I had no previous research experience at the start this fellowship. Although I had contact with research before, this was only from a reader's standpoint. Prior to the start of the research study and interviewing patients, I attended several training courses. Despite this, I believe that my lack of research experience impacted in the development of the study, especially in the interviews with patients. Due to my clinically focused approach, the interviews with patients seemed to have been medically focused. Although, I tried to refine my approach while interviewing, my innate clinical approach of interviewing seemed to take over throughout the interviews. I reviewed and listened to my interviews with patients as I was conducting them, in order to refine my approach at interviewing. The issues found seemed to be related with the reduced number of open questions, especially when exploring in-depth topics mentioned by patients. Despite the fact that my interviewing skills improved with time, they did not reach the desired level of improvement.

My perception about the research topic changed as I developed the research work and interviewed patients. At the start of the study, I believed I would be able to solve a clinical issue and guide clinicians when initiating discussions with patients. However, the research topic and findings seemed to increase in complexity as time evolved. Patients' preferences for palliative care discussions are underpinned by several aspects that evolve as disease severity advances and are patient-specific. This initial assumption impacted on the design and development of the study and on the interviews with patients. This mindset changed as I analysed the data generated from the interviews with patients.

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My preconceptions impacted upon patient interviews and data analysis. In the interviews, due to my professional background, I inherently focused on the different treatments and care available to patients. Thus, I introduced myself to patients as a COPD nurse that was also conducting research. As a consequence, patients seemed keen to discuss medical and self-management topics, such as

inhaler therapies, medication regimens and healthcare utilization. Moreover, my passion about this topic may have influenced patients in recognizing the importance of palliative care discussions. This may have led patients to provide favourable opinions about palliative care discussions and in providing answers that they believed I expected from them. My social and cultural background led me to share views about the world, life and COPD with some patients. This may have facilitated the interpretation of their thoughts.

A reflexive journal was kept throughout the research study, but especially during phase 2. Please refer to **Table 3** to find 3 entries to reflexive journal. The first entry relates post-interview thoughts, whilst the other 2 entries share thoughts about data collection process.

Table 3 Entries from the reflexive journal
"I think today's interview went very fast. I was able to cover all the information I needed, however I don't think I have explored all topics in depth. The patient was very concise in her answers and I noticed that she tried to take the conversation elsewhere instead of covering the interview topics. Was she avoiding getting hurt by talking about future care and treatments? Was it an uncomfortable subject? I'm not sure why. This lady seems very independent and said that she wanted to be kept alive only if she had quality of live and was independent. She said that she would hate to be bedbound or in a wheelchair and that she would be happy for treatments to be stopped if that ever happened. ***Other relevant patient details:*** *obesity, moderate COPD – never smoked, bilateral knee replacement, but considers herself to be quite healthy."* **Post interview thoughts with participant 14 with moderate COPD – 9th of July 2017**
"During the transcription of some interviews, I came to realise that I need to be more assertive on what I want to know. Also, I tend to talk a bit during the interviews, since I have to explain most concepts to patients, especially palliative care. It is such a complex concept for patients that it isn't very clear when it starts or finishes. Also, when I talk about future treatments and care, patients think of these as being their inhalers (immediate treatments). This seems to be their main worry when talking about treatments – their inhalers." **Thoughts about data collection – 29th of May 2017**
"While transcribing and interviewing patients, I noticed that they keep trying telling me "how well they are doing now" and "how many things they can do." Are they doing this to avoid being questioned about the future? Or is it because they think that palliative and future care conversations aren't appropriate for them now (and it isn't because we are sort of planning for the future)? Do they think they're too well to start talking about this? Are they afraid of having their treatments and care stopped? Or is this a strategy to avoid being emotional upset by talking about palliative care and the future?"

Appendix I

Thoughts after presenting at a research conference – 15th of June 2017

Appendix J Interview topic guide – COPD Patients

Interviews used a semi-structure approach and they were guided and led patients. The interviewer picked up patients' cues and followed their language. Patients were monitored throughout the interview for signs of emotional distress and appropriate action was taken as required. The topics discussed with COPD patients included:

- **Understanding and meaning of COPD;**
  - Meaning of COPD
  - Information received at diagnosis
  - The impact of COPD in the future – concerns and thoughts
  - Previous discussions about future care and treatments

- **Understanding for palliative and advance care planning–** this topic was discussed with patients with severe disease;
  - Meaning of palliative care and advance care planning
  - Previous discussions about palliative care and end of life

- **Preferences care and treatments and healthcare-related past experiences;**
  - Current and future preferences for care
  - Impact of previous personal or other people's experiences in preferences

- **Preferences and understanding of when, how, where and who should have these conversations with themselves;**
  - Doctors and nurses find it difficult to discuss palliative care with patients
  - Preferred timing for discussions
  - Preferred lace of discussions
  - Preferred clinicians to discuss palliative care
  - Preferred approach when starting and conducting discussions

- **Actions following research interview.**
  - What are you going to do with this?
  - Is there anything else you would like to discuss?

Appendix K Data collection form – COPD patients

Participant's ID: _____ Date: _____

Interview Group: 1 | 2 | 3

Demographics

Age: _____years_ Gender:

_____

Level of Education:

_____

Current Profession:

_____

Smoking Status: Never Smoked / Current Smoker / Ex-Smoker

Smoking Pack-year: _____ Care Network: _____

_____

Clinical Data

Spirometry Results of performed on the: _____

FEV1 – _____ FEV1/FVC - _____

FVC - _____

Last Arterial Blood Gas Date - _____/_____/_____

pH - _____ PaO_2 - _____kPa

$PaCO_2$ - _____kPa Sats - _____%

MRC Score: 1 | 2 | 3 | 4 | 5

Appendix K

HADS score

Anxiety score- _____ Depression score- _____

Bode Index

Points scored- _____ Approximate 4 years Survival- _____%

Dose Index

Points scored- _____ Disease severity- _____

Number of previous COPD-related hospital admissions:

_____

_____

____

Previous COPD-related ITU admissions

No Yes

No. admissions- _____

Date/s of admission/s-_____

Duration of Stay- _____

Intubation- _____

Presence of Long-term Oxygen Therapy

No Yes

Date of start- _____

Appendix K

Amount of O_2- _____

Daily use of O_2- _____

Presence of Non-invasive ventilation (NIV)

No Yes

Date of start- _____

Settings- _____mmHg_____l/min

Daily use of NIV- _____

Appendix L Hospital Anxiety and Depression Scale (HADS)

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how they currently describes their feelings.

Participant's ID: _____ Date: _____/____/____

A	I feel tense or 'wound up':	
	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0

D	I still enjoy the things I used to enjoy:	
	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3

A	I get a sort of frightened feeling as if something awful is about to happen:	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0

D	I can laugh and see the funny side of things:	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3

A	Worrying thoughts go through my mind:	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0

D	I feel cheerful:	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0

A	I can sit at ease and feel relaxed:	
	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3

D	I feel as if I am slowed down:	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

A	I get a sort of frightened feeling like 'butterflies' in the stomach:	
	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3

D	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0

A	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0

D	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3

A	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0

D	I can enjoy a good book or radio or TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

	Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.	
	0-7 = Normal	
	8-10 = Borderline abnormal	
	11-21 = Abnormal	

Appendix M Lone Researcher Process

Interviews took place in the most convenient place for the participant. Therefore, most participants were interviewed in their homes. During these interviews, potential risks could arise to the researcher conducting them. Potential risks included emotional or physical injury, breakdown, accident and threat to personal safety. In order to minimize these potential risks different actions were taken prior, during and after the interviews. These actions followed the university's Lone Interviewing Guidance (RA2), the Lone Interviewing Checklist (RA3) and the Contact Procedure Form (RA4) were used. The actions included:

- Completion of RA4 and confirmation of a line of contact and action to be taken if the researcher does not return a call to the nominated person after the interview;
- Log of the interview with the Research and Enterprise Services Office;
- Understanding of the place of the interview by the researcher and the confirmation of the interview by the interviewee. If any concerns arise, this should be discussed with the study's supervisors;
- Carriage of a fully charged mobile phone by the researcher;
- Advised the membership with a breakdown service;
- Transport of a torch if interviewing after dark;
- If the interviewee, relative/s or pet/s become aggressive then the interview should be stopped and the researcher should leave at earliest opportunity;
- If the interviewee or relative/s "touch" the researcher in an unacceptable manner, the researcher should request that this be stopped or halt the interview and leave the site;
- If any other concerns arise or any of the above situation happen, the researcher should de-brief with the study's supervisors at the earliest opportunity.

Appendix N Consent Form – COPD Patients

Study title: Preferences of people with respiratory problems for conversations about future care with doctors and nurses.

Researcher name: Nuno Tavares, PhD Student, Southampton University, 104 Burgess Rd, SO17 1BJ Southampton, nct1g14@soton.ac.uk

Ethics reference: 203444

Please initial the boxes if you agree with the statement(s):

I have read and understood the information sheet (insert date /version no. of participant information sheet) and have had the opportunity to ask questions about the study.	☐
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	☐
I understand my participation is voluntary and I may withdraw at any time without my medical care being affected.	☐
I agree that my medical and social care notes be reviewed.	☐
I agree to have my interview audiotape recorded.	☐
I agree that anonymised quotes are used in the results section of the study.	☐
I agree that my General Practitioner will be informed of my participation in the study.	☐
I am happy to be contacted regarding other research projects reviewed by an appropriate research ethics committee. I therefore consent to the University retaining my personal details on a database, kept separately from the research data detailed above. The 'validity' of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time.	☐

	Yes	No
Would you like to be contacted with the results of the study once it is concluded?	☐	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)……

Signature of participant……..

Date……

_____ _____

Nuno Tavares Date

Appendix O Analytical approach for IPA

Table 1. Analytical approach for IPA	
	Details about the use of IPA in this study
• **Looking for themes in each case/participant** • Read transcripts several times; • Line-by-line analysis - Summarize/comment/take notes of the participant's experiential claims, concerns and understandings; • Read the comments and transform them into concise phrases (emerging themes) to capture the essential quality in the text, emphasizing convergence and divergence, commonality and nuances;	This step was fully followed.
• **Connecting the themes** • Themes are listed in a single sheet and one looks for connections – cluster themes and have superordinate concepts. • Check that the clustered themes and connections made represent the primary transcript – check interpretation versus transcript and keep quotes that support themes; • Drop themes if they do not fit in emerging structure or have weak evidential bases; • Produce a table with themes ordered coherently; • Develop a structure of themes and name clusters of themes;	Step 2 was removed from the analysis. This step was not done for every participant. However, this step was completed using the final list of themes.
• **Produce a dialogue** • Develop a dialogue using the data with nodes and the knowledge gathered from patients, which explains the mean that patients attribute to their concerns, leading to a interpretative account;	This step was only completed for the themes that answered the research question or provided relevant context.
• **Continuing the analysis in other cases and compare cases** • Use themes from first case to analyse following cases; • Discern repeating themes and acknowledge new themes; • Respect convergences and divergences; • Construct a final table with themes once all cases are analysed; • Review previous transcripts if new themes emerge later in the analysis; • Convergences in higher level themes can be found between cases, but divergences in lower level themes – theoretical convergence.	This step was fully completed.
• **Use supervision and collaboration**	This step was fully completed.

• Involve the study supervisors/collaborators in auditing and testing coherence and plausibility of the interpretation;	
• **Develop a narrative** • Explain in detail and provide evidence using data extracts, which illustrates the researcher's interpretation, using themes;	This step was fully completed.
• **Reflection** a. Keep a reflexive journal of the researcher's own perceptions, conceptions and processes through data analysis.	This step was fully completed.

Appendix P Progress of primary and secondary nodes in Phase 2

Table 1. List of deductive nodes before analysing transcripts	
Node name	**Description**
Action after the interview	Actions that patient are likely to take after the research interview.
Approach	Preferences of patients of how they would like to be approached to discuss palliative care with clinicians.
Care preferences	Patients' care preferences for the future and/or present.
COPD Diagnosis	Patients' narrative of the COPD diagnosis process.
Discussing future treatment options	Discussion of patients' treatment options for the future and/or patients' questions about the treatment options.
End of life or end of life care	Patient talking about the end of life phase and/or the care they wish to receive at the end of life.
Future	Patients discussing all aspects related with the future with COPD.
Information at Diagnosis	Information provided by clinicians at diagnosis about COPD, self-management and the future.
Meaning of COPD	Patients discussing what COPD means to them and/or what it means to live with COPD.
Palliative care	Patients discussing all aspects related with palliative care.
Person-clinician	Patients discussing the preferences for the clinicians with whom they would discuss palliative care.
Preferences for discussions	Discussion of other topics related with palliative care discussions.
Previous discussions	Patients' narrative of previous discussions about palliative care with clinicians or relatives.
Site	Preferences for site when discussing palliative care with clinicians.
Stopping treatments	Discussions about the process of stopping treatments in COPD.
Thoughts about COPD	Patients' general thoughts about COPD.
Timing	Preferences for timing to initiate and maintain palliative care discussions.
Understanding of COPD	Patients' understanding of COPD.
Usefulness of interview	Patients' thoughts of the importance of the research interview and of how this is likely to change the future.

Table 2. Inductive nodes generated by the first analysis of the interview transcripts	
Node name	**Description**
Accepting getting worse	Discussion of accepting getting worse as a consequence of COPD.
Afraid of Exacerbations	Patient share their concern of getting a chest infection.
After death thoughts	Patients share thoughts about after their death, including funeral and plans.
Bad hospital experiences	Patients share information about negative hospital experiences.
Barrier for discussions	Barriers for palliative care discussions as perceived by patients.
Bothering GP	Patients discuss concerns of disturbing their GP.
Care preferences	Patients discuss their care preferences for the present/future.
Comparison with Peers	Patient compare themselves with other COPD patients.
COPD Diagnosis better than cancer	Discussions about COPD being a better diagnosis than cancer or not a bad diagnosis at all.
COPD Management	Self-management strategies and concerns.
Coping mechanisms	Patients' coping mechanisms to live with COPD and deal with the future.
Cure or Miracle	Constant focus on someone inventing the cure for COPD or the next big inhaler/medication that will make everything better again.
Daily activity	Patient's daily activity.
Data collection form	Information collected that is kept in the data collection form (practical node).
Decision making process	Discussions about the decision making process when dealing with healthcare issues.
Difficult to get message across to Medics	Difficult to show clinicians how they feel about certain aspects of life.
Discussion about care preferences	Discussion about patient's preferences.
Disease perception and the reality of their condition	Differences between the perception of their disease and the severity of their disease.
Disease Severity	Discussion around perceptions of disease severity by patients.
Effects of palliative care discussions	The effects of palliative care discussions on patients, such as depression and reduced hope.
Exacerbations	Discussions about previous COPD exacerbations, without hospital admission.
Future with COPD	Reflections about the future when living with COPD.
General information about COPD	Discussing the need for more information about COPD and information provided by clinicians about COPD in general.
GP practice issues	Issues found by patients in GPs surgeries.
Hospital admissions	Patients share experiences from previous hospital admissions.
Impact of COPD in their life	Overall impact of COPD in the patients' lives.
Implications of COPD diagnosis	Implications of living with a life-limiting disease.
Looking after Partner	Patients share experiences of looking after partners with COPD or how partners help the patients.
Looks awful in eyes of family	Patient feel they look awful/embarrassed when coughing and/or breathless.
Other illnesses	Other illness apart from COPD.

Other people's experiences	Talking about the experiences of other people with COPD or other illnesses.
Partner 1st to notice exacerbations	Patients think partners are the first to notice chest infections.
Past experiences	Share of past experiences of living with COPD
Pulmonary Rehabilitation	Patients discuss attendance and/or importance of pulmonary rehabilitation.
Progress of COPD	Progress of COPD over the years and the impact in their lives.
Regular Meds & inhalers	Patient discuss the medication and inhalers they take daily.
Regular symptoms or issues	Regular symptoms and issues in COPD.
Relevant Quotes	Interesting/powerful thoughts shared by patients.
Results of Palliative care discussion	Effects of palliative care discussions in patients.
Smoking history	Patient talking about their smoking history.
Stigma in COPD	Discussion about the stigma surrounding COPD, as a self-inflicted disease.
Treatments	Discussion of treatments for COPD.
Uncertainty about Future	Concern regarding an uncertain future when living with COPD.
Unsure if COPD or other illness causing problems	Difficult to ascertain if is COPD or other illnesses that are troubling patients.
Unwell or deterioration	Patient discuss the process of becoming unwell or deteriorating.
Worries about relatives	Patients discuss their worries with relatives, especially after their death.

Table 3. List of inductive and deductive nodes after reorganization

Inductive nodes	
Accepting getting worse	Hospital admissions
Afraid of Exacerbations	Impact of COPD in their life
Bad hospital experiences	Implications of COPD diagnosis
Barrier for discussions	Looking after Partner
Bothering GP	Looks awful in eyes of family
Comparison with Peers	Other illnesses
COPD Diagnosis better than cancer	Other people's experiences
COPD Management	Partner notices exacerbations first
Coping mechanisms	Pulmonary Rehabilitation
Cure or Miracle	Progress of COPD until today
Daily activity	Regular medication and inhalers
Data collection form	Regular symptoms or issues
Decision making process	Relevant Quotes
Difficult to get message across to Medics	Smoking history
Disease perception and the reality of their condition	Stigma in COPD
Disease Severity	Unsure if COPD or other illness causing problems
Effects of palliative care discussions	Understanding of becoming unwell
Exacerbations	Worries about relatives

General information about COPD	
Deductive nodes	
Action after the interview 1. No discussion after interview 2. Other steps apart from discussions 3. Discussion with relatives 4. Patient will think about next steps 5. Would have discussion if clinician aware 6. Yes - will discuss it	**Primary Node** **Secondary nodes**
Approach • Barriers for discussions • Honest information versus promote patients' hope • Patient focuses on the present • Patient waits for clinicians to start discussion • Quantity of information • Raise the subject themselves • Type of information and practicalities of delivering this information	**Primary Node** **Secondary nodes**

Care preferences
• Future preferences
  ○ Mild disease
  ○ Moderate disease
  ○ Severe disease
• Preferences for the present
  ○ Mild disease
  ○ Moderate disease
  ○ Severe disease
	Primary Node
	Secondary nodes
	Tertiary Nodes
	Secondary nodes
	Tertiary Nodes

COPD Diagnosis	**Primary Node**
Discussing future treatment options	**Primary Node**

End of life or end of life care
• After death thoughts
• Approaching the end of life
• End of life thoughts
• Funeral
• Inevitability of death
• Other peoples' experiences
• People avoid the word death
• Talking about the dying moment
  ○ Best way to die
  ○ Expected dying moment
	Primary Node
	Secondary nodes
	Secondary nodes
	Tertiary Nodes

Future	**Primary Node**

• Adjust to the future with COPD • Concerns for the future • Doing everything to avoid or delay progress • Euthanasia • Focus on present • Has plan for future • Hoping for the best • Inevitability of getting worse/dying • No changes in health for the future • Patient didn't think about future • Patient is judged by decisions made • Patients “Take it as it comes” • Preferences change over time • Previous thoughts about future • Progress of COPD in Future • Unpredictability of the future	**Secondary nodes**
Information at Diagnosis	**Primary Node**
2. GP did not mention COPD diagnosis to patient 3. Information received from other clinicians 4. Large amount information received 5. Little information received at diagnosis 6. Patients look at information themselves 7. No interest in looking for further information **8.** Interested in receiving more information	**Secondary nodes**
Meaning of COPD	**Primary Node**
Palliative care	**Primary Node**
1. Disease severity a. Mild disease b. Moderate disease c. Severe disease	**Secondary nodes**
	Tertiary Nodes
2. Knowledge about palliative care 3. Opinion or thoughts about palliative care 4. Other people's experiences 5. Palliative care involvement **6.** Patient agrees to palliative care in future, if needed	**Secondary nodes**
Person-clinician	**Primary Node**

• Consultant • Don't know • Expectations from clinicians • Family • Favourite person • GP • Other person • Patient focuses on present • Practice nurse	**Secondary nodes**
Previous discussions ○ With clinicians ○ None ○ Would like to discuss this ○ Yes ○ With relatives ○ None ○ Would discuss in future ○ Yes	**Primary Node**
	Secondary nodes
	Tertiary Nodes
	Secondary nodes
	Tertiary Nodes
	Secondary nodes
Timing for discussions 6. After a bad chest infection 7. Discussion in a few years' time 8. Don't know 9. Focus on the present 10. Now a. Mild disease b. Moderate disease c. Severe disease 11. On a regular or annual basis 12. Patient considering discussing in the near future 13. Stage of illness more important than timing in COPD a. Mild disease b. Moderate disease c. Severe disease **14.** Unpredictable when it should be discussed	**Primary Node**
	Secondary nodes
	Tertiary Nodes
	Secondary nodes
Understanding of COPD	**Primary Node**
Usefulness of research Interview	**Primary Node**

Table 4. List of nodes with number of sources (patients) and references (transcript extracts)		
Deductive nodes (primary nodes are highlighted in bold)		
Name	**Sources**	**References**
Action after the interview	26	40
Clinician discussion	5	6
Discussion with relatives	9	9
No discussion after interview	6	6
Other steps apart from discussions	7	9
Patient will think about next steps	7	8
Would to discuss palliative care if clinician aware	2	3
Yes - will discuss it	10	13
Approach	32	70
Barriers in discussions	6	6
Honest information versus promote patient's hope	7	9
Patient focus on the present	1	1
Patient waits for clinicians to start discussion	16	20
Quantity of information	11	16
Raise the subject themselves	14	19
Type of information and practicalities of delivering information	22	35
Care preferences	33	164
Avoids discussion	2	2
Future preferences	33	176
Mild disease	8	28
Moderate disease	15	62
Severe disease	10	78
Preferences for the present	16	26
Mild disease	7	12
Moderate disease	6	10
Severe disease	3	4
COPD Diagnosis	32	69
Discussing future treatment options	21	38
End of life or end of life care	21	47
After death thoughts	6	14
Approaching end of life	5	7
Funeral	3	7
Inevitability of death	1	1
No End of life thoughts	1	1
Not ready or wiling to die	2	2
Other people experiences	2	2
People avoid the word death	4	5
Stopping treatments	1	1
Talking about the dying moment	11	13
Best way to die	7	8
Expected dying moment	5	5
Future	33	153
Adjust to the future with COPD	8	15
Concerns for the future	27	65
Doing everything to avoid or delay progress	13	22
Euthanasia	1	1
Focus on present	15	19
Has plan for future	9	14

Hoping for the best	6	7
Inevitability of getting worse or dying	15	24
No changes in health for the future	4	5
No option apart from hospital	1	1
Patient didn't think about future	19	26
Patient is judged by decisions made	1	1
Patients take it as it comes	13	22
Preferences change over time	2	2
Previous thoughts about future	3	3
Progress COPD in future	15	24
Unpredictability of future	3	7
Information at Diagnosis	26	46
General Practitioner did not mention diagnosis to patient	1	2
Information from other clinicians	12	14
Interested in receiving more information	2	2
Large amount information received	4	6
Little information received at diagnosis	21	29
No interest in looking for further information	2	2
Patient looked for information themselves	8	9
Meaning of COPD	20	24
Palliative care	15	31
Disease severity	15	30
Mild disease	2	2
Moderate disease	4	7
Severe disease	9	21
Knowledge about palliative care	9	14
Opinion or thoughts about palliative care	13	17
Other people's experience	1	1
Palliative care involvement	2	3
Patient agrees to palliative care in future if needed	8	10
Person-clinician	33	162
Consultant	20	32
COPD specialist clinician	7	9
Don't know	2	2
Expectation from clinicians	24	42
Family	9	10
Favourite person	24	36
General practitioner	32	101
GP practices issues	4	4
Other person	4	4
Patient focus on present	2	2
Practice nurse	25	50
Previous discussions	23	40
With clinicians	20	21
None	19	19
Would like to discuss this	1	1
Yes	2	2
With relatives	19	27
None	7	8
Will discuss in future	1	1
Yes	14	19
Timing	33	78

After a bad chest infection	2	5
Discussion in a few years' time	8	11
Don't know	5	6
Focus on the present	3	6
Now	10	17
Mild disease	3	5
Moderate disease	5	8
Severe disease	2	4
On a regular or annual basis	5	10
Patient considering discussing in near future	1	1
Stage of illness more important than timing in COPD	18	25
Mild disease	3	3
Moderate disease	9	14
Severe disease	6	8
Unpredictable when it should be discussed	6	7
Understanding of COPD	28	40
Usefulness of Interview	7	7
Inductive nodes		
Accepting getting worse	2	2
Afraid of Exacerbations	1	1
Bad hospital experiences	6	11
Barrier for discussions	17	37
Bothering GP	3	3
Comparison with Peers	12	24
COPD and work	1	1
COPD Diagnosis better than cancer	5	6
COPD Management	14	22
Coping mechanisms	13	24
Cure or Miracle	14	23
Daily activity	9	10
Data collection form	6	6
Decision making process	20	25
Difficult to get message across to clinicians	2	3
disease perception and the reality of condition	4	8
Disease Severity	13	18
Dust or smoke exposure	4	5
Effects of palliative care discussions	11	13
Exacerbations	29	63
Friends and neighbours	10	13
General information about COPD	12	25
Hospital admissions	29	79
Impact of COPD in their life	28	73
Implications of COPD diagnosis	9	13
Looking after Partner	10	16
Worries about relatives	1	1
Looks awful in eyes of family	3	3
Never Smoked	1	1
NHS problems	3	3
Other illnesses	25	88
Other people's experiences	20	54
Partner notice exacerbations first	1	1

Perception of clinicians' jobs	1	1
Perceptions in smoking	1	1
Pulmonary Rehabilitation	12	20
Progress of COPD until today	28	57
Regular medication and inhalers	14	38
Regular symptoms or issues	15	16
Relevant Quotes	2	2
Research	2	2
Smoking history	13	19
Spirituality	2	2
Stigma in COPD	5	5
Support groups	7	8
Taking time off	1	1
Things I used to enjoyed	6	8
Understanding of becoming unwell	9	9
Unsure if COPD or other illness causing problems	3	3

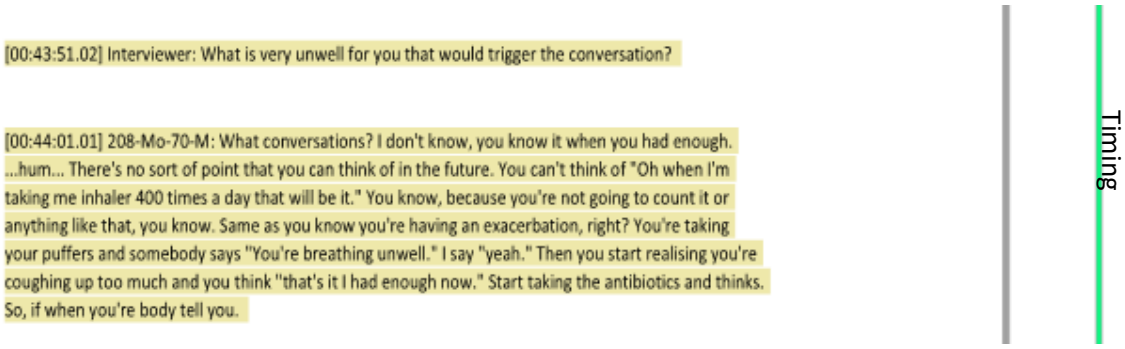
Appendix Q Progress of an interview transcript using deductive and inductive nodes

1. No nodes at the start of the analysis

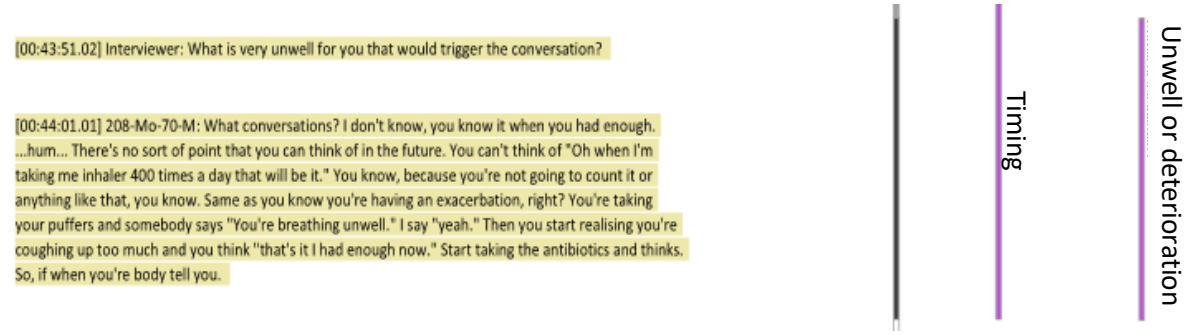
[00:43:51.02] Interviewer: What is very unwell for you that would trigger the conversation?

[00:44:01.01] 208-Mo-70-M: What conversations? I don't know, you know it when you had enough. ...hum... There's no sort of point that you can think of in the future. You can't think of "Oh when I'm taking me inhaler 400 times a day that will be it." You know, because you're not going to count it or anything like that, you know. Same as you know you're having an exacerbation, right? You're taking your puffers and somebody says "You're breathing unwell." I say "yeah." Then you start realising you're coughing up too much and you think "that's it I had enough now." Start taking the antibiotics and thinks. So, if when you're body tell you.

2. The transcript was attributed a deductive code



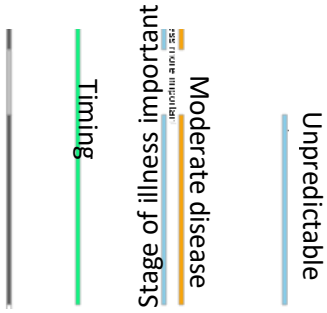
3. The transcript was attributed an inductive code



4. The deductive primary nodes were divided into secondary nodes

[00:43:51.02] Interviewer: What is very unwell for you that would trigger the conversation?

[00:44:01.01] 208-Mo-70-M: What conversations? I don't know, you know it when you had enough. ...hum... There's no sort of point that you can think of in the future. You can't think of "Oh when I'm taking me inhaler 400 times a day that will be it." You know, because you're not going to count it or anything like that, you know. Same as you know you're having an exacerbation, right? You're taking your puffers and somebody says "You're breathing unwell." I say "yeah." Then you start realising you're coughing up too much and you think "that's it I had enough now." Start taking the antibiotics and thinks. So, if when you're body tell you.

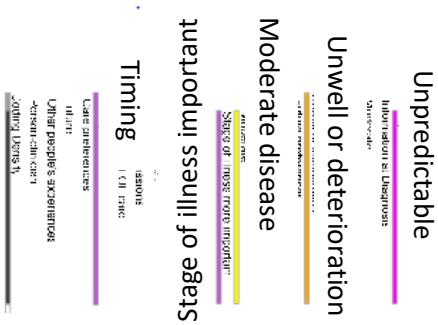


5. Final combination of inductive and deductive nodes

[00:43:51.02] Interviewer: What is very unwell for you that would trigger the conversation?

12 / 14

[00:44:01.01] 208-Mo-70-M: What conversations? I don't know, you know it when you had enough. ...hum... There's no sort of point that you can think of in the future. You can't think of "Oh when I'm taking me inhaler 400 times a day that will be it." You know, because you're not going to count it or anything like that, you know. Same as you know you're having an exacerbation, right? You're taking your puffers and somebody says "You're breathing unwell." I say "yeah." Then you start realising you're coughing up too much and you think "that's it I had enough now." Start taking the antibiotics and thinks. So, if when you're body tell you.



Appendix R Pen Portraits of COPD patients

Pen portraits outlining information about patients can be found below. A total of 9 pen portraits with information about patients at different stages of their disease trajectory are presented below. These pen portraits belong to the first 3 patients recruited in each disease severity group.

Mild disease

102-Mi-65-M

This 65 year old gentleman was diagnosed with COPD, less than 1 year before the interview, and believed that his condition to be mild. As well as COPD, this gentleman had a myocardial infarction requiring an emergency operation. 102-Mi-65-M recalled this hospital admission to illustrate his perspectives about palliative care discussions. 102-Mi-65-M had 1 exacerbation in the last year and was never admitted to hospital due to his respiratory condition. 102-Mi-65-M stated that he did not want to have aggressive treatments if he had little quality of life. He mentioned this to his family, but never discussed it with a clinician.

105-Mi-61-M

105-Mi-61-M was a 61 year old gentleman, who was diagnosed with COPD 10 years prior to the interview and was suffering with recurrent chest infections. 105-Mi-61-M was recruited to the study while seeing the respiratory consultant. This gentleman was a smoker and had a large smoking history. Moreover, this gentleman suffered from Asthma and had pleural thickening. As a consequence, 105-Mi-61-M had a high symptom burden when considering his condition, but no respiratory hospital admissions. This gentleman did not think smoking had a large impact on his current condition and would like to receive all treatments that could help his condition. 105-Mi-61-M did not discuss palliative care with his family or clinicians.

107-Mi-76-M

This 76 year old gentleman had been recently diagnosed with COPD, less than 2 years prior to the interview. 107-Mi-76-M had a small smoking history and his COPD was related to occupational exposure to vehicle exhaust fumes. This gentleman worked on the roads most of his life and this

was a contributing factor to his COPD. 107-Mi-76-M attended 2 local peer support group dedicated to people with heart and lung illnesses. Moreover, 107-Mi-76-M participated in several research studies, as he was interested in research and in helping other people. This gentleman stated that he would like to discuss future care and treatments in his next appointment with his GP. Thus, he was able to briefly share his wishes with the family, which focused on palliative care if his condition was advanced and irreversible.

Moderate disease

201-Mo-85-F

This 85 year old lady was diagnosed with COPD about 13 years prior to interview. This lady seemed to have a down-to-earth and practical approach towards her health and wellbeing. This lady was very clear about her care preferences and signed a “Do Not Attempt Cardiopulmonary Resuscitation” (DNACPR) form, in order to avoid unnecessary suffering. 201-Mo-85-F considered herself to be an atheist and favoured euthanasia. This lady recalled 2 past experiences where her mother and husband had bad experiences at the end of life. No previous palliative care discussions with clinicians, but would like to discuss this with her GP after the interview. Lastly, this lady prepared letters and information for her family in case she passed away suddenly.

202-Mo-62-F

This 62 year old lady was recruited from the respiratory consultant clinic. This lady was still working at the time of the interview and seemed to be focused on living and managing the present. 202-Mo-62-F stated that she did not think about the future and a possible deterioration. Despite this, 202-Mo-62-F had 3-4 chest infections a year and reported that her second to last exacerbation was very severe. 202-Mo-62-F lived on her own and feared another exacerbation, as this could mean a hospital admission. This lady was also suffering from depression and felt unsupported by her family.

203-Mo-79-M

This 79 year old gentleman was interviewed 10 days before his birthday, when he was planning to cycle 80 miles. This gentleman considered himself very fit when comparing himself with other people. Apart from COPD, this gentleman had no other comorbidities of note and his smoking

history was small. This gentleman believed that quality of life should dictate the treatments and care for the future and he declined to be kept alive if he lost his independence. 203-Mo-79-M had not discussed his care preferences with a clinician, but briefly mentioned it to his daughter (who had similar preferences for the future).

Severe disease

301-S-68-M

This 68 year old gentleman was diagnosed with COPD 9 years prior to the interview. 301-S-68-M had recurrent exacerbations and several hospital admissions. This gentleman had very severe COPD and had previous discussions about palliative care with respiratory consultants. The first conversation happened during a hospital admission, when 301-S-68-M was told that he would not survive that admission. Sometime later, 301-S-68-M had another discussion about DNACPR, future hospital admissions and ventilation during an outpatient clinic. This gentleman stated that the end was near and that he wanted to be kept comfortable at the end of life. 301-S-68-M had previously received palliative care and would be willing to receive further palliative care if he required this in the future. Lastly, 301-S-68-M discussed his preferences with his family, however one of his sons disagreed with his preferences and refused to discuss the inevitable future/deterioration. His son's decision seemed to have caused some distress to 301-S-68-M, who became upset while discussing this.

304-S-62-F

62 year old lady diagnosed with COPD 5 years prior to the interview. This lady had very severe COPD with a FEV1 percent predicted of 16%. 304-S-62-F mentioned in different occasions her concern of being a burden to her family, especially to her husband. As a consequence of this and of her breathlessness, 304-S-62-F had become depressed and gradually more isolated from her friends and family. 304-S-62-F was having recurrent chest infections, however continued to smoke e-cigarettes. This lady could not tolerate being admitted to hospital and feared invasive treatments. 304-S-62-F discussed her preferences with the consultant and both agreed on signing a DNACPR form, stopping aggressive treatments and admissions to intensive care. 304-S-62-F discussed her preferences with her son and husband, but had not been able to discuss them with her daughter.

Appendix R

305-S-69-M

305-S-69-M was a 69 year old gentleman who was diagnosed with COPD 5 years prior to the interview. 305-S-69-M lived alone, but sought different activities to reduce social isolation. This gentleman stated that he could not imagine a deterioration in his condition, despite fearing the next winter and possible exacerbations. 305-S-69-M was focused on the present and did not think about the future with COPD. However, 305-S-69-M stated that he would not like to lose his independence and that this would be a genuine concern. This gentleman had not discuss his preferences with clinicians or family, as he would only make his decisions about treatments or care at a time of need.

Appendix S Interview topics – Clinician interviews

- **Ideal clinician to initiate discussions about palliative care with patients:**
  - Patients seem to prefer someone with more knowledge and power;
  - Patient seem to prefer discussing palliative care with specialist clinicians;
  - Patients stated that GPs lacked knowledge, power and time to discuss palliative care;
  - Patients believed that appointments were generally short and discussions about palliative care were not a clinical priority
  - Relationship between patient and clinician were seen as important;
  - Continuity of care was highlighted as an issue by patients;
  - Confidence, knowledge and power when initiating discussions.
- **Timing to initiate discussions with COPD patients:**
  - Earlier discussions with patients;
  - Different points of the disease trajectory;
  - Psychological, emotional and physical impact of discussions in patients;
  - Patients seemed to prefer initiate discussions with clinicians in the future, when their condition had deteriorated.
  - Patients seemed to postpone discussions as their disease severity advanced.
- **Approaches to initiate and conduct discussions with patients:**
  - Majority of patients preferred to be approached by clinicians when they were ready to discuss;
  - A smaller number of patients preferred to approach clinicians, if they believed the time had come to start discussions;
  - Quantity and type of information during discussions with patients;
  - The decision-making process when discussing and deciding treatments and care for patients.
- **Palliative care discussions with COPD patients:**
  - Discuss previous conversations with COPD patients;
  - Barriers and practicalities that prevent the start of discussions;
  - Palliative care discussions in daily clinical practice;
  - Theory versus Practice in palliative care discussions;
  - Improving the frequency and quality of discussions with patients.

Appendix T Data collection form - Clinicians

Participant's ID: _____ Date: _____

Interview Group: General Practitioner | Practice Nurse

Hospital Specialists | Respiratory Nurses

Demographics

Age: _____years Gender: Female | Male

Current Occupation: _____

Years of experience: _____

Clinical Data

Number of COPD patients seen weekly: _____

Number palliative care conversations with COPD patients in the previous month?

_____

Clinical Background/Experience:

_____

_____

_____

_____

Interest or Training in COPD/Palliative care:

_____

_____

_____

Contact at the end of the Study:

No | Yes _____

Appendix U Participant Information Sheet – Clinicians

Study Title: Palliative care conversations in COPD - patients' preferences and clinicians' judgements

Researcher: Nuno Tavares

ERGO number: 203444

My name is Nuno Tavares and I'm a Clinical Academic Research Fellow. I work as a respiratory specialist nurse for 3 days a week and I develop my PhD for the rest of the time. My main interest is to improve the care provided to COPD patients when approaching the end of life.

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Most people who suffer from COPD (Chronic Obstructive Pulmonary Disease) do not discuss the care they want with their clinician. This makes it very difficult for healthcare professionals to provide the best care and treatments when people become too sick to speak for themselves. I interviewed people with COPD and discussed their thoughts about COPD, the future and palliative care. Moreover, patients' shared their preferences for discussions about palliative care with clinicians.

In this phase of the study, I am interviewing healthcare professionals that provide direct care to patients with COPD. The aim of these interviews is to understand the clinicians' judgements and decision making factors when starting and conducting palliative care discussions with patients.

This research study is part of a PhD degree in the University of Southampton. The sponsors of the study are Portsmouth Hospitals NHS Trust and NIHR CLARHC Wessex.

Why have I been asked to participate?

Since you look after COPD patients, I would like to understand your thoughts about palliative care conversations with patients and what leads you to initiate and conduct these conversations.

What will happen to me if I take part?

If you take part, I will invite you for a 15-30min interview. This interview will be scheduled considering your diary and your commitments. During this, I will be asking you some questions about previous conversations with COPD patients and I will register your thoughts and opinions about these conversations. All questions will be based in real patients' information. The interview will be audiotape recorded and the transcripts will be archived at the University of Southampton for a minimum of 10 years. After the interview, I will analyse the interview and use some anonymised quotes in the findings section of the study.

Are there any benefits in my taking part?

There are no direct benefits.

Are there any risks involved?

There are no obvious risks.

What data will be collected?

Data containing your thoughts about palliative care conversations with COPD patients will be collected during the interview. Moreover, minimal demographic information (age and gender identity) and information about your professional background (such as current occupation and past experience) will be collected. The information collected will only be used for the purposes of this study and accessed by the study supervisors and myself. I will not be collecting personal identifiable information, unless you would like to be contacted regarding the results at the end of the study. Hard data will be kept in locked cabinets in the University of Southampton and identifiable information will be kept separate locked cabinets (following the data protection policy). Moreover, identifiable information will only be accessed by myself and it will be safely disposed once the study finishes. All other information will be anonymised and kept securely in a password protected computer.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Interviews will be audiotape recorded and transcribed at a later stage. The recordings will be destroyed once the study has finished. All identifiable information will be coded and anonymised to ensure that all data is strictly confidential. The anonymised transcripts will be archived at the University of Southampton for a minimum of 10 years.

All information that you provide will be anonymised and will be kept securely in a password protected computer and/or in a locked filling cabinet closed behind code-locked doors in the University of Southampton.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. If you change your mind, I will immediately stop the

interview or prevent it from happening and I will remove your participation from the study. However, I will not be able to withdraw your participation 7 days after the interview. Please contact me using the details at the end of this sheet, if you would like to withdraw from the study at any stage.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. The results of the research will be written up, published and presented to fellow researchers and healthcare professionals. This will include the use of anonymised quotes from interviews.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. Moreover, if you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager:

5. **Address:** University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ
6. **Tel:** +44 (0)23 8059 5058
7. **Fax:** +44 (0)23 8059 5781
8. **Email:** rgoinfo@soton.ac.uk

Where can I get more information?

9. If you would like to receive more information and/or participate in the study, you can contact me directly using the following methods:

10. **By Telephone:** — 07514 741881

11. **By Email:** nct1g14@soton.ac.uk

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read the information sheet and to consider taking part in the research.

Yours Sincerely,

Nuno Tavares

Appendix V Consent Form – Clinicians

Study title: Palliative care conversations in COPD - patients' preferences and clinicians' judgements

Researcher name: Nuno Tavares

ERGO number: 203444

Participant Identification Number*:* _____

Please initial the boxes if you agree with the statements:

I have read and understood the information sheet (*08/11/2018 and version 3.0*) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw at any time for any reason without my participation rights being affected.	
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.	

Name of participant (print name)……..……..

Signature of participant…….

Date…….

Name of researcher (print name)……..……

Signature of researcher ……..……

Date……..……..

Appendix W Coding Matrix

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
Clinician discussing palliative care with patients	**Frequency of discussions**	Most patient haven't had a palliative care discussion – less than 30% of patients. Discussions started with patients at the end of life and/or with patients with very severe COPD	2 patients had a previous discussion. These patients had severe to very severe disease.	Discussions were often started in secondary care – some COPD specialist nurses discuss this often or doctors on the wards. Variance in number of discussions started by primary care clinicians.	Most patients don't discuss palliative care, however when they do they are very unwell and approaching the end of life. Lack of discussions in primary care and variance noted across GPs and GP practices.
	Clinician starting the discussion	Relationship patient-clinician very important No specific clinician identified when starting discussions	Knowledgeable person is the most important characteristic. Relationship with clinician important, but less so than knowledge. Time available for discussions valued by patients. But it seemed that patients would expect clinicians to have time for discussions if they did require them. No specific clinician – patients' preferences for	Patient-clinician relationship most important trait for clinicians. Skills important, but less than relationship Time available for discussion also valued	Knowledge, relationship important when discussing palliative care. Patients and clinicians differ on how important knowledge and relationship are. No specific clinician identified when starting the discussions – clinician characteristics more important than specific professional background.

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
			best clinicians evenly distributed.		
	GPs	**Silence**	GPs lack knowledge, time, power and continuity of care. Long waits for appointments. Only seeing GPs when very unwell, since GPs only see ill patients. Easier to access GPs than secondary care clinicians. Different care and training across GP practices.	GPs lack of knowledge, time, power and continuity of care. GPs practices are a post-code lottery – different care and training across practices. GPs have more knowledge about community support than secondary clinicians. Long waits for appointments. GPs concerned that preferences were not respected if patients were admitted to hospital.	Most GPs do not seem suitable to start discussions since they lack of knowledge, time, power and continuity of care. Long appointments reported, despite easier access than secondary care clinicians. Large variance across practices and GPs. Patients think these clinicians are only see people who are unwell and do not have time to discuss palliative care. GPs worried that patients may not have their preferences respected if admitted to hospital.
	Consultants	Consultants have knowledge but not necessarily the required patient-clinician relationship.	Consultants are powerful and knowledgeable clinicians, which makes them suitable clinicians to discuss palliative care.	Consultants are powerful and knowledgeable clinicians, which makes them suitable clinicians for palliative care discussions with patients.	Consultants are knowledgeable (but have less community knowledge) and powerful clinicians that would be suitable clinicians to initiate discussions.

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
			Patients expected to be able to build relationship, even on wards to be able to discuss palliative care. Some patients had less positive experiences when seeing consultants. Two previous discussions started by consultants – very severe patients.	Consultants aren't always able to build relationship – especially on the wards. Discussions started in hospital are less compassionate, due to lack of time, patient-clinician relationship and patient's severe condition. Consultants have less community-related knowledge. Consultants have regular discussions on the wards. Practice nurses believe patients trust and follow consultants' advice more than primary care's.	Patients aren't always able to build relationships with consultants, especially on the wards, which leads to brief and cold discussions. However, patients think this to be the opposite. Clinicians believe patients trust and follow consultants' advice, however patients' negative experiences in previous encounter can reduce trust in these clinicians.
	Practice Nurse	**Silence**	Practice nurses are suitable clinicians. They have a large knowledge base. Practice nurses are approachable and easy to talk to. Patient identified issues in accessing these nurses – no practice nurses with COPD training available at the practice.	Practice nurses face similar issues regarding service provision as GPs – lack of knowledge about COPD and palliative care, time and confidence in starting discussions. Little to no COPD or palliative care training provide to practice nurses. This resulted in poor quality care and lack of	Very different perspectives between patients and clinicians about discussions with practice nurses. Practice nurses don't feel confident nor knowledgeable to discuss this. Whilst patients think they're approachable, knowledgeable and would like to discuss this with them. Some patients highlighted some difficulties in accessing them.

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
				confidence in starting discussions. Practice nurses are able to build relationships, however they only see patients with mild COPD, who do not need discussions (according with practice nurses).	Lack of training to these clinicians regarding palliative care and COPD was commonly highlighted. Practice nurses believed discussions should only be started with patients with advanced COPD.
	COPD Nurses	**Silence**	COPD nurses were less mentioned by patients. Despite this, patients had a good impression about them. COPD nurses were seen as knowledgeable and with more time than other clinicians. Despite this COPD nurses were difficult to access due to limited area covered and strict criteria.	COPD nurses reported regular discussions with patients. Participants seen as having large knowledge base, time and skills. Participants believed COPD nurses were able to build relationships with patients COPD nurses were trusted by other clinicians. Lack of discussions in COPD nurses with little experience.	COPD nurses are seen as knowledgeable clinicians with extra time for discussions – potentially ideal clinicians when starting discussions. Able to build relationships with patients, however difficult to access.
Timing for palliative care discussions	**Future**	Most discussions occurred when patients were very unwell. Discussions were associated with poor prognosis – which doesn't seem to be ideal approach.	Most patients preferred future discussions – started when poor self-prognosis. Since I'm in good condition at present – no eminent threat – no need for discussions.	Timing depends on the individual. However, vast majority of discussions at present are usually associated with poor prognosis and increased symptoms.	Current discussions happen late in the disease trajectory. However, most patients seemed to prefer later discussions as well. Despite this, late discussions are not best practice. Discussions focused on end of life care, withdrawing treatments and giving up –

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
		Difficulty in prognosticating in COPD – constant focus on milestones.	"I'll discuss it when I deteriorate."	Complex and unpredictable disease, which results in discussions only at and about end of life and withdrawing treatments. Clinicians look at red flags when starting discussions.	which can emotionally affect patients and clinicians. Complex and unpredictable disease prevents earlier discussions. Clinicians focus on red flags when starting discussions.
	Now	Discussions should be started early, when patients' conditions are stable. However, it is difficult to know exactly when the best timing is.	Less patients preferred starting discussions now and some patients that did didn't seem ready to start discussions. These patients had a clear idea on declining and avoiding certain treatments – based on their own or other people's past experiences. Patients want to discuss it while their condition is stable and before something happens. "So, that I can get prepared."	Early and regular discussions are best in COPD Discussions should be general at start and then become more specific and in-depth over time. Less emotional impact if early and gradual discussions, especially when having in-depth discussion at the end of life. Patients are able to plan ahead and to see their wishes respected.	Despite recommending early discussions with patients, clinicians focused on poor prognosis and in starting discussions near the slippery slope. Literature and clinicians recommended early and regular discussions in COPD as the best approach. However, only a small proportion of patients preferred this. Patients see this as an opportunity to refuse treatments and to make their voices heard. However, some didn't seem prepared to start discussions. Clinicians believe that discussion should start gradually from the general to specific treatments and increase in-depth throughout the disease trajectory.
	Exacerbations and past experiences	**Silence**	Exacerbations provide information and raise patients' awareness about the severity of their condition.	Patients and other people's experience help raise awareness, increase willingness for discussions and provide	Patients and other people's experiences provide information, raises awareness and increase willingness for discussions. However, discussion shouldn't be started while patients are exacerbating.

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
			Discussions shouldn't be raised at times of exacerbations – too unwell to discuss it	them with information about treatments available. Patients are more willing to start discussions an exacerbation. Not a good time to discuss while exacerbating – too unwell and patients may think that death is imminent	
	Regular discussions	Early and regular discussions while stable are recommended.	Review seen as important to discuss progress so far, plan care and possibly discuss palliative care. Patients can get updated information at the time of the review about the severity of their condition, which can help contextualizing the discussion. Not all patients have an annual review with their practice nurse.	Regular and gradual discussions are recommended by clinicians. Discussion in annual review seems to be well accepted by some clinicians. An opportunity to discuss preferences for care should be offered to patients, not forced. Lack of time and lack of training for practice nurses can prevent discussions with patients during the annual review.	Patients saw the annual review as an important timing, since this provided them with updated and accurate information about their condition. This information allows patients to put things into perspective and raises awareness. Clinicians advocate regular and early discussions, annual reviews can be suitable, by providing patients the opportunity to discuss it. However, not all patients had access to the annual review, practice nurses lacked knowledge about COPD and palliative care, and reviews are very time limited.
Methods of discussions	**Person starting discussions**	Silence	Most patients preferred to have clinicians starting discussions.	Clinicians started most discussions with patients.	Most clinicians start discussions with patients, which agrees with patients' preferences. This is related to patient's

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
palliative care			A small amount of patients preferred to start discussions themselves. Patients with severe disease want to keep control over the start of discussions in an effort to delay them.	Patients used indirect approaches when starting discussions themselves. Patients lacked knowledge about disease awareness and knowledge about COPD, hence less willingness to start discussions themselves.	lack of knowledge and disease severity awareness. Patients used indirect approaches when they starting discussions. Patients who preferred to start discussions themselves were also likely to prefer starting discussions in the future – control over the start of discussions.
	Starting discussions	Tension between hope reality of patient's condition, character and nature of COPD. Frank discussions impact hope, therefore clinicians withheld information and avoided strong words. Patients did not consider discussions harmful for themselves.	Most patients preferred honest and open information about disease severity, treatments and likely outcomes. However, some patients preferred gradual and timely information to make sure it doesn't affect their hope. Lack of information provided by clinicians was often reported.	Method used to start and conduct discussions varied on clinician and patient basis. Clinicians used a direct or indirect approach – anxious patients and direct clinicians. Clinicians avoided death related words and the term palliative care.	Clinicians seemed to duel between damaging patients' hope and being truthful about patient's condition, future and the effectiveness of treatments – walking on egg shells. Clinicians varied their approach when starting and conducting discussions – this depended on patients, clinicians and the point in time in the disease trajectory where the discussion was started. Most patients preferred more information, while others preferred gradual and digestible information that didn't affect their hope. Lack of information was often reported.
	Amount and type of information	Patients that prefer all information – does not mean that patients actually want to know about everything.	Most patients preferred large amounts and detailed information. Long waits and little information provided by	Amount of information provided depends on the patient and clinician. Gradual discussions are best rather than one off discussions	Clinicians seemed to believe that patients preferred little information, whilst patients preferred large amounts of regular information about their condition. Despite this, patients seemed

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
		Most palliative care topics are not discussed. Clinicians preferred to discuss topics related with the impact of the non-adherence to treatments would cause, as if influencing patients to choose treatments. Topics that should be discussed with patients: -Character and nature of COPD; -Respect and accommodate patients' preferences; -Share medical opinion -Provide a philosophy and plan of treatments and care.	clinicians are the norm at present. Small amount of patients preferred enough information - gradual and little information. Patients' information needs include: -disease progression -prognosis -treatments options and likely outcomes	– however, this contrasts with current clinical practice. Practical discussions were most frequent, focusing on treatment withdrawal and end of life care. Topics recommended in discussions with patients: -Preferences for care and information -Discuss Treatment options; -Follows patients' lead; -Explore concerns; -Use and follow framework – AACP.	to expect receiving positive rather than negative information. Different perspectives about the amount and type of information between patients and clinicians seems to result in a lack of information provided by clinicians. Service-related barriers are also a large problem that prevent the regular provision of information by clinicians. Some patients just wanted small amounts of information regularly. Clinicians focus on treatment withdrawal and start discussions by exploring patients' understanding about their condition. Patient focus on treatments available and disease progression. Most discussions focused on practical discussions – treatment withdrawals. An individualized approach was recommended by clinicians.
	Sharing decision making process	Decision making should be shared with patients – develop a care plan based on patients'	Sharing decision making was seen as very important by patients. More information should be provided so that patients can	Sharing decision making seen as very important by clinicians. Some patients can have unrealistic expectations, which	Sharing decision making seen as very important, by clinicians and patients. Patients' willing to participate in decision making and should be encouraged to

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
		preferences during the discussion.	participate in decision making. Involving family was also seen as important. However, most patients would just follow clinicians' recommendations and did not feel capable to challenge medical decision making.	can become a difficult to manage. Clinicians struggled to balance medical and patient input in treatment decisions.	participate, however patients need more information to be able to participate. Despite this, most patients just follow clinicians' recommendations. Difficult to keep balance of patient and medical decisions.
Practicalities of palliative care discussions	**Barriers**	Overcoming barriers for discussions meant more discussions with patients. Less barriers and more facilitators resulted in more discussions.	Many barriers for discussions were highlighted by patients, which prevented the start of discussions. Different factors seemed to reduce willingness for discussions and impacted patients emotionally. These factors increased anxiety and reduced trust in clinicians. The future was commonly mentioned and this was associated with: concerns about disease progression, increased symptoms and exacerbations. These concerns affected patients' willingness for discussions, preventing their start.	Willingness for discussions impacted by different factors Lots of barriers identified - service rationing was seen as the biggest issue by clinicians. Please see table with barriers for discussions.	Barriers from the different phases were combined in a separate document. Barriers affect all aspects of discussions and can also increase the emotional impact of discussions on patients. Less barriers and more facilitators result in more discussions.

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
			As a consequence, most patients did not think about the future.		
	Effects of discussions	Discussions were associated with higher health status and more quality of death and dying. Patients with previous discussions reported receiving best care. This meant that clinicians knew what patients preferred and were able to follow patients' wishes. Discussions did not feel harmful for patients.	Some patients said that this having the discussion provided them with reassurance. However, other saw discussions as morbid. The effects of discussions depended on type of information shared.	Effects of discussions in emotional wellbeing depended on the individual patient. Some patients felt relieved, while others became distressed and upset. Most patients were initially socked (surprised), but then appreciated the start of discussions. Starting discussions too early or while exacerbations could have worse emotional impact – patients may believe that death is imminent or lead patients to worry unnecessarily. Early and gradual discussions can reduce the emotional impact.	Patients that felt reassured for having a discussion with clinicians also wanted to have the discussion now. Discussions can affect patients' emotional wellbeing differently. These effects are individual based. Many factors influence the impact of discussions on patients. Discussions would affect patients' wellbeing less, if they had early and gradual discussions with clinicians.
	Place for discussions	Most discussions occurred on the wards and ITU units. These discussions focused on end of life, rather than palliative care and advance care planning.	No "real" mention However since patients preferred to discuss this when very unwell – hospital wards seem the most likely place.	The place for discussion should be comfortable for patients and clinicians, such as home or clinic. Despite this, most discussions occurred in hospital wards. Wards are inappropriate due to	Current late discussions mean discussions in hospital wards. These environments were characterised as being too cold, noisy and busy. Patients generally feel hopeless and vulnerable at this stage

	Phases / Sub-themes	Phase 1	Phase 2	Phase 3	Data integration
		Hospital wards were seen as inappropriate for discussions.		noise, cold and busy environment. Patients unwell and vulnerable at this stage. If patient are in their own environment, they have more control over discussions and may have the support of their family.	Best place is at home – more comfortable, more support from family and patients retain more power. Also families can be present and participate in discussions.
	Palliative care	Patients did not see palliative care as part of COPD care. Patient had a poor understanding about treatments and care. Patients need more information about palliative care, in which clinicians fall short.	Patients had little to no knowledge about palliative care. This led patients to have misconstrued ideas about palliative care – only seen as end of life care. Some patients would consider palliative care if very unwell. Patients believe that the general public does not discuss death and seems to deny it. Patients often discussed concerns about after death and dying moment and focused on end of life.	Clinicians have little knowledge about palliative care this was seen as end of life care. Clinicians believe patients have poor understating about palliative care. Patients' attitudes towards death vary from patient to patient. Death anxiety Cultural barrier prevents discussions about death.	Patients and clinicians have little to no understanding about palliative care. Palliative care was seen as end of life and exclusive of acute treatments. Patients have different attitudes towards death and dying, which impacts discussions. Clinicians should provide more education about COPD and palliative care. Cultural barriers in talking about death – impacts clinicians and patients understanding and perceptions about death.

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