

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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