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The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study

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Abstract

Background: Chronic obstructive pulmonary disease (COPD) is a major cause of death worldwide and there are concerns that end-of-life care for these patients is inadequate. Advance care planning is encouraged, with the hope that it will improve communication and avoid unwanted interventions, which have been particular concerns; in practice, these discussions rarely occur. We have little knowledge of the views of patients with COPD on advance care planning. Understanding this could help integrate advance care planning into the routine management of patients with COPD.

Aim: To explore the views of people with severe COPD about advance care planning.

Design: Qualitative design, with data collection incorporating audio recorded semi-structured interviews. Analysis followed a grounded theory approach.

Setting/participants: Patients with severe COPD (n =10, Gold Standards Framework criteria) were recruited from primary and secondary care settings.

Results: Participants felt they had not been given enough information about their diagnosis and prognosis, and were keen for more discussion with healthcare professionals. They wanted more involvement in decisions about their treatment when those decisions were required. Participants were happy to discuss their general views about future care, but felt uncomfortable with the traditional model of binding 'advance directives'.

Conclusions: Considering advance care planning as a repeated process of discussion of prognosis, concerns and probable preferences for care would be more useful than encouraging binding advance decisions. Further research should assess the effectiveness of this approach. Local coordination of who is responsible for information provision is needed, and greater involvement of patients with COPD in management decisions as they arise.

Keywords
Advance care planning, chronic obstructive pulmonary disease, palliative care, decision making

Introduction

Chronic obstructive pulmonary disease (COPD) is a major cause of morbidity and mortality, and is expected to become the third leading cause of death worldwide by 2030.[1] There has been growing interest and discussion over the past 15 years in palliative care needs and provision for patients with COPD.[2,3] One area of concern is whether end-of-life care is managed adequately; specifically, whether patients have more interventions and hospital admissions towards the end of their lives than they want or that are appropriate.[4,5] In addition, several research studies have identified that patients with COPD may not receive as much information about their diagnosis and prognosis as they want to have.[6–8]

Advance care planning is a process of discussion between an individual and their care provider to help the individual anticipate how their condition may affect them in the future.[9] This can include discussion of the individual's understanding of their diagnosis and prognosis, any concerns, and preferences and wishes for care or treatment in the future. This

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often leads to the completion of documentation recording these preferences, either legal documents or informal records. These documents can then inform decisions about the individual's care should they lose the ability to make or communicate those decisions. Advance care planning is considered an intrinsic part of end-of-life care, and consideration of its use is recommended for any adult with capacity with a life-limiting condition.[10] There is some evidence of the benefits of advance care planning in elderly hospitalised patients with various diagnoses, with those who had participated in advance care planning discussions having less intensive interventions towards the end of their lives and with improved outcomes for bereaved relatives.[11] However, in another large study the benefits were less clear.[12]

Advance care planning is recommended on a policy level for patients with COPD.[13,14] It could potentially reduce concerns about patients receiving unwanted interventions and hospital admissions, as well as providing opportunities for discussion about diagnosis and prognosis. Despite these potential improvements in end-of-life care, advance care planning is not commonly done with patients with COPD.[5] Research into the perspectives of healthcare professionals on advance care planning in patients with COPD has identified several barriers,[4,15] including concerns about how patients would perceive discussions of end-of-life issues, and whether patients understand about the terminal nature of COPD.

There has not previously been research into what patients with COPD think about the concept of advance care planning, so it is not known whether they feel it could improve their care, and if so how. This information could provide insight into how to usefully integrate advance care planning into the care of patients with COPD.

Methods

Research question

This study aimed to answer whether people with COPD think that advance care planning could be a useful part of their care, and to explore their reasoning behind this view. This included discussion of their knowledge of their diagnosis, as well as their thoughts about their future and any discussions about their future that had taken place. Their opinion on the advance care planning process was explored, including their feelings about the discussions.

Research team

The principal researcher (AM), a registrar in palliative medicine, conducted all interviews. The participant was excluded if the principal researcher knew them in a clinical capacity, and the role was clearly defined as a researcher rather than clinician, although participants were aware of the researcher being a clinician prior to the interview. An experienced qualitative researcher (CW) reviewed the transcriptions of two early interviews to advise on interview technique, and a consultant in palliative medicine and a consultant in respiratory medicine provided guidance throughout.

Participants

Potential participants were identified through electronic records at a large general practitioner (GP) practice and through the hospital respiratory team, who consulted the community COPD team and home oxygen team records. Participants were those known to the teams, and those identified through screening records. Participants were excluded if they were acutely unwell or unable to give consent. Patients who met the criteria of having severe COPD, as defined by the Gold Standards Framework[16] (Box 1), were sent a letter of invitation, including information about the study (Supplementary Appendix 1), and then telephoned by a respiratory nurse one week later. If interested, an interview was arranged, with written consent obtained from the participant on the day of interview.

Criteria for inclusion

Fulfils the indicators recognised to be predictors of advanced COPD, i.e. have a diagnosis of COPD and one or more of:

- Disease assessed to be severe e.g. (FEV1 <30% predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils long-term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors, e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steroids for COPD in the preceding 12 months

Box 1. Standards Framework Criteria for Severe COPD[16]

Data collection

A Breathe-Easy group (support group of patients with lung conditions, supported by the British Lung Foundation) was consulted before the study to inform the initial topic guide. The participants were interviewed in their own homes, with a relative present if they preferred, using a semi-structured approach with a broad topic guide that evolved during the study (Supplementary Appendix 2). Each interview was digitally audio recorded, with field notes added immediately afterwards. All interviews were completed on one visit between September 2010 and February 2011.

Data analysis

The digital recordings of each interview were transcribed verbatim with the field notes added alongside. Each transcript

Table 1. Descriptive information for participants (*n*=10).

Participant information			
Male:	9 (90%)	Female:	1 (10%)
Age:	58–86 years		
White British origin:	10 (100%)		
Living with spouse:	7 (70%)	Living alone:	3 (30%)
Severe COPD criteria			
Home oxygen:		7 (70%)	
Exercise tolerance less than 100 metres on the flat:		9 (90%)	
Continuous or frequent steroids:		3 (30%)	
Professionals involved in participants' care			
Regular contact with GP:	10 (100%)		
Regular respiratory out-patients:	3 (30%) – another 4 (40%) had been discharged		
Community COPD team:	4 (40%)		
Community matron:	3 (30%)		
Previous pulmonary rehab:	4 (40%)		
Community palliative care team:	1 (10%) – telephone contact only as felt more input not required		
Interview characteristics			
Duration:	30–120 minutes		
Interviewed alone:	6 (60%)		
Spouse present:	Whole interview: 2 (20%)	Part interview: 2 (20%)	
Recruitment site:	Primary care: 4 (40%)	Secondary care: 6 (60%)	

was read and sections representing opinions, experiences or emotions were coded, and a rough coding tree formed. These codes were then examined and the coding framework adjusted. Two transcripts were also coded by another author (CW) to minimise bias and ensure all themes were identified and explored. The coding framework was iteratively developed from the data with both descriptive codes and analytical codes used. The software package Transana[17] was used to assist with transcription and data management. A grounded theory approach was used to generate theories from the data collected, based entirely on the themes and subthemes identified.

The results were sent to those participants still well enough, but as almost half were not, the results have not been adjusted after their feedback.

Ethical considerations

Ethics Committee Approval for the study was gained from NW12 Research Ethics Committee Lancaster (REC ref. 10/H1015/58).

Participants were aware before starting that they could interrupt or stop the interview at any time. Prior to the interview, consent was obtained for the researcher to discuss any distress or unmet need with a healthcare professional, such as the participant's GP or respiratory team. The participants' GPs and respiratory consultants were contacted with participants' consent following all interviews to follow up any issues arising from the discussions. Confidentiality was respected throughout. All data collected was anonymised at the point of transcription, and securely stored at all times.

Findings

Patients included

Forty-two patients were approached (twenty-five from primary care, seventeen from secondary care): eleven consented to be interviewed, and one was then excluded due to problems with consent. Participant characteristics are described in Table 1. Most patients who refused said they were not interested in the topic or did not give a reason. One person approached was upset and offended by the word palliative, used in the letter describing the principal researcher. One person had already completed an advance care planning document, and did not want to have the same discussions again. There were no obvious differences seen by the screening teams between those who participated and those who refused in terms of severity of disease, age or sex. No one dropped out of the study after agreeing to participate.

As detailed, participants' spouses were present during whole or part of the interview if the participant wished. The spouses' comments were also transcribed, and included in analysis if they expanded on or clarified what participants said.

After 10 interviews it was felt that saturation had been reached to answer the research question posed.

Overview of themes

The main issues that emerged were related to information provision, decision making, discussions that had taken place about the future and the participants' views on planning for their future, particularly their future place of care.

Information provision

Exploring participants' feelings about previous discussions of their diagnosis and their future gives useful insight into what discussions are wanted. Most participants reported having had little discussion with healthcare professionals about COPD itself, causing anger in some participants, particularly about a perceived lack of communication around the time of diagnosis:

> Nobody's ever talked to me about anything really, seriously. I did...I said to you I didn't even know I had COPD. That's how much the doctors have talked to me. Participant 09

Despite this, all were aware of the progressive and ultimately fatal nature of the disease. They assumed this after observing what had happened to people they knew with COPD, or from feeling how it had progressed so far in themselves. Participants were not upset about talking about this, and seemed accepting of this outcome:

> There's no cure for it, just err, just relieving, you know. Relieving medications and that for it. That was all they could do. I mean, I know it'll get worse and worse until it'll see me off. Participant 08

This led to a fatalistic attitude to life in many participants, describing feeling that they would die whatever happened and there was little that they or anyone could do to affect what happened up to that point.

Discussions about the future

Two participants reported having had some discussion about the future with healthcare professionals. The first had consisted of a district nurse mentioning that he [the participant] was very unwell, and had he thought about the future, which he took to mean had he planned his funeral . He had become very upset by this, and had complained about that nurse.

Only one participant had discussed advance care planning with his healthcare team. He had initially discussed his prognosis with a Respiratory Registrar while an inpatient and was asked to think about what healthcare he might want in the future. This discussion led him to think more about his mortality, and initially did upset him:

> Interviewer: How did you feel about those sorts of questions when they asked you?
> Participant: Well at first I were a bit upset, but now it doesn't bother me.
> Interviewer: Yes.
> Participant: I've got used to it now, like I've plenty of time when I go to bed, to think about it. Participant 11

The week after his interview he was due to meet his community matron to complete a 'preferred priorities of care' document. He knew that he would prefer to be at home; however, he was uncomfortable documenting this, and felt that this decision could change depending on the circumstances:

> They kept asking me in the hospital, well what do you want to do? Do you want to be at home, do you want to be in here? Well you don't know until it happens. Participant 11

He and his wife were also unsure about how useful documented preferences would be:

> But this is why (matron) said about writing his thing out, if it's during the night and you ring for an ambulance they don't know you. And like they will probably take you in. You know, unless it were too late. But you see they'd take him in. But if he was ill he'd have to go in wouldn't he. I don't know. Wife of participant 11

All other participants described consultations with health professionals being very focused on the present, usually on their current problem. Their future or preferences for treatments were never discussed, and some participants were unable to imagine discussing these issues within the consultations they had:

> Well I think it would [surprise him if the future was discussed] like, because I mean when I go to the surgery, like, it's always me who's doing the talking like. Because I've got to go there. You know. Participant 03

Most participants wanted more information about how their disease would progress, and more discussion about the future. They found it difficult to raise these discussions themselves, despite wanting to:

> Interviewer: Do they ever talk about things in future when you go up to the appointments and things?
> Participant: No.
> Interviewer: Do they sort of stick to what's happening at the moment?
> Participant: Yes….I'd like to know what's going to happen to me. Participant 05

A few participants did not feel that further discussion of the future was necessary, mainly because they felt the discussions would not change anything. However, even then they were very clear that the subject being broached would not upset them:

> Interviewer: If the people caring for you did bring something like this up [discussing the future and preferences], would it upset you at all?
>
> Participant: It wouldn't upset me no. I'd just tell them what I thought and that would be it. Just take it as it comes, like, when it comes. Participant 08

Decision making

Participants were keen to be involved in decisions about their treatment and to discuss treatment options. When treatments were decided without any discussion with the patient, this damaged their relationship and trust with their healthcare provider:

> I said, put them bloody tablets back. [after one of usual medications stopped in hospital, followed by him feeling unwell] Don't take stuff off me without telling me. And I swore at him, [hospital doctor] I did, I was blazing. For giving me a dodgy thing again. But that's what you've got to put up with you see. Participant 09

A few patients preferred their doctors to generally make decisions, and they would be happy to go along with their advice, believing it to be the patient's responsibility to raise any concerns they had about the proposed treatment. However, even in these cases patients welcomed inclusion in decisions, feeling this showed the healthcare professional had respect for their opinion.

Planning for the future

Despite being keen for more involvement in current decisions about their care, participants were wary about making advance decisions about future treatment. Similar to the concerns of the participant due to complete an advanced care planning document, participants had concerns about knowing their future treatment preferences and did not see why making decisions in advance would be helpful. Participants recognised that their symptoms varied significantly, and all had adapted to this by making routine decisions on a day-to-day basis. They generally had a reasonable idea of their preferences, but not enough to make a binding decision that would then be applicable in the future:

> I mean, because I don't know how I would feel until I get there, you know, so... I don't make advance decisions, you know. Participant 08

People had often discussed these general preferences for care with family members, and would expect their family to have input into decisions if unable to decide for themselves. Participants had not discussed these preferences with healthcare professionals, but, as above, all participants stated they would be comfortable with these discussions if asked. The participant who had previously been upset after a nurse brought up planning for the future was very comfortable talking about what treatment he may want and where he would want to be cared for.

There were difficulties in identifying the need for making decisions in advance. Some felt that if they were dying, they would be unaware of what was happening and therefore what happened to them was less important. Participants also found it difficult to imagine a scenario in which they wouldn't be able to make a decision at the time:

> I think if I can't tell them personally then I must be in a bloody bad way, so I'd be glad of anything, I think! Participant 03

Overall, participants would welcome more discussion around their illness and how it could affect them in the future, along with general discussion of treatment preferences. Participants did not want healthcare professionals to make decisions based on previously stated preferences without reviewing those preferences with them and their family in the immediate circumstance those decisions apply to.

Place of care

Participants identified the place of their care as the most important future consideration, and had often thought about this, whereas they had not considered specific treatments, such as ventilation or resuscitation. People were concerned about where they would live if their health deteriorated, and also about where they would prefer to be cared for if they were acutely unwell.

Two main factors influenced participants' preference of place of care: their previous experiences of care and the support available to them at home. Participants' previous experience of care in certain environments was a strong determinant of whether they would want to go back there; specifically, several participants who had negative experiences in hospital did not want to go back there unless there was no alternative. These participants chose home as where they would want to be cared for not because of any positive benefits of being at home, but because of wanting to avoid further negative experiences in hospital:

> Last thing at night, nurses had some rubbish and they'd go up with the lid then, let go of the lid and crash! And this is all I remember. That was my main complaint. They were coming round with drugs at two, three o'clock in the morning. You're up again at five. Oh, I just couldn't get no sleep. And nobody could tell me what was wrong with me. Nobody could tell me what was wrong with me. And I swore I would never go back there again. Participant 03

The main negative factors identified were perceived lack of care from healthcare staff in hospital, a lack of communication to the patient about their management, and treatment in hospital being no different to the treatment they could have at home.

The other important influence on decisions about place of care was the amount of social support the participant had at home. Participants recognised that they would need more support and care if they became more unwell, and particularly those living alone felt that this need would not be met at home:

> I was here on my own at the time. Wife was away, so I went in because I got that I just couldn't cope at home, you know. It was no different really. Participant 08

People identified their family as the main source of support at home; they felt that if their family could not support them at home, they would go to hospital.

Discussion

This qualitative study shows that forms of advance care planning focusing mainly on documenting fixed decisions do not fit with the way that patients with COPD think. The idea of making binding decisions about future care is not helpful when suffering from a disease following an unpredictable course with wide variability of symptoms. This may have implications on how advance care planning is considered in other chronic diseases. These results agree with previous research[8] that information provision continues to be inadequate, which has been questioned by previous studies[15]. It follows that these patients are often not involved in decisions about their treatment as they occur; this research showed a real desire for more inclusion. The impact of this information on clinical practice, and how it fits with other research, will be discussed below.

Initially, advance care planning processes encouraged people to make fixed decisions about their preferred treatments in certain scenarios. Over time, research has found that encouraging fixed decisions and the completion of documents such as advance directives is not the part of advance care planning that improves end-of-life care.[18,19] The parts found to be more useful have included focusing on goals of care rather than specific treatments[11] and the discussions involved in the process.[18] Thinking of advance care planning as a regularly reviewed discussion of disease and prognosis, discussing any concerns, and talking about treatment options and possible preferences fits better with the needs identified in this study and the elements recent research has found to be useful. This process would be particularly relevant to chronic diseases, which do have a less predictable decline and in which information and preferences may be less certain.

Several barriers to decision-focused advance care planning were identified in this study, which fit with previous research. The fatalistic attitude of participants has been found in previous qualitative studies involving patients with other chronic diseases[20–22] and this could be a barrier to thinking about the future and seeing the potential benefit of advance care planning.[23] This difficulty in thinking about the future and imagining future scenarios could lead to problems in being able to identify treatment preferences in future situations. Other factors making decisions around treatment preferences more difficult include knowing the options available, again coming into the category of ensuring adequate information provision. Some research has shown that people in worse states of background health find it more difficult to be sure of their treatment preferences;[24] this is consistent with the participants in this study, who all had severe COPD and found it very difficult to be sure of what they would want. Using advance care planning as a process of discussion of disease status and potential preferences would better fit with this way of thinking.

The role of palliative care in the management of patients with COPD, including the place of discussions about end-of-life issues, is currently undefined and debated. The transition to a predominantly palliative care approach is clearer where there is a more predictable disease trajectory. Despite the various prognostic indicators available, it remains difficult to accurately determine prognosis in COPD, and the appropriate timing for transition to palliative care is therefore more difficult. Recent research has suggested that patients with COPD also do not see a clear progression of their own disease, adding more weight to the concept that there is not a point when palliative care and discussions around end-of-life issues suddenly become appropriate.[2] A better fit with this disease journey would be a more integrated approach to palliative care, including regular discussions around symptoms, prognosis and concerns from an early stage, then advance care planning discussions building on this. This fits with the needs identified by participants in this study. Patients with COPD can adapt to a high symptom burden and may not identify themselves as needing to discuss end-of-life issues or any form of advance care planning;[3] however, participants in this study did want more discussion in these areas and often had clear preferences for treatment. Clearly, discussions need to be sensitively and individually tailored to information needs and preferences, but also problems actively looked for rather than being hidden by patients' passive acceptance.

Ensuring that people receive information about COPD, particularly around the time of diagnosis, has been identified as a problem for some time by patients[8] and the professionals involved in their care.[15] The participants of this study identified that this issue continues. In addition, patients who felt they had not received adequate information tended to have a worse relationship with their healthcare team, suggesting that early information provision is essential to form an effective therapeutic relationship. Previous research with healthcare professionals identified concerns about initiating advance care planning discussions with patients with COPD, as they felt patients were not aware COPD could lead to their death;[9] this research does not confirm that as a valid concern. Healthcare professionals have also been concerned that these discussions may upset patients,[9] but, although this clearly can occur, most participants of this study did not find these discussions upsetting and conversely would welcome them. Sensitive initial exploration on top of prior discussion and increased information provision about diagnosis and prognosis could avoid distress, and the environment may then be created where patients feel they could discuss concerns for the future.

In addition to increasing information provision, participants also identified wanting more involvement in decisions about their management as they are made. The value of involving patients in chronic disease management is known,[25,26] and this research supports that, with participants identifying that this would potentially improve their relationship with their healthcare team, their compliance and their overall satisfaction with services.

There are limitations to these results. Only 10 people with severe COPD were interviewed, and their opinions may not reflect the views of patients with COPD more generally. Participants of this study were from one area and an ethnically similar group, but the results fit well with previous research in different groups,[23,27] so their opinions are unlikely to be very different. Researchers' backgrounds and attitudes are known to affect data collection and analysis, and the principal researcher being a clinician in palliative medicine is relevant to this. The affect of this was reduced by regular feedback on data collection and emerging analysis by the research team. The main limitation of this study is that participants were those who responded to the invitation to discuss these issues, and so were a self-selecting group of people less likely to be upset by discussing end-of-life issues and preferences. However, the response rate of people approached to participate was reasonable, so with sensitive exploration of these issues on top of a background of increased information provision and discussion at an earlier stage it is hoped minimal distress would be caused. The participants' spouses were included in the interview if the participant wished, and this may have affected how the participant responded; the researcher was aware of this and specifically tried to ensure the individual opinions were included.

Implications for practice

These recommendations are taken directly from the results of this research.

Patients may find advance care planning more useful if it is part of a process of discussion of their illness and general preferences for care. Improved information provision, communication and discussion throughout the patient's illness could naturally lead to advance care planning as a consequence. This discussion needs to be reviewed on a regular basis, and preferences revisited when a decision needs to be made. Promoting patients making binding decisions on treatment preferences is less helpful. Patients should be involved in decisions about their care as decisions are made. This will improve the relationship between healthcare professional and patient, improve compliance and increase satisfaction on both parts. Although this approach is advocated based on the results of this research into COPD, it is easy to see how it could potentially improve the effectiveness and reduce the distress of advance care planning in other patient groups, particularly those with other chronic diseases.

Routinely offering more information about the diagnosis of COPD and its implications at an earlier stage may help to create an environment in which patients feel included in their care. Robust local coordination of who is responsible for giving this information to patients with COPD is needed to ensure all patients access this. This does not need to be the role of specialist palliative care, but needs to be part of the more integrated palliative care approach to chronic disease management as proposed by other recent research into the role of palliative care in COPD.[2] This does not necessarily fit with current policy, including The Gold Standards Framework in the UK.[28]

The findings have emphasised the importance of considering simple things in the hospital environment. Concentrating only on increasing care for people at home, when for some people the main reason they want to be at home is to avoid the environment of hospital, misses a large part of the problem. Research has shown that for most people home is the preferred place of death,[29] but there has not been as much research into why, although one study looking at the reasons behind preferences for place of death in patients with terminal cancer also identified previous experiences of services as one of the main reasons.[30] The reasons people in this study did not want to go to hospital would be simple to change; for example, quiet bins, timely drug administration and discussing treatment changes with patients.

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Conflict of interest

None declared.

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