

1 **Journal of Hospice and Palliative Nursing**

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4 **Clinician perspectives on how to hold earlier discussions about palliative and end of life care with**
5 **COPD patients – a qualitative study**

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September 2021

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29 **Authorship declaration**

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

31 **Funding**

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

34 **Declaration of interest**

35 The Authors declare that there is no conflict of interest.

36 **Research Ethics**

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

39 **Data management**

40 All data are kept in the University of Southampton repositories for a minimum of 10 years. For
41 more information please contact the University’s Data Protection Officer at
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43 **Acknowledgments**

44 The authors are grateful to all clinicians that took their time to participate in the research study.

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48 **Abstract**

49 COPD is associated with progressive symptoms and increased treatment burden, especially at
50 the end of life. However, most patients do not receive palliative care until late in their lives or

51 discuss their end of life preferences with clinicians. This study explored clinicians' perspectives
52 on the timing and nature of palliative care discussions.

53 Qualitative interviews were conducted with seven physicians and seven nurses working in
54 primary and secondary care settings. Data was analysed using a thematic analysis.

55 Participants advocated for early, gradual and informed palliative and future care discussions,
56 as these discussions were thought to be less traumatic and better accepted by patients. Despite
57 this, patient and clinician-related barriers severely affected clinicians' ability to start
58 discussions at earlier stages. Participants felt many patients were not ready for these discussions
59 and feared damaging hope if the subject was broached. Therefore, clinicians delayed
60 discussions until patients approached the end of life.

61 Stand-alone conversations about and near the end of life were described as current practice,
62 however clinicians believed these discussions reduced patients' hope and were potentially
63 upsetting. Instead, individualised early, regular and gradual discussions about immediate and
64 long-term care plans were thought to be less negative and be better accepted.

<p>Keywords: COPD; palliative care; communication; patient-clinician communication; patient-centre care; palliative care excellent; long-term conditions</p>

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67 **Introduction**

68 Chronic obstructive pulmonary disease (COPD) is a progressive and life-limiting illness
69 that causes breathlessness and chronic cough ¹. COPD patients have a high symptom burden ²,
70 ³, which is typically managed by means of complex, invasive and burdensome treatments as
71 disease progresses and patients approach the end of life ⁴.

72 Palliative care can support COPD patients holistically and improve quality of life, by
73 reducing symptom and treatment burden ⁵. Different models of palliative care services for
74 COPD patients have emerged in recent years, including integrated services, short-term
75 palliative care and outpatient services, however, research suggests that these patients still have
76 limited access to palliative care ^{6, 7}. In fact, before accessing palliative care services,
77 conversations about patient's preferences and future care need to take place ⁸. However, the
78 unpredictable and complex disease trajectory in COPD makes the early identification of
79 patients in need of palliative care challenging ⁹. Therefore, identifying with some degree of
80 certainty the 'right time' to initiate palliative and future care conversations with patients
81 becomes a difficult job for clinicians.

82 Previous evidence suggested that discussing patient preferences and creating advanced
83 care plans could ultimately result in improved experiences at the end of life while reducing
84 patients' symptom burden throughout the disease trajectory ¹⁰. However, most COPD patients
85 are still denied the opportunity to discuss their preferences before they approach the end of life
86 ^{11,12}. In an effort to improve the frequency and quality of patient-centred discussions, a previous
87 study, using interviews with patients at various stages of the COPD disease trajectory, provided
88 an in-depth understanding of patients' preferences for discussions with clinicians ¹³. Yet,
89 clinicians' thoughts and attitudes towards patient-centred discussions in COPD remain
90 unknown ¹¹. This study aimed to explore clinicians' perspectives on when and how to initiate

91 and conduct palliative care discussions with COPD patients, when considering patients'
92 preferences for these discussions.

93 **Methods**

94 This paper reports the findings of the third component of a larger study looking at how
95 and when to start conversations about palliative and advance care planning in COPD. A
96 systematic literature review ¹¹ and a qualitative study of patients' preferences and opinions for
97 the timing and nature of discussions ¹³ formed the first components of the study. The first two
98 components informed the design of this study, the recruitment strategy and the interview topic
99 guide (such as patient perceptions about the lack of expertise in primary care and their
100 preference in delaying these discussions).

101 *Sample*

102 The study used a purposive sample and recruited clinicians who provided direct care to
103 COPD patients at different stages of their condition, which included practice nurses; general
104 practitioners (GPs); COPD consultants and COPD specialist nurses.

105 Clinicians were recruited by email or by letter. The NIHR Clinical Research Network
106 (CRN) signposted primary care clinicians to the study. Secondary care clinicians were
107 signposted to the study by the research department of their local Trust. Clinicians were sent
108 information about the study and were asked to contact the research team if willing to
109 participate. Written informed consent was obtained for all participants. The study was approved
110 by the Health Research Authority and the Hampshire B Research Ethics Committee in February
111 2017 with the following IRAS ID number: 203444.

112 *Data collection*

113 Interviews were audiotaped, lasted 20-45 minutes and followed a semi-structured
114 approach. Interviews were conducted by NT, who had completed appropriate training on
115 qualitative interviewing and had no relationship with the participants. The questions focused

116 on exploring clinicians' thoughts and attitudes towards the nature and timing of palliative care
117 discussions and in debating patients' preferences for these discussions. The interview
118 questions, scope and depth were tailored to participants on an individual basis.

119 Individual interviews were conducted at a time and place convenient to the participant,
120 usually in GP practices and NHS Trusts. Data collection was carried out between December
121 2018 and March 2019 and stopped at data saturation point. Data saturation was judged to be
122 achieved when no new themes/topics were discovered. The decision to stop data collection was
123 discussed and agreed within the research team.

124 *Data analysis*

125 All interviews were transcribed verbatim and anonymised. Data were managed using
126 qualitative software Nvivo 11 and analysed using thematic analysis ¹⁴. Transcripts were
127 thoroughly read, prior to coding. Codes were developed, defined, reviewed and grouped into
128 larger categories of codes and, finally, into themes. All transcripts were analysed by NT, whilst
129 all authors monitored and supervised the transcript analysis and participated in the development
130 of codes and themes, ensuring the trustworthiness and methodological quality of the study. The
131 consolidated criteria for reporting qualitative research (COREQ) were used to report the
132 research findings ¹⁵.

133 **Results**

134 Fourteen clinicians, out of 22 clinicians contacted, participated in the study and their
135 characteristics are summarised in **Table 1**. Data analyses yielded 59 deductive codes and 50
136 inductive codes. The deductive codes focused on addressing the aim of the study, whereas
137 inductive codes provided context and further information on clinicians' thoughts. These
138 different codes were grouped and collapsed initially into 4 main themes comprising 7
139 subthemes/categories. (see **Table 2**). Quotations, selected to illustrate themes from a range of
140 participants, were edited for relevance, clarity and anonymity.

141 *Palliative care discussions across disciplines and settings – COPD expertise and patient-*
142 *clinician relationships*

143 Participants felt that palliative care discussions should be “*everybody’s job*” and not be
144 conducted by one specific group of healthcare professionals (e.g. respiratory consultants or
145 practice nurses). Participants reported that patients should discuss care preferences with a well-
146 known clinician, since this was thought to increase trust and familiarity in both. When
147 analysing interdisciplinary differences, physicians felt more confident in initiating and
148 conducting discussions than nurses. Nurses often reported lack of knowledge about the patient,
149 disease progression and palliative care. Communication skills and knowledge about COPD,
150 palliative care and services available were believed to be essential skills. Despite this,
151 participants’ knowledge and skills differed across settings, but also across and within
152 professional backgrounds.

153 *Unless the GP has a specific respiratory interest, they'll have a broad*
154 *understanding, but they might not actually know as much as we do (respiratory*
155 *nurses). Just because they can't. You can only store so much information in your*
156 *brain. Same with the practice nurses, potentially in most surgeries there's one,*
157 *potentially two, respiratory focused (nurses). Otherwise, they're doing the ears,*
158 *smears, flu clinics, you know? Everything else, as well as, their chronic disease*
159 *management.* (COPD Nurse)

160 Most participants seemed to have little understanding about palliative care. For
161 instance, palliative care was often viewed as end of life care and exclusive of acute treatments.
162 As a consequence, palliative care discussions were seen as death conversations and some
163 participants’ reported that their colleagues felt uncomfortable discussing this with patients. The
164 negative emotional distress of discussions for patients and clinicians was reported as a reason

165 for this uncomfortable feeling. Despite this, no participant reported that they shared these
166 feelings or found such discussions particularly difficult.

167 *Palliative care discussions in secondary care*

168 COPD consultants reported conducting palliative care discussions regularly in outpatient
169 clinics, however most discussions were conducted on hospital wards and with end-stage
170 patients. Participants across settings and disciplines believed that consultants were in a strong
171 position to conduct discussions due to their medical background; COPD expertise; patient-
172 relationship; and regular contact with “*end-stage patients.*”

173 COPD specialist nurses often discussed end of life care with patients and were seen by
174 other participants as COPD experts. COPD nurses offered longer patient appointments, which
175 resulted in closer relationships with patients. Despite this, some COPD specialist nurses did
176 not always have the confidence to initiate discussions with patients, so they often sought
177 support from medical colleagues when patients required these discussions.

178 *So if it's a practice nurse for example (who discusses palliative care with the*
179 *patients), but that would have to be with support of her GP. I wouldn't have a*
180 *conversation with a patient without the support of a consultant.*

181 *(COPD Nurse)*

182 *Palliative care discussions in primary care*

183 Increasingly, higher pressures on services reported in primary care resulted in short
184 appointments and long waits, which reduced patient contact, continuity of care and patient-
185 clinician relationships. The reasons suggested for this shortness of time included service
186 rationing, reduction in primary care staff and increased complexity of patients' medical and
187 social conditions. Despite this, GPs reported a good overview of the patient's medical and
188 social history, which, they felt, provided them vital information when starting discussions with
189 patients. Practice nurses rarely discussed palliative care with patients, since they reported a

190 lack of training and expertise in COPD and palliative care. Moreover, practice nurses often saw
191 patients with milder forms of COPD, which nurses believed did not require palliative care
192 discussions.

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

198 *Predicting when to start discussions in COPD*

199 The timing of discussions was a recurrent concern, therefore participants estimated
200 patients' individual prognosis before engaging in discussions. Estimating patients' prognosis
201 accurately was described as a complex process, so participants looked for factors that signalled
202 a poor prognosis when starting discussions, such as starting long-term oxygen, regular hospital
203 admissions and recurrent acute exacerbations. This approach often resulted in discussions
204 being started when patients were in an advanced and deteriorating stage, usually at the end of
205 life.

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

213 In contrast to their described practice, participants believed that early and regular
214 discussions should be offered instead, since these discussions may reduce the emotional impact

215 of late discussions. Early discussions were thought to be less threatening to patients, since death
216 was not imminent, and allowed them to plan ahead. Participants suggested that early
217 discussions could allow for a steady transition from aggressive to comfort-focused
218 treatments/care as disease severity progressed, mitigating against the complex nature of COPD.
219 In addition, regular discussions were thought to provide digestible information to patients that
220 could increase in depth as their condition deteriorated.

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

226 *Current approaches to palliative care discussions*

227 Participants reported that patients and families rarely started discussions using a direct
228 approach, instead they provided cues when they were ready to discuss palliative and future
229 care. The lack of discussions started by patients was attributed to their poor understanding
230 about the severity and progressive nature of their condition, and the difficulty in differentiating
231 between acute exacerbations and chronic decline.

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

237 Participants tailored their approach to patients and juggled many factors when they
238 started and conducted palliative care discussions. Participants often considered patients'
239 anxiety levels, understanding of disease severity, healthcare setting (primary and secondary

240 care), prognosis and urgency of palliative care discussions when approaching patients. The
241 result of this analysis led participants to use a direct or an indirect approach when to starting
242 and conducting discussions with patients. **Table 3** describes some approaches used by
243 participants when discussing palliative care with patients. These strategies were a result of
244 participants' clinical experience and trial and error attempts, while other strategies were
245 described as ideal approaches to discuss the subject. The degree participants were able to use
246 these approaches in clinical practice depended on the individual patient, clinicians' expertise
247 and on time and service-related barriers. For example, participants would use indirect
248 approaches when discussing palliative and end of life care with anxious and depressed patients
249 and direct approaches when death was seen as imminent.

250 *Often the conversation with COPD patients is merging what active treatments they*
251 *want and where the limit of active treatments are. Once you talked about the limits*
252 *of active treatments and the things that aren't going so well, then, you can go into*
253 *their fears and concerns and use that as a lead into what treatments they want. So,*
254 *you can use their anxiety. But with some patients it is very difficult to get an*
255 *opening, especially over a conversation about palliative care. You sort of dance*
256 *around and talk about the issues that are in palliative care. So, things about their*
257 *chosen place of death, their ceiling of care, what symptoms most bother them and*
258 *things like that. You can have those conversations, without ever sort of overtly*
259 *talking about palliative care. (Respiratory consultant)*

260

261 Discussions were occasionally started in a “roundabout way” (indirect approach), in an
262 effort to reduce patients' anxiety levels and increase their chances of accepting discussions.
263 In contrast, a small proportion of participants adopted a direct approach to discussions –
264 “open and honest “ - and provided accurate and direct information to patients about the

265 severity of their advanced condition. Emotive words, such as “palliative care,” “death” and
266 “end of life,” were avoided by all participants, since these could cause distress and reduce
267 patients’ hope. Regardless of the approach adopted, most conversations focused on
268 discussing withdrawing treatments, life-limiting approaches and the end of life.

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

274 *Intricacies of patients’ readiness for discussions*

275 Before engaging in palliative care discussions, participants often looked for cues to
276 identify patients’ readiness for discussions. Participants suggested that a multitude of factors
277 could impact on patients’ readiness to discuss palliative care. **Table 4** provides examples of
278 these factors as suggested by participants. The outcomes of the assessment of patients’
279 readiness seemed to dictate the participant’s willingness to start palliative care discussions.

280 Poor understanding about the progressive nature of COPD and disease severity was
281 thought to reduce patients’ readiness and willingness to discuss palliative care. This poor
282 understanding was attributed to the lack of information provided to patients throughout their
283 disease trajectory. Despite acknowledging the importance of patient education, some
284 participants purposely withheld information about the progressive nature of COPD, for fear of
285 emotionally distress patients.

286 *I did (talk to patients about palliative care) when they were first diagnosed in a*
287 *sense. Because I talked to them about what COPD was and I'd give them the*
288 *booklet. I tried to avoid it being an aggressive or progressive disease. I didn't say*

289 *anything about palliative care. I would say if you carry on smoking things might*
290 *worsen, you might end up on oxygen and things like that. (Practice nurse)*

291 **Discussion**

292 *Discussion of findings*

293 Participants in the study believed that clinicians with increased expertise and good
294 relationships with patients were in a better position to start palliative care discussions but there
295 was no agreement on which clinicians were ultimately responsible to lead these discussions.
296 Previous research has highlighted a lack of clarity on who is responsible for initiating
297 discussions with patients and the implications for patient care ¹¹. Although clinical expertise
298 and patient-relationships are paramount when discussing palliative care ¹⁶, the lack of a
299 designated clinician responsible for initiating discussions with patients can lead to nobody
300 starting them. This uncertainty and diffusion of responsibility may mean that discussions either
301 do not take place at all, or that they are conducted poorly, due to clinicians' lacking experience
302 and expertise in conducting these discussions. Specific guidance on who is responsible for
303 starting discussions, and on the timing and approach for palliative care conversations may
304 facilitate the development and implementation of interventions that can help improve the
305 frequency and quality of discussions ¹⁷.

306 Conflicting thoughts about best and current practice for the timing of discussions were
307 noted across participants. Most participants had a one-off discussion with patients often at the
308 end of life, whilst they believed discussions should be started early and held regularly with
309 patients. The problems associated with late or absent discussions has also been reported in other
310 life-limiting conditions, such as heart failure and chronic kidney disease ¹⁸. As reported in the
311 literature, late discussions were often a consequence of clinicians' poor understanding about
312 palliative care (confined to the end of life) and of the difficulty of prognosticating in COPD ¹⁹,
313 ²⁰. We found that a lack of COPD knowledge as well as palliative care training, reduced practice

314 nurses' confidence and ability in starting discussions. In order to increase clinicians'
315 knowledge about palliative care, several training programmes have been developed, ranging
316 from one-time learning activities to year-long programmes ²¹. As an example, the US-based
317 Center to Advance Palliative Care developed an online curriculum for primary palliative care
318 education and a learning pathway for respiratory clinicians that provide care to COPD patients
319 ²². However, until palliative care skills are embedded as standard in undergraduate and graduate
320 training curricula, mid-career palliative care education remains a critically important
321 undertaking ²¹.

322 Previous work suggests that a considerable proportion of patients would like to discuss
323 palliative care with their practice nurses ¹³. However, service rationing, clinician and patient-
324 specific barriers, such as unpredictable disease trajectories and short appointments ¹⁹, were
325 highlighted as key causes for late discussions. Minimizing the impact of these barriers to early
326 discussions, is likely to require a change to current approaches. Stand-alone discussions at and
327 about the end of life need to give way to early, regular and successive discussions throughout
328 the disease trajectory. Doing this may help improve the frequency and quality of palliative care
329 discussions.

330 The role of social determinants on palliative care discussions was seldom mentioned by
331 clinicians, despite it being commonly reported in previous research ²³. Lack of power and
332 knowledge can lead patients to devolve all expertise and decision power to clinicians, which
333 limits their participation in palliative care discussions ²⁴, which perpetuates COPD patients'
334 difficulties in accessing palliative care. Poor disease understanding and low health literacy are
335 often caused by the lack of information provided by clinicians about patients' condition and its
336 progress over time ^{17, 25}. This was evidenced by participants providing inaccurate and limited
337 information about the progression and implications of COPD to newly diagnosed patients. In
338 order to reduce inequalities in access to healthcare, and palliative care in particular, patients

339 need open and honest information, through early and informative discussions about all aspects
340 of COPD, palliative care and future treatments. Late discussions further reduce patients' power,
341 since they will often be at their most vulnerable when they require palliative care.

342 *Limitations*

343 The first limitation is that participants were self-selecting. Most expressed interest/
344 training in palliative care discussions. This possibly enabled participants to have more
345 knowledge and confidence about palliative care discussions than clinicians with less
346 interest/training, who might have been able to say more about clinicians' challenges or
347 concerns had they participated. Another limitation of the study was the lack of ethnic diversity
348 in the sample, which prevented any exploration of the impact of ethnicity on palliative care
349 discussions. This may have been especially important when considering the spiritually attached
350 to palliative care discussions.

351 **Conclusion**

352 Our data suggests that clinicians with increased expertise and established relationships
353 with patients feel that they are in the best position to start palliative care discussions. Clinicians
354 involved in COPD care perceive that the current practice of stand-alone discussions are difficult
355 to time and conduct appropriately and sensitively, resulting in a lack of, or late discussions with
356 patients. Instead, discussions about prognosis and treatment goals should be started from
357 diagnosis, develop over time and information should be provided gradually. The discussion
358 should be patient-led and patient-centred, focused on patients' preferences for short to medium-
359 term care and held in a comfortable and private environment. A shift in the model of care, from
360 stand-alone end of life care conversations to integrating palliative care early in the disease
361 trajectory, is required.

362 **References**

- 363 1. National Institute for Health and Care Excellence. Chronic obstructive pulmonary
364 disease in adults - Quality standard. Available at:
365 <https://www.nice.org.uk/guidance/qs10>. Accessed July 2021.
- 366 2. Miravittles M, Ribera A. Understanding the impact of symptoms on the burden of
367 COPD. *Respiratory Research*. 2017; 18(1):67.
- 368 3. National Institute for Health and Care Excellence. Chronic obstructive pulmonary
369 disease in over 16s: diagnosis and management 2018.
- 370 4. Crisafulli E, Barbeta E, Ielpo A, Torres A. Management of severe acute exacerbations
371 of COPD: an updated narrative review. *Multidisciplinary Respiratory Medicine*. 2018;
372 13(1):36.
- 373 5. WHO. WHO Definition of Palliative Care. *World Health Association*. Available at:
374 <http://www.who.int/cancer/palliative/definition/en/>. Accessed June 2018, 2018.
- 375 6. Fu Y, Mason A, Boland AC, et al. Palliative Care Needs and Integration of Palliative
376 Care Support in COPD: A Qualitative Study. *Chest*. 2021; 159(6):2222-2232.
- 377 7. Bloom CI, Slaich B, Morales DR, Smeeth L, Stone P, Quint JK. Low uptake of
378 palliative care for COPD patients within primary care in the UK. *Eur Respir J*. 2018;
379 51(2).
- 380 8. NICE. End of life care for adults - Quality Standard. In: Department of Health, ed;
381 2017.
- 382 9. Smith L-JE, Moore E, Ali I, Smeeth L, Stone P, Quint JK. Prognostic variables and
383 scores identifying the end of life in COPD: a systematic review. *International journal
384 of chronic obstructive pulmonary disease*. 2017; 12:2239-2256.

- 385 **10.** Houben CHM, Spruit MA, Luyten H, et al. Cluster-randomised trial of a nurse-led
386 advance care planning session in patients with COPD and their loved ones. *Thorax*.
387 2019; 74(4):328-336.
- 388 **11.** Tavares N, Jarrett N, Hunt K, Wilkinson T. Palliative and end-of-life care conversations
389 in COPD: a systematic literature review. *ERJ Open Research*. 2017; 3(2).
- 390 **12.** Houben CHM, Spruit MA, Schols JMGA, Wouters EFM, Janssen DJA. Patient-
391 Clinician Communication About End-of-Life Care in Patients with Advanced Chronic
392 Organ Failure During One Year. *Journal Of Pain And Symptom Management*. 2015.
- 393 **13.** Tavares N, Hunt KJ, Jarrett N, Wilkinson TM. The preferences of patients with chronic
394 obstructive pulmonary disease are to discuss palliative care plans with familiar
395 respiratory clinicians, but to delay conversations until their condition deteriorates: A
396 study guided by interpretative phenomenological analysis. *Palliative Medicine*. 2020;
397 34(10):1361-1373.
- 398 **14.** Kiger ME, Varpio L. Thematic analysis of qualitative data: AMEE Guide No. 131.
399 *Medical Teacher*. 2020; 42(8):846-854.
- 400 **15.** Tong A, Craig J, Sainsbury P. Consolidated criteria for reporting qualitative research
401 (COREQ): a 32-item checklist for interviews and focus groups. *International Journal*
402 *for Quality in Health Care*. 2007; 19(6):349-357.
- 403 **16.** Tavares N, Hunt K, Jarrett N, Wilkinson T. The preferences of patients with chronic
404 obstructive pulmonary disease are to discuss palliative care plans with familiar
405 respiratory clinicians, but to delay conversations until their condition deteriorates: A
406 study guided by interpretative phenomenological analysis. *Palliative Medicine*. 2020;
407 34(10):1361-1373.
- 408 **17.** Gott M, Gardiner C, Small N, et al. Barriers to advance care planning in chronic
409 obstructive pulmonary disease. *Palliative Medicine*. 2009; 23(7):642-648.

- 410 **18.** Mandel EI, Bernacki RE, Block SD. Serious Illness Conversations in ESRD. *Clinical*
411 *Journal of the American Society of Nephrology*. 2017; 12(5):854-863.
- 412 **19.** Landers A, Wiseman R, Pitama S, Beckert L. Severe COPD and the transition to a
413 palliative approach. *Breathe (Sheffield, England)*. 2017; 13(4):310-316.
- 414 **20.** Lockett T, Agar M, Phillips J. Palliative Care in Chronic Illness and Multimorbidity.
415 In: MacLeod RD, van den Block L, eds. *Textbook of Palliative Care*. Cham: Springer
416 International Publishing; 2018:1-15.
- 417 **21.** Bowman B, Meier DE. Palliative care for respiratory disease: An education model of
418 care. *Chronic Respiratory Disease*. 2017; 15(1):36-40.
- 419 **22.** Center to Advance Palliative Care. Pulmonology. Available at:
420 <https://www.capc.org/training/learning-pathways/pulmonology/>. Accessed
421 22/12/2021.
- 422 **23.** Pleasants RA, Riley IL, Mannino DM. Defining and targeting health disparities in
423 chronic obstructive pulmonary disease. *International journal of chronic obstructive*
424 *pulmonary disease*. 2016; 11:2475-2496.
- 425 **24.** Laue J, Melbye H, Risør MB. Self-treatment of acute exacerbations of chronic
426 obstructive pulmonary disease requires more than symptom recognition – a qualitative
427 study of COPD patients’ perspectives on self-treatment. *BMC Family Practice*. 2017;
428 18(1):8.
- 429 **25.** Gardener AC, Ewing G, Kuhn I, Farquhar M. Support needs of patients with COPD: a
430 systematic literature search and narrative review. *International journal of chronic*
431 *obstructive pulmonary disease*. 2018; 13:1021-1035.
- 432
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- 434

435 **Tables**

Table 1. Clinicians' characteristics	
Gender – Female (%)	10 (71%)
Mean age in years (SD)	50 (8.5)
Years in practice (SD)	22 (12.5)
Number of COPD patients seen a week (SD)	17 (8)
Number of discussions a monthly (SD)	3 (5)
Special interest or training in palliative care (%)	6 (43%)
Professional background:	
• COPD consultants	3 (23%)
• COPD specialist nurses	3 (23%)
• Practice nurses	4 (27%)
• General practitioners	4 (27%)

436

437

Table 2. Categories and themes generated from interviews with clinicians	
Categories	Themes
<ul style="list-style-type: none"> • Approaches when discussing palliative care • End of life and end of life care • Future with COPD • Palliative care • Person starting and conducting discussions • Timing for discussions with patients • Previous discussions with patients 	<ul style="list-style-type: none"> • Palliative care discussions across disciplines and settings – COPD expertise and patient-clinician relationships • Predicting when to start discussions in COPD • Anecdotal approaches to palliative care discussions • Intricacies of patients' readiness for discussions

438

439

Table 3. Approaches used by participants when discussing palliative care with patients	
Before the discussion	Knowing and having a good relationship with the patient was thought to provide a strong starting point for discussions
Starting the discussion	<p>Strategies used by participants:</p> <ul style="list-style-type: none"> • Discussions were started in a “<i>roundabout way</i>” to help reduce anxiety in patients with mental health issues; • Participants often explained the severity of the patient’s condition and implication for the future at the start of the discussion.
	<p>Ideal strategies described by participants:</p> <ul style="list-style-type: none"> • Patients’ readiness for discussions could be gauged by picking up cues; • Providing additional opportunities for patients to discuss concerns/thoughts in consultations, including palliative care; • Patients could be asked to reflect on the advanced stage of their condition and on its implications for the future.
Conducting the discussion	<p>Strategies used by participants:</p> <ul style="list-style-type: none"> • Open questions were sometimes used to enquire about patients’ preferences for treatments and care; • Participants often explored and unpicked patients’ concerns about treatments, future deteriorations and end of life; • Focusing on the mechanical completion of advance care planning forms with patients was thought to remove the emotional impact

	<p>of discussions on patients and clinicians.</p> <p>Ideal strategies described by participants:</p> <ul style="list-style-type: none"> • Early, regular and gradual discussions with patients as their disease severity worsened. • Discussions could be framed positively, by focusing on ways to support the patients and on symptom relief; • Discussions could be conducted using a direct or indirect approach - open and honest discussions versus hope fostering discussions – depending on the individual patient (e.g. disease severity), clinician (e.g. preferred method) and setting.
<p>Concluding the discussion</p>	<p>Strategies used by participants:</p> <ul style="list-style-type: none"> • Participants often allowed patients to ask questions at the end of the conversation; • Some participants provided written information that supported the discussion, which patients could revisit after the consultation;
	<p>Ideal strategies described by participants:</p> <ul style="list-style-type: none"> • Concluding the discussion on a positive note was suggested by some participants, since it could reduce the emotional impact of the discussion on patients; • Participants recommended feeding back the outcome of the discussion to other members of the multidisciplinary team, especially to clinicians working in different healthcare settings.

Table 4. List of suggested factors that impacted patients' readiness for discussions

- Patient's age;
- Patient's understanding about COPD and severity their condition;
- Patient's perception about palliative and future care discussions;
- Patient's attitude towards death;
- Patient's personality;
- Patient's or other people's healthcare experiences;
- Clinicians' approach when engaging in discussions;
- Focus of the discussion.

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