

ORIGINAL ARTICLE

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 have 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

Key messages

What is the key question?

- What is the prevalence of conversations about end-of-life care between patients with chronic obstructive pulmonary disease (COPD) and their healthcare professionals?
- What are each parties' preferences for their timing and content?
- What are the facilitators and blockers?

What is the bottom line?

- Although a substantial minority of patients with COPD do not want end-of-life care conversations with their healthcare professionals, most do but are not being given the opportunity to have such a discussion due to a wide range of barriers.

Why read on?

- COPD is a leading cause of death. This paper discusses the implications of avoidance of conversations and makes recommendations on how they might be approached.

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.⁸ 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 strategy³ 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 phase: uncertainty over the extent to which a cancer model for EOLC fits with the unpredictable course of COPD has stimulated this review.

EOLC conversations are not taking place as policy recommends in COPD.^{11 12} HPs are more likely to have such discussions with patients with cancer than those with COPD.¹³ This is despite frequent contact providing multiple opportunities for discussions: of those hospitalised with an exacerbation, 74% see their general practitioner (GP) in the month before admission, 31% three or more times.¹⁴

A 2011 BMJ editorial highlighted the need to establish how patients with COPD will respond to EOLC discussions and their appropriate timing.¹⁵ We seek to address these issues in the first systematic literature review of the attitudes of 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 strategy^{3 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

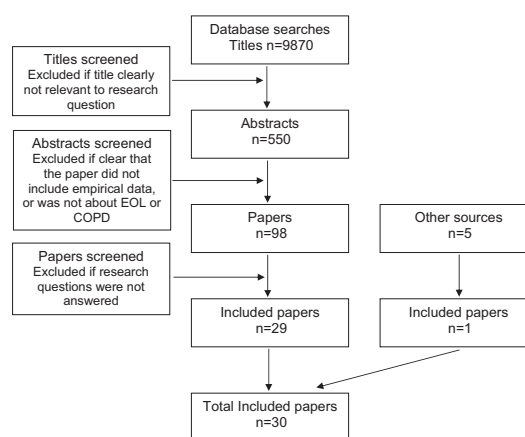


Figure 1 Flow diagram. COPD, chronic obstructive pulmonary disease; EOL, end of life.

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

HPs 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

HPs are unsure when to initiate EOLC conversations. In practice, HPs 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,²⁵ 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 begin^{12 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 28} experience in dealing with EOLC matters,²⁸ adequate training in breaking bad news¹² and specialist knowledge^{12 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^{29–31} 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.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.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 involvement in decision making.³⁴ HPs are rarely able to predict individuals' EOLC preferences,³⁰ including preferences for discussions.

Additionally, patients' understanding of COPD as a life-limiting disease is poor; when stating preferences for further information they may be unaware of the implications of such discussions. Patients often see COPD 'not so much as an illness, more a way of life' with attitudes to death comparable to those 'in a normal elderly population'.²⁷

One major barrier is the uncertainty of prognosis creating difficulty in providing patients with information on the likely future course of their illness. Discussions might usefully cover explanation of the functional decline common in COPD, the possibility of fatal exacerbations and the potential for cardiovascular and other causes of death, including sudden death.²⁹

No single group of HPs felt that their roles, relationships with patients or work settings made them the most appropriate HPs to have EOLC conversations. The NHS EOLC strategy emphasises the importance of multidisciplinary involvement³: while these conversations are a 'collective responsibility',²⁸ held on multiple occasions, the danger remains that no HP takes the responsibility.

Ensuring that patients who wish to discuss EOLC have the opportunity to do so is challenging. Practitioners and healthcare systems need to address the wide range of barriers that exist, for example, more time is required for consultations or training of healthcare professionals to have these difficult conversations. However, discomfort around the subject of EOL and the uncertainty and difficulties in prognostication are likely to remain.

HPs frequently worry that EOLC discussions may remove hope,^{13 16 26 31} however avoidance of discussions may give false

Box 1 Suggested approach to end-of-life care conversations in chronic obstructive pulmonary disease

Respect autonomy: allow the patient to decide whether to have an end-of-life care conversation, when and with whom.

Patient centred: content, timing and pace set by the patient.

Multiple opportunities: for the patient to explore issues if they wish.

Maintain balance: combine realistic hope with practical planning. Honest information: including acknowledgement of uncertainty.

Document discussion: enable other healthcare professionals to be aware of the patient's preferences for care.

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'.³⁵ 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.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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Box 1. Search strategy used in PsycINFO

Search terms for COPD

"chronic airflow obstruction" OR COPD OR "chronic obstructive pulmonary disease" OR "chronic obstructive lung disease" OR "chronic obstructive airway disease" OR COAD OR "airway* obstructive disease" OR "chronic airflow limitation" OR "chronic respiratory disease" OR "chronic obstructive airways disease" OR "chronic respiratory disability" OR "respiratory failure" OR "respiratory insufficiency" OR "chronic lung disease"

Search terms for discussions

address OR discuss* OR approach OR chat OR communicat* OR consider* OR consult* OR debate OR deliberat* OR inform* OR introduce OR mention OR raise OR talk OR verbalise OR verbalize OR vocalise OR vocalize OR (bring ADJ up) OR (go ADJ into) OR "truth disclosure" OR disclos* OR exp COMMUNICATION/ OR exp COMMUNICATION BARRIERS/ OR exp VERBAL COMMUNICATION/ OR exp INTERPERSONAL COMMUNICATION/ OR exp NONVERBAL COMMUNICATION/ OR exp PERSUASIVE COMMUNICATION/ OR exp WRITTEN COMMUNICATION/ OR exp COMMUNICATION SKILLS/ or communication

Search terms for EOL issues

"advance* care plan*" OR exp ADVANCE DIRECTIVES/ OR "advance directive" OR "advance direction" OR "artificial respiration" OR "bad news" OR exp DEATH INSTINCT/ OR exp DEATH EDUCATION/ OR exp DEATH ATTITUDES/ OR exp DEATH ANXIETY/ or exp DEATH AND DYING/ OR death OR (decision ADJ mak*) OR exp DECISION MAKING/ OR exp DISEASE COURSE/ OR "disease course OR (dnr ADJ status) OR dnr OR "do not resuscitate" OR (dnr ADJ order) OR resuscitation OR (dying ADJ care) OR dying OR (end adj3 life) OR eolc OR exacerbat* OR exp NURSES/ OR exp NURSING HOMES/ OR exp HOME CARE/ OR exp CAREGIVERS/ OR exp ASSISTED LIVING/ OR (respite ADJ care) OR exp HOSPICE/ OR hospice OR exp HOSPITALIZATION/ or hospitalization OR (hospital ADJ admission) OR intubation OR (life ADJ expectancy) OR exp LIFE EXPECTANCY/ OR (life ADJ sav*) OR "life support" OR exp LIFE SUSTAINING TREATMENT/ OR (life ADJ sustaining) OR (living ADJ will) OR (mechanical ADJ respiration) OR "no code order" OR palliat* OR exp PALLIATIVE CARE/ OR exp PROGNOSIS/ or prognosis or "medical futility" or "supportive care" OR "terminal care" OR exp TERMINALLY ILL PATIENTS OR exp CHRONIC ILLNESS/ OR exp TREATMENT REFUSAL/ OR (refus* adj treat*) OR exp TREATMENT WITHHOLDING/ OR exp PROFESSIONAL ETHICS/ OR "withholding treatment" OR exp TREATMENT TERMINATION/ OR exp TREATMENT COMPLIANCE/ OR exp TREATMENT BARRIERS/ OR treatment OR exp QUALITY OF LIFE/ OR "quality of life"

Combined search terms for COPD AND discussions AND EOL issues

Limits: January 1987 to October 2011

Online supplement

Discussing an uncertain future: End of Life Care conversations in COPD. A systematic literature review and narrative synthesis.

Methods

A search was undertaken in CINAHL, PsycINFO and Medline from January 1987 to October 2011allycertain future:End of Life Care in COPD. A systematic literature review and narrative synthesis. lot of the paper . This aimed to identify all papers reporting studies of adult patients with COPD and/or their HPs concerning EOLC discussions, that were written in English and published in peer reviewed journals, concerning:

- 1) The prevalence of conversations
- 2) The preferences of COPD patients and HPs for the timing and content of conversations
- 3) The barriers and facilitators to conversations.

Search terms are summarised in Box 1. The following topics were not included: knowing or telling the diagnosis, understanding treatment, symptom management, how clinicians formulate prognosis and patient-family communication. Papers concerning mechanical ventilation (MV) or intubation were not included either; such conversations have implications for EOLC but were regarded as distinct discussions. Discussion articles, guidelines, and theory or opinion pieces without new empirical data were excluded. Papers presenting data on EOLC discussions in a variety of conditions, without separating out data concerning COPD were also excluded.

An information technologist (IK) assisted in devising the search; this was challenging due a lack of MeSH terms for this topic.(1, 2) One reviewer screened titles, excluding

articles clearly unrelated to the research question. The remaining abstracts were read independently by two reviewers, to identify potentially pertinent papers, with any disagreements resolved by discussion. The included papers were checked and hand-searching of *CHEST*, *Family Practice* and *Palliative Medicine* was carried out.

Box 1: Search strategy used in PsycINFO

Two reviewers extracted data independently, employing framework analysis (3) and using a coding frame derived from the review questions to record relevant empirical data (aims, participant characteristics, research methods, analysis methods and findings relevant to the research questions). Data was then entered into NVivo for narrative synthesis.(4) Each included paper was weighted using Gough's weight of evidence criteria, which requires researchers to assess papers on four criteria:

1. Coherence & integrity of the evidence in its own terms
2. Appropriateness of form of evidence for answering review question
3. Relevance of the evidence for answering review question
4. Overall assessment of study contribution to answering review question.(5)

The weightings (low, medium or high) given to each paper are shown in the final column of Table 1, with the weighting given for overall assessment of study contribution (criteria 4) in bold.

PRISMA guidelines (6) were referred to during the design, to ensure the research question was formulated taking into consideration the subjects of interests (adult patients with heart failure and their HPs) and the event of interest (conversations

about end of life care). Additionally it was referred to in the writing phases, to ensure all the relevant information was reported.

Results

The search strategy was complex and generated a large number of titles. After screening and discussion by reviewers,(Figure 1) 29 were found met the inclusion criteria. One additional paper (7) was found when hand-searching *CHEST*, electronically published ahead of print. In total, 30 papers were included.(Table 1)

Figure 1: Selection of papers

Table 1: Included papers

Two studies each produced two included papers: Elkington et al (8) and Mulcahy et al;(9) and Au et al (7) and Reinke et al.(10) One further paper (11) contained the datasets of four included papers.(7, 10, 12, 13)

Although papers which presented data on a number of conditions without separating them out were excluded, there were two exceptions: one (14)where 87% of subjects had COPD (the remainder having different respiratory conditions); and a second,(15) whose subjects had “chronic lung disease”. Due to this heterogeneity of the respondents, these were weighted ‘low’ on the “appropriateness of the form of evidence”.

Are these discussions taking place?

A minority of patients report having discussed EOLC with their HPs: ranging from none to 32%.(7, 14-21) Where patients were asked about different aspects of EOLC discussions, many were found to be unaddressed.(10, 13) One paper including only patients who expressed an interest in learning more about EOL issues, reported six out of seven had EOL discussions with clinicians.(22) In a study of intensive care unit (ICU) nurses, it was reported that less than 25% of COPD patients had had a discussion about EOLC whilst on ICU.(23) Limited information is given (24, 25) with issues like prognosis and disease progression rarely addressed.(10-13)

HPs confirm this. They “very rarely initiate” EOLC discussions as described in the NHS EOLC Strategy (26, 27) and agree that prognosis and dying are infrequently discussed.(12) A minority of GPs reported ‘usually’,(28) ‘often’ or ‘always’ discussing prognosis with severe COPD patients; however, 75% agree that “some patients” who would like discussions do not get the chance.(8) One study reported a majority of HPs to hold EOLC discussions, but this was limited to potential interventions.(29)

Patient attitudes towards EOLC discussions

Studies report a range of patients to want more information about their illness and the future: between 42% and 100%.(7, 14, 15, 18, 19, 24, 30, 31) want all available information to enable planning ahead.(31, 32) “Silence about the course of the disease” can lead patients to feel neglected.(25) Around half of patients, however, do not want further information,(24, 30) citing the potentially distressing nature.(24) Opinions regarding discussions about Advance Directives and MV or intubation

varied: from “informative and reassuring” for 51%, to “too anxiety-provoking to have” for 1%.(14) In studies asking patients to rate clinicians’ quality of EOLC communication, this was rated low (11, 12) as EOL had not been addressed.(12)

Most patients expect initiation by HPs,(14, 24) although a substantial minority believe physicians should wait for patients to broach the subject.(14)

Patient preference for timing of discussions

The limited literature concerning timing indicates a patient preference to wait until COPD is advanced.(25, 33)

Health professional attitudes towards EOLC discussions

HPs face a dilemma. While the majority view these discussions as necessary,(8, 9, 29) they believe only a minority of patients want to know their prognosis and it is difficult to recognise who these individuals are.(8, 9) Others question the appropriateness of conversations as described by the NHS EOLC strategy,(26, 27) while acknowledging that avoidance limits patient choice (27) and is “less than candid”.(28)

HPs are concerned not to create anxiety or destroy hope.(8, 20, 34) Around one-third of GPs find starting the discussion difficult; one-third do not find this hard.(8, 9) Many doctors find conversations initiated by patients easier (29, 34) but admit to feeling uncomfortable even when patients ask about EOLC directly.(34)

HP preference for timing of discussions

HPs are unsure when to initiate EOLC conversations, due to the unpredictability of COPD,(29, 34) the lack of a clear terminal phase (27) and the preferences of individual patients.(35)

In practice, HPs report that discussions often take place when the patient's health has deteriorated (29) and they may be too unwell to make decisions.(27) While some suggest discussions should be early in the illness,(29) in practice this rarely occurs; few think it appropriate to raise EOLC at diagnosis (35) and only a small minority of GPs initiate discussions early on.(27)

A range of indicators of greater 'certainty' (34) signal the need for EOLC discussions: admission for an exacerbation,(27, 35) the first episode of non-invasive MV,(35) or the need for long term oxygen therapy.(27) Signs of deterioration are suggested as prompts;(29) functional measures are lower in patients wanting EOLC discussions.(15)

Barriers, cues and facilitators to EOLC discussions

The disease and its management

The uncertain prognosis in COPD creates ambiguity over when the patient has reached the EOL, and when discussions should begin.(21, 27, 34) Objective measures of function such as the BODE index help little with prognostication, and clinicians lack confidence in discussing prognostic uncertainty.(28)

HPs report they are more likely to have discussions in cancer than COPD due to a clearer dying trajectory (9) and the greater provision of services.(34) The chronicity of COPD results in an approach focused on treatment,(28) living with the disease (34) and self-management.(27) For some HPs keeping COPD patients alive and maintaining their quality of life conflicts with EOLC discussions.(19, 20, 27) Many patients also view their desire to focus on staying alive as a barrier to discussing death.(20) The chronicity and severity of COPD creates resignation among some patients that nothing can be done and that discussions about EOLC would be futile.(16, 36)

Understanding and perceptions of COPD

Understanding of COPD among patients and the general public is limited.(27, 31, 34) HPs avoid the terms 'death' and 'dying' letting it be "the implied alternative" to future intervention,(29, 34) and use euphemisms, like 'asthma', or 'breathing problems'.(27) Patients often do not understand the terms used or the implications of COPD.(16, 24) For some, once cancer was excluded, concern about dying from their disease disappeared.(25) Exacerbations are commonly a time when patients consider themselves ill but these are often viewed as curable infections, not potentially terminal events.(27, 36)

Relationships, roles and health systems

Established relationships are important for facilitating EOLC discussions;(20, 21, 27-29, 37) for patients, being unsure which doctor would care for them if they were very sick was a barrier.(20) HPs report that lack of continuity leads to patients' awareness

remaining unexplored; poor documentation of previous discussions and patients' care preferences hinders discussions about the future.(8, 28, 34)

EOLC discussions require time for sensitive exploration of fears and hopes for the future, but time pressures are felt by patients (19, 20, 25, 30) and HPs.(9, 20, 27, 34) Working within an environment which expected EOLC discussions is a facilitator.(20)

HPs are unclear whose responsibility EOLC conversations are. Those with a good rapport with the patient,(27, 28) experience in dealing with EOLC matters (28) and specialist knowledge (27, 28) are seen as particularly suited. Primary care practitioners feel that EOLC issues should be raised by specialists;(27, 28) while those working in secondary care feel it is more appropriate in primary care due to longer-term relationships with patients.(27) Additionally they feel their setting is busy, noisy and lacks privacy; and that they lack training.(16) The majority of GPs felt they had an important role to play in discussions,(8) although patients normally being unwell when they saw them and short consultations were raised as barriers.(27) Practice nurses do not feel they have been adequately trained to break bad news and view the 'terminal' COPD patients as being seen by GPs at home.(27) Respiratory Nurse Specialists stated that they were a constant point of contact for COPD patients, but again felt they had not received the necessary training.(27)

Cues and opportunities

HPs look for opportunities to start EOLC discussions, responding to subtle and indirect cues from patients, rather than explicitly placing EOLC on the agenda.(28, 34) They then seek to reassure the patient, using the "unavoidable uncertainty" to

soften the impact of discussions,(28) although both HPs (28) and patients (31) value honesty in these conversations.

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