

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

5

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7

8 **Abstract**

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

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

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

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

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

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

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

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

## 31 **Background**

32 Patients with chronic obstructive pulmonary disease (COPD) have a high symptom burden, which is typically  
33 managed by means of aggressive and invasive treatments as patients approach the end of life (1-4). Providing  
34 more aggressive and invasive treatments throughout the disease trajectory increases the burden of  
35 treatment for patients and is associated with poor experiences at the end of life (5-8). Whilst this increase in  
36 burden of treatment is inadvertent as it results from efforts to manage deterioration and reduce the  
37 increasing symptom burden, it nonetheless challenges the *ethos* of palliative care. Instead, palliative care  
38 aims to alleviate symptoms and support patients holistically through minimally invasive treatments and  
39 patient-centred care (9).

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

## 49 **Methods**

### 50 *Design*

51 This paper combines and integrates the findings from a research study conducted over 3 phases that,  
52 although different, complemented and informed each other. The first phase encompassed a systematic  
53 literature review looking at published evidence about the timing and nature of palliative care discussions in  
54 COPD (12). The literature search was conducted in February 2016 (updated in June 2019 with new data  
55 incorporated). This review suggested that there were several barriers to palliative care discussions and that  
56 understanding of patients' preferences for these discussions was limited (12). The second phase used  
57 qualitative interviews to explore patients' preferences for the timing and nature of palliative care discussions  
58 with clinicians (14). Patients preferred to discuss palliative care with clinicians that had greater expertise and  
59 an established patient-relationship, usually once their condition had deteriorated significantly (14). Patients'  
60 preferences identified in phase 2 were used to inform and design the interviews with clinicians in phase 3  
61 and their recommendations for discussions were explored (15). Forty-seven participants were interviewed in

62 both phases – 33 COPD patients and 14 healthcare professionals (patient and clinicians characteristics can  
63 be found in **Table 1**). Patients’ interviews were analysed using an interpretative phenomenological analysis  
64 [18-19], whilst clinicians’ interviews used a thematic analysis (16-19).

#### 65 *Data analysis*

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

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

## 81 **Findings**

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

83 The frequency and quality of palliative care discussions in COPD remains poor with only 30% of patients  
84 reporting a previous discussion with clinicians (12). In fact, only two (6%) patient participants reported having  
85 had a previous palliative discussion with a clinician (14). In contrast, previous studies have shown that most  
86 patients want to have the opportunity to discuss their preferences with clinicians (12). When discussions did  
87 occur, they often took place in secondary care and with deteriorating patients who were approaching the  
88 end of life (12, 14, 15). The cause for late discussions was often attributed to the difficulty in producing an  
89 accurate prognosis for the patient (12, 15). Therefore, clinicians considered important milestones in the  
90 disease trajectory in an effort to guide the start of palliative care discussions, some of these milestones  
91 included hospital admissions, severe exacerbation or the start of long-term oxygen therapy (12, 15).  
92 Discussions were emotionally difficult, as most focused on end of life care and treatment withdrawal (12,  
93 15).

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

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

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

113

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

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

#### 120 Patient-related factors

121 Patient-related barriers for discussing palliative care with clinicians were individual-dependent and were  
122 often influenced by past experiences (14, 15). Patients had limited understanding of COPD, were unaware of  
123 the progressive nature of their condition and the severity of their condition (14). Therefore, clinicians believed  
124 that education about COPD, specifically about the progressive character of COPD was essential, since lack of  
125 understanding in both parties prevented the start of discussions (15). Moreover, patients had little to no  
126 knowledge about palliative care and viewed it as terminal care, exclusive of acute treatments (12, 14, 15).

127 Limited direct contact with death and lack of discussions about death were seen as societal barriers, which  
128 may provide an explanation for patients' poor understanding about palliative care (14, 15).

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

#### 134 Clinician-related factors

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

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

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

#### 154 Service rationing

155 Clinicians' lack of time was the single most common factor associated with the lack and delay of palliative  
156 care discussions in COPD (12, 14, 15). This was primarily reported in primary care by GPs and practice nurses  
157 (14, 15) who described a battle for time and the need to readjust services to be able to cope with increasing  
158 demand, compromising patient care (15). Primary care offered short appointments, which affected COPD  
159 management especially palliative care discussions (14, 15). Since patients struggled to access primary care,  
160 they only sought medical advice when their condition had acutely and severely deteriorated (14). Because

161 patients did not view palliative care conversations as a priority, they delayed discussions, or fear of taking up  
162 other people's appointments (14). Consequently, patients deferred discussions until their condition had  
163 significantly deteriorated and they found it difficult to manage on their own (14).

164 Patient-clinician relationships were seen by both parties as a key barrier to discussing palliative care in COPD  
165 (12, 14, 15). However, service rationing severely reduced clinicians' ability to build and maintain therapeutic  
166 relationships with patients (14, 15). GPs were the clinicians most affected by this (14, 15). Since patients  
167 struggled to build relationships in primary care, some expected to build a relationship with consultants once  
168 they were admitted to hospital (14). However, due to an increased workload and lack of time, consultants  
169 found it difficult to build relationships with hospitalised patients (15). The mismatch between patients'  
170 expectations and clinicians' capacity in building relationships in hospital seemed to contribute to the reported  
171 emotional distress associated with discussions that took place in secondary care (14, 15).

172

### 173 *Participants' recommended and preferred approaches to palliative care discussions in COPD*

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

183 Patients preferred to receive accurate and comprehensive information about their condition, treatment  
184 options and outcomes throughout their disease, especially when discussing future and palliative care (12,  
185 14). A small proportion of patients preferred filtered information to limit emotional distress and maintain  
186 their hope (14). Therefore, patients and clinicians suggested tailored and patient-centred approaches when  
187 addressing patients' needs and preferences (14, 15). In line with previous literature, clinicians recommended  
188 avoiding the use of strong and death-related words in an effort to limit the emotional impact of discussions  
189 on patients (12, 15).

190 Patients preferred to receive in-depth information about the status of their condition, prognosis and the  
191 different treatments available, since this information helped them make informed decisions and share the  
192 decision making with families and clinicians (12, 14). In contrast, clinicians suggested providing small amounts  
193 of information over time, since they believed patients struggled to retain and grasp large amounts of

194 information (15). These different perspectives on the amount and type of information that clinicians should  
195 provide, seem to have led to incongruity of expectations, as patients often reported little to no information  
196 about their condition (14, 15).

## 197 **Discussion**

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

208 Patients and clinicians often confused palliative and future care discussions with end of life and death  
209 conversations (14, 15). This was illustrated by clinicians' focus on treatment withdrawal and in starting  
210 discussions when patients had end-stage COPD, such as during an acute hospital admission (15). Moreover,  
211 clinicians believed that offering palliative care meant a cessation of hope and giving up on patients, rather  
212 than providing care that focused on reducing symptom and treatment burden (9). Previous studies have  
213 noted healthcare professionals' poor understanding of palliative care, viewing it as a failure of acute care (22,  
214 23). Indeed, we found that clinicians' poor understanding about palliative care contrasted with patients'  
215 preferences for discussions with clinicians expert in COPD and palliative care (14). The root of  
216 misunderstandings about palliative care seems to be multifactorial, arising from an *ethos* of care focused on  
217 "cure at all costs," lack of training about palliative care and a belief that palliative care is a nurse's job (22,  
218 24). Consequently, we found that clinicians avoided discussions or, according to patients, framed discussions  
219 negatively – withdrawing or restricting access to treatments – resulting in emotional distress and in patients  
220 avoiding discussions. Improving clinicians' understanding about the *ethos* and meaning of palliative care is  
221 paramount (25, 26). This may be achieved by spelling out the differences between current COPD care and  
222 care that addresses symptom and treatment burden concomitantly (25, 26).

223 Patients' preferences for late palliative care discussions were often related to their poor understanding about  
224 palliative care and COPD (14). Patients saw palliative care discussions as terminal discussions that aimed at  
225 stopping their treatments and care (14). This poor perception was reinforced by clinicians' approach when  
226 discussing palliative care, which led patients to delay discussions in an effort to continue to receive  
227 treatments and care (14). Another driver to late discussions was patients' poor understanding about the

228 progressive character of their condition (14, 27). In line with other studies, patients often reported a lack of  
229 information about the progress of their condition and called for frequent, honest and in-depth information  
230 from clinicians (12, 14). Poor understanding about COPD has been associated with patients being less able to  
231 start and participate in discussions, and with fewer preferences for discussions with clinicians (28, 29). In  
232 order to improve patient understanding, clinicians recommended further information at diagnosis, and  
233 regular discussions with patients about the progress of their condition and their care preferences (15).

234 The accumulated evidence suggests that a viable solution to reduce distressing end of life discussions in COPD  
235 is frequent conversations about how patients experience their condition, associated symptoms and its  
236 treatments. Offering less burdensome treatments in line with patient preferences may avoid the concerns  
237 highlighted above (15). Instead of emotionally loaded (and what patients perceived as life-limiting)  
238 conversations at and about end of life, practice should focus on time-evolving and regular discussions, that  
239 evolve over time from the point of diagnosis, may prove more beneficial. These should progress from generic  
240 and brief, to specific and in-depth discussions. Incorporating these discussions during the annual review was  
241 suggested by clinicians as a potential approach (15). Embedding patient-centred discussions throughout the  
242 disease trajectory may provide an opportunity for patients to share concerns about their condition and their  
243 preferences for future care, and may result in patients receiving less aggressive treatments (8, 30). Indeed,  
244 previous research has suggested that early palliative care discussions were associated with better  
245 experiences and reduced treatment burden at the end of life, resulting in greater quality of life for patients  
246 (31, 32). Reducing treatment burden can be achieved by acknowledging and discussing its impact on patients'  
247 lives and the support they need to self-manage (8, 33). These principles of patient-centred discussions can  
248 be embedded into the disease trajectory of other long-term conditions, such as heart failure and chronic  
249 kidney disease. Their progressive and unpredictable character – shared with COPD - requires the use of  
250 proactive discussions, where patients can communicate their care preferences to clinicians, whilst enhancing  
251 their perceived quality of life. Despite this, further research is required to understand if discussions  
252 addressing treatment burden and quality of life are well accepted by patients, and if these discussions result  
253 in the seamless progression to discussions about palliative care when the time is right.

## 254 **Conclusion**

255 The current approach towards palliative care discussions results in a lack of conversations between patients  
256 and clinicians, distressed patients, and overuse of burdensome treatments at the end of life. Regular and  
257 gradual discussions that focus on patients' illness, treatment experiences and in offering treatments based  
258 on patients' preferences and coping mechanisms might avoid the emotional effect of late discussions and  
259 facilitate natural progression to discussions about palliative care when the time is right for the patient. This  
260 approach should help to promote a culture of open awareness about the progressive nature of COPD and of  
261 shared decision making, by empowering patients to play a key role in defining their treatment pathway.





263 **Authorship declaration**

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

265

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268

269 **Declaration of interest**

270 The authors declare that there is no conflict of interest.

271

272 **Research Ethics**

273 The study was approved by the Health Research Authority and the Hampshire B Research Ethics Committee

274 in February 2017 with the following IRAS ID number: 203444.

275

276 **Data management**

277 All data are kept in the University of Southampton repositories for a minimum of 10 years. For more

278 information please contact the University's Data Protection Officer at [data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk).

279

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282

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**Table 1**

<b>Table 1 - Patient and clinician characteristics</b>	
<b>Patient characteristics</b>	
<b>Characteristics</b>	<b>Number</b>
<b>Gender (Male/Female patients (total))</b>	<b>22/11 (33)</b>
<b>Age in years (mean (SD))</b>	<b>72.5 (7.5)</b>
<b>Smoking status</b>	
Current smoker (%)	5 (15%)
<b>Disease severity - lower FEV1 % predicted suggests increased disease severity</b>	
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%)
<b>Hospital admissions (number of patients admitted (mean number of admissions))</b>	<b>13 (1.6)</b>
<b>Number of patients on long-term oxygen therapy (%)</b>	<b>4 (12%)</b>
<b>Clinician characteristics</b>	
<b>Gender – Female (%)</b>	10 (71%)
<b>Mean age in years (SD)</b>	50 (8.5)
<b>Years in practice (SD)</b>	22 (12.5)
<b>Professional background:</b>	
COPD consultants	3 (23%)
COPD specialist nurses	3 (23%)
Practice nurses	4 (27%)
General practitioners	4 (27%)

**Table 2**

<b>Table 2 Factors that prevent and/or delay palliative care discussions in COPD.</b>	
<b>Service-related barriers</b>	<ul style="list-style-type: none"> <li>• Staff shortages and long waits for appointments (14, 15).</li> <li>• Restructure of primary care services into larger and impersonal medical centres reduced continuity of care (12, 14, 15).</li> <li>• Reluctance of palliative care services to care for patients with COPD (12).</li> <li>• Complex discharge planning for COPD patients, due to limited service integration (12).</li> <li>• Increased clinician workloads resulting in limited availability and shortened appointments (12, 14, 15).</li> <li>• Limited and variance across clinicians’ training about COPD and palliative care, especially in primary care (14, 15).</li> </ul>
<b>Patient-related barriers</b>	<ul style="list-style-type: none"> <li>• Unpredictable disease trajectory (12, 15).</li> <li>• Cognitive impairment or severe mental health issues (12, 15).</li> <li>• Limited understanding about COPD, palliative care, treatment options, healthcare and palliative care (12, 14, 15).</li> <li>• Negative perception about palliative care discussions – discussions perceived as conversations about death and dying (12, 15).</li> <li>• Difficulty in accepting disease severity, future disease progression and death (12, 15).</li> <li>• Unsure about preferences for future care (14, 15).</li> <li>• Lack of trust in their physician (12).</li> <li>• Negative emotional impact of palliative care discussions on family members (15).</li> </ul>
<b>Clinicians-related barriers</b>	<ul style="list-style-type: none"> <li>• 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).</li> <li>• Lack of a patient-clinician relationship and limited information about the patient’s condition made palliative care discussions difficult to start (14, 15).</li> <li>• Lack or limited documentation of previous discussions led to inconsistent messages across different clinicians or settings (12, 15).</li> <li>• Belief that discussions may take away patients’ hope (12).</li> <li>• Perception that clinical priority is to treat ill people and an ethos of “<i>cure at all cost</i>” (12, 14).</li> <li>• Uncertainty as to who, how and when to start discussions (12).</li> </ul>