**Palliative Medicine Journal**

**The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: a study guided by interpretative phenomenology analysis**

**Authors:**

N Tavares, BSc (Hons) RN,¹²³ KJ Hunt, PhD MSc PGCert BN (Hons) RN,³ N Jarrett, PhD BSc (Hons) PGCert RN,⁴ T M A Wilkinson, MBBS PhD MA Cantab FRCP²³⁵

¹Solent NHS Trust,

²NIHR CLAHRC Wessex,

³University of Southampton,

⁴University of Portsmouth,

⁵University Hospital Southampton

Corresponding author’s contact details: Nightingale Building, Faculty of Health Sciences, University Road, Southampton SO17 1BJ - nct1g14@soton.ac.uk

Word count - 3400

**May 2020**

# Abstract

**Background:** Chronic obstructive pulmonary disease is associated with an uncertain trajectory, which challenges prognostication and means that most patients are not involved in advance care planning and do not receive palliative and end of life care.

**Aim:** To understand the preferences of patients with chronic obstructive pulmonary disease for discussions about palliative and advance care planning with clinicians.

**Design:** Semi-structured interviews were conducted with patients with chronic obstructive pulmonary disease. Data analysis was guided by principles of interpretative phenomenological analysis, of which symbolic interactionism and interpretation principles were employed throughout.

**Setting/Participants:** 33 British patients with chronic obstructive pulmonary disease at different stages of their disease trajectory.

**Results:** Patients preferred to discuss palliative care with clinicians they perceived had greater levels of competency and authority in care and with whom they had an established relationship, usually a specialist. Patients favoured large amounts of information about treatments and care, but reported a lack of illness-related information and problems accessing appointments with clinicians. Consequently, patients deferred discussions to the future, usually once their condition had deteriorated significantly or planned to wait for clinicians to initiate conversations. This was not rooted in patient preferences, but related to clinicians’ lack of time, absence of an established relationship and belief that appointments were for managing current symptoms, exacerbations and disease factors rather than future care and preferences.

**Conclusion:** Different perceptions, competing priorities and service rationing inhibit patients from initiating early discussions with clinicians, so palliative care conversations should be initiated by respiratory-expert clinicians who know the patient well. After a sudden deterioration in the patient’s condition may be a suitable time.

|  |
| --- |
| **Keywords:** chronic obstructive pulmonary disease; palliative care; communication; patient-clinician communications; patients’ preferences; qualitative research; primary and secondary care |

|  |
| --- |
| **What is already known about the topic?**   * Conversations about palliative care and future treatments are the first step in ensuring that patients’ wishes are respected throughout their disease trajectory. * The frequency and quality of conversations about palliative care and future treatments in COPD are low. * Patients and clinicians cite many barriers to starting palliative care discussions. |
| **What this paper adds?**   * Patients prefer to have conversations with COPD-expert clinicians with whom they have an established relationship. * Patients see palliative care and future treatment discussions as end of life conversations, therefore they do not recognize the need for discussions until their condition severely deteriorates. * Clinicians need to initiate conversations with patients and provide larger amounts of information about all aspects of future treatments and palliative care. |
| **Implications for practice, theory or policy**   * Open and early discussions about treatments and care for the future might change patients’ perceptions about conversations, and improve their understanding about COPD and the different treatment/care options * The integration of palliative care conversations in the COPD disease trajectory according with patients’ preferences might improve the quality of the care provided to patients. * Services need to accommodate and facilitate palliative and future care discussions with patients. As an example, annual COPD reviews are valuable engagement opportunities with patients that could allow discussions about the immediate and long-term future and the development of contingency plans. |

# Background

Chronic obstructive pulmonary disease (COPD) is a life-limiting illness characterised by progressive breathlessness and chronic productive cough ([1](#_ENREF_1), [2](#_ENREF_2)). Worldwide, it is estimated that 250 million people have COPD and it is responsible for 5% of all deaths ([3](#_ENREF_3)). COPD symptoms severely impact patients’ lives, as they are associated with a decline in quality of life, overall health status and prognosis ([4](#_ENREF_4), [5](#_ENREF_5)). Patients with severe symptoms should be identified and offered palliative care, in order to address their physical, social and emotional needs ([1](#_ENREF_1), [6](#_ENREF_6), [7](#_ENREF_7)). Palliative care can reduce symptom burden and invasive treatments, and provide further psychosocial support to COPD patients ([8](#_ENREF_8)). However at present, only a small proportion of patients receive palliative care, increasing the likelihood of patients dying whilst on aggressive treatments ([9](#_ENREF_9)). Difficulty in prognosticating in COPD, in predicting individual mortality risk, and in moving the focus from therapeutic to palliative care are significant barriers ([10](#_ENREF_10), [11](#_ENREF_11)). 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 ([8](#_ENREF_8), [12-15](#_ENREF_12)). 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 ([16](#_ENREF_16)).

Regular and early discussions allow patients to express their preferences and ensure that well planned care based on patients’ preferences is delivered ([10](#_ENREF_10), [17-20](#_ENREF_17)). A recent systematic literature review highlighted that only one third of COPD patients at different disease stages had discussed palliative care with a clinician ([21](#_ENREF_21)). 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 ([8](#_ENREF_8), [21-25](#_ENREF_21)). 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 ([21](#_ENREF_21)). 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.

# Method

Design

Patients’ preferences for palliative and advance care planning discussions with clinicians are influenced by a multitude of factors, including the meaning that they attribute to these discussions, their perception about their condition, previous healthcare-related experiences, and their social background ([26](#_ENREF_26), [27](#_ENREF_27)). As a consequence, understanding patients’ preferences for palliative care discussions requires more than mere description of their thoughts and concerns. Instead, this complexity can only be understood if patients’ thoughts are interpreted considering their personal background and the researchers’ own background ([28](#_ENREF_28)).

Interpretative Phenomenological Approach (IPA) was the methodology used in this study, since it encompasses all the dimensions required to understand patients’ preferences – symbolic interactionism, interpretation and an idiographic approach ([28](#_ENREF_28)). However, the study used a pragmatic approach to IPA, since the study sought to answer a practical research question that focused on future events. In addition, the study required a larger sample so that patients at different stages of their disease trajectory could be interviewed. As a consequence of using a large sample, the idiographic approach was only achieved at a disease severity group level ( refer to supplement 1 for more information on the use of IPA in the study).

Sample

The disease severity and symptom and treatment burden may influence patients’ preferences for palliative care discussions ([29](#_ENREF_29)). Therefore, the study used a purposive sample, where COPD patients at different stages of their disease trajectory were recruited. By using a purposive sample, we were able to explore and triangulate the opinions and preferences of patients at different stages of their disease trajectory. 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%) ([30](#_ENREF_30)). The clinical team directly looking after the patient reviewed their medical notes to ensure they met the inclusion criteria, before signposting them to the study. Patients with mild COPD were recruited from General Practitioner (GP) practices by practice nurses, whilst patients with moderate and severe/very severe COPD were signposted to the study by respiratory consultants and research nurses 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. Whilst, GP practices were approached and recruited through the Clinical Research Network Wessex. Informed written consent for interviews and case-note review was obtained from all patients by the first author (NT). See Table 1 for inclusion and exclusion criteria.

|  |  |  |
| --- | --- | --- |
| Table 1 - 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; * Patients unable to fully express themselves 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, after reviewing their medical records. |

Data collection

Interviews were audiotaped, lasted 45-90 minutes and followed a semi-structured approach. Interviews were conducted by the first author (NT), who had no clinical involvement in the care of participants at any time and was trained in qualitative interviewing. The questions followed a topic guide that focused on exploring patients’ preferences for the timing, clinician, approach and site for palliative care discussions. The construction of the topic guide was based on the findings of a previously conducted systematic literature review ([21](#_ENREF_21)). This review highlighted 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 ([21](#_ENREF_21)). 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 these 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 the participant - using their own words to describe certain concepts, following the direction set out by participants and discussing topics as far as they were willing to discuss them (please refer to Supplement 2 to find the interview topics). Support, reassurance and the possibility of stopping/pausing the interview was available for participants that became emotionally distressed with the interview content. Moreover, patients were signposted to their GP if there was concern about their physical or psychological health.

Interviews were conducted 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 when no new themes were identified. 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 and emerging themes was discussed by 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.

Data analysis

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 ([31-36](#_ENREF_31)). 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 authors, the 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 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) ([37](#_ENREF_37)).

# Results

A total of 33 patients with COPD were recruited and interviewed. Patients’ characteristics can be found in Table 2. 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 2 - 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)) – higher scores suggest an increased exposure to cigarette smoke | **44.5 (34)** |
| Disease severity - lower FEV1 % predicted suggests increased disease severity |  |
| Mild disease (number (mean FEV1 % predicted)) | 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)** |
| 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))- higher scores suggest increased levels of breathlessness | **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 3**). Quotes were selected purposively and edited to illustrate the interpretation of patients’ thoughts. Unnecessary information or irrelevant pauses were removed.

|  |  |
| --- | --- |
| Table 3 - List of themes | |
| Super-ordinate themes | **Lower-order themes** |
| Preferred person to discuss palliative care | * Assessment of competency * Building of a trusted relationship * Practicalities of discussions * Care authority |
| Preferred timing for palliative care discussions | * In the future: “Becoming unwell” * Present moment: “Ready now” * COPD reviews and future uncertainty |
| Initiating and conducting palliative care conversations | * Initiating discussions with clinicians * Content of palliative care discussions * Sharing the decision-making process |
| Palliative care and the end of life | * Previous discussions and next steps * Barriers and effects of discussions * Comfort care when approaching the dying moment |
| Future with COPD | * Inevitable progression of COPD * “I accept all treatments, if they are beneficial” * Care and treatment options |

Patients differed in their preferences for the timing and nature of palliative care discussions, regardless of their disease severity. Table 4 displays the distribution of patient’s preferences per domain of the timing and nature of palliative care discussions – person, timing and approach.

|  |  |  |
| --- | --- | --- |
| Table 4 - Participants with similar preferences for the timing and nature of palliative care discussions. | | |
| *Patient’s preferences* | ***Number of patients*** | |
| Preferred healthcare professional | | |
| General Practitioner | 10 | |
| Respiratory Consultant | 9 | |
| Practice Nurse with respiratory expertise | 8 | |
| Timing for discussions | | |
| Distant future | 17 | |
| Present moment | 8 | |
| Who should start the discussion? | | |
| Healthcare professional | 19 | |
| Patient | 12 | |
| Amount and type of information shared during discussions | | |
| Detailed and honest information | | 20 |
| Gradual and digestible information | | 3 |

Preferred person to discuss palliative care

A third of patients viewed GPs as suitable clinicians to start discussions due to their familiarity and easy access, however some of these patients found that GPs lacked time and expertise to start discussions. Service pressures, short appointments and GPs hesitation in starting palliative care discussions resulted in some patients delaying or avoiding discussions and in starting them very late in their disease trajectory. In contrast, some patients elected GPs based on the fact that they were the clinicians with whom they were likely to discuss their preferences, rather than the fact that they were perceived as ideal clinicians.

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.” (Patient 12 with 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 other healthcare professionals.

*“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.” (Patient 2 with 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.” (Patient 20 with moderate COPD)*

Some patients believed GPs had the power to start the processof *“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. On the other hand, 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).” (Patient 27 with severe COPD)*

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.” (Patient 29 with 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 5).

*“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.” (Patient 17 with moderate COPD)*

Palliative care discussions were seen as difficult and some patients only wanted to start them if absolutely necessary. Since to patients felt that initiating 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.” (Patient 24 with very severe COPD)*

|  |
| --- |
| Table 5 - Patients’ definition for what *“becoming unwell” -* in the context a palliative care discussions |
| * Recurrent, increased and/or severe breathlessness; * Increased hospital admissions and/or COPD exacerbations; * Continued decline of their condition; * Little treatment effectiveness or exhaustion of treatments; * Thoughts around “I had enough”; * Limited or reduced mobility caused by breathlessness; * Sudden and severe deterioration in condition, such as cardiac arrest. |

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, but 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.” (Patient 9 with moderate COPD)*

Patients that preferred to discuss palliative care *“now”* had a clear idea of the care they did not wantto 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?” (Patient 4 with 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.” (Patient 6 with mild COPD)*

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?” (Patient 24 with 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.” (Patient 29 with 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.” (Patient 8 with mild COPD)*

Palliative care and end of life

In general, patients had little knowledge about the concept of ‘palliative care’, even for the patient who had previously received palliative care. 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. (Patient 24 with 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?” (Patient 25 with 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% certain of what it is. It’s a little bit like exacerbations, it took me months to realised exacerbations were actually chest infections.” (Patient 28 with 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. (Patient 7 with 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.”*

*(Patient 26 with 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...”*

*(Patient 9 with 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.” (Patient 13 with moderate COPD)*

Future with COPD

Most patients had not thought about their future lives with COPD, since they focused on “*living the moment*” and on positive experiences. 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. Despite this, 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?” (Patient 26 with severe COPD)*

# Discussion

*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 ([38-41](#_ENREF_38)), most COPD patients had not discussed palliative care with clinicians. This emphasises the need for research interventions to improve the frequency of discussions, which may in turn help increase patients’ access to palliative care delivery.

*Discussion of findings*

A recurrent theme from interviews was the challenges faced by primary care. The increasingly large workload, related to the increasing number of patients with multiple chronic illnesses, and staff shortages has led to a loss in trust in these services ([42-44](#_ENREF_42)). 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 expertize. 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, as clinicians focused on treating acutely ill patients.

The lack of time in appointments was also highlighted by other healthcare professionals in previous studies ([45](#_ENREF_45), [46](#_ENREF_46)). Insufficient time for direct patient care is a concern frequently reported in healthcare ([47](#_ENREF_47), [48](#_ENREF_48)) 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. Service rationing contrasts with patients preferences to see a COPD clinician with whom they have an established relationship. In fact, previous literature has suggested that continuity of care has been associated with more palliative care discussions and patient satisfaction ([45](#_ENREF_45), [49](#_ENREF_49)). Poor continuity of care was primarily felt in primary care, creating a paradox, since continuity of care is a core value and traditionally provided by general practice ([50](#_ENREF_50)). 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 ([51](#_ENREF_51), [52](#_ENREF_52)). General practices and teams have become larger and have been managing an increasingly bigger patient list, which can increase consultation times, but reduce continuity of care ([51](#_ENREF_51), [52](#_ENREF_52)). 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 a 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 ([7](#_ENREF_7), [21](#_ENREF_21)). 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 ([21](#_ENREF_21)).

The first factor for patients preferring late discussions is related to patients’ poor understanding about COPD, palliative care and future care/treatments. 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 ([53](#_ENREF_53), [54](#_ENREF_54)). Moreover, a large proportion of patients with COPD have a lower socioeconomic status which negatively impacts their participation in palliative care discussions ([55](#_ENREF_55)). 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 ([56](#_ENREF_56)), 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 ([57](#_ENREF_57), [58](#_ENREF_58)). 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 ([59](#_ENREF_59)). Stigma is commonly reported by patients and can affect their self-esteem, access to healthcare and discussions about their preferences ([60](#_ENREF_60), [61](#_ENREF_61)). 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 ([60](#_ENREF_60), [61](#_ENREF_61)).

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 ([62](#_ENREF_62)). In contrast to current practice, patients favoured detailed information about the progress of their condition and the different treatment options. The lack of information meant 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 ([63](#_ENREF_63)). Instead, patients adapt to their condition and hope to recover from exacerbations, which they do not necessarily see as potentially fatal ([63](#_ENREF_63)).

Currently, clinicians only initiate discussions about palliative care and future care/treatments when patients are approaching the end of life ([21](#_ENREF_21)). Discussions focus on withdrawing aggressive treatments and in initiating end of life care ([22](#_ENREF_22)). 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 patient 24 (page 11) and by the large amount of patients that discussed death and dying in the interview (a total of 15 patients). 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 ([64](#_ENREF_64)). In fact, death anxiety is associated with lower quality of life ([65](#_ENREF_65), [66](#_ENREF_66)), which is commonly found in COPD ([67](#_ENREF_67), [68](#_ENREF_68)). 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 particular impact on how patients construct their perception about their condition and about conversations with clinicians ([62](#_ENREF_62)). 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 and dying ([17](#_ENREF_17), [18](#_ENREF_18)). This approach reinforces the model that integrates palliative with curative care, rather than an abrupt transition from chronic to end of life care ([69](#_ENREF_69)).

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 ([70](#_ENREF_70), [71](#_ENREF_71)). 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 ([8](#_ENREF_8), [72](#_ENREF_72)). 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 ([73](#_ENREF_73), [74](#_ENREF_74)). Since, over half of patients studied with the highest BODE score were still alive after 3 years ([75](#_ENREF_75)). The lack of prognostic accuracy seems to be a contributing factor for the lack of palliative care delivery ([70](#_ENREF_70), [71](#_ENREF_71)), 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 ([76-78](#_ENREF_76)). 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 ([79](#_ENREF_79), [80](#_ENREF_80)). 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 ([80](#_ENREF_80)). Interestingly, even at the end of life most patients opted for aggressive treatments, such as cardiopulmonary resuscitation and ventilation ([81](#_ENREF_81)). This seems to be related to patients’ limited understanding of their condition, especially about the life-limiting character of COPD and the viability of treatments ([54](#_ENREF_54)).

## *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. The Ethics committee justified this request upon the basis that discussing these terms with patients would provoke unnecessary distress to patients and instead calling it “future care and treatments”. 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. A final limitation was the recruitment of patients with mild COPD from GP practices and patients with more severe COPD from hospital–based services. This meant that research participants were recruited from different sites. Patients with mild COPD were recruited from GP practices, rather than hospital settings (principal recruitment site), since these patients tend to use less secondary care services ([82](#_ENREF_82)) and their recruitment from secondary care would extend recruitment period beyond the time limit of this study. In order to mitigate against recruiting patients from different sites, recruitment only took place in the geographical area covered by the hospital trust. 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.

*Implications for clinical practice*

The current model of care, largely impacted by service rationing and prognosis uncertainty, results in most patients delaying discussions or not having the opportunity to discuss their preferences with a clinician. In order reduce the impact of the current model, patients should be offered the opportunity to openly discuss their preferences with clinicians early and throughout their disease trajectory. These conversations should be patient-centre and patient-led and focus on their illness, symptom and treatment experience, and their preferences for treatments and care. Early conversations would allow the gradual integration of palliative care into current COPD care. Current COPD management typically focuses on symptom management, but pays little attention to the impact of different treatments in patients’ lives and to their preferences for care. The integration of open and early conversations about treatments and care into current COPD management may require some degree of service and consultation adjustments.

# 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. Patients’ perceptions about healthcare professionals and services, and about the current format of palliative care discussions result in patients delaying discussions and in preferring them when they have “become unwell,” typically at the end of life. 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.

# References

1. NICE. Chronic obstructive pulmonary disease - Quality Standard. In: Health Do, editor.: National Institute for Health and Care Excellence; 2011.

2. Department of Health. An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England. In: Health Do, editor.: Department of Health; 2011. p. 56.

3. Chronic obstructive pulmonary disease (COPD) [press release]. 2017.

4. National Institute for Clinical Excellence. Chronic obstructive pulmonary disease in over 16s: diagnosis and management. NICE guideline (CG101). 2010.

5. Miravitlles M, Ribera A. Understanding the impact of symptoms on the burden of COPD. Respiratory Research. 2017;18(1):67.

6. WHO. WHO Definition of Palliative Care: World Health Association; 2016 [Available from: <http://www.who.int/cancer/palliative/definition/en/>.

7. WHO. Palliative care for older people: better practices. Denmark: World Health Organization; 2011.

8. Curtis JR. Palliative and end-of-life care for patients with severe COPD. The European respiratory journal. 2008;32(3):796-803.

9. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. Thorax. 2000;55(12):1000-6.

10. Curtis J. Palliative care for patients with chronic obstructive pulmonary disease. Respiratory Medicine: COPD Update. 2006;2:86-90.

11. Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M, et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. Palliative Medicine. 2007;21(4):313-22.

12. Gardener AC, Ewing G, Farquhar M. Enabling patients with advanced chronic obstructive pulmonary disease to identify and express their support needs to health care professionals: A qualitative study to develop a tool. Palliat Med. 2019;33(6):663-75.

13. Johnston B, Coole C, Jay Narayanasamy M. An end-of-life care nurse service for people with COPD and heart failure: stakeholders' experiences. Int J Palliat Nurs. 2016;22(11):549-59.

14. Donnelly WJ. The SUPPORT Project and Improving Care for Seriously III Patients. Jama. 1996;275(16):1228-.

15. Claessens MT, Lynn J, Zhong ZS, Desbiens NA, Phillips RS, Wu AW, et al. Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT. Journal of the American Geriatrics Society. 2000;48(5):S146-S53.

16. Jorgenson A, Sidebottom AC, Richards H, Kirven J. A Description of Inpatient Palliative Care Actions for Patients With Acute Heart Failure. The American journal of hospice & palliative care. 2016;33(9):863-70.

17. NICE. Opioids for pain relief in palliative care overview. In: Department of Health, editor. Manchester: NICE; 2005.

18. Ford DW, Koch KA, Ray DE, Selecky PA. Palliative and End-of-Life Care in Lung Cancer: Diagnosis and Management of Lung Cancer, 3rd ed: American College of Chest Physicians Evidence-Based Clinical Practice Guidelines. Chest. 2013;143(5, Supplement):e498S-e512S.

19. NCPC. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives. Southampton: The National Council for Palliative Care; 2012.

20. NICE. End of life care for adults - Quality Standard. In: Department of Health, editor. 2017.

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

22. Sullivan KE, Hebert PC, Logan J, O'Connor AM, McNeely PD. What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation? CHEST. 1996;109(1):258-64.

23. McNeely PD, Hebert PC, Dales RE, Oconnor AM, Wells G, McKim D, et al. Deciding about mechanical ventilation in end-stage chronic obstructive pulmonary disease: How respirologists perceive their role. Canadian Medical Association Journal. 1997;156(2):177-83.

24. Curtis JR. Communicating with patients and their families about advance care planning and end-of-life care. Respir Care. 2000;45(11):1385-94; discussion 94-8.

25. Gaspar C, Alfarroba S, Telo L, Gomes C, Barbara C. End-of-life care in COPD: a survey carried out with Portuguese pulmonologists. Revista portuguesa de pneumologia. 2014;20(3):123-30.

26. Jabbarian LJ, Zwakman M, van der Heide A, Kars MC, Janssen DJA, van Delden JJ, et al. Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. Thorax. 2018;73(3):222-30.

27. Wong JS, Gottwald M. Advance Care Planning Discussions in Chronic Obstructive Pulmonary Disease: A critical review. J Palliat Care. 2015;31(4):258-64.

28. Gray JR, Grove SK, Sutherland S. Burns and Grove's the practice of nursing research: appraisal, synthesis and generation of evidence. Eight Edition ed. Misouri: Elsevier; 2017.

29. Reinke LF, Feemster LC, McDowell J, Gunnink E, Tartaglione EV, Udris E, et al. The long term impact of an end-of-life communication intervention among veterans with COPD. Heart & lung : the journal of critical care. 2017;46(1):30-4.

30. Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management and prevention of chronic osbtrcutive pulmonary disease 2018.

31. Smith JA. Qualitative psychology: a practical guide to research methods. Third edition ed. London 2015.

32. Larkin M, Thompson A. Interpretative phenomenological analysis. In: Andrew Thompson DH, editor. Qualitative research methods in mental health and psychotherapy - a guide for students and practitioners. Oxford: John Wiley & Sons; 2012. p. 99-116.

33. Smith JA. Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. Psychology & Health. 1996;11(2):261-71.

34. Smith JA. Evaluating the contribution of interpretative phenomenological analysis. Health Psychology Review. 2011;5(1):9-27.

35. Smith JA, Flower P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research: Sage Publications; 2009.

36. Pietkiewicz I, Smith J. A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology2014. 7-14 p.

37. Tong A, Craig J, Sainsbury P. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-57.

38. Janssen DJ, Spruit MA, Schols JM, Wouters EF. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. CHEST. 2011;139(5):1081-8.

39. Leung JM, Udris EM, Uman J, Au DH. The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD. American journal of respiratory and critical care medicine. 2011;183 (1 MeetingAbstracts).

40. Seamark D, Blake S, Seamark C, Hyland ME, Greaves C, Pinnuck M, et al. Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study. Primary care respiratory journal : journal of the General Practice Airways Group. 2012;21(3):261-6.

41. Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF, Jr., Desbiens N, et al. Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. Annals of internal medicine. 1997;127(1):1-12.

42. Buchan J, Charlesworth A, Gershlick B, Seccombe I. A critical moment: NHS staffing trends, retention and attrition. 2019.

43. The King's Fund. Make or break? ; 2018.

44. World Health Organization. The global burden of chronic 2019 [Available from: <https://www.who.int/nutrition/topics/2_background/en/>.

45. Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. CHEST. 2005;127(6):2188-96.

46. Aslakson RA, Wyskiel R, Thornton I, Copley C, Shaffer D, Zyra M, et al. Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of-life care for surgical ICU patients: a qualitative exploration. Journal Of Palliative Medicine. 2012;15(8):910-5.

47. Dugdale DC, Epstein R, Pantilat SZ. Time and the patient-physician relationship. Journal of general internal medicine. 1999;14 Suppl 1(Suppl 1):S34-S40.

48. Erickson SM, Rockwern B, Koltov M, McLean RM, Practice ftM, Physicians QCotACo. Putting Patients First by Reducing Administrative Tasks in Health Care: A Position Paper of the American College of PhysiciansPutting Patients First by Reducing Administrative Tasks in Health Care. Annals of internal medicine. 2017;166(9):659-61.

49. Hjortdahl P, Laerum E. Continuity of care in general practice: effect on patient satisfaction. British Medical Journal. 1992;304(6837):1287-90.

50. Guthrie B, Wyke S. Personal continuity and access in UK general practice: a qualitative study of general practitioners' and patients' perceptions of when and how they matter. BMC family practice. 2006;7(1):11.

51. Adler R, Vasiliadis A, Bickell N. The relationship between continuity and patient satisfaction: a systematic review. Family Practice. 2010;27(2):171-8.

52. Barker I, Steventon A, Deeny SR. Association between continuity of care in general practice and hospital admissions for ambulatory care sensitive conditions: cross sectional study of routinely collected, person level data. Bmj. 2017;356:j84.

53. Roberts NJ, Ghiassi R, Partridge MR. Health literacy in COPD. International journal of chronic obstructive pulmonary disease. 2008;3(4):499-507.

54. Gauronskaite R, Zemnickiene S, Liustrickyte I, Poceviciute D, Danila E, Kibarskyte R. How COPD patients understand their disease and what are their future expectations? European Respiratory Journal. 2016;48(suppl 60):PA4342.

55. Prescott E, Vestbo J. Socioeconomic status and chronic obstructive pulmonary disease. Thorax. 1999;54(8):737-41.

56. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient education and counseling. 2014;94(3):291-309.

57. Laue J, Melbye H, Risør MB. Self-treatment of acute exacerbations of chronic obstructive pulmonary disease requires more than symptom recognition – a qualitative study of COPD patients’ perspectives on self-treatment. BMC family practice. 2017;18(1):8.

58. Simon J. Attitudes of Hungarian asthmatic and COPD patients affecting disease control: empirical research based on Health Belief Model. Frontiers in Pharmacology. 2013;4:135.

59. Say RE, Thomson R. The importance of patient preferences in treatment decisions--challenges for doctors. BMJ (Clinical research ed). 2003;327(7414):542-5.

60. Johnson JL, Campbell AC, Bowers M, Nichol A-M. Understanding the Social Consequences of Chronic Obstructive Pulmonary Disease. Proceedings of the American Thoracic Society. 2007;4(8):680-2.

61. Berger BE, Kapella MC, Larson JL. The Experience of Stigma in Chronic Obstructive Pulmonary Disease. Western Journal of Nursing Research. 2010;33(7):916-32.

62. Gardener AC, Ewing G, Kuhn I, Farquhar M. Support needs of patients with COPD: a systematic literature search and narrative review. International journal of chronic obstructive pulmonary disease. 2018;13:1021-35.

63. Giacomini M, DeJean D, Simeonov D, Smith A. Experiences of living and dying with COPD: A systematic review and synthesis of the qualitative empirical literature. Ontario Health Technology Assessment Series. 2012;12(13):1-47.

64. Brown AJ, Shen MJ, Ramondetta LM, Bodurka DC, Giuntoli RL, 2nd, Diaz-Montes T. Does death anxiety affect end-of-life care discussions? International journal of gynecological cancer : official journal of the International Gynecological Cancer Society. 2014;24(8):1521-6.

65. Sherman DW, Norman R, McSherry CB. A Comparison of Death Anxiety and Quality of Life of Patients With Advanced Cancer or AIDS and Their Family Caregivers. Journal of the Association of Nurses in AIDS Care. 2010;21(2):99-112.

66. Cella DF, Tross S. Death Anxiety in Cancer Survival: A Preliminary Cross-Validation Study. Journal of Personality Assessment. 1987;51(3):451-61.

67. Wacker ME, Jörres RA, Karch A, Wilke S, Heinrich J, Karrasch S, et al. Assessing health-related quality of life in COPD: comparing generic and disease-specific instruments with focus on comorbidities. BMC Pulmonary Medicine. 2016;16(1):70.

68. Zamzam MA, Azab NY, El Wahsh RA, Ragab AZ, Allam EM. Quality of life in COPD patients. Egyptian Journal of Chest Diseases and Tuberculosis. 2012;61(4):281-9.

69. Hardin KA, Meyers F, Louie S. Integrating Palliative Care in Severe Chronic Obstructive Lung Disease. COPD: Journal of Chronic Obstructive Pulmonary Disease. 2008;5(4):207-20.

70. Shipman C, Gysels M, White P, Worth A, Murray SA, Barclay S, et al. Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. Bmj. 2008;337:a1720.

71. Goff SL, Eneanya ND, Feinberg R, Germain MJ, Marr L, Berzoff J, et al. Advance care planning: a qualitative study of dialysis patients and families. Clinical journal of the American Society of Nephrology : CJASN. 2015;10(3):390-400.

72. Halliwell J, Mulcahy P, Buetow S, Bray Y, Coster G, Osman LM. GP discussion of prognosis with patients with severe chronic obstructive pulmonary disease: a qualitative study. The British journal of general practice : the journal of the Royal College of General Practitioners. 2004;54(509):904-8.

73. Sundh J, Janson C, Lisspers K, Ställberg B, Montgomery S. The Dyspnoea, Obstruction, Smoking, Exacerbation (DOSE) index is predictive of mortality in COPD. Primary Care Respiratory Journal. 2012;21(3):295-301.

74. Powrie DJ. The BODE index: a new grading system in COPD. Thorax. 2004;59(5):427-.

75. Esteban C, Quintana JM, Moraza J, Aburto M, Aguirre U, Aguirregomoscorta JI, et al. BODE-Index vs HADO-score in chronic obstructive pulmonary disease: Which one to use in general practice? BMC Medicine. 2010;8:28-.

76. den Herder-van der Eerden M, Hasselaar J, Payne S, Varey S, Schwabe S, Radbruch L, et al. How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries. Palliat Med. 2017;31(10):946-55.

77. Scheerens C, Chambaere K, Pardon K, Derom E, Van Belle S, Joos G, et al. Development of a complex intervention for early integration of palliative home care into standard care for end-stage COPD patients: A Phase 0-I study. PLoS One. 2018;13(9):e0203326.

78. Siouta N, Clement P, Aertgeerts B, Van Beek K, Menten J. Professionals' perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: a qualitative study in Belgium. BMC Palliat Care. 2018;17(1):103.

79. Pinnock H, Kendall M, Murray SA, Worth A, Levack P, Porter M, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. BMJ: British Medical Journal (Overseas & Retired Doctors Edition). 2011;342:d142-d.

80. Harb N, Foster JM, Dobler CC. Patient-perceived treatment burden of chronic obstructive pulmonary disease. International journal of chronic obstructive pulmonary disease. 2017;12:1641-52.

81. Bereza BG, Troelsgaard Nielsen A, Valgardsson S, Hemels MEH, Einarson TR. Patient preferences in severe COPD and asthma: a comprehensive literature review. International journal of chronic obstructive pulmonary disease. 2015;10:739-44.

82. Johansson G, Mushnikov V, Bäckström T, Engström A, Khalid JM, Wall J, et al. Exacerbations and healthcare resource utilization among COPD patients in a Swedish registry-based nation-wide study. BMC pulmonary medicine. 2018;18(1):17-.

**Authorship declaration**

All authors participated in the different components of the reaserch study.

**Funding**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors’.

**Declaration of interest**

The Authors declare that there is no conflict of interest.

**Research Ethics**

The study was approved by the Health Research Authority and the Hampshire B Research Ethics Committee in February 2017 with the following IRAS ID number: 203444.

**Data management**

All data are kept in the University of Southampton repositories for a minimum of 10 years. For more information please contact the University’s Data Protection Officer at [data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk).

**Acknowledgments**

The authors are grateful to all clinicians that signposted patients to the study, especially the clinicians working at Portsmouth Hospitals NHS Trust.