**Patient-Centered Discussions About Disease Progression, Symptom, and Treatment Burden in Chronic Obstructive Pulmonary Disease Could Facilitate the Integration of End-of-Life Discussions in the Disease Trajectory: Patient, Clinician, and Literature Perspectives: A Multimethod Approach**

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**Abstract**

*Background*: Patients with chronic obstructive pulmonary disease seldom discuss preferences for future care/treatments with clinicians. The lack of discussions prevents the delivery of care grounded on patient preferences. Instead, treatments become increasingly burdensome as disease progresses and patients approach the end of life.

*Objective*: Identify current and best practice in initiating and conducting conversations about future and palliative care, by integrating data from multiple sources.

*Design*: Multi-phasic study where the findings of a systematic literature review and qualitative interviews were combined and synthesised using a triangulation protocol.

*Setting/participants*: Thirty-three patients with chronic obstructive pulmonary disease and 14 clinicians from multiple backgrounds were recruited in the United Kingdom.

*Results*: Clinicians’ and patients’ poor understanding about palliative care and chronic obstructive pulmonary disease, difficulties in timing and initiating discussions, and service rationing were the main factors for late discussions. Divergent perspectives between patients and clinicians about palliative care discussions often prevented their start.

Instead, early and gradual patient-centred discussions on treatment choices, symptom and treatment burden were recommended by patients, clinicians and the literature. Earlier patient-centred discussions may reduce their emotional impact and enable patients to participate fully, whilst enabling clinicians to provide timely and accurate information on illness progression and appropriate self-management techniques.

*Conclusion*: Current approaches towards palliative care discussions in chronic obstructive pulmonary disease do not guarantee that patients’ preferences are met. Early and gradual patient-centred discussions may enable patients to fully express their care preferences as they evolve over time, whilst minimising the impact of symptom and treatment burden.

**Keywords**: COPD; palliative care; communication; treatment burden; patient-clinician communication; patient preferences; qualitative research; advance care planning

**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 (1-4). Providing more aggressive and invasive treatments throughout the disease trajectory increases the burden of treatment for patients and is associated with poor experiences at the end of life (5-8). 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 challenges the ethos of palliative care. Instead, palliative care aims to alleviate symptoms and support patients holistically through minimally invasive treatments and patient-centred care (9).

Access to person-centred palliative care in COPD is dependent on clinicians and patients initiating conversations about these topics (10, 11). However, most patients do not get the opportunity to discuss their preferences for palliative and future care with clinicians (12). Research exploring interventions to improve the frequency of palliative and future care discussions in COPD have had little success, especially in sustaining long-term effect (12, 13). This paper explored current and best practices in initiating and conducting conversations about future and palliative care by integrating results from three phases of a research study that explored how palliative care discussions could be embedded into COPD care. This involved combining and analysing data collected from COPD patients, healthcare professionals, and scientific literature using a triangulation protocol.

**Methods**

*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 encompassed a systematic literature review looking at published evidence about the timing and nature of palliative care discussions in COPD (12). The literature search was conducted in February 2016 (updated in June 2019 with new data incorporated). This review suggested that there were several barriers to palliative care discussions and that understanding of patients’ preferences for these discussions was limited (12). The second phase used qualitative interviews to explore patients’ preferences for the timing and nature of palliative care discussions with clinicians (14). Patients preferred to discuss palliative care with clinicians that had greater expertise and an established patient-relationship, usually once their condition had deteriorated significantly (14). Patients’ preferences identified in phase 2 were used to inform and design the interviews with clinicians in phase 3 and their recommendations for discussions were explored (15). Forty-seven participants were interviewed in both phases – 33 COPD patients and 14 healthcare professionals (patient and clinicians characteristics can be found in Table 1). Patients’ interviews were analysed using an interpretative phenomenological analysis [18-19], whilst clinicians’ interviews used a thematic analysis (16-19).

*Data analysis*

Data integration and analysis of the three phases was guided by principles of a triangulation protocol, which is often found in mixed methods research (20). This method allowed the study of a problem using different methods, for example by combining qualitative and quantitative methods and data from different datasets and population groups (21). Triangulation refers to the process of combining and analysing different subsets of data (21), in order to understand palliative care discussions from patients, clinicians and previously published literature. This approach provided a more complete picture about a phenomenon and facilitated the integration and combination of data after the separate analysis of each phase of the study (21).

The analysed findings from each phase were combined in a single table (Coding Matrix) using the themes of the initial research phase (please refer to a shortened version of this coding matrix for a single theme in Supplement 1). After this, data were compared across phases and the integrated results were entered into a fourth column. The findings from data integration were analysed and relationships between themes explored using principles of thematic analysis. Recurrent themes, similarities and divergences were identified and explored across the three phases. Meta-themes across research phases emerged from the data analysis and are presented in the next section. Data analysis was conducted primarily by the first author (NT), but cross-checked and closely monitored by the authorial team.

**Findings**

*Timing and nature of current palliative care discussions in COPD*

The frequency and quality of palliative care discussions in COPD remains poor with only 30% of patients reporting a previous discussion with clinicians (12). In fact, only two (6%) patient participants reported having had a previous palliative discussion with a clinician (14). In contrast, previous studies have shown that most patients want to have the opportunity to discuss their preferences with clinicians (12). When discussions did occur, they often took place in secondary care and with deteriorating patients who were approaching the end of life (12, 14, 15). The cause for late discussions was often attributed to the difficulty in producing an accurate prognosis for the patient (12, 15). Therefore, clinicians considered important milestones in the disease trajectory in an effort to guide the start of palliative care discussions, some of these milestones included hospital admissions, severe exacerbation or the start of long-term oxygen therapy (12, 15). Discussions were emotionally difficult, as most focused on end of life care and treatment withdrawal (12, 15).

Since most discussions occurred during hospitalizations, clinicians were unfamiliar to the patient and conversations were often started abruptly, in a cold manner and were brief (15). Clinicians felt that these conversations occurred when patients were more vulnerable, unwell and less able to participate in discussions at this time (15). The timing and type of discussion resulted in patients delaying palliative care discussions to a distant future – to a time when their condition had severely deteriorated (14). Patients often associated palliative care discussions with imminent death, negative emotional impact and clinicians giving up on them (14). Consequently, clinicians worried about damaging patients’ hope, if they were to discuss palliative care and the reality of their condition (12, 15).

Clinicians and patients seemed to expect different outcomes from palliative care discussions. Clinicians focused on reducing the amount of treatments with little benefit to the patients and, when possible, in gathering patients’ preferences for care (15). These discussions had a practical and well-defined outcome, such as producing a DNACPR order (14, 15).

In contrast, patients preferred to gather information about their condition and about new and innovative treatments that could alleviate symptoms and improve their condition (14). Patients felt clinicians were stopping life sustaining treatments and were giving up on them (14). Consequently, discussions were emotionally difficult and patients shied away from them (14, 15). This mismatch between patients and clinicians’ perspectives meant that, from the patient’s perspective, clinicians focused on stopping or restricting access to treatments, whilst patients focused on hope-fostering topics (14, 15). These differences seemed to reduce patients’ willingness to start discussions and resulted in emotional distress (14, 15).

*Patient, clinician and service-related factors that negatively impact the occurrence and emotional aftermath of palliative care discussions*

Several patient, clinician and service-related factors have resulted in the delay and prevention of palliative care discussions between patients and clinicians, or have negatively affected patients’ psychological wellbeing when discussions did occur (12, 14, 15). Table 2 summarises the key limiting factors collated from the different phases of the study.

Patient-related factors

Patient-related barriers for discussing palliative care with clinicians were individual-dependent and were often influenced by past experiences (14, 15). Patients had limited understanding of COPD, were unaware of the progressive nature of their condition and the severity of their condition (14). Therefore, 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 (15). Moreover, patients had little to no knowledge about palliative care and viewed it as terminal care, exclusive of acute treatments (12, 14, 15). Limited direct contact with death and lack of discussions about death were seen as societal barriers, which may provide an explanation for patients’ poor understanding about palliative care (14, 15).

Patients’ attitudes towards death and dying were also found to affect their willingness to discuss palliative care (15). These attitudes were individual-specific and included fear, death anxiety and/or non-acceptance of death and dying (12, 15). In general, relatives and younger patients or younger clinicians were found to be less acceptant of death, whilst some patients approaching the end of life felt increasingly threatened by the notion of death (15).

Clinician-related factors

The presence of COPD expertise was identified as a key factor when starting and conducting discussions with patients (12, 14, 15), yet clinicians often had limited understanding about what palliative care could offer their patients (12, 15).

GPs often saw patients with a wide range of conditions, which limited their ability to accumulate COPD-specific knowledge and experience in conducting discussions about palliative care (14, 15). Patients saw practice nurses as clinicians with a large knowledge base, however practice nurses did not feel confident in starting discussions, so they deferred discussions to GPs (14, 15). The labelling of practice nurses as “COPD nurses” or “respiratory nurses” and the delegation of most COPD management to these clinicians seemed to create a false expectation on patients that practice nurses were highly trained and COPD experts (14, 15). COPD consultants and COPD nurses had a larger COPD-related knowledge base and were considered skilled clinicians by patients, however patients often struggled to build long-term relationships with them (14, 15). Instead, patients preferred COPD-expert clinicians with whom they had an established relationship, good communication skills and the ability to ensure the achievement of their preferences in the future (14).

COPD patients frequently highlighted restricted access to healthcare professionals (14). GPs were particularly difficult to access, especially when patients required longer appointments (14, 15). Secondary care clinicians were also difficult to access, since patients had to meet certain criteria for referral, otherwise they would only see these clinicians if admitted to hospital (14, 15). COPD nurses were also difficult to access, but this was due to their limited geographical availability (14, 15). On the contrary, patients considered practice nurses to be accessible, approachable and easy to talk to (14).

Service rationing

Clinicians’ lack of time was the single most common factor associated with the lack and delay of palliative care discussions in COPD (12, 14, 15). This was primarily reported in primary care by GPs and practice nurses (14, 15) who described a battle for time and the need to readjust services to be able to cope with increasing demand, compromising patient care (15). Primary care offered short appointments, which affected COPD management especially palliative care discussions (14, 15). Since patients struggled to access primary care, they only sought medical advice when their condition had acutely and severely deteriorated (14). Because patients did not view palliative care conversations as a priority, they delayed discussions, or fear of taking up other people’s appointments (14). Consequently, patients deferred discussions until their condition had significantly deteriorated and they found it difficult to manage on their own (14).

Patient-clinician relationships were seen by both parties as a key barrier to discussing palliative care in COPD (12, 14, 15). However, service rationing severely reduced clinicians’ ability to build and maintain therapeutic relationships with patients (14, 15). GPs were the clinicians most affected by this (14, 15). Since patients struggled to build relationships in primary care, some expected to build a relationship with consultants once they were admitted to hospital (14). However, due to an increased workload and lack of time, consultants found it difficult to build relationships with hospitalised patients (15). The mismatch between patients’ expectations and clinicians’ capacity in building relationships in hospital seemed to contribute to the reported emotional distress associated with discussions that took place in secondary care (14, 15).

*Participants’ recommended and preferred approaches to palliative care discussions in COPD*

Clinicians and the published literature recommend early, regular and gradual palliative care discussions throughout the disease trajectory (12, 15). According to clinicians, early discussions could improve patients’ understanding about the progressive nature of their condition and reduce the emotional impact of end of life discussions (15). However, only a small proportion of COPD patients preferred early discussions with clinicians (14). These patients had a better awareness of the progressive nature of their illness, were more likely to have clearer preferences for future treatments, to prefer planning ahead and to be able to fully share their preferences with clinicians than patients preferring late discussions (14). In contrast, patients that preferred late discussions often saw them as end of life discussions where clinicians would stop life sustaining treatments and remove all hope (14).

Patients preferred to receive accurate and comprehensive information about their condition, treatment options and outcomes throughout their disease, especially when discussing future and palliative care (12, 14). A small proportion of patients preferred filtered information to limit emotional distress and maintain their hope (14). Therefore, patients and clinicians suggested tailored and patient-centred approaches when addressing patients’ needs and preferences (14, 15). 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 (12, 15).

Patients preferred to receive in-depth information about the status of their condition, prognosis and the different treatments available, since this information helped them make informed decisions and share the decision making with families and clinicians (12, 14). In contrast, clinicians suggested providing small amounts of information over time, since they believed patients struggled to retain and grasp large amounts of information (15). These different perspectives on the amount and type of information that clinicians should provide, seem to have led to incongruity of expectations, as patients often reported little to no information about their condition (14, 15).

**Discussion**

The findings suggest that late palliative care conversations at and about the end of life were common. As a consequence, these discussions were started abruptly by clinicians unfamiliar to the patient and focused on treatment withdrawal. Clinicians’ and patients’ limited understanding about palliative care and COPD, difficulties in timing and initiating discussions, and service rationing were the main contributors for late palliative care discussions. Divergent perspectives between patients and clinicians about the timing and nature of palliative care discussions often prevented their start. Instead, early patient-centred discussions on treatment choices, symptom and treatment burden were recommended by patients, clinicians and the literature. Earlier patient-centred discussions were thought to reduce their emotional impact and enable patients to participate fully, whilst enabling clinicians to provide timely and accurate information on illness progression and appropriate self-management techniques.

Patients and clinicians often confused palliative and future care discussions with end of life and death conversations (14, 15). This was illustrated by clinicians’ focus on treatment withdrawal and in starting discussions when patients had end-stage COPD, such as during an acute hospital admission (15). 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 (9). Previous studies have noted healthcare professionals’ poor understanding of palliative care, viewing it as a failure of acute care (22, 23). Indeed, we found that clinicians’ poor understanding about palliative care contrasted with patients’ preferences for discussions with clinicians expert in COPD and palliative care (14). 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 nurse’s job (22, 24). Consequently, we found that clinicians avoided discussions or, according to patients, framed discussions negatively – withdrawing or restricting access to treatments – resulting in emotional distress and in patients avoiding discussions. Improving clinicians’ understanding about the ethos and meaning of palliative care is paramount (25, 26). This may be achieved by spelling out the differences between current COPD care and care that addresses symptom and treatment burden concomitantly (25, 26).

Patients’ preferences for late palliative care discussions were often related to their poor understanding about palliative care and COPD (14). Patients saw palliative care discussions as terminal discussions that aimed at stopping their treatments and care (14). This poor perception was reinforced by clinicians’ approach when discussing palliative care, which led patients to delay discussions in an effort to continue to receive treatments and care (14). Another driver to late discussions was patients’ poor understanding about the progressive character of their condition (14, 27). 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 (12, 14). Poor understanding about COPD has been associated with patients being less able to start and participate in discussions, and with fewer preferences for discussions with clinicians (28, 29). In order to improve patient understanding, clinicians recommended further information at diagnosis, and regular discussions with patients about the progress of their condition and their care preferences (15).

The accumulated evidence suggests that a viable solution to reduce distressing end of life discussions in COPD is frequent conversations about how patients experience their condition, associated symptoms and its treatments. Offering less burdensome treatments in line with patient preferences may avoid the concerns highlighted above (15). Instead of emotionally loaded (and what patients perceived as life-limiting) conversations at and about end of life, practice should focus on time-evolving and regular discussions, that evolve over time from the point of diagnosis, may prove more beneficial. These should progress from generic and brief, to specific and in-depth discussions. Incorporating these discussions during the annual review was suggested by clinicians as a potential approach (15). Embedding patient-centred discussions throughout the disease trajectory may provide an opportunity for patients to share concerns about their condition and their preferences for future care, and may result in patients receiving less aggressive treatments (8, 30). Indeed, 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 (31, 32). Reducing treatment burden can be achieved by acknowledging and discussing its impact on patients’ lives and the support they need to self-manage (8, 33). These principles of patient-centred discussions can be embedded into the disease trajectory of other long-term conditions, such as heart failure and chronic kidney disease. Their progressive and unpredictable character – shared with COPD - requires the use of proactive discussions, where patients can communicate their care preferences to clinicians, whilst enhancing their perceived quality of life. Despite this, further research is required to understand if discussions addressing treatment burden and quality of life are well accepted by patients, and if these discussions result in the seamless progression to discussions about palliative care when the time is right.

**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, treatment experiences and in offering treatments based on patients’ preferences and coping mechanisms might avoid the emotional effect of late discussions and facilitate natural progression to discussions about palliative care when the time is right for the patient. This approach should help to promote a culture of open awareness about the progressive nature of COPD and of shared decision making, by empowering patients to play a key role in defining their treatment pathway.

**Authorship declaration**

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

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**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.

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**Table 1**

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| Table 1 - Patient and clinician characteristics |
| Patient characteristics  |
| Characteristics | **Number** |
| Gender (Male/Female patients (total)) | **22/11 (33)** |
| Age in years (mean (SD)) | **72.5 (7.5)** |
| Smoking status |  |
| Current smoker (%) | 5 (15%) |
| 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%) |
| Hospital admissions (number of patients admitted (mean number of admissions)) | **13 (1.6)** |
| Number of patients on long-term oxygen therapy (%) | **4 (12%)** |
| Clinician characteristics |
| Gender – Female (%) | 10 (71%) |
| Mean age in years (SD) | 50 (8.5) |
| Years in practice (SD) | 22 (12.5) |
| Professional background: |
| COPD consultants | 3 (23%) |
| COPD specialist nurses | 3 (23%) |
| Practice nurses | 4 (27%) |
| General practitioners  | 4 (27%) |

# Table 2

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| Table 2 Factors that prevent and/or delay palliative care discussions in COPD. |
| Service-related barriers | * Staff shortages and long waits for appointments (14, 15).
* Restructure of primary care services into larger and impersonal medical centres reduced continuity of care (12, 14, 15).
* Reluctance of palliative care services to care for patients with COPD (12).
* Complex discharge planning for COPD patients, due to limited service integration (12).
* Increased clinician workloads resulting in limited availability and shortened appointments (12, 14, 15).
* Limited and variance across clinicians’ training about COPD and palliative care, especially in primary care (14, 15).
 |
| Patient-related barriers  | * Unpredictable disease trajectory (12, 15).
* Cognitive impairment or severe mental health issues (12, 15).
* Limited understanding about COPD, palliative care, treatment options, healthcare and palliative care (12, 14, 15).
* Negative perception about palliative care discussions – discussions perceived as conversations about death and dying (12, 15).
* Difficulty in accepting disease severity, future disease progression and death (12, 15).
* Unsure about preferences for future care (14, 15).
* Lack of trust in their physician (12).
* Negative emotional impact of palliative care discussions on family members (15).
 |
| Clinicians-related barriers | * Little knowledge about COPD and/or palliative care – perception that palliative care is confined to last days of life and exclusive of life sustaining treatments (12, 14, 15).
* Lack of a patient-clinician relationship and limited information about the patient’s condition made palliative care discussions difficult to start (14, 15).
* Lack or limited documentation of previous discussions led to inconsistent messages across different clinicians or settings (12, 15).
* Belief that discussions may take away patients’ hope (12).
* Perception that clinical priority is to treat ill people and an ethos of *“cure at all cost”* (12, 14).
* Uncertainty as to who, how and when to start discussions (12).
 |