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**Palliative and end of life care conversations in COPD - a systematic literature review**

Running title: Communication about palliative care in COPD

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# Abstract

**Background:** Chronic obstructive pulmonary disease (COPD) is a chronic life-limiting disorder characterised by persistent airflow obstruction and progressive breathlessness. Discussions/conversations between patients and clinicians ensure palliative care plans are grounded in patients’ preferences.

**Aim:** This systematic review aims to explore what is known about palliative care conversations between clinicians and COPD patients.

**Methods:** A comprehensive search of all major healthcare-related databases and websites was performed following PRISMA guidelines. Studies were quality assessed employing widely used quality assessment tools with only papers scoring moderate-high quality included. All relevant data was extracted. A narrative synthesis was used to analyse, process and present the final data.

**Results:** Findings indicate that the frequency and quality of palliative care conversations is generally poor. Patients and physicians identify many barriers, and important topics are not discussed. Patients and clinicians report tension between remaining hopeful and the reality of the patients’ condition. When discussions do happen they often occur at an advanced stage of illness and in respiratory wards and intensive care units.

**Conclusion:** In conclusion, current care practices do not facilitate satisfactory conversations about palliative care between COPD patients and clinicians. This impacts upon the fulfilment of patients’ preferences at the end of life.

# Background

Chronic obstructive pulmonary disease (COPD) is characterised as a chronic disorder with persistent airflow obstruction, progressive breathlessness and chronic productive cough [[1](#_ENREF_1), [2](#_ENREF_2)]. COPD is associated with anxiety, depression, lack of energy, anorexia and restricted mobility [[3-6](#_ENREF_3)]. In the UK, it is estimated that 3 million people have COPD [[7](#_ENREF_7), [8](#_ENREF_8)] and it is responsible for 30,000 deaths per annum [[9](#_ENREF_9)].

People suffering from life-threatening illnesses, such as advanced COPD, should receive palliative care in order to improve their and their families’ quality of life [[10](#_ENREF_10), [11](#_ENREF_11)]. Palliative care focuses on the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of all physical, psychosocial and spiritual issues affecting the patient and his/her relatives [[10](#_ENREF_10), [11](#_ENREF_11)]. Any palliative care provided within the last 12 months of life is considered as end of life care, the last phase of palliative care [[12](#_ENREF_12)].

The NHS End of Life Care strategy recommends open conversations between healthcare professionals and patients as the end of life approaches [[9](#_ENREF_9), [13](#_ENREF_13)]. These discussions are the first step in ensuring that well planned care is delivered [[14](#_ENREF_14)]. Indeed, awareness that death is approaching and what can be expected is seen as a prerequisite of a ‘good death’ [[5](#_ENREF_5)].

Difficult prognostication in COPD and in identifying with confidence the patients who are likely to die within 6 months poses an important barrier for early palliative care delivery [[15](#_ENREF_15)]. Despite the development of different prognostic tools, the uncertainty regarding the start of palliative care for COPD patients remains challenging [[15](#_ENREF_15)]. Gore and colleagues found in 2000, that patients with end stage COPD suffer from multiple severe symptoms, such as breathlessness, anxiety and depression; only a small proportion of patients receive palliative care and social support; and patients are likely to die whilst on aggressive treatments and in intensive care unit settings [[16](#_ENREF_16)]. Considering this and acknowledging the difficulties in prognosticating, it remains the physician’s responsibility to educate patients about palliative care and to understand and respect their preferences [[15](#_ENREF_15)]. Professionals should consider patients’ opinions and preferences when developing treatment escalation plans, emergency and resuscitation decisions, palliative care interventions and hospice care [[15](#_ENREF_15)]. Preferences can only be understood, debated and agreed in early conversations with COPD patients [[15](#_ENREF_15)].

Despite sharing similar health status, care trajectories and symptom burden [[16](#_ENREF_16), [17](#_ENREF_17)], the quality and the proportion of patients with COPD who receive palliative care compares poorly to the care received by patients with cancer [[18-21](#_ENREF_18)]. Patients with COPD receive less palliative care and die following more aggressive treatments at the end of life than patients with lung cancer, despite having the same preferences for palliative care [[22](#_ENREF_22)]. Although this suggests inequality in care provision based on diagnosis, it presents an opportunity to learn from practices in cancer care.

Given the importance of communication about palliative care between COPD patients and healthcare professionals, it was sought to systematically review the literature on palliative and end of life care discussions between healthcare professionals and patients with COPD in order to identify best practice, as well as the barriers, facilitators, challenges and meaning of these conversations.

Previous narrative and systematic reviews have been published in this subject [[5](#_ENREF_5), [15](#_ENREF_15), [21-26](#_ENREF_21)]. However, a comprehensive, evidence-based and systematic review was thought to be necessary to contextualize newly developed research. Considering the limitations of previous reviews, a systematic literature review was developed. This review offers evidence gathered from virtually all relevant health-related databases and websites, presents evidence developed from the year 1996 to 2015 and places equal importance on all types of literature, includes only papers with moderate to high quality and systematically analyses the data gathered from all papers. Furthermore, this review highlights new information which previous reviews did not provide. The new topics consist of the following: place, frequency, quality, importance, and disease features that triggered palliative care communication; in-depth information about barriers and facilitators; comparison of communication in COPD and cancer; and, finally, approaches to improve communication about palliative care in COPD. Healthcare professionals looking after COPD patients and researchers developing studies within this subject can use this review as an accurate reference for their day-to-day clinical practice.

# Methods and analysis

Prior to the development of the systematic literature review, a literature review protocol was outlined. Therefore, only a brief description of the protocol will be presented here. This review was conducted in accordance with PRISMA guidelines and the Centre for Reviews and Dissemination Guidelines, and was based in the systematic reviews included in this review [[5](#_ENREF_5), [23](#_ENREF_23), [27](#_ENREF_27), [28](#_ENREF_28)]. In order to find a comprehensive number of studies all major healthcare-related databases and websites were included (see **Table 1**). The search strategy included search terms and Medical Subject Headings (**Supplement 1**). Last search was conducted on the 2nd of February of 2016. The reference list of every included paper was scanned to identify further papers of interest (**Figure 1**) [[18](#_ENREF_18), [27](#_ENREF_27)]. The inclusion criteria are presented in **Table 2**. As part of the inclusion criteria, a topic list to objectively search papers was outlined. This list resulted from a primary search of the literature and the inclusion of these topics was agreed by all authors. The topics outlined represent what a palliative care discussion should include. One of the topics is “What is the patient’s and healthcare professional’s understanding of palliative care?” This topic focuses on what COPD patients think of palliative care, future treatments, approaching the end of life and of the impact of COPD in their future. This is one of the most relevant aspects and barriers when discussing palliative care with COPD patients [[5](#_ENREF_5), [29](#_ENREF_29), [30](#_ENREF_30)].

The selection process was completed by the main author and validated by the co-authors. Papers were selected, at first, by their title, secondly, by assessing their abstract, and finally, by analysing the whole article. The papers included in the review were screened by all authors and papers which raised uncertainty regarding criteria for inclusion were assessed, discussed and included/rejected by all authors. Therefore, actions to limit the impact of having one researcher screening the databases were adopted. These actions included: a very objective search strategy outlined in the literature review protocol; all authors reviewed and agreed on the inclusion of all papers and on the exclusion of papers that raised some uncertainty, and lastly, the reference list of all the papers included and of excluded papers about palliative care in COPD was thoroughly screened.

All papers were quality assessed using widely used appraisal tools. Qualitative papers were assessed using the tool: Criteria for Evaluating Qualitative Studies, whilst quantitative papers were assessed using the form: Quality Assessment Tool for Quantitative Studies[[27](#_ENREF_27), [31](#_ENREF_31), [32](#_ENREF_32)]. At the end of each assessment using these two tools, a formal quality score was given to each paper according with the score obtained in each section. Based on this assessment, papers were scored as strong, moderate or weak quality, only papers with moderate or strong/high quality were included (**Figure 1**). The rationale behind this was to increase reliability and validity of the findings of the review.

Data was extracted onto a Data Extraction Form [[27](#_ENREF_27), [33](#_ENREF_33)]. To ensure validity and reliability, quality assessment and data extraction was completed by the main researcher, and 15% of all papers were assessed by all researchers. Given the diverse nature of the included studies, data analysis and synthesis were carried out using a narrative synthesis approach [[34](#_ENREF_34)]. All researchers discussed and reached a consensus regarding the themes.

# Results

The initial search retrieved 28040 papers, after which all papers were scanned for eligibility criteria. Papers were excluded if not addressing the review’s subject, if geographically irrelevant, if included a small percentage of COPD patients and/or if shown a small proportion of relevant information (refer to **Figure 1** for more information). However, no papers were excluded based on the quality assessment as being of poor quality. The total number of papers included in this review was 37 (see **Supplement 2**). Fourteen were quantitative studies, 11 were qualitative studies and 12 were diverse including narrative and systematic reviews, and comparative studies. The majority of papers were originated from the USA (n=20), 7 from the UK, 4 were from other European countries, and the remaining 6 from other countries.

Most papers studied patients aged above 65 years old, with severe to very severe airflow obstruction, who were oxygen dependent, previous exacerbations of COPD and an estimated prognosis of death of more than one year. When healthcare professionals were included in the studies, they were usually respiratory physicians. Outpatient clinics were the most common setting where conversations were studied. The majority of the papers generated from the USA (a total of 14/20) were from the geographic area of Seattle. Finally, some of these studies used the same sample, but processed the data in different forms and/or developed cross-sectional studies with the same participants.

Quantitative methods were most frequently employed and a lack of good quality in-depth qualitative research was noted. This was especially noted in the following themes: barriers for palliative care conversations, time, place and person to hold discussions, quality of communication, and importance and impact of conversations.

## Quality of Evidence

All papers included in this review were quality assessed as described earlier. Fifty-eight percent of the qualitative papers included in the review were rated as high quality, whilst 42% were rated as being of moderate quality. The reasons for which papers were score with moderate quality included: lack of comprehensive information regarding the methods chosen, recruitment process, exclusion and inclusion criteria; language used during interviews, the use of somehow leading questions was noted; and lack of discussion or limitations section. Quantitative papers had their quality evenly distributed, 47% of papers were rated as high quality, whilst 53% of papers showed moderate quality. Some reasons for rating papers with moderate quality were: the small percentage of participants that agreed to be included in the study; lack of representativeness of the sample chosen; and lack of control for cofounders. For more information regarding the specific weak and strong points of each paper, please refer to **Supplement 2**.

## Frequency of discussions

One reason why COPD patients receive poor quality palliative care is that patient-physician communication about this is unlikely to occur [[21](#_ENREF_21)]. Seventeen out of 37 papers, highlighted that a variable percentage of COPD patients had discussed palliative care topics, this ranged from 0% to 56%, [[5](#_ENREF_5), [19](#_ENREF_19), [21](#_ENREF_21), [24](#_ENREF_24), [25](#_ENREF_25), [29](#_ENREF_29), [30](#_ENREF_30), [35-44](#_ENREF_35)]. Within this group, the majority (n=9), reported rates of discussion equal or lower than 30% of patients [[19](#_ENREF_19), [29](#_ENREF_29), [30](#_ENREF_30), [35-39](#_ENREF_35), [43](#_ENREF_43)][[1]](#footnote-1).Patients, who reported having had a palliative care discussion in the past, had a worse overall health status than patients who did not have a discussion [[19](#_ENREF_19)].

In a primary care study 41% of General Practitioners (GPs) reported that they discussed prognosis often or always with their patients, while 15% reported discussing the subject rarely or never [[40](#_ENREF_40)]. Moreover, 30% GPs left it for patients or their relatives to raise the subject [[40](#_ENREF_40)].

The desire to discuss palliative care topics was reported by more than half of the patients [[19](#_ENREF_19), [36](#_ENREF_36)]. This desire was acknowledged by half of GPs, who stated that some patients who would like to discuss prognosis did not get the opportunity [[40](#_ENREF_40)]. Despite this, almost three quarters of patients thought that their doctor probably or definitely knew the type of care they would want if they were too sick to speak for themselves [[37](#_ENREF_37)]. In contrast, approximately 33% of patients stated that they did not wish to discuss palliative care with a healthcare professional [[19](#_ENREF_19), [36](#_ENREF_36)]. When comparing GPs from Auckland and London, Auckland-based GPs reported they discussed prognosis more often with severe COPD patients [[45](#_ENREF_45)]. Interestingly, two-thirds of both groups agreed that they were more likely to discuss prognosis with cancer than COPD patients [[45](#_ENREF_45)]. Furthermore, Dutch patients reported having these conversations significantly less frequently (12.3% in The Netherlands vs 17.6% in the US) and with less quality than US patients, despite the fact that Dutch patients had worse disease severity [[46](#_ENREF_46)].

## Time, Place and Person to discuss palliative care

Conversations about treatment preferences were reported to occur when the patient’s COPD was advanced or when a serious decline was noted [[3](#_ENREF_3), [25](#_ENREF_25), [44](#_ENREF_44), [47](#_ENREF_47)]. Furthermore, the majority of physicians chose to initiate conversations when the Forced Expiratory Volume after 1 second (FEV1) was <30% [[3](#_ENREF_3), [47](#_ENREF_47)]. In contrast, all respiratory physicians agreed that this should ideally be initiated when a patient was in a stable condition, however patients’ individuality and differing rates of disease progression added to the difficulty in timing the conversation [[3](#_ENREF_3)]. The right time to discuss these topics was more defined in cancer than in COPD, where cancer specialist nurses (CNS) were involved from diagnosis until the patient’s deterioration [[18](#_ENREF_18), [22](#_ENREF_22)]. CNS’s provided personalized holistic care to cancer patients from the breaking of bad news, through their clinical treatment until the inevitable deterioration [[18](#_ENREF_18)].

The disease features that most commonly triggered palliative care discussions according with clinicians were: FEV1<30% of the predicted value; on or prior to an intensive care unit (ICU/ITU) admission; when a sudden event had happened, such as the introduction of long-term oxygen and/or non-invasive ventilation; when maximum therapy was achieved; and when all curative treatments were exhausted [[3](#_ENREF_3), [25](#_ENREF_25), [44](#_ENREF_44), [47](#_ENREF_47)]. These features were chosen by clinicians as these mark an important point in the deterioration of the overall health status of the patient [[3](#_ENREF_3), [25](#_ENREF_25), [44](#_ENREF_44), [47](#_ENREF_47)].

When considering the place of conversations, two reviews and a small qualitative study reported that respiratory physicians thought discussions occurred more often in hospital wards and intensive care units than in outpatient clinics [[22](#_ENREF_22), [25](#_ENREF_25), [47](#_ENREF_47)]. Furthermore, this study reported that only 23% of all palliative care conversations occurred during outpatients’ clinics, when compared with 77% in intensive care units and respiratory wards [[47](#_ENREF_47)]. Hospital admissions for COPD exacerbations were considered chaotic experiences and were not seen as an appropriate place to discuss palliative care [[38](#_ENREF_38)].

A small qualitative study conducted in secondary care, reported that patients desire someone they knew and who knew them when discussing palliative care [[38](#_ENREF_38)]. This usually translated to their GP, whereas a respiratory physician or a specialist nurse was seen as someone with the clinical knowledge, but not necessarily the personal relationship [[38](#_ENREF_38)].

## Quality of Communication

Patients have identified communication as one of the most important skills of physicians in providing adequate end of life care [[35](#_ENREF_35)]. However, the majority of studies that assessed the quality of end of life care communication, reported that COPD patients rated the quality as low [[35](#_ENREF_35), [36](#_ENREF_36), [39](#_ENREF_39), [46](#_ENREF_46)]. Only a single study showed that communication was perceived as satisfactory by patients [[41](#_ENREF_41)]. Quality of communication appeared to remain poor as patients approached their end of lives, even after the use of interventions to improve the frequency and quality of these discussions [[36](#_ENREF_36), [39](#_ENREF_39)]. Interventional studies demonstrated potential for improvement the quality of conversations, but only in two domains: patients’ feelings about deterioration and spiritual beliefs [[36](#_ENREF_36), [39](#_ENREF_39)].

The quality of end of life care communication was rated low, mainly because most end of life care topics were not discussed [[39](#_ENREF_39), [46](#_ENREF_46), [48](#_ENREF_48)]. These topics included, talking about spiritual and religious beliefs, what dying might be like and prognosis [[39](#_ENREF_39)]. When discussed, however, the quality was rated moderate to good [[39](#_ENREF_39)].

When comparing Dutch with US patients both groups reported very low scores for quality of communication about end of life care, however the Dutch group reported lower quality of general and end of life care communication (median score for Dutch patients was 0.0 (Interquartile Range: 0.0–2.0) versus 1.4 for US patients (Interquartile Range: 0.0–3.6)) [[46](#_ENREF_46)][[2]](#footnote-2).

## Content of Discussions

Patients and healthcare professionals reported tension between remaining hopeful and the reality of the patients’ condition, as this could pose a barrier for conversations and have an emotional impact on them [[18](#_ENREF_18), [29](#_ENREF_29)]. When patients were asked how much information they wanted, the initial answer was “all information”, however simply asking this was not adequately enough to elicit informational needs [[49](#_ENREF_49)].

Some patients believed that frank prognostic information might negatively impact their hope and increase symptoms of anxiety and depression; therefore some physicians purposely withheld information to avoid this [[20](#_ENREF_20), [25](#_ENREF_25), [49](#_ENREF_49)], as this poses a barrier when discussing palliative care with patients [[37](#_ENREF_37)]. However, while suggesting it may be harmful for other patients, none considered it harmful for themselves [[29](#_ENREF_29)]. Finally, many patients expressed the importance of individualising the clinician’s approach for hope and prognosis, and of longstanding relationships with physicians [[49](#_ENREF_49)].

Interestingly, participants often reported the use of the terms ‘emphysema’ and ‘respiratory insufficiency’ by physicians, but very rarely used ‘COPD’; and patients used ‘asthma’ and ‘allergy’ to describe their disease [[41](#_ENREF_41)]. In contrast, the word "death" was not used, but it was the implied alternative if the patient chose not to be intubated [[3](#_ENREF_3)]. Patients and their families rated emotional support as one of the skills they most prized in physicians [[50](#_ENREF_50)].

Several studies reported the most frequent and the least discussed topics during palliative care discussions, these are highlighted in the **Table 3** [[3](#_ENREF_3), [15](#_ENREF_15), [20](#_ENREF_20), [21](#_ENREF_21), [35](#_ENREF_35), [39](#_ENREF_39), [41](#_ENREF_41), [44](#_ENREF_44), [46-48](#_ENREF_46), [51-53](#_ENREF_51)]. Overall, patient education about palliative care was ranked as one of the most important topics by patients with COPD [[51](#_ENREF_51)]. This suggested that for patients with end-stage COPD, education was an especially important domain in which physicians may fall short [[15](#_ENREF_15), [42](#_ENREF_42), [51](#_ENREF_51)]. The vast majority of patients did not recognise palliative care as an option for COPD and some did not understand the meaning of cardiopulmonary resuscitation and of non-invasive ventilation [[42](#_ENREF_42)]. The most important educational areas for end-stage COPD patients was the progressive and irreversible nature of COPD [[51](#_ENREF_51)].

## Barriers and Facilitators

The identification and overcome of barriers for palliative care communication will thereby promote high-quality palliative care for COPD patients [[37](#_ENREF_37)]. Most studies reported that patients with COPD and physicians identified several barriers and few facilitators when discussing palliative care. **Table 4** contains the most commonly endorsed barriers and facilitators by patients and clinicians when discussing palliative care. The second column of the table describes the barriers and facilitators endorsed by patients, whilst, the third column describes the barriers and facilitators endorsed by clinicians. Moreover, patients which reported palliative care conversations identified fewer barriers and more facilitators than patients who did not have previous discussions [[37](#_ENREF_37)].

## Importance of palliative care discussions in COPD and the comparison with cancer

It may be useful for physicians to know whether the conversation about end of life care can reflect on a patient’s perceived quality of care and whether these conversations can lead to perceptions of worse overall health status [[19](#_ENREF_19)]. The occurrence of discussions was associated with higher health status, and of a higher quality of dying and death [[54](#_ENREF_54)]. Patients were also more likely to report having received the best possible care, to acknowledge that their provider knew the treatments they wanted and to state that their doctor provided a very good explanation of their breathing problems if they engaged in conversations [[54](#_ENREF_54)]. The majority of GPs and hospital physicians reported that conversations about prognosis were essential in the management of severe COPD and that they had an important role in facilitating these discussions [[40](#_ENREF_40), [44](#_ENREF_44), [45](#_ENREF_45)].

Several differences between patients with COPD and patients with cancer were found in the included papers. When comparing COPD and cancer patients with regards to open awareness to end of life issues, various differences were evident. For instance, open awareness of death and dying was the norm for cancer patients [[18](#_ENREF_18), [19](#_ENREF_19), [22](#_ENREF_22)] and patients with cancer were more likely than patients with COPD to describe their diagnosis by name [[53](#_ENREF_53)]. Furthermore, COPD patients were more likely to express little or no understanding of their illness or diagnosis and received less education about their condition [[53](#_ENREF_53)]. In contrast, patients with cancer were more likely to introduce prognosis in conversations regarding their disease [[53](#_ENREF_53)].

## Improving palliative care communication

When patients asked their physicians that they would like to receive all available treatments, physicians often concluded that those patients wished to try all imaginable treatments, regardless of their benefit and invasiveness [[55](#_ENREF_55)]. However, researchers argue that the most appropriate response was to discuss the patient’s underlying treatment values and non-medical concerns and to provide accurate information about the patient’s illness, prognosis and possible outcomes of life-sustaining treatments [[55](#_ENREF_55)].

In order to improve the quality and frequency of palliative care discussions, five studies reported the use of an intervention to facilitate conversations [[36](#_ENREF_36), [43](#_ENREF_43), [52](#_ENREF_52), [56](#_ENREF_56), [57](#_ENREF_57)]. These interventions were widely accepted and considered meaningful by the majority of participants. The interventions tested in these studies included: the use of computer-based reminders by physicians to improve frequency of conversations and completion of advance directives; the use of a short retreat to provide training to medical residents about communication skills; the use of feedback forms containing information about patients’ preferences for future care; the use of home sessions to provide care, education and discussions about advance care planning and palliative care; and finally, the use of a computer program to provide education and training regarding palliative care for patients, in order to facilitate conversations with their clinicians [[36](#_ENREF_36), [43](#_ENREF_43), [52](#_ENREF_52), [56](#_ENREF_56), [57](#_ENREF_57)]. The studies used different approaches to improve palliative care communication and used patients and/or clinicians as the main targets.

Despite the fact that all interventions were designed to improve frequency and/or quality of communication, only a modest impact in improving the characteristics of palliative care communication was noted [[36](#_ENREF_36), [43](#_ENREF_43), [52](#_ENREF_52), [56](#_ENREF_56), [57](#_ENREF_57)]. One of the reasons why these interventions may have had little impact was that the interventions may have made the patients feel uncomfortable [[36](#_ENREF_36)].

## Suggestions for improving palliative care communication

A series of recommendations for palliative care conversations with COPD patients resulted from the data analysis and synthesis of the papers included in the review. These suggestions may provide some help to clinicians when approaching patients with COPD. The different suggestions are as follows:

* Conversations should be started early in the disease course or opportunities to start discussions should be identified [[30](#_ENREF_30)]. This will help to build a therapeutic relationship with the patient [[30](#_ENREF_30)]. These opportunities/triggers can be:
	+ The presence of *cor pulmonale* [[22](#_ENREF_22)];
	+ The need for ventilation in the previous year [[22](#_ENREF_22)];
	+ Arterial partial pressure of carbon dioxide >45mmHg or FEV1 <30% [[22](#_ENREF_22)];
	+ Recent hospital admission or consultation [[26](#_ENREF_26), [30](#_ENREF_30), [39](#_ENREF_39), [50](#_ENREF_50)];
	+ Oxygen dependency or weight loss [[22](#_ENREF_22)];
	+ Observed deterioration in the patient’s condition [[22](#_ENREF_22), [30](#_ENREF_30), [39](#_ENREF_39), [50](#_ENREF_50)];
	+ Age above 70 years [[18](#_ENREF_18), [22](#_ENREF_22)];
	+ Assessment of therapy options [[30](#_ENREF_30), [50](#_ENREF_50)].
* Discussions should be prepared and include the implications of diagnosis and of possible outcomes of life-sustaining treatments [[30](#_ENREF_30), [50](#_ENREF_50), [55](#_ENREF_55)]. Patient’s understanding about his/her condition and his/her desired informational needs should be sought [[50](#_ENREF_50)]. Patient’s relatives should be included in discussions, if the patient so desires [[41](#_ENREF_41), [49](#_ENREF_49)]. In agreement with this, clinicians should identify and acknowledge patient’s preferences [[18](#_ENREF_18), [55](#_ENREF_55)];
* Clinician should share his/her medical opinion and propose a philosophy and plan of treatment, considering the patient’s needs and wishes [[50](#_ENREF_50), [55](#_ENREF_55)]. During this, patients may feel upset or emotional, therefore, support should be provided [[30](#_ENREF_30), [50](#_ENREF_50)]. Any disagreements identified should be negotiated with the patient, to come to a shared decision [[24](#_ENREF_24), [50](#_ENREF_50), [55](#_ENREF_55)];
* Patients may request burdensome treatments, in this case harm-reduction strategies should be chosen [[55](#_ENREF_55)]. Considering this, all patients should set goals and plan for the future with their clinicians [[50](#_ENREF_50)];
* Clinicians should document all the information discussed and agreed, and should work closely with other professionals to ensure that the patient’s wishes are fulfilled [[26](#_ENREF_26), [50](#_ENREF_50)]. Conversations should be restarted when new triggers arise or whenever the patient requires. [[30](#_ENREF_30), [50](#_ENREF_50)].

# Discussion

The majority of studies included in the review showed that only a small percentage of patients with COPD had discussed palliative care with their clinicians. Clinicians in those studies reported several reasons behind this, such as the unpredictability of COPD, the fear of destroying patients’ hope, and the lack of understanding about palliative care and COPD by patients and physicians.

The small proportion of COPD patients who receive palliative care may be a reflection of the lack of conversations between patients and clinicians. However, the lack of accurate prognostic tools in COPD makes it difficult for clinicians to judge when the ideal time to initiate palliative care discussions is. Various tools have been suggested, but most of them have inadequate prognostic ability. For example, the tools used during the SUPPORT study showed that, at 5 days prior to death, patients with COPD were predicted to have >50% chance of surviving for 6 months [[22](#_ENREF_22)]. Other tools can be included in this list, such as BODE, DECAF and DOSE score. DOSE score can be used as a prognostic instrument for mortality in COPD, however only 57.1% of patients with the highest score died within 5 years of follow-up [[58](#_ENREF_58)]. When looking at the BODE score, 63.2% of patients with the highest BODE score were still alive at 3 years [[59](#_ENREF_59)]. This shows the unpredictability and complexity of COPD, and makes it challenging to predict with certainty when a patient is approaching the end of life. Therefore, early conversations about all aspects of the disease should be held and these should include discussions about palliative care interventions, as well as preferences for end of life care.

Another important factor when communicating palliative care with COPD patients was the patient’s willingness to discuss this with a clinician. Most of the papers highlighted the importance of patients’ willingness to discuss palliative care as a key factor to a successful discussion. Two studies showed that 33% of patients did not wish to discuss palliative care, however further research looking into patients’ willingness to discuss palliative care was not found. The recruitment of patients not willing to discuss this topic may have posed very difficult, hence, the lack of research in this area. The hypothetical explanation that led these patients to participate in the studies was that the studies targeted mainly healthcare professionals, instead of patients themselves. Despite this, several actions can be taken in clinical practice to reduce the impact of this, these actions include: picking up cues about patients’ readiness/willingness to discuss palliative care, slowly titrating the amount of information provided to patients about palliative care (this should be done according with the patient’s own pace) and when patients/relatives raise this subject on their own.

The quality of end of life care communication was found to be poor and this was mainly because most topics were not discussed (refer to **Table 3** for further information). However, when topics were discussed the quality was found to be moderate to good. This suggests that the problem resided in the initiation of conversations and not in the clinicians’ skills [[39](#_ENREF_39)]. Therefore, it is suggested that healthcare professionals should make these conversations part of their day-to-day agenda. A lack of detailed information about the frequency and quality of conversations was also noted. If important topics were not discussed, the quality of communication related to these topics cannot be assessed. This leaves a large proportion of the conversation with unknown quality.

Patients with previous palliative care discussions were found to rate their medical care and their clinicians’ skills higher than patients who did not. This may be because they had a discussion about preferences of care with their clinicians which meant that their wishes were respected and their care adjusted to their preferences. This suggests an important link between palliative care discussions and patient assessments of care quality and should be explored in future work. However, it was noted a paucity of in-depth information about the impact and the importance of conversations for patients so further qualitative research is required to explore the importance and impact of conversations, and to understand with certainty which factors of discussions have greater impact for patients.

Participants stated that the preferred clinician with whom to have the conversation was their GP and the best place was within outpatient clinics or GP appointments. Although participants reported that the best time was early in the disease trajectory, the majority of conversations happened very late in the disease trajectory. The need for earlier, planned and stress-free conversations make further research very important. Most of this data was generated from quantitative research, yet much could be gained from in-depth qualitative research specifically collecting information from patients describing the most appropriate timing, place and person to discuss palliative care, describing the reasons behind their choices and suggesting ways to achieve their preferences at all times.

Several studies tested the effect of interventions on improving the frequency and/or quality of palliative care discussions, however, all studies had a small impact on discussions. . Only one study focused on improving and measuring physicians’ skills at the end of the study [[57](#_ENREF_57)], whilst the other studies focused on the impact of the interventions in improving the frequency and/or quality of discussions. This study concluded that only “responding to emotion” improved in clinicians’ skills and that clinicians tended to lose their skills with time, especially when considering emotional empathy. Another study showed that when clinicians do discuss palliative care their discussions are rated as moderate to good by patients [[39](#_ENREF_39)]. This suggests that the quality and frequency of conversations were not linked with lack of skills of clinicians, but with the high number of barriers for conversations and the difficulty in initiating them [[36](#_ENREF_36), [56](#_ENREF_56), [57](#_ENREF_57)]. Hence, the little impact of interventions in improving discussions. Minimizing the barriers for discussions about palliative care will greatly enhance their frequency and quality.

The frequency of end of life care conversations in cancer is remarkably similar to the frequency seen in COPD, 21-37% [[60](#_ENREF_60), [61](#_ENREF_61)]. However, several differences between patients with COPD and cancer were highlighted when considering these discussions. The majority of these differences are thought to be disease-related and due to the awareness that the general public has of both diseases. Cancer brings the expectation of death and hence people with cancer expect conversations regarding ultimate prognosis and its impact on treatment and care, whereas in COPD the progression over time is variable and difficult to predict, consequently these aspects of care planning are not expected or requested [[18](#_ENREF_18)]. Patients and healthcare professionals need further education regarding all illness-related aspects, including the inevitable life-limiting character of COPD.

## Strengths and Limitations

Our findings follow a systematic literature search and include data from only moderate or high quality papers, thus enriching the quality of the information presented and increasing reliability. Finally, the use of a narrative synthesis framework provided a systematic approach to process, analyse and synthesize the data extracted from the research studies.

However, only papers written in English were included which may have excluded important information, potentially leading to cultural and demographic bias. However, only two papers fell into this category and had poor quality. A second limitation is the small number of papers, especially the lack of controlled trials and objective comparisons of approaches and their influence on outcomes for patients. Another limitation is the number of COPD patients contained in the papers. Papers were only included if their sample included at least 50% COPD patients. However, this may have only excluded a marginal amount of information. The last limitation was the use of one author when screening for papers in databases, websites, journals and reference lists. By having only one author screening the papers, this may have resulted in some papers being missed. However, to mitigate this, all authors agreed on the inclusion of all papers, the reference lists of the included papers and of papers related with the subject were screened and an objective search strategy was developed by all authors before the screening process.

# Conclusion

In conclusion, the current literature suggests that despite evidence of real benefit when conducted, the frequency and quality of palliative care conversations between patients and health care professionals is poor. Patients and physicians cite a large number of barriers; and most topics are not discussed. When discussions do take place they do so at an advanced stage of disease, often in a busy, acute and stressful environment and often with clinicians who do not have an established relationship with the patient. Moreover, differences in experiences between patients with cancer and COPD suggest that long-standing inequalities based on diagnosis continue to pervade.

Given the relationship between conversations about care and the meeting of patient preferences, this lack of optimal communication between clinicians and patients is likely to impact upon care quality, patient satisfaction, and ultimately, the likelihood of a “good death.” Further research needs to be performed to guide development and testing of new pathways and practices to improve outcomes for COPD patients by ensuring timely and appropriate integrated palliative care and advance care planning through open discussions with healthcare professionals.

**Tables and Figures**

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| --- |
| Table 1 Databases and Websites Searched |
| Databases Searched | Medline; CINAHL; PsycINFO; HMIC; AMED; Web of Science; ASSIA; IBSS; Delphis; PubMed; ScienceDirect; Cochrane Library; EMBASE; BNI; AgeInfo and Scopus |
| Websites  | Thorax Website; British Thoracic Society (BTS); National Institute For Health And Care Excellence (NICE); Medical Research Council (MRC); Department Of Health (DoH); Economic And Social Research Council (ESRC); National Institute For Health Research (NIHR); American Thoracic Association (ATS); British Lung Foundation (BLS); The National Council For Palliative Care (NCPC); The European Association For Palliative Care (EAPC); Association For Palliative Medicine (APM). |

|  |
| --- |
| Table 2 Inclusion criteria of papers selected for review |
| Paper Language  | Papers were included if written in English. The first language of all authors is English, therefore the inclusion of papers written in any other language would pose a barrier to thoroughly analyse the papers. |
| Participants  | The participants included were people with COPD and healthcare professionals aged above 18 years old. The COPD diagnosis should be done according with the Global Initiative for Chronic Obstructive Lung Disease (GOLD), in which a spirometry is performed showing a FEV1/FVC lower than 70%.Papers were included if the sample represented 50% or more of patients with COPD, except if the papers were purposely comparing COPD with other diseases. Papers had to include approximately the same amount of COPD patients and patients with other conditions. A 10% margin was used to include or exclude papers. However, the 10% margin was only applied to the larger categories of patients with other diseases.  |
| Study Design | All study designs were included in the review. The main purpose of the review was to identify and analyse all data published regarding this subject. Therefore, all study designs were included. |
| Study Quality  | Papers were included if presented high or moderate quality. The inclusion of papers with low quality would contaminate the overall findings and conclusion of the review, leading to inaccurate and unreliable data. |
| Country Restriction | Only papers from North America, Europe, Australia and New Zealand were included. This is thought relevant as literature from countries with different cultural believes towards health and from countries with small healthcare resources would not provide relevant and usable data for a European and North American society.  |
| Information PResented in Papers | Papers were included if more than 50% of the information included was about palliative care conversations with COPD patients. This was done using word count. The papers excluded using this approach contained 30% or less of relevant information. Furthermore, the information contained in these papers did not present new information about the topic discussed.  |
| Intervention | Conversations included were conversations about the topic – palliative care –between a person with COPD and a healthcare professional. |
| Discussion Topics | The palliative care discussions addressed at least one of the following topics: * “What are the patient’s wishes and preferences for palliative and end of life care?”
* “What is the patient’s and clinician’s understanding of palliative care?”
* “What care can be offered to the dying patient?”
* “What may the end of life care and/or death look like?”
* “What may the future be like?”
* “What are the patient’s preferences for life-sustaining treatments?”
* “How long does the patient have to live?”
* “What is the desired place of death?”
* “Who would the patient like to be present in the time of death?”
* “What are the arrangements for after death?”
 |

**Figure 1** Literature Search Flow Diagram

37 papers included

14 quantitative studies

11 qualitative studies

27631 papers excluded on basis of not discussing one of the following topics: “Communication, “Palliative Care”, or “COPD”

214 full-text articles assessed for eligibility

207 duplicates removed (total n=27833)

28040 of records combined

27997 records identified through database searching

43 additional records identified through Website searching

177 papers excluded:

* 73 irrelevant for the review question;
* 2 geographically irrelevant;
* 18 general communication;
* 46 not about COPD or small percentage of COPD patients;
* 38 small amount of relevant information.

12 papers identified through citation searching of included studies

202 papers identified on basis of title and abstract screening

12 other study designs

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| Table 3 topics discussed during palliative care conversations[[3]](#footnote-3) |
| Rarely discussed Topics | **Frequent Topics** |
| * The process of dying and the discussion of prognosis;
* Spiritual or religious beliefs;
* What dying might be like;
* How long the patient has to live;
* Getting sicker;
* Future treatment decisions;
* Preferences for life sustaining treatments, such as intubation, tracheostomy, oxygen, tube feeding, intravascular fluids and hospital care.
 | * The possibility of an ICU admission;
* The intubation procedure;
* The patient’s inability to speak or to eat while being ventilated;
* The likelihood of death if mechanical ventilation was not performed;
* The death rate associated with mechanical ventilation
 |

|  |
| --- |
| Table 4 MOST COMMON BARRIERS AND FACILITATORS ENDORSED BY PATIENTS AND PHYSICIANS  |
|  | **PATIENTS** | **PHYSICIANS** |
| Barriers | 1. Patients focused on staying alive [[18](#_ENREF_18), [21](#_ENREF_21), [37](#_ENREF_37)];
2. Patients not certain of which doctor would be taking care of them [[21](#_ENREF_21), [37](#_ENREF_37)];
3. Patients do not know what kind of care they would want in the future [[21](#_ENREF_21), [37](#_ENREF_37)];
4. Limited understanding of palliative care and COPD [[5](#_ENREF_5), [29](#_ENREF_29)];
5. Denial of health status and of the possibility of dying [[15](#_ENREF_15), [18](#_ENREF_18), [24](#_ENREF_24)] ;
6. Emotional distress of conversations and of palliative care [[18](#_ENREF_18), [29](#_ENREF_29), [38](#_ENREF_38)];
7. Patients’ readiness to discuss palliative care [[37](#_ENREF_37)];
 | 1. Lack of time in appointments to discuss all topics [[18](#_ENREF_18), [37](#_ENREF_37)];
2. Discussions may take way patients’ hope [[37](#_ENREF_37)];
3. Lack of feedback and documentation [[18](#_ENREF_18), [30](#_ENREF_30), [40](#_ENREF_40), [45](#_ENREF_45)];
4. Lack of thorough knowledge of the patient [[3](#_ENREF_3), [18](#_ENREF_18)];
5. Difficulty to start conversations and to choose the right time [[3](#_ENREF_3), [18](#_ENREF_18), [22](#_ENREF_22), [26](#_ENREF_26), [30](#_ENREF_30), [39](#_ENREF_39), [40](#_ENREF_40), [44](#_ENREF_44), [45](#_ENREF_45)];
6. Difficulty for patients to understand and accept information in short periods of time [[3](#_ENREF_3), [29](#_ENREF_29), [52](#_ENREF_52)];
7. Vision of palliative care as confined to the last days of life and exclusive of life sustaining treatments [[29](#_ENREF_29), [30](#_ENREF_30)];
8. Uncertainty to prognose in COPD [[5](#_ENREF_5), [18](#_ENREF_18), [22](#_ENREF_22), [39](#_ENREF_39), [40](#_ENREF_40), [45](#_ENREF_45)];
9. Reluctance of palliative care services to care for patients with COPD [[29](#_ENREF_29)];
10. Complex discharge planning for COPD patients [[18](#_ENREF_18)].
 |
| Facilitators | 1. Patients who had relatives or friends who had died recently [[37](#_ENREF_37)];
2. Patients’ trust in their physician [[37](#_ENREF_37)];
3. Patients interpret physicians’ skills as very good [[37](#_ENREF_37)];
4. Patients’ belief that physicians truly care about the patient [[37](#_ENREF_37)].
 | 1. Good patient-physician relationship [[29](#_ENREF_29), [37](#_ENREF_37)];
2. Physicians who cared for many patients with lung disease [[37](#_ENREF_37)];
3. Physicians who care for patients with previous acute episodes [[37](#_ENREF_37)].
 |

**Supplement 1** KEYWORDS USED TO SEARCH THE LITERATURE

|  |  |
| --- | --- |
| “COPD”, “Chronic Obstructive Pulmonary Dis\*", “Chronic Obstructive Airway Dis\*”, “Chronic Lung Dis\*”, “Chronic Lung Illness”, “Chronic Pulmonary Illness”, “Chronic Pulmonary Dis\*”, "Chronic Bronchitis", "Palliative Car\*", “End Of Life”, "End Of Life", “Terminal Care”, “Terminally Ill\*”, “Hospice Care”, “End-Stage Care”, “Care Of The Dying”, “Dying Care”, “Death”, “Dying”, “Discuss\*”, “Conversat\*”, “Communicat\*”, “Inform\*”, “Barriers”, “Facilitators”, “Therapeutic”, “Disclos\*”, “Decision Making”,  | "Pulmonary Emphysema", “Chronic Disease”, “Lung Disease”, “Critical Illness”, “Advanc\* Illness”, “Obstructive Lung Dis\*”, “Pulmonary Dis\*”, “Hospice”, “Advance Care Planning”, “Advance Directives”, “Prognosis”, “Family”, “Patient”, “Patient Care Conferenc\*”, “Patient-Family Conferenc\*”, “Psychology”,“Attitude Of Health Personnel”, “Patient satisfaction”, “Physician-patient relations”, “Physician-patient communicat\*”, “Nurse-patient relations”, “Professional-patient relations”, “Health Professional”, “Nurses”, “Physicians”, “Hospital”,“Medical Staff” |

**Supplement 2** –Description of the papers included in the review

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Reference and Country | Aim | Study designPatient group and sample | Findings | Weak Points | Strong Points |
| [[50](#_ENREF_50)], USA | To model pertinent end of life care communication and discuss practical tips to incorporate goals of care and advance care planning into a primary care practice. | Case Report* 71-year-old male patient with chronic obstructive pulmonary disease.
 | * General internists and family medicine practitioners in primary care are central to eliciting patients’ goals of care and achieving optimal end of life outcomes for their patients.
 | * The method chosen in the study – case report;
* Prevents generalization for other patients/cases;
* Approach suggested to establish goals of care was not tested before and does not include patients’ opinions.
 | * Describes feelings, concerns and thoughts of one COPD patient and his relative about palliative care conversations.
 |
| [[36](#_ENREF_36)], USA | To improve the occurrence and quality of end of life communication with a simple communication intervention using a patient-specific feedback. | Cluster randomized trial* 92 respiratory physicians;
* 182 COPD patients in the control group and 194 in the intervention group.
 | * The baseline quality of communication in both treatment and control groups was poor.
* Participants frequently reported that they would like to discuss end of life care preferences.
 | * Does not provide in-depth information about patients’ and clinicians’ opinions, feelings and thoughts;
* Study developed in one healthcare facility, generalization may be difficult;
* Small percentage of women in the study;
* Patients and clinicians approached during only one clinic to assess the conduction of conversations.
 | * Clustered randomized controlled trial – robust findings;
* Included clinicians and patients across all backgrounds and disease stages.
 |
| [[18](#_ENREF_18)], UK | To explore the experiences of respiratory healthcare professionals in their conversations with COPD patients. | Qualitative phenomenology – Interviews* 2 respiratory physicians;
* 3 respiratory nurse specialists;
* 2 lung cancer nurse specialists.
 | * The timing of discussions is crucially dependent on the patient’s illness pathway.
* Picking up on subtle visual and verbal cues were highlighted.
* Moral and ethical dilemmas, as well as the futility of treatment, were raised.
 | * Small sample of clinicians used;
* No patients were included in the study;
* Lack of details regarding the methods used, exclusion/inclusion criteria, recruitment process and data collection;
* Results cannot be generalized;
* Clinicians interviewed regarding interviews that they recalled having had in the past.
 | * Description of clinicians’ experiences and concerns regarding palliative care conversations with patients;
* Comparison of discussions between patients with cancer and COPD;
* Description of the 5 most frequent themes regarding conversations with patients.
 |
| [[25](#_ENREF_25)], uSA | To review what is known about communicating with patients and their families about end of life care in ITU settings. | Narrative ReviewSample - Not Applicable | * Discussing dying with patients and their families is an extremely important part of providing good quality care for patients with chronic pulmonary diseases and families of patients in the ITU.
* Providing sensitive and effective communication about end of life care requires training and practice as well as planning.
 | * Narrative review – which does not comprehend all studies published;
* Includes data regarding all critical respiratory diseases;
* Old review – published by the end of 2000;
* No description of methods of data collection, analysis and synthesis;
* No description of the limitations of the study.
 | * Comprehensive paper about palliative care and advance care planning in the intensive care unit;
* Clinically orientated review;
 |
| [[22](#_ENREF_22)], USA | To examine problems in the delivery of high-quality palliative care to patients with severe COPD and to identify ways in which to address these problems. | Narrative ReviewSample - Not Applicable | * Improving communication represents an important opportunity for the improvement of the quality of palliative and end of life care received by these patients.
* Poor palliative care in COPD was linked to poor communication.
 | * Small section dedicated to palliative care discussions;
* No description of methods of data collection, analysis and synthesis;
* No description of the limitations of the study;
* Narrative review – which does not comprehend all studies regarding the subject being reviewed.
 | * Study very much focused in patients with severe COPD;
* Describes practice focused recommendations for clinicians and patients.
 |
| [[49](#_ENREF_49)], USA | To examine the interaction between the desire to have hope supported and the need to receive explicit prognostic information on the part of patients and family members.  | In-depth longitudinal qualitative interviews* 55 patients (25 with COPD);
* 36 family members;
* 31 physicians;
* 25 nurses.
 | * Asking patients directly how much information they wanted was not useful to identify informational needs.
* Respondents identified two approaches to communicate prognosis: the direct and indirect approach.
 | * Sample chosen may have affected overall findings of study, as only physicians with good communication skills were chosen to recruit their patients into the study;
* Findings are generated from participants in their last year of life, therefore conclusions can only be drawn for this specific group of COPD patients;
* Difficult to generalize due to the type of study;
* Small participation rate of physicians.
 | * Interesting study looking at desire for hopeful versus prognostic information;
* Lack of comparison between COPD and cancer;
* In-depth information about the views of patients with COPD and cancer about 4 diagrams describing communication in the last year of life.
 |
| [[62](#_ENREF_62)], USA | To identify specific areas of communication about end of life care that patients report are not occurring and to identify specific areas of good and poor quality communication. | Questionnaires and Interviews* 115 COPD patients;
* 55 respiratory physicians.
 | * Poorly discussed topics: talking about how long the patient has to live, talking about what dying might be like, talking with loved ones about what dying might be like and asking about the patient’s spiritual or religious beliefs.
* Depression symptoms was associated with quality of communication scores.
 | * Somehow old study, with data collected from 1999-2002;
* Authors chosen a sample of patients with severe/advanced disease, therefore data can only be compared with patients in the same disease severity stage;
* Lack of fully detailed description of inclusion criteria;
* Difficult to generalize, due to type of study;
* Small participation rate of patients;
* Questionnaire used to ascertain the quality of communication;
* Small interaction between qualitative and quantitative research.
 | * In-depth information about palliative care communication with patients with severe COPD;
* Large participation rate of physicians;
* Thorough description of the quality of palliative care communication, however one cannot understand the true quality of discussions as most items were not discussed with patients.
 |
| [[21](#_ENREF_21)], USA | To provide a narrative review of recent research regarding patient-physician communication about palliative care for COPD patients and to summarize the authors’ perspective on the research agenda. | Narrative ReviewSample - Not Applicable | * One reason for poor palliative care delivery in COPD was the lack of patient-physician communication about end of life care.
* Patients and physicians identify many barriers to start conversations.
* Depression has an important impact in end of life care communication.
 | * Lack of descriptions of the methods used to complete the narrative review;
* Lack of discussion, limitations and strengths sections in the review;
* Some information is based in studies done with patients with different conditions.
 | * Comprehensive review about palliative care communication with COPD patients;
* Offers several recommendations to healthcare professionals;
* Focused in the development of further research in this area.
 |
| [[51](#_ENREF_51)], USA | To elucidate the important aspects of physician skill at providing end of life care. | Focus Groups and Content Analysis* 24 COPD patients;
* 36 AIDS patients;
* 19 Cancer patients.
 | * Remarkable similarities were found in the perspectives of all patients including the importance of emotional support, communication, and accessibility and continuity.
* For patients with COPD, the most concerning domain was the physicians’ ability to provide patient education.
* Patients with COPD desired education in: diagnosis and disease process, treatment, prognosis, what dying might be like, and advance care planning.
 | * Somehow old study using data from 2001;
* Difficult to generalize the findings due to the type of study;
* Findings are generated from patients with severe/terminal disease.
 | * Interesting study looking at the skills of healthcare professionals discussing palliative care;
* In-depth information gathered using interviews with patients;
* Thorough description of methods used in the study.
 |
| [[43](#_ENREF_43)], USA | To test the hypothesis that reminding primary care physicians to discuss advance directives would stimulate such conversations and lead to the establishment of more advance directives. | Randomized Controlled Trial* 1009 patients (46% with a COPD diagnosis);
* 147 primary care physicians.
 | * Physicians who did not receive reminders discussed advance directives with 4% of the patients compared with 24% for physicians who received both types of reminders.
* Physicians who did not receive reminders completed advance directive forms with only 4% of their patients compared with 15% for physicians who received both types of reminders.
* Overall, 45% of patients with whom advance directives were discussed completed at least one type of advance directive.
 | * Old study, used data from 1997;
* Computer literacy may have changed the overall results if the study was to be repeated nowadays;
* Physicians were encouraged to discuss advance directives with patients prior the study, this may have influenced the final results;
* Majority of participating physicians were faculty members who had larger knowledge about research and physiopathology, which may have influenced results;
* Lack of data concerning patients’ thoughts about discussions and about the appropriateness of the methods used.
 | * Robust study, which used a randomized controlled trial;
* Used an innovative computer-based programme to encourage palliative care conversations with patients;
* Large participation rate in study;
* Comprehensive description of the methods used in the study.
 |
| [[40](#_ENREF_40)], UK | To investigate the role that conversations of prognosis play in GPs' management of patients with severe COPD and the factors that influence those discussions. | Survey* 214 General Practitioners
 | * 72.5% thought that conversations of prognosis were often necessary or essential in severe COPD.
* 82% felt that GPs have an important role in these discussions.
* 50% of GPs were undecided as to whether patients with COPD wanted to know about their prognosis.
* The majority of GPs that reported not discussing end of life with patients stated several reasons.
 | * Old study, which used information from 1999;
* Lack of in-depth information of GP’s regarding conversations about prognosis;
* Small participations rate;
* Lack of thorough information regarding the development of the survey.
 | * Robust study with a large sample of participants;
* Survey piloted with small sample and based in previous interviews and literature review.
 |
| [[48](#_ENREF_48)], USA | To describe the domain structure and the construct validity of the Quality of Communication Questionnaire. | Questionnaire* 113 COPD patients;
* 83 hospice patients.
 | * Findings support the construction of two scales: a “general communication skills” scale and a “communication about end of life care” scale;
* The two scales met standards of scale measurement;
* This questionnaire represents an important step towards providing a measure of the quality of end of life communication.
 | * Small amount of information regarding the quality of discussions in clinical practice;
* Somehow old study, used findings from 1998-2002;
* Sample only included patients with very severe disease;
* Questionnaire not used before, therefore may have not generated accurate results;
* Lack of information from patients and physicians regarding their perspectives about the use of the questionnaire.
 | * Comprehensive description of the development of the Quality of Communication Questionnaire;
* Large sample of patients;
* Hypothesis were supported by findings.
 |
| [[42](#_ENREF_42)], UK | To evaluate the understanding of palliative care as an option in COPD and to identify any barriers to resuscitation conversations in this group of patients. | Questionnaire* 30 COPD patients.
 | * Thirteen patients understood the term non-invasive ventilation, and 11 of those would consider it again if needed.
* Only 13% of patients knew that palliative care is an option in COPD.
* Eleven patients understood the term cardiopulmonary resuscitation, and only five ever had a conversation regarding resuscitation.
 | * Questionnaire developed by the study authors without previous piloting;
* Lack of description of the methods and data used to develop the questionnaire;
* Lack of information stating the validity and reliability of the questionnaire, which may have biased the results;
* Lack of clinicians and patients’ feedback regarding the use and feasibility of the study;
* Small sample size;
* Recruitment process may have influenced results, due to the recruitment of patients immediately after an acute exacerbation of their disease.
 | * Study developed in the United Kingdom;
* Several different assessment tools were used and their results were compared with the results of questionnaires.
 |
| [[44](#_ENREF_44)], Portugal | To evaluate the practice of Portuguese respiratory physicians in end of life communication and palliative care in COPD. | On-line Survey* 136 respiratory physicians.
 | * 48.5% of physicians reported that they have rarely introduced end of life care conversations.
* 68% had never/rarely suggested decision-making on the use of invasive mechanical ventilation;
* Discussions were described as occurring mostly during/after a major exacerbation.
* Most participants perceive the discussion of end of life issues as being difficult/very difficult.
* The most common reasons given were the feeling that patients were not prepared for this conversation, fear of taking away the patient’s hope and lack of training.
 | * Lack of detailed information about the perspectives of the participants included in the study;
* Small participation rate;
* Lack of information regarding the patients’ opinions about these discussions.
 | * Robust study, showing data from another European country;
* Comprehensive descriptions of the methods used in the study;
* Only clinicians who looked after patients with COPD were included;
* Recent study.
 |
| [[30](#_ENREF_30)], New Zealand | To identify strategies that general practitioners can use to facilitate conversation of prognosis with patients who have COPD. | Telephone interviews* 15 General Practitioners;
* 5 Respiratory Consultants.
 | * Seven strategies were identified to facilitate discussion of prognosis: be aware of implications of diagnosis; use uncertainty to ease conversation; build relationship with patients; be caring and respectful; begin conversation early in disease course; identify and use opportunities to discuss prognosis; and work as a team.
 | * Somehow old study, done in 2003;
* Telephonic interviews used;
* Exclusion of patients with COPD and other healthcare professionals;
* Small sample of respiratory physicians;
* Criteria of the questionnaire/questions of interview may have confused the participants.
 | * Showed in-depth perspectives of clinicians looking after COPD patents;
* Data analysis and data synthesis.
 |
| [[39](#_ENREF_39)], The Ntherlands | To examine the quality of end of life care communication during one year follow-up of patients with advanced chronic organ failure. | Questionnaires during home visits* 265 patients, of whom 105 had COPD.
 | * Quality of end of life care communication was rated low at baseline and did not change over one year.
* Quality of end of life care communication was comparable for patients who completed two-year follow-up and patients who died during the study.
* The correlation between quality of end of life care communication and satisfaction with medical treatment was weak.
 | * Lack of detailed information about the quality of communication;
* Inclusion only of patients with advanced/terminal disease;
* Questionnaire used to assess quality of communication was not piloted or tested before, therefore the validity and reliability of the tool remains unknown;
* Lack of detailed information about the perspectives of clinicians.
 | * Very recent study;
* Inclusion and comparison of patients with COPD with patients with other chronic illnesses;
* Longitudinal study of a cohort of patients;
* Large sample size.
 |
| [[46](#_ENREF_46)], USA and The Netherlands | To compare quality of patient–clinician communication about end of life care, and endorsement of barriers and facilitators to this communication in the Netherlands and the USA. | Comparison Study* 122 Dutch patients with COPD;
* 391 North American patients with COPD.
 | * Dutch patients reported lower quality of communication about end of life care.
* Clinicians in both countries rarely discussed life-sustaining treatment preferences, prognoses, dying processes or spiritual issues.
 | * Data gathered from patients in different time periods, using different methods, and patients with different disease stages and comorbidities;
* Difficult to generalize due to regional differences;
* Lack of objective measures to assess the quality of communication.
 | * Interesting comparison between patients with COPD living in the US and in The Netherlands;
* Comprehensive description of the methods used to compare the two cohort of patients.
 |
| [[35](#_ENREF_35)], the Netherlands | To assess life-sustaining treatment preferences, advance care planning, and the quality of end of life care communication in Dutch outpatients with clinically stable but severe COPD or Chronic Heart Failure (CHF). | Prospective and Observational study* 105 patients with severe COPD;
* 80 patients with severe CHF.
 | * Advance directives were discussed with the physician specialist by 5.9% of patients with COPD and 3.9% of patients with CHF.
* Patients rated quality of patient-physician end of life care communication as poor.
* Physicians rarely discussed prognosis, dying and palliative care.
 | * Small amount of information dedicated to communication about end of life care;
* Large differences between the two cohorts of patients;
* Small participation rate;
* Exclusion of clinicians from the study;
* Use of cross-sectional study;
* Inclusion of patients with severe disease, may have prevented future comparisons with patients in different stages.
 | * Comprehensive description of the methods used in the study;
* Comparison between patients with COPD and patients with heart failure.
 |
| [[24](#_ENREF_24)], USA | To show how physicians and other health care professionals can help their patients with advance care planning and assess patient preferences for care at the end of life. | Narrative ReviewSample - Not Applicable | * Most patients did not participate in advance care planning, yet many were willing to discuss end of life care.
* One way to determine patients’ preferences for end of life care was to discuss hypothetical situations.
 | * Lack of information regarding the methods used in the report;
* Lack of the discussion and limitations sections;
* Somehow old study;
* Report generated for the general patient regardless of their disease, therefore there is a lack of specific guidance for COPD.
 | * Report focused in clinical practice and in clinicians;
* Presentation of a practical guide to discuss palliative care with patients.
 |
| [[37](#_ENREF_37)], USA | To identify the barriers and facilitators to end of life care communication as a first step to overcoming barriers and capitalizing on facilitators. | Focus groups and Cross Sectional Study* 115 oxygen-dependent COPD patients;
* 56 respiratory physicians.
 | * 32% of patients reported having had a discussion about end of life care.
* The most commonly endorsed barriers were “I’d rather concentrate on staying alive,” and “I’m not sure which doctor will be taking care of me”.
* The greater the number of barriers endorsed by patients, the less likely they were to have discussed end of life care with physicians.
 | * Somehow old study, used findings collected in 1999-2002;
* Inclusion of patients with only severe disease;
* Small information regarding the development of the questionnaire used in the study;
* Prospective cross-sectional study;
* Lack of detailed information regarding the barriers and facilitators of the conversations collected;
* Small participation rate of physicians.
 | * Robust study with large number of participants;
* Large participation rate of patients;
* First study considering the barriers and facilitators of palliative care discussions with patients with COPD;
* Comprehensive study detailing the methods used in the study.
 |
| [[19](#_ENREF_19)], USA | To determine whether patients who reported having end of life conversations also reported higher perceived markers of quality of care and health status. | Cross-sectional study* 376 patients with COPD
 | * 14.6% of patients reported having end of life discussions.
* Individuals who reported having end of life conversations with their physicians were significantly more likely to rate their quality of care as the best imaginable and to be very satisfied with their medical care.
* Discussions were more likely to have occurred among patients with worse health status.
 | * Cross-sectional study;
* Patients may have been excluded, if they did not acknowledge a discussion about palliative care that they actually had in the past;
* Lack of detailed information about the effects of conversations in the patients’ healthcare delivery and in their condition;
* Exclusion of clinicians;
* Lack of information regarding the content of conversations with patients and its consequent effect;
* Somehow old, used data collected from 2004-2007;
* Small number of women included in the study.
 | * Comprehensive description of the methods used during the study;
* First study looking at the effects of discussions in the lives and wellbeing of patients with COPD;
* Large sample size.
 |
| [[47](#_ENREF_47)], CAnada | To determine when respiratory physicians approach patients with end-stage COPD to decide about the use of mechanical ventilation, what information they provide to patients and how they provide it. | Questionnaire* 279 respiratory physicians
 | * Conversations were reported to occur most often at advanced stages of COPD.
* 43% stated that they discuss mechanical ventilation with 40% or less of their COPD patients before an exacerbation necessitates ventilatory support.
* 55.2% described the decision-making process as a collaboration between patient and physician.
* 53% of the respondents indicated that they occasionally, often or always modify the information provided to patients in order to influence their decision.
 | * Old study, used data collected in 1996 or before;
* Lack of detailed information regarding the topic from patients or physicians;
* Exclusion of patients;
* Only respiratory physicians were included in the study.
 | * Large sample size and large participation rate;
* Comprehensive description of the methods used during the study;
* Detailed information regarding the development, piloting and administration of the survey.
 |
| [[5](#_ENREF_5)], UK | To show the results of a literature review about end of life care conversations COPD. | Systematic Literature ReviewSample - Not Applicable  | * Most patients reported that they have not had end of life conversations with healthcare professionals.
* Many patients would like these conversations, a potentially large minority would not.
* Healthcare professionals find these discussions difficult and many prefer patients to initiate them.
 | * Lack of detailed methods used in the development of the review;
* Small overall review, more details would benefit review;
* Small number of databases searched;
* Exclusion of grey and unpublished literature.
 | * Robust systematic review, which used a large and diverse number of references;
* Recent review;
* Presentation and synthesis of the review when compared with the large number of papers included.
 |
| [[53](#_ENREF_53)], USA | To explore the responses of patients living with serious illness to the question “what is your understanding of your illness?” and to identify similarities and differences in themes and language used by cancer and non-cancer patients to discuss their illness. | Qualitative Analysis* 209 patients, of whom 70 had a diagnosis of COPD.
 | * 5 major themes were identified: naming the diagnosis or describing the pathophysiology, illness history, prognosis, symptoms, and causality.
* Responses varied by diagnosis. Cancer patients’ responses more often included specific diagnostic details and prognosis, while non-cancer patients referenced symptoms and causality.
 | * Difficult to generalize findings because of the heterogeneity of the participants included;
* Exclusion of clinicians;
* Inclusion of patients with only severe disease;
* Somehow old study, findings from 2004-2007;
* Lack of detailed information from patients and clinicians.
 | * Inclusion and comparison of patients with different diseases and demographics;
* Evenly distribution of patients with different diseases;
* Comprehensive description of the methods used in the study.
 |
| [[45](#_ENREF_45)], New ZEaland and UK | To compare the views of GPs in Auckland, New Zealand (NZ) and London, United Kingdom (UK) on conversations of prognosis in severe COPD. | Questionnaire* General Practitioners from London;
* General Practitioners from New Zealand.
 | * Most GPs in both samples stated that discussions on prognosis are necessary in severe COPD and that GPs have an important role in discussing prognosis.
* Smaller proportions of both samples reported usually having such conversations, although Auckland GPs (55.6%) were more likely to hold the discussions.
* Auckland GPs were more likely to agree that patients with severe COPD wanted to discuss prognosis and that patients valued these conversations.
* One-third of the Auckland GPs and nearly half the London GPs believe that some patients with severe COPD who want to discuss prognosis are not given the opportunity to do so.
 | * Somehow old study, used data gathered in 2003;
* Comparison study;
* May not be representative and generalizations may not be possible because of the heterogeneity of the sample;
* Small response rate.
 | * Interesting comparison between 2 different groups of GP’s in London and New Zealand;
* Identical questions were asked to the two groups of GP’s.
 |
| [[29](#_ENREF_29)], Australia | To explore the views of patients with COPD and healthcare professionals, focusing upon information needs and treatment preferences. | Interviews and focus groups* 10 COPD patients;
* 18 nurses;
* 7 respiratory doctors;
* 6 allied healthcare professionals.
 | * The theme underpinning all discussions was of tension between maintaining hope and negotiating the reality of the illness and its consequences.
* Patients tended to be optimistic, viewed acute exacerbations as separate from their underlying chronic illness, and were keen for intensive treatments, including intubation if acutely unwell.
* Both patients and healthcare workers believed that information around end of life should be offered routinely.
 | * Difficult to generalize due to the type of study – qualitative study;
* Small participation rate and small sample size;
* Particular inclusion criteria for the recruitment of patients, patients included if severe disease.
 | * In-depth perspectives of patients and clinicians regarding the information needs and end of life decisions;
* Presentation of most discussed themes during interviews and focus groups;
* Recent study.
 |
| [[55](#_ENREF_55)], USA | To review the approach to requests for “everything” and to provide examples of how physicians can manage some aspects of the conversation. | Narrative Review/Expert Opinion* 75-year–old man with oxygen dependent COPD
 | * Clinicians should not take the request for “everything” at face value, but should instead use it as a basis for broader conversation.
* The clinician should propose a philosophy of treatment and make recommendations that capture the patient’s values.
* Clinicians should respond to emotional reactions, negotiate disagreements, and use harm-reduction strategies.
 | * Methodology and methods of study not presented;
* Study used as an example a COPD patients, however the language and general information is dedicated to patients with all sorts of diseases;
* Lack of description of the discussion and limitations/strengths sections.
 | * Comprehensive information focused in clinical practice, with practical information given to clinicians;
* Step-by-step approach to hold conversations with patients/relatives who want everything.
 |
| [[15](#_ENREF_15)], USA | To provide a brief narrative review of recent research regarding patient–physician communication about palliative care for patients with COPD. | Narrative ReviewSample - Not Applicable | * One reason these patients may receive poor quality palliative care is that patient–physician communication about palliative and end of life care is unlikely to occur.
* Understanding the barriers to this communication may be an important step to improve communication about end of life care and improve patient-centred outcomes.
 | * Lack of the following sections: methods, discussion and limitations/strengths;
* May have missed important studies due to narrative review character;
* Somehow old review;
* Unable to understand the criteria, databases, data analysis and data synthesis methods used.
 | * Succinct and focused review in discussions about palliative care.
 |
| [[52](#_ENREF_52)], uSA | To explore whether educating patients via web conferencing would equip them with knowledge and skills to engage in conversations about end of life care. | Feasibility Study* 7 patients with severe to very severe COPD.
 | * 6 patients had completed advanced care planning forms but only half had shared these with their clinicians.
* Most patients felt confident about discussing end of life care preferences.
* Five felt the webinar was an acceptable option.
* At 3 months, all participants had taken further action on end of life planning.
 | * Small sample size and sample not representative of the majority of the COPD population;
* Very difficult to generalize and to draw conclusions from the sample used;
* Lack of a control group;
* Intervention presented in the study cannot be used with the general COPD patient due to high technology and education skills required.
 | * Interventional research study to improve conversations about end of life care wishes;
* Comprehensive description of methods and of steps used during the study;
* Description of implications of the study in future research.
 |
| [[54](#_ENREF_54)], USA | To describe patient-clinician communication practices about end of life care in patients with COPD using self-reported questionnaires. | Cross-Sectional Study* 376 patients with COPD
 | * All end of life care topics were under-addressed.
* Four topics were not addressed 77-94% of the time.
* None of the quality of communication items varied significantly by clinician type.
 | * Lack of in-depth information regarding end of life care topics;
* Use of a cross-sectional study of data collected previously;
* Small number of female patients included.
 | * Comprehensive description of the methods and steps used during the study;
* Medium-large participation rate in the study;
* Novel study comparing clinicians’ characteristics with the non- conversation of end of life care topics;
* All types of clinicians included.
 |
| [[41](#_ENREF_41)], France | To provide a description of the information provided by respiratory physicians to their COPD patients at regular follow-up visits and of the information received by COPD patients and their relative about COPD-related ICU stays. | Interviews* 126 COPD patients;
* 102 relatives;
* 173 respiratory physicians;
* 135 ICU physicians.
 | * For 41% of patients and 54% of relatives, ITU admission had never been expected prior to admission.
* One half of patients were not routinely informed by their respiratory physicians about possible ITU admission.
* Treatment options were not explained to COPD patients during regular respiratory visits.
* Respiratory physicians and ITU physicians have different perceptions of the decision-making process pertaining to ITU admission and intubation.
 | * Lack of in-depth information about the perspectives of patients and clinicians;
* Lack of information regarding the patients who died during their stay in the intensive care unit;
* Clinicians who participated in the study did not look after the patients who were also included.
 | * Very recent study;
* Large participation rate in the study;
* Large number of intensive care units included in the study;
* Comprehensive description of methods and steps taken in the study;
* Data may be generalized to other areas of France, country of origin of the study.
 |
| [[38](#_ENREF_38)], UK | To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for Advance Care Planning (ACP) and to understand, from the patient perspective, the optimum circumstances for ACP. | Interviews* 16 COPD patients;
* 15 Relatives.
 | * No patients recalled conversations about resuscitation or planning for the future.
* Hospital admission and discharge was seen as chaotic and lacking in continuity.
* Some patients welcomed the opportunity to discuss ACP and felt that their GP would be the best person for this.
* Others wished to avoid end of life care conversations but there was evidence that, with empathetic and knowledgeable support, these discussions could be initiated.
 | * Small number of female participants;
* Difficult to generalize information due to qualitative character of the study;
* Exclusion of clinicians in the study.
 | * Somehow recent Study;
* Comprehensive and thematic description of the patients’ perspectives regarding the use of hospital admissions to initiate conversations about resuscitation, ventilation and advance care planning;
* Inclusion of patients in different stages of their disease.
 |
| [[56](#_ENREF_56)], Canada | To offer some preliminary observations from a qualitative doctoral study to explore the question: What is required for meaningful, acceptable ACP in the context of advanced COPD? | Interventional Study* 8 patients with COPD;
* 7 informal carers.
 | * Despite initial resistance on the part of six out of eight patients, all were able to discuss end of life care concerns and appreciate some aspects of doing so.
* The sessions were an opportunity to: (1) learn more about end of life care options; (2) consider/document end of life care preferences; (3) counter the silence around the subject; and/or (4) have their illness concerns and experiences heard.
 | * May have included some leading questions, which may have biased some of the findings;
* Lack of details regarding exclusion and inclusion criteria, limitations and strengths and final conclusion;
* Only patients with severe disease were included;
* Small sample size.
 | * Comprehensive description of methods used in the study;
* Very much focused on the patient with COPD;
* Well-structured interventional study.
 |
| [[23](#_ENREF_23)], UK | To highlight the key components and challenges for patients and health professionals discussing end of life care in non-malignant respiratory disease. | Systematic Literature ReviewSample - Not Applicable | * Three themes involving components and challenges in end of life conversations were identified: the conversation, the health professional/patient relationship, and patient perceptions.
 | * Inclusion of patients with several non-malignant respiratory diseases;
* Small number of databases and papers included;
* 11-year window for the publication of papers;
* Exclusion of other reviews in the study;
* PICO framework used, therefore it led into a quantitative based review.
 | * Comprehensive description of the methods used during the review;
* Well-structured systematic review;
* Succinct, yet comprehensive review;
* Somehow recent review, used data published from 1999 to 2010.
 |
| [[3](#_ENREF_3)], Canada | To examine how the physician perceives the decision-making process. | Interviews* 15 respiratory physicians.
 | * Narratives were very similar in content and seemed well rehearsed.
* Fourteen respiratory physicians emphasized the importance of knowing patients as individuals prior to initiating this conversation.
* Individual physician comfort also appeared to affect the timing of the conversation.
* Physicians discussed the many elements that make the mechanical ventilation discussion difficult for physicians and patients.
 | * Old study, findings dating from 1995;
* Exclusion of patients from the study;
* Difficult to generalize due to qualitative and regional character of the study;
* Small number of female participants included;
* Findings may only reflect what physicians perceive as ideal communication and not what physicians actually perform in practice.
 | * In-depth details of the physicians’ thoughts regarding communication about intubation and ventilation;
* Large participation rate in the study;
* Majority of clinicians included had large clinical experience;
* Comprehensive description of the methods used during the study.
 |
| [[57](#_ENREF_57)], USA | To study whether a day-long communication skills training retreat would lead to enhanced performance of and confidence with specific end of life care conversations. | Randomized Controlled Trial* 23 medical residents in retreat group;
* 26 medical residents in control group.
 | * Retreat participants demonstrated higher T2 scores for breaking bad news, discussing direction of care, and responding to emotion.
* Comparing T2 to T1, the retreat group's improvement in responding to emotion was statistically significant.
* The retreat group's confidence improved significantly only for the breaking bad news construct.
 | * May have included medical trainees who do not provide care to patients with COPD;
* Lack of in-depth information about the communication skills of clinicians;
* Exclusion of patients from the study;
* Small sample size;
* Results may have been biased somehow, because control group received feedback about their communication skills after being assessed.
 | * Robust information from a randomized controlled trial;
* Large response rate;
* Comprehensive description of the methods used during the study.
 |
| [[26](#_ENREF_26)], canada | To provide guidance for advance care planning as it pertains to the inpatient setting. | Narrative ReviewSample - Not Applicable | * Clinicians can use the “surprise” question or more detailed clinical criteria to identify high-risk patients.
* When discussing goals of care with patients, clinicians should ask patients which family members they would like present and involve them.
* Discussions about goals of care and any decisions made should be clearly documented in the patient’s medical record.
 | * Lack of methods, discussion and limitations sections in the study;
* Inclusion of information and suggestion for patients with serious illnesses, therefore information was not specific tailored for patients with COPD.
 | * Recent Study;
* Practical review, very much focused in clinical practice;
* Important and interesting suggestions made by the authors.
 |

# References

1. NICE, *Chronic obstructive pulmonary disease - Quality Standard*, D.o. Health, Editor. 2011, National Institute for Health and Care Excellence.

2. Department of Health, *An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England*, D.o. Health, Editor. 2011, Department of Health. p. 56.

3. Sullivan, K.E., et al., *What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation?* CHEST, 1996. **109**(1): p. 258-264.

4. Halldórsdóttir, B.S. and E.K. Svavarsdóttir, *Purposeful Therapeutic Conversations: Are they effective for families of individuals with COPD: A quasi-experimental study.* Nordic Journal of Nursing Research & Clinical Studies / Vård i Norden, 2012. **32**(1): p. 48-51.

5. Momen, N., et al., *Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis.* Thorax, 2012. **67**(9): p. 777-80.

6. Wilson, D.M., et al., *The care needs of community-dwelling seniors suffering from advanced chronic obstructive pulmonary disease.* Canadian Journal on Aging, 2008. **27**(4): p. 347-357.

7. NICE, in *Chronic Obstructive Pulmonary Disease: Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care*. 2010: London.

8. Smith, S. and P. Kirkpatrick, *Use of solution-focused brief therapy to enhance therapeutic communication in patients with COPD.* Primary Health Care, 2013. **23**(10): p. 27-32.

9. Scullion, J. and S. Holmes, *Improving care for COPD.* Independent Nurse, 2009: p. 33-33.

10. World Health Association. *WHO Definition of Palliative Care*. 2016.

11. World Health Organization, *Palliative care for older people: better practices*. 2011: Denmark.

12. NICE, *End of life care for adults - Quality Standard*, D.o. Health, Editor. 2011.

13. Department of Health, *End of Life Care Strategy - Fourth Annual Report*, D.o. Health, Editor. 2012, Department of Health. p. 73.

14. National Institute for Health and Care Excellence, *Opioids for pain relief in palliative care overview*, D.o. Health, Editor. 2005, NICE: Manchester.

15. Randall Curtis, J., *Palliative care for patients with chronic obstructive pulmonary disease.* Respiratory Medicine: COPD Update, 2006. **2**: p. 86-90.

16. Gore, J.M., C.J. Brophy, and M.A. Greenstone, *How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer.* Thorax, 2000. **55**(12): p. 1000-6.

17. White, P., et al., *Palliative care or end-of-life care in advanced chronic obstructive pulmonary disease A prospective community survey.* British Journal of General Practice, 2011. **61**(587): p. 362-370.

18. Crawford, A., *Respiratory practitioners' experience of end-of-life discussions in COPD.* British Journal of Nursing, 2010. **19**(18): p. 1164-1169.

19. Leung, J.M., et al., *The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD.* CHEST, 2012. **142**(1): p. 128-133.

20. Curtis, J.R., et al., *Patient-physician communication about end-of-life care for pateints with severe COPD.* European Respiratory Journal, 2004. **24**(2): p. 200-205.

21. Curtis, J.R., et al., *Communication about palliative care for patients with chronic obstructive pulmonary disease.* Journal of Palliative Care, 2005. **21**(3): p. 157-164.

22. Curtis, J.R., *Palliative and end-of-life care for patients with severe COPD.* Eur Respir J, 2008. **32**(3): p. 796-803.

23. Stephen, N., et al., *End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review.* J Palliat Med, 2013. **16**(5): p. 555-65.

24. Kass-Bartelmes, B.L. and R. Hughes, *Advance care planning: preferences for care at the end of life.* Journal of Pain & Palliative Care Pharmacotherapy, 2004. **18**(1): p. 87-109.

25. Curtis, J.R., *Communicating with patients and their families about advance care planning and end-of-life care.* Respir Care, 2000. **45**(11): p. 1385-94; discussion 1394-8.

26. You, J.J., R.A. Fowler, and D.K. Heyland, *Just ask: discussing goals of care with patients in hospital with serious illness.* CMAJ: Canadian Medical Association Journal = Journal De L'association Medicale Canadienne, 2014. **186**(6): p. 425-432.

27. Centre for Reviews and Dissemination, *Systematic Reviews - CRD's guidance for undertaking reviews in health care.* 2008.

28. Liberati, A., et al., *The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration.* BMJ, 2009. **339**: p. b2700.

29. Philip, J., et al., *Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals.* Internal Medicine Journal, 2012. **42**(7): p. 816-822.

30. Halliwell, J., et al., *GP discussion of prognosis with patients with severe chronic obstructive pulmonary disease: a qualitative study.* Br J Gen Pract, 2004. **54**(509): p. 904-8.

31. Thomas, B.H., et al., *Quality Assessment Tool for Quantitative Studies.* The Effective Public Health Practice Project (EPHPP), 1998.

32. Bromley, H., et al. *Criteria for Evaluating Qualitative Studies*. 2002; Available from: <http://www.depts.ttu.edu/education/our-people/Faculty/additional_pages/duemer/epsy_5382_class_materials/Evaluating-Qualitative-Studies.pdf>.

33. Saks, M. and J. Allsop, *Doing a Literature Review in Health*, in *Researching Health: Qualitative, Quantitative and Mixed Methods* S.P. Ltd, Editor. 2007, SAGE Publications Ltd: London. p. 32-54.

34. Popay, J., et al., *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews - A Product from the ESRC Methods Programme.* 2006.

35. Janssen, D.J., et al., *A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure.* CHEST, 2011. **139**(5): p. 1081-1088.

36. Au, D.H., et al., *A Randomized Trial to Improve Communication About End-of-Life Care Among Patients With COPD.* CHEST, 2012. **141**(3): p. 726-735.

37. Knauft, E., et al., *Barriers and facilitators to end-of-life care communication for patients with COPD.* CHEST, 2005. **127**(6): p. 2188-2196.

38. Seamark, D., et al., *Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study.* Prim Care Respir J, 2012. **21**(3): p. 261-6.

39. Houben, C.H.M., et al., *Patient-Clinician Communication About End-of-Life Care in Patients with Advanced Chronic Organ Failure During One Year.* Journal Of Pain And Symptom Management, 2015.

40. Elkington, H., et al., *GPs' views of discussions of prognosis in severe COPD.* Fam Pract, 2001. **18**(4): p. 440-4.

41. Schmidt, M., et al., *Intensive care unit admission in chronic obstructive pulmonary disease: patient information and the physician's decision-making process.* Crit Care, 2014. **18**(3): p. R115.

42. Fahim, A. and J.A. Kastelik, *Palliative care understanding and end-of-life decisions in chronic obstructive pulmonary disease.* Clin Respir J, 2014. **8**(3): p. 312-20.

43. Dexter, P.R., et al., *Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. A randomized, controlled trial.* Ann Intern Med, 1998. **128**(2): p. 102-10.

44. Gaspar, C., et al., *End-of-life care in COPD: a survey carried out with Portuguese pulmonologists.* Rev Port Pneumol, 2014. **20**(3): p. 123-30.

45. Mulcahy, P., et al., *GPs' attitudes to discussing prognosis in severe COPD: an Auckland (NZ) to London (UK) comparison.* Fam Pract, 2005. **22**(5): p. 538-40.

46. Janssen, D.J., et al., *Patient-clinician communication about end-of-life care for Dutch and US patients with COPD.* Eur Respir J, 2011. **38**(2): p. 268-76.

47. McNeely, P.D., et al., *Deciding about mechanical ventilation in end-stage chronic obstructive pulmonary disease: How respirologists perceive their role.* Canadian Medical Association Journal, 1997. **156**(2): p. 177-183.

48. Engelberg, R., L. Downey, and J.R. Curtis, *Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care.* Journal Of Palliative Medicine, 2006. **9**(5): p. 1086-1098.

49. Curtis, J.R., et al., *An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer.* Journal of Palliative Medicine, 2008. **11**(4): p. 610-620.

50. Ahia, C.L. and C.M. Blais, *Primary palliative care for the general internist: integrating goals of care discussions into the outpatient setting.* The Ochsner Journal, 2014. **14**(4): p. 704-711.

51. Curtis, J.R., et al., *Patients' perspectives on physician skill in end-of-life care - Differences between patients with COPD, cancer, and AIDS.* Chest, 2002. **122**(1): p. 356-362.

52. Reinke, L.F., et al., *Feasibility of a Webinar for Coaching Patients With Chronic Obstructive Pulmonary Disease on End-of-Life Communication.* American Journal of Hospice & Palliative Medicine, 2011. **28**(3): p. 147-152.

53. Morris, D.A., et al., *What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness.* J Gen Intern Med, 2012. **27**(11): p. 1460-6.

54. Reinke, L.F., et al., *Patient-Clinician Communication about End-of-Life Care Topics: Is Anyone Talking to Patients with Chronic Obstructive Pulmonary Disease?* Journal of Palliative Medicine, 2011. **14**(8): p. 923-928.

55. Quill, T.E., R. Arnold, and A.L. Back, *Discussing treatment preferences with patients who want "everything".* Annals of Internal Medicine, 2009. **151**(5): p. 345-349.

56. Simpson, A.C., *An opportunity to care? preliminary insights from a qualitative study on advance care planning in advanced COPD.* Progress in Palliative Care, 2011. **19**(5): p. 243-253.

57. Szmuilowicz, E., et al., *Improving residents' end-of-life communication skills with a short retreat: a randomized controlled trial.* J Palliat Med, 2010. **13**(4): p. 439-52.

58. Sundh, J., et al., *The Dyspnoea, Obstruction, Smoking, Exacerbation (DOSE) index is predictive of mortality in COPD.* Primary Care Respiratory Journal, 2012. **21**(3): p. 295-301.

59. Esteban, C., et al., *BODE-Index vs HADO-score in chronic obstructive pulmonary disease: Which one to use in general practice?* BMC Medicine, 2010. **8**: p. 28-28.

60. Wright, A.A., et al., *Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment.* JAMA, 2008. **300**(14): p. 1665-73.

61. Zhang, B., et al., *Health care costs in the last week of life: Associations with end-of-life conversations.* Archives of Internal Medicine, 2009. **169**(5): p. 480-488.

62. Curtis, J.R., et al., *Patient-physician communication about end-of-life care for patients with severe COPD.* Eur Respir J, 2004. **24**(2): p. 200-5.

1. The frequency for palliative care discussions in COPD was generated from 17 papers. These papers included qualitative and quantitative studies with moderate and high quality, papers which compared COPD patients and patients with other diseases, and narrative reviews. [↑](#footnote-ref-1)
2. The tool used was the Quality of Communication Questionnaire [48]. Rating of quality of communication varies from 0 (very worst quality) to 10 (very best quality). [↑](#footnote-ref-2)
3. The table shows the results of the gathering of all topics reported in several studies [3, 13, 16, 19, 32, 36, 37, 39, 45-47, 49, 51, 53, 54]. [↑](#footnote-ref-3)