Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis

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ABSTRACT
Background Guidelines recommend open discussions between patients and healthcare professionals as the end-of-life (EOL) approaches. Much of the knowledge about the EOL is based on the needs of patients with cancer and the applicability of this to other diseases is often queried. A literature review was undertaken concerning EOL care (EOLC) conversations in chronic obstructive pulmonary disease (COPD).
Design A systematic literature review and narrative synthesis obtained papers reporting on EOLC conversations between patients with COPD and their healthcare professionals with respect to the prevalence of conversations; each party’s preferences for timing and content; and the facilitators and blockers. Inclusion criteria were articles published in peer-reviewed journals, written in English, reporting studies of adult patients with COPD and/or their healthcare professionals concerning discussions of care at the EOL.
Results 30 papers were identified. Most patients reported that they had not had EOLC discussions with healthcare professionals. While many patients would like these conversations, a potentially large minority would not; the proportions varied among studies. Healthcare professionals find these discussions difficult and many prefer patients to initiate them.
Conclusions Patients’ preferences for EOLC conversations vary greatly. Healthcare professionals need to respect the wishes of those not wanting to discuss EOLC and provide multiple opportunities for those who do wish to have these discussions. Recommendations on how to approach the conversation are made.

INTRODUCTION
Chronic obstructive pulmonary disease (COPD) is a progressive, incurable lung disease punctuated by acute exacerbations that are characterised by airflow obstruction caused by chronic inflammation.1 It is estimated that by 2020, COPD will be the third leading cause of death worldwide.2

Patients with advanced COPD need palliation of symptoms, such as breathlessness and anxiety, throughout the long duration of their illness. End-of-life care (EOLC) focuses more on the final stages of the illness and has been defined as care that ‘enables the supportive and palliative care needs of patient and family to be identified and met throughout the last phase of life and into bereavement’.3 Prognostication in COPD is, however, challenging: death often occurs ‘before the patient is perceived as being “terminal”’;4 Many patients die ‘with’, rather than ‘of’, COPD: causes of death include respiratory (35%), cardiovascular (26%), cancer (21%) and other (18%).5 The best current prognostic model is the BODE Index, which is better at predicting death than forced expiratory volume in 1 s (FEV1) alone.6 As with all such models, this is of some use with groups of patients but of little help with individuals. The consequence is often a ‘prognostic paralysis’; and because prognosis is so uncertain EOLC issues are not addressed.7

The palliative and EOLC needs of people living with COPD have only recently been recognised in health policy, the previous focus being on active disease management. The National Institute for Health and Clinical Excellence stated in its 2004 COPD guideline1 that ‘the full range of palliative care services should be offered to people with
COPD. The American Thoracic Society stated that palliative care should be available throughout all stages of illness.³ The National Institute for Health and Clinical Excellence highlighted the need to involve multidisciplinary palliative care teams in advanced COPD.⁹

The UK NHS EOLC strategy⁹ calls for open discussions between healthcare professionals (HPs) and patients as the end-of-life (EOL) approaches. This is the first step of the ‘EOLC pathway’,³ to ensure well planned care is delivered. Patient knowledge that death is approaching and of what can be expected is seen as a prerequisite of a ‘good death’.¹⁰ Concern has been expressed that EOLC policy and services are based on the needs of patients with cancer, which has a clearer terminal pathway than COPD.¹³ This means that patients with COPD, and those of their HPs.

**METHODS**

The search aimed to identify all papers reporting studies of adult patients with COPD and/or their HPs concerning EOLC discussions in Medline, PsycINFO and CINAHL that were written in English and published in peer-reviewed journals, concerning:

1. the prevalence of conversations;
2. the preferences of patients with COPD and HPs for the timing and content of conversations;
3. the barriers and facilitators to conversations.

The exclusion criteria and process for the literature search, search strategy (box 1 in online supplement), paper selection and the narrative synthesis are described in the online supplement to this paper.

**RESULTS**

The search strategy was complex and generated a large number of titles. After screening and discussion by reviewers (figure 1), 29 papers were found that met the inclusion criteria. One additional paper¹⁶ was found when hand-searching Chest, electronically published ahead of print. In total, 30 papers were included (see table 1 in online supplement).

A summary of the findings is presented below. The online supplement presents the results in greater detail.

**Are these discussions taking place?**

A minority of patients report having discussed EOLC with their HPs. HPs confirm this. They ‘very rarely initiate’ EOLC discussions as described in the NHS EOLC strategy³ ¹² and agree that prognosis and dying are infrequently discussed.¹⁷

**Patient attitudes towards EOLC discussions**

Studies report a range of patients to want more information about their illness and the future. Some want all available information to enable planning ahead.¹⁸ ¹⁹ Around half of patients, however, do not want further information,²⁰ ²¹ citing the potentially distressing nature.²⁰

**Patient preference for timing of discussions**

The limited literature concerning timing indicates a patient preference to wait until COPD is advanced.²² ²³

**HP attitudes towards EOLC discussions**

H Ps face a dilemma. While the majority view these discussions as necessary,¹³ ²⁴ ²⁵ they believe only a minority of patients want to know their prognosis and it is difficult to recognise who these individuals are.¹³ ²⁴ HPs are concerned that such discussions may create anxiety or destroy hope.¹³ ²⁶ Many doctors find conversations initiated by patients easier.²⁵ ²⁶ but admit to feeling uncomfortable even when patients ask about EOLC directly.²⁶

**HP preference for timing of discussions**

H Ps are unsure when to initiate EOLC conversations. In practice, H Ps report that discussions often take place when the patient’s health has deteriorated²⁵ and they may be too unwell to make decisions.¹² While some suggest discussions should be early in the illness,²⁶ in practice this rarely occurs; only a small minority of GPs initiate discussions early on.¹²

**Barriers, cues and facilitators to EOLC discussions**

A wide range of barriers were identified, such as the difficulty in prognostication in COPD which leads to uncertainty over when discussions should begin¹² ¹³ ²⁶ ²⁷; and the poor understanding of COPD among the general public.¹² ¹⁸ ²⁶ Additionally, many HPs do not identify EOLC discussions as their responsibility. A good rapport with the patient,¹² ²⁶ experience in dealing with EOLC matters,²⁸ adequate training in breaking bad news¹² and specialist knowledge¹² ²⁸ are seen as particularly important.

**DISCUSSION**

**Principal findings**

Conversations about EOLC are rare in COPD. Patient preference varies: some want all available information, while others wish to avoid potentially distressing conversations. HPs acknowledge the value of conversations but find them difficult, recognising that not all patients want these conversations. There are numerous barriers and each party prefers that the other initiates...
the discussion. Patients’ preferences are mainly for discussions when disease is advanced; in practice they usually occur late in the disease course (if at all) when there is greater ‘certainty’, though patients are less able to participate. Three previous non-systematic reviews\textsuperscript{39–41} found a similar prevalence for conversations and planning.

**Strengths and weaknesses of this study**

Although the search strategy used only the three most pertinent databases, it appears to have been effective. Additional searches identified only one further paper, electronically published ahead of print. Only English language papers were included: most are from the UK or USA, with fewer from Canada, New Zealand or Europe. Additionally, unpublished data and the grey literature were not included.

The literature is relatively recent; only three papers were published before 2000. Studies presented a uniform picture with regards to the prevalence of conversations. The data concerning patient preferences were more diverse, partly due to studies investigating a variety of aspects of EOLC conversations, and the diversity of patient samples and disease severity.

**Explanations and implications**

There are many patients living with the life-limiting illness of COPD who are not being given the opportunity to discuss its progression, their future care and the EOL. A range of barriers inhibit these discussions.

Not all patients wish to have such conversations.\textsuperscript{32} Some may feel they do not have EOLC needs, preferring to focus on management of the disease and its symptoms, having lived with it for years.\textsuperscript{33} Patients not wishing to discuss EOLC preferences are often those who estimate their prognosis to be excellent, report quality of life to be good and do not desire active interventions.\textsuperscript{34} Patients estimating their prognosis to be excellent and their future course of their illness. Discussions might usefully cover the disease course (if at all) when there is greater certainty and difficulty around the subject of EOL and the uncertainties and difficulties in prognostication are likely to remain.

HPs frequently worry that EOLC discussions may remove hope,\textsuperscript{13, 16, 31} however avoidance of discussions may give false hope and deny patients the opportunity to prepare and plan. A balance needs to be struck between optimism and realism: ‘I encourage you to hope for and expect the best, but it is also wise to prepare for the worst’.\textsuperscript{15} To maintain hope, HPs need to give patients time to get used to their poor prognosis, ‘redirecting’ them from hope for recovery to hope for quality time and a comfortable death.\textsuperscript{19}

How to do that in practice remains a considerable challenge (box 1). As Sir William Osler wrote, ’If it were not for the great variability among individuals, medicine might as well be a science and not an art’.

**Contributors** The study was designed and led by SB, literature searching was undertaken by NM, ES and IK, screening of abstracts and papers by NM, PH, SB and ES, data extraction by NM and PH, journal hand-searching by NM and PH, and synthesis by NM, PH and SB. All the authors have contributed to writing the paper. SB is the guarantor.

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**REFERENCES**


