

Advance care planning for patients with chronic respiratory diseases: A systematic review of preferences and practices

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ABSTRACT

Background

Advance care planning (ACP) supports patients in identifying and documenting their preferences and timely discussing them with their relatives and healthcare professionals (HCPs). Since the British Thoracic Society encourages ACP in chronic respiratory disease, the objective was to systematically review ACP practice in chronic respiratory disease, attitudes of patients and HCPs and barriers and facilitators related to engagement in ACP.

Methods

We systematically searched 12 electronic databases for empirical studies on ACP in adults with chronic respiratory diseases. Identified studies underwent full review and data extraction.

Results

Of 2509 studies, 21 were eligible: 10 were quantitative studies. Although a majority of patients was interested in engaging in ACP, ACP was rarely carried out. Many HCPs acknowledged the importance of ACP, but were hesitant to initiate it. Barriers to engagement in ACP were the complex disease course of patients with chronic respiratory diseases, HCPs' concern of taking away patients' hopes and lack of continuity of care. The identification of trigger points and training of HCPs on how to communicate sensitive topics were identified as facilitators to engagement in ACP.

Conclusions

In conclusion, ACP is surprisingly uncommon in chronic respiratory disease, possibly due to the complex disease course of chronic respiratory diseases and ambivalence of both patients and HCPs to engage in ACP. Providing patients with information about their disease can help meeting their needs. Additionally, support of HCPs through identification of trigger points, training, and system-related changes can facilitate engagement in ACP.

INTRODUCTION

Chronic respiratory diseases have grown in prevalence and are major causes of health burden and death.^{1,2} Chronic pulmonary disease (COPD), for example, has become the fourth leading cause of death worldwide.³ Patients with chronic respiratory diseases, such as COPD or pulmonary fibrosis, experience a complex and often unpredictable disease course,⁴ which is characterized by a gradual decline, interrupted by sudden and life-threatening exacerbations.^{5,6} As the disease progresses, complications may become more frequent and complex.⁷ Disease progression may also lead to a variety of symptoms, such as dyspnoea and comorbidities, which can reduce the quality of life of patients substantially.⁷ Patients, their relatives and healthcare professionals (HCPs) are faced with treatment decisions throughout the disease course. Acute deterioration of health can,⁷ for instance, result in respiratory failure requiring mechanical ventilation and the necessity of having to make ad hoc decisions on how to proceed.⁸

Since patient preferences for treatments such as mechanical ventilation vary,⁹ patient-centred discussions about goals of care are needed, while taking into account patients' preferences for content and timing of such discussions.¹⁰ The British Thoracic Society and American College of Chest Physicians acknowledge advance care planning (ACP) as an integral part of cardiopulmonary medicine and encourage end-of-life discussions about goals of care.^{11,12} ACP is a means to support patients in identifying their preferences of care, discussing these preferences timely with their relatives and HCPs and, if desired, documenting them in an advance directive (AD). In other disease groups, such as frail nursing home residents, ACP has been found to have beneficial effects on the communication between patients and HCPs and patients' quality of life.¹³ ACP has also been found to have the potential to increase patients' satisfaction with care and care being delivered in accordance with patients' preferences.¹³

To date, there is no thorough overview of the use of ACP for patients with chronic respiratory diseases, of the attitudes towards ACP of those who may be involved in it and of comprehensive ACP programmes in this context. This systematic review aims to describe ACP practice in chronic respiratory disease, summarising findings on (1) how ACP is defined in chronic respiratory disease, (2) the experiences with and attitudes towards ACP of patients and HCPs, (3) the barriers and facilitators related to engagement in ACP and (4) the effects of ACP programmes.

METHODS

Registration of the review

This systematic review was registered at the PROSPERO register (registration number: CRD42016039787). The full form can be accessed online at <https://www.crd.york.ac.uk/PROSPERO/>

Inclusion and exclusion criteria

We conceptualised ACP following the comprehensive definition of the National Academy of Medicine (NAM):

Advance care planning refers to the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes. Ideally, these conversations (1) occur with a person's healthcare agent and primary clinician, along with other members of the clinical team; (2) are recorded and updated as needed; and (3) allow for flexible decision making in the context of the patient's current medical situation.¹⁴

Based on this definition, we identified four core elements of ACP (see box).

We included studies with interventions, programmes, or activities that were labelled as 'advanced care planning' by the authors or studies addressing one or more core elements of ACP as defined by the NAM.¹⁴ This concerned standalone programmes or activities, as well as activities or programmes as part of a bigger (palliative care) intervention. However, if the ACP components in such a bigger intervention were not clearly described, we excluded the study.

Box Inclusion and exclusion criteria for the current review

Inclusion criteria:

1. Original empirical research on the definitions of advance care planning (ACP), the experiences with and attitudes towards ACP of patients and healthcare professionals (HCPs), the barriers and facilitators related to engagement in ACP and the effects of ACP programmes.
2. Research in the field of chronic respiratory disease.
3. Studies must address ACP, defined as:
 - a. Interventions, programmes, or activities that the authors label as 'advance care planning' or
 - b. Studies addressing one or more core elements of ACP as defined by the National Academy of Medicine¹⁴
 1. discussing values and goals for future medical care and treatment with an HCP
 2. clarifying values and goals for future medical care and treatment
 3. involving a personal representative
 4. documenting patients' wishes.
4. Studies published in English.

Exclusion criteria:

1. Studies in which ACP is only an element of a more complex care programme, such as palliative care, and specific content on ACP are not clearly described.
2. Studies involving children and adolescents.

Information sources and search

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist for reporting systematic reviews was used as the underlying structure of this review.¹⁵ A systematic search strategy was developed with the aid of a biomedical information specialist of the Erasmus MC medical library. The following electronic databases were used: Embase, MEDLINE, Web of Science, Scopus, CINAHL EBSCO, PsycINFO, Cochrane, PubMed, LILACS, SciELO, ProQuest and Google Scholar.

The search was conducted on 26 June 2015. The search terms for the databases can be found in the online supplementary file (S-box 1–11).

Study selection

Duplicates of the retrieved studies were removed. Based on the inclusion and exclusion criteria (box), two reviewers (LJJ and MZ) independently screened titles and abstracts for eligibility. Thereafter, they reviewed the full text of the remaining studies. Disagreements were discussed, if necessary including IJK and JACR, and solved. The reviewers used the web-based software platform Covidence (www.covidence.org) for screening and reviewing the studies.

Data extraction

We developed a data extraction form for this systematic review and used it to extract data on the study characteristics and results of the studies. We extracted the elements of ACP that were described in the conducted studies. Furthermore, we extracted data on the patients' as well as the HCPs' perspective on ACP, organising the results into experiences with and attitudes towards ACP, barriers and facilitators related to engagement in ACP and the effects of ACP programmes. We defined barriers and facilitators as predisposing factors reported by either patients, HCPs or both that hamper or facilitate engagement in ACP. We solely included those barriers and facilitators that were endorsed by at least 10% of the participants of the particular study. We chose for the cut-off point of 10% of participants to include as much information as possible, while at the same time keeping the information relevant and meaningful. The extraction was completed by one author (LJJ) and checked by another author (MZ). Disagreements were discussed and solved.

Risk of bias assessment and quality appraisal

Risk of bias assessment

The quantitative studies were assessed by two reviewers (LJJ and MZ) with a standardised form of seven items in a modified version of the guidelines for methodological quality assessment of the Dutch Cochrane Centre.¹⁶ The checklist assesses the (1) research hypothesis, (2) study population, (3) selection bias, (4) exposure, (5) outcome, (6) confounding and (7) a general opinion on the study's validity and applicability. A score of 1 was assigned when the criterion had been met sufficiently, a score of 0 when the criterion had not been met sufficiently and a question mark when the information for rating the criterion was lacking. The rating resulted in a total score from 0 to 7. A score of three or less was considered a study of low quality.

Quality appraisal

For the quality appraisal of the qualitative studies, two reviewers (LJJ and MZ) used the 'Consolidated criteria for reporting qualitative research' (COREQ) list,¹⁷ which is recommended by Cochrane Netherlands. The COREQ is a 32-item checklist, developed to promote explicit and comprehensive reporting of qualitative studies. The checklist evaluates qualitative studies on three domains: (1)

research team and reflexivity, (2) study design and (3) analysis and findings. A plus (+) was assigned when the criterion had been properly described (score 1), a minus (-) when it was described unclearly (score 0), and a plus-minus (+/-) when the description was incomplete (score 0.5). Points were added for a total score ranging from 0 to 32.

RESULTS

Study selection

Our systematic search identified 4031 studies as potentially eligible for this review. After removing duplicates, 2509 studies remained, which were screened based on title and abstract. 2264 studies were excluded, mostly because ACP was only an element of an overarching intervention, such as a palliative care programme, and the ACP-specific components were not clearly described. Full text of 245 studies was assessed for eligibility. In the end, 21 studies were included for the analysis (see figure 1).

Study characteristics

Of the 21 studies, 10 had a quantitative study design (table 1).¹⁸⁻²⁷ Out of these 10 studies, eight were observational, cross-sectional and retrospective.^{19 20 22-27} Nine studies had been conducted in the USA.^{18 20-23 25 26 28 29} Studies involved patients with COPD (n=13),^{18 19 23-25 27 30-36} chronic lung diseases (n=5),^{20-22 29 37} cystic fibrosis (n=2),^{26 28} and progressive idiopathic fibrotic interstitial lung disease (n=1).³⁸ Sixteen studies described the patients' perspective on ACP,^{18 21-26 28-30 33-38} nine described the perspective of HCPs.^{19 20 24 25 27 29 31 32 38} Sixteen studies had been conducted in an outpatient setting.^{18-26 29 30 32 33 35-37} Sample sizes varied from 17 to 513 in the studies with a quantitative design and from 7 to 67 in those with a qualitative design. Five studies evaluated an ACP programme.^{18 21 33 35 37} Studies were published between 1996 and 2014.

Online supplementary tables 1 and 2 present the results of the risk of bias assessment of the quantitative studies and the results of the quality appraisal of the qualitative studies, respectively. One study, that was described in a 'short communication', was of low quality (score of 2), due to concerns about the rationale of the study, study population and selection bias, as well as potential confounding.²⁷ The quality scores of the remaining quantitative studies ranged from 4 to 7, indicating overall good quality of the studies. One study had the maximum score of 7.²⁴ Four studies had a score of 6. The results of these studies should be interpreted in the light of concerns about confounding^{18 21} and selection bias.^{23 25} These concerns were also the most prominent quality issues of the quantitative studies in general (risk of possible confounding in 6 out of 10 studies, concerns about selection bias in 4 out of 10 studies).

The mean quality appraisal score of the qualitative studies was 16.5 of 32 (range 12–26.5). Almost all studies had poor ratings on the first domain, 'Research team and reflexivity'. Studies with the

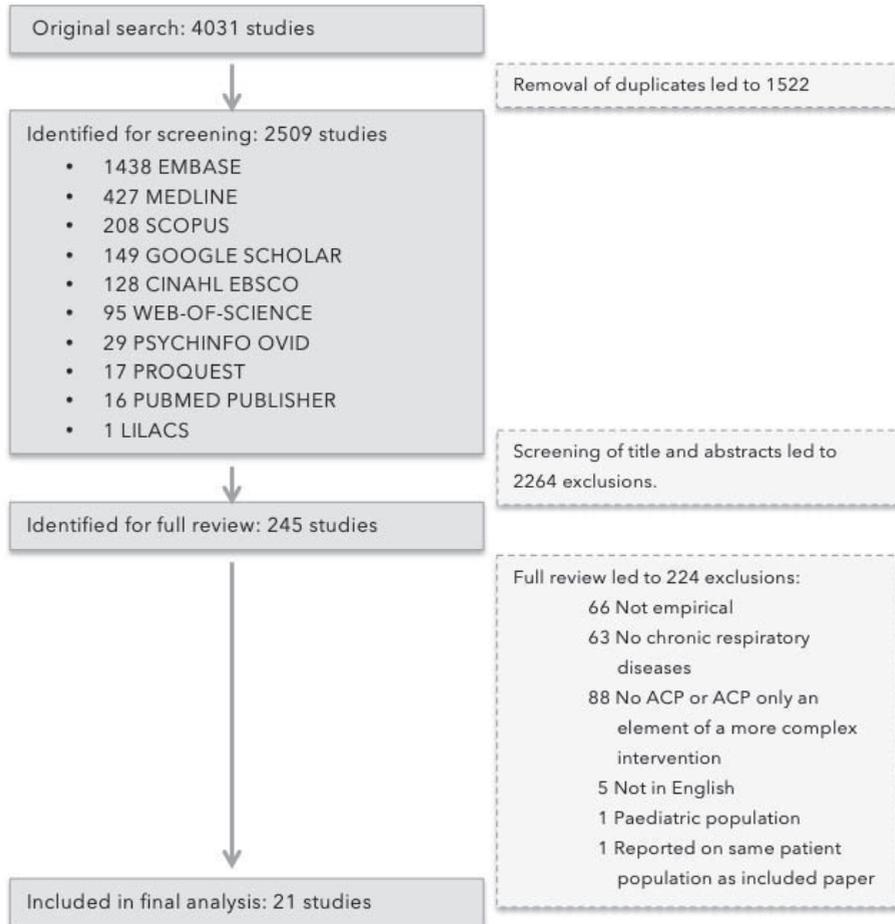


Figure 1. Flow diagram of article inclusion for this review. ACP, advance care planning.

lowest scores also provided insufficient information on the domains 'Study design' and 'Analysis and findings'. The first domain 'research team and reflexivity' was reported the poorest throughout all studies, which clearly had a detrimental impact on the overall quality of the studies.

Synthesis of results

Core elements of ACP studied in chronic respiratory disease

Our first aim was to summarise how ACP is defined in chronic respiratory disease. We therefore gathered which elements of ACP were described in the conducted studies (table 2). The vast majority of studies investigated the discussion of end-of-life care in their studies. The documentation of patients' wishes was investigated in about half of the studies.

Table 1. Study characteristics of the included studies

First author (year)	Study design	Country	Setting	Type of disease	Sample size (response rate (%))
Quantitative study design					
Target group: patients					
Au (2012) ¹⁸	Experimental Longitudinal Prospective	USA	Outpatient clinic	COPD	306 (81)
Heffner (1997) ²¹	Experimental Longitudinal Prospective	USA	Outpatient clinic	Chronic lung diseases	93 (ns)*
Heffner (1996) ²²	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Chronic lung diseases	105 (100)
Janssen (2011) ^{23,†}	Observational Cross-sectional Retrospective	NL/USA	Outpatient clinic	COPD	513 (ns)*
Sawicki (2008) ²⁶	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Cystic fibrosis	234 (77)
Target group: patients and healthcare professionals					
Janssen (2011) ²⁴	Observational Cross-sectional Retrospective	NL	Outpatient clinic	COPD	105 patients (63), 101 HCPs (96)
Knauff (2005) ²⁵	Observational Cross-sectional Retrospective	USA	Outpatient clinic	COPD	115 patients (40), 56 HCPs (86)
Target group: healthcare professionals					
Gaspar (2014) ¹⁹	Observational Cross-sectional Retrospective	Portugal	Inpatient and outpatient clinic	COPD	136 (29)
Heffner (1996) ²⁰	Observational Cross-sectional Retrospective	USA	Outpatient clinic	Chronic lung diseases	218 (63)
Smith (2014) ²⁷	Observational Cross-sectional Retrospective	Australia	Inpatient clinic	COPD	17 (41)
Qualitative study design					
Target group: patients					
Brown (2012) ³⁰	Semi-structured interviews	Australia	Outpatient clinic	COPD	15
Dellon (2010) ²⁸	Semi-structured interviews	USA	Inpatient clinic	Cystic fibrosis	36
MacPherson (2012) ³⁶	Semi-structured interviews	UK	Inpatient clinic, GP practices	COPD	10
Seamark (2012) ³⁴	Semi-structured interviews	UK	Inpatient clinic	COPD	16
Simpson (2011) ³⁵	Semi-structured interviews	Canada	Outpatient clinic	COPD	8
Nguyen (2013) ³³	Qualitative descriptive	Canada	Outpatient clinic	COPD	12

Table 1. Study characteristics of the included studies (continued)

First author (year)	Study design	Country	Setting	Type of disease	Sample size (response rate (%))
Burge (2013) ³⁷	Prospective semi-structured interviews	Australia	Inpatient and outpatient clinic	Chronic lung diseases	67
Target group: patients and healthcare professionals					
Bajwah (2012) ³⁸	Semi-structured interviews	UK	Inpatient clinic	PIF-ILD	8 patients 6 HCPs
Hajizadeh (2014) ²⁹	Semi-structured interviews	USA	Outpatient clinic	Chronic lung diseases	11 patients five physicians
Target group: healthcare professionals					
Crawford (2010) ³¹	Semi-structured interviews	UK	Inpatient clinic	COPD	7
Gott (2009) ³²	Focus group	UK	GP practices	COPD	39

*ns=response rate not specified.

‡Data of a part of the included patients in this study were also used in the analysis of the study by Jansen et al. 2011²⁴

COPD, chronic obstructive pulmonary disease; GP, general practitioner; PIF-ILD, progressive idiopathic fibrotic interstitial lung disease; NL, the Netherlands.

Experiences with and attitudes towards ACP in chronic respiratory disease from a patient perspective

Involvement in discussions about end-of-life care preferences was addressed in 11 articles. Six of these studies had a quantitative study design. Seven studies involved patients with COPD. Per study, 12%–32% of patients could recall involvement in end-of-life care discussions.^{18 23-26} The qualitative studies found that patients could rarely recall these discussions.^{29 30 34 36}

Eight studies addressed patients' interest in discussing end-of-life care preferences. Two quantitative studies, each of high quality, involved patients with COPD and chronic lung diseases in an outpatient setting and found that 68% and 99% of the patients, respectively, were interested in discussing end-of-life care preferences (online supplementary table 3).^{18 22} In five qualitative studies patients with a variety of chronic respiratory diseases expressed willingness to discuss end-of-life care preferences.^{29 30 34 36 38} Two of these qualitative studies revealed some hesitation of patients to talk about end-of-life care preferences, mainly due to uncertainty about the stability of their preferences and the sensitive nature of the topic.^{34 36}

Seven studies addressed the documentation of preferences. Two quantitative studies of high quality, in an outpatient setting with patients with chronic lung diseases and cystic fibrosis, found that 30% and 42% of patients reported documentation of their wishes through an AD.^{22 26} Documentation of patients' wishes however did not always result in those wishes being discussed with the HCP, merely 19% of the patients in this study discussed their ADs with their HCPs.²² In four qualitative studies, involving patients with a variety of chronic respiratory diseases in inpatient as well as outpatient clinics, only a minority of the interviewed patients had heard of an AD.^{29 30 34 38}

Table 2. Core elements of advance care planning studied in chronic respiratory disease (n=21)

Core elements of advance care planning	Specific core elements of advance care planning as addressed in studies in chronic respiratory disease (n=21)
1) Discussing end-of-life care	20 ^{18-36 38}
2) Clarifying values and goals	7 ^{18 19 23 24 27 29 33}
3) Involving a personal representative	7 ^{18 26 27 29 30 35 37}
4) Documenting patients' wishes	11 ^{19-22 26 29 30 33-36}

Experiences with and attitudes towards ACP in chronic respiratory disease from a HCP perspective

Eight studies addressed the experiences with and attitudes towards ACP from the HCP perspective (online supplementary table 4). Four of these were quantitative studies, in both inpatient as well as outpatient settings, and addressed the engagement of HCPs in ACP discussions.^{19 20 24 27} The percentage of self-reported engagement in ACP was 20%–33% in the three high-quality studies^{19 20 24} and 13% in a pilot study of low quality.²⁷

Two of these high-quality studies and the pilot study of lower quality found that 42-77% of HCPs recognised the importance of discussing end-of-life care topics.^{19 20 27}

The vast majority of HCPs in two qualitative studies with patients with COPD and chronic lung diseases in an outpatient setting endorsed the need of discussing end-of-life care.^{29 32} HCPs in one of these studies stated that not discussing end-of-life care would limit patient choice.³² The pilot study that was carried out in Australia found that 41% of HCPs thought that their patients would be willing to discuss their wishes.²⁷

The same Australian study found that 77% of HCPs felt comfortable to talk about end-of-life care,²⁷ while a high-quality study from Portugal revealed that 89% of HCPs found it difficult to engage in discussions on end-of-life care preferences.¹⁹ Two qualitative studies, that involved patients with COPD and progressive idiopathic fibrotic interstitial lung disease (PIF-ILD) in an inpatient clinic showed that HCPs had doubts about the right moment to initiate these discussions on end-of-life care preferences^{31 38} and felt uncomfortable to share prognostic estimates such as life expectancy.²⁹ In one qualitative study³¹ that involved COPD inpatients, HCPs emphasized that the timing of engaging in these discussions was crucially dependent on the patients' disease pathway and highlighted a clear difference between diseases.³¹

Barriers and facilitators related to patient and HCPs' engagement in ACP

Table 3 shows the most frequently described barriers and facilitators related to patient and HCPs' engagement in ACP.^{19 21 23 25 27-34 37 38} The barriers and facilitators described in these 13 studies were related to the level of the patient, the HCP and the healthcare system.

Table 3. Barriers and facilitators related to engagement in ACP

	Patient related	HCP related	System related
Barriers	Insufficient patient knowledge about their own disease. ^{23 25 29 32 38}	Perceived hesitance of HCPs to discuss preferences and engage in ACP. ^{21 23}	Ethos of 'cure at all costs' in health care. ³²
	Unpredictable disease course and difficult prognostication. ^{19 25 27 31 32}	HCP's perceived fear of taking away patients' hope. ^{19 25}	Perceived HCP's time constraints. ^{23 25 27 29 32 34 38}
	Perceived patient hesitation for considering and discussing treatment preferences. ^{19 25 27}		Lack of organisational support and formal training on communicating end-of-life care options. ^{19 22 32 37 38} Lack of continuity and coordination of care including uncertainty on whose responsibility it is to initiate and follow-up on ACP discussions. ^{21 23 25 30 32 38}
Facilitators	Increased patient knowledge on terminal nature of their disease. ^{28 33}	Advanced stage of disease. ^{23 25 27 29}	Patient initiation of ACP (as experienced by HCPs), ³¹ HCP initiation of ACP (as experienced by patients). ^{23 25 28}
	Patients accepting their disease, increasing readiness to discuss end-of-life care. ^{27 31 33}	Identification of the right moment and setting to engage in an ACP discussion. ^{28 31 32}	Implementation of trigger points to discuss ACP. ³²
	Patient worry to become a burden for the family. ^{23 25}	HCPs' experience with care for patients at the end of life/ with lung diseases. ^{23 25 34}	Continuity of care, including good HCP-patient relationship. ^{23 25 31 33 34}
	Patient experience with end of life. ^{23 25 33}		

Two high-quality quantitative studies and three qualitative studies, involving patients with COPD and PIF-ILD, and their HCPs described insufficient awareness of patients about the nature of their disease, especially about its severity, as a barrier to ACP.^{23 25 29 32 38} Four studies, among which one high-quality quantitative study, found that the unpredictable disease course of these diseases, particularly COPD, makes it difficult for HCPs to define and communicate the prognostic estimates to patients.^{19 27 31 32} The same four studies and an additional high-quality quantitative study found that the complex disease course of chronic respiratory diseases also makes it difficult for HCPs to identify trigger points for the initiation of ACP, especially in chronic lung diseases.^{19 25 27 31 32} Besides, HCPs perceive patients to be hesitant to consider and discuss end-of-life care,^{19 25 27} while patients perceived HCPs to be reluctant to initiate ACP discussions.^{21 23} This impression by patients aligns with HCPs acknowledging their fear of taking away patients' hope. This might be related to an ethos of 'cure at all costs', as identified by three studies in the UK, USA and Portugal involving patients with COPD.^{19 25 32}

Seven studies reported system-related barriers to ACP, among which time constraints,^{23 25 27 29 32 34 38} a lack of structural support, such as a lack of continuity of care,^{21 23 25 30 32 38} and a lack of formal training in communicating end-of-life care options.^{19 22 32 37 38} Two quantitative and two qualitative studies found that both patients and HCPs perceived lack of continuity and coordination of care as a barrier,^{23 25 30 38} resulting in uncertainty about whose responsibility it is to initiate ACP discussions and to follow-up on these discussions.^{21 32}

Two qualitative studies, involving patients with COPD and cystic fibrosis, identified patient knowledge and understanding of the nature of their disease as a facilitator for engagement in ACP.^{28 33} Patients' acceptance of their disease was mentioned as another facilitator.^{27 31 33} Three studies with patients with COPD and cystic fibrosis found that patient acceptance might increase with disease progression.^{23 25 28} Two high-quality quantitative studies suggested that with disease progression, patients' worries about becoming a burden for loved ones increased, which in turn was found to be a facilitator for engagement in ACP.^{23 25} Engagement in ACP was more acceptable to patients who previously experienced loved ones having to decide about end-of-life care or who had experienced loved ones dying.^{23 25 33}

Three quantitative studies, among which two of high quality and one qualitative study, found that patients as well as HCPs perceived talking about ACP to be easier when patients had an advance disease stage.^{23 25 27 29} The identification of the right moment and setting to engage in ACP discussions was perceived as beneficial by both,^{28 31 32} as well as the HCPs' expertise in caring for patients with lung disease or end-of-life care.^{23 25 34}

While patients with COPD and cystic fibrosis preferred ACP discussions to be initiated by HCPs,^{23 25 28} one qualitative study with patients with COPD in the UK found that HCPs preferred patients to start discussions on end-of-life care.³¹ The implementation of trigger points to discuss ACP, such as the start of oxygen therapy, could help to overcome this dilemma.³² Patients and HCPs experienced a good patient–HCP relationship, characterised by trust and continuity, as supportive for engagement in ACP.^{23 25 31 33 34}

Effects of ACP programmes

Five studies, two quantitative and three qualitative, evaluated the effects of an ACP programme (online supplementary table 5).^{18 21 33 35 37} Two high-quality quantitative studies evaluated a patient-specific feedback form to stimulate ACP conversations in patients with COPD¹⁸ and educational workshops on ADs and other end-of-life topics for patients with chronic lung diseases.²¹ The interventions increased quality of end-of-life care communication¹⁸ and resulted in an increased number of completed living wills.²¹

The three qualitative studies evaluated programmes ranging from delivering video material to patients with COPD,³³ to ACP conversations based on a conversation guide for patients with chronic lung diseases and COPD.^{35 37} Some patients perceived the information presented as confrontational, nevertheless they agreed about the need to gain a thorough understanding of treatment options.^{33 35 37} Considering the timing of the discussions, a study on the effects of a DVD movie covering information on end-of-life care options found that most patients wished their HCPs to mainly be sensitive to their individual needs.³³

DISCUSSION

This is the first systematic review thoroughly describing ACP practice in chronic respiratory disease, summarising findings on how ACP is defined in chronic respiratory disease, the experiences with and attitudes towards ACP of patients and HCPs, the barriers and facilitators related to engagement in ACP and the effects of ACP programmes. We summarised the findings of 21 studies. Only five of these studies, which mostly had a qualitative study design, evaluated an ACP programme, suggesting that ACP programmes are less commonly studied in chronic respiratory disease than in other disease groups such as motor neuron disease and with nursing home residents.^{39,40} By looking at the definitions of ACP in chronic respiratory disease and the elements being investigated in the 21 studies themselves, we found that only 10 studies provided an explicit operationalisation of ACP. The remaining studies did not mention the term ACP at all. This suggests that the concept of ACP is not widely known or used in chronic respiratory disease.

The assessment of the elements of ACP described in the conducted studies revealed that in contrast to the NAM definition most of the studies did not include the clarification of patients' values and goals in their studies. According to the American Thoracic Society, comprehensive ACP however is a holistic approach, tailored to individual needs. Solely discussing treatment options without grounding these in the discussion about patients' values and goals lowers the chance that patient-centred treatment decisions are made.⁸ We also found that the descriptions of ACP only rarely included the involvement of a personal representative in ACP. While traditionally ACP focused mainly on the completion of written documents, the American Thoracic Society⁸ nowadays acknowledges the importance of patient-centred conversations about treatment decisions as well as the involvement of a personal representative. Involving family caregivers can ensure that patient preferences will still be taken into account, even if patients lose their decision-making capacity.⁸

ACP is widely embraced by professional bodies such as the British Thoracic Society, American Thoracic Society and the American College of Chest Physicians.^{8,11,12} Cumulative evidence, predominantly from studies in other disease groups, has established the positive effect of communication between patients and HCPs on patients' quality of life.¹³ Our systematic review shows that many patients with chronic respiratory diseases and their HCPs are interested in engaging in ACP, while less patients reported to have had such conversations. The low uptake of these discussions seems to be comparable with other disease groups: 20% of general medicine patients and 29% of hospitalised cancer patients reported having had ACP discussions.^{41,42} Apparently, there is a discrepancy between the expressed interest in ACP discussions and the extent to which ACP discussions take place. Our systematic review suggests three main explanations for this phenomenon.

First of all, chronic respiratory diseases are often characterised by a complex and unpredictable disease course.⁴⁵ Murray *et al*⁶ describe the illness trajectory of lung failure as long-term limitations with intermittent serious episodes. Patients with chronic respiratory diseases are usually ill for a longer period of time, interrupted by occasional acute and often severe exacerbations. As a result, it

is difficult for HCPs to provide the patient with prognostic estimates,⁶ hence complicating the choice of timing and content of ACP discussions.

Stapleton and Curtis¹ advise to engage in ACP in any case earlier than it is usually done. They advise to start when patients are still relatively well and able to participate in decision making⁸ to prevent that the impact of their decisions on their (end-of-life) care is limited.⁴³ This advice might be of particular importance for patients with COPD, since Lau et al⁴⁴ found 26.9% of patients having their first ACP discussions only 3 days before death. While indeed ACP discussions can start any time, they can become more targeted as the patient's health condition worsens.⁴⁵ To support HCPs in finding a good moment for ACP discussions, Bernacki and Block⁴³ made an effort to identify trigger points for starting ACP discussions. Examples of such trigger points are ongoing oxygen requirement of patients with COPD or lack of further treatment options. A negative response on the 'surprise question' (*'Would you be surprised if this patient died in the next year?'*) could serve as an indication for HCPs to initiate ACP,⁴³ although further validation of this question is necessary in this population. Another way of enabling ACP discussions is to remain alert for patient-induced triggers. Patients reported that experiences with death and dying of family and friends facilitated their thinking about end-of-life care. Responding to and elaborating these experiences can help to initiate ACP discussions.

The second explanation for the low frequency of ACP in chronic respiratory disease is that despite of HCPs recognising the importance of engaging in ACP, they often fear taking away patients' hope. Related to this, HCPs also reported a lack of training on communicating sensitive topics such as end-of-life care options without threatening the patients' emotional wellbeing and feelings of hope. However, a qualitative study on the perspectives of nurses on meeting patients' needs for hope and illness information⁴⁶ and a review on hope in palliative care found that honest information about the patient's illness can contribute to patient hope.⁴⁷ Patients were, for example, hoping to live to the fullest in the time they have left.⁴⁷ In fact, being able to talk about death and dying gave patients a sense of control and made them less afraid of the process of decision making.⁴⁷ Our review also found that patients do not feel well informed and educated about their disease, and HCPs confirmed that patients lack knowledge particularly about the severity of their disease. Patients seem to appreciate information about their disease, if sensitively introduced. This also highlights the importance of good communication skills and training for HCPs. Providing information on the disease, possible disease course and treatment options, can be the first step of ACP.

The third explanation for the low frequency of ACP discussions in chronic respiratory disease is that system-related barriers such as time constraints and lack of continuity of care limit the opportunity for both patients and HCPs to engage in ACP during medical encounters. Patients' care trajectory is often characterised by profound breaks in care settings and HCPs. These breaks in care make it a complex task for HCPs to assess patients' level of awareness and readiness to engage in ACP. Continuity of care can be strengthened by documenting discussions on diagnosis, prognosis, treatment, and care options in the medical file. A reliable system for storing written advance care documents

can ensure that these documents can be retrieved and transferred easily. Besides, it can be valuable to look for settings in which patients with chronic respiratory diseases are treated throughout their disease trajectory, such as pulmonary rehabilitation.^{21 22} Due to their long-term relationship with the patient, general practitioners might be in a good position to be involved in ACP as well.⁴⁸

Limitations

This review however has some limitations. First, we aimed at a comprehensive search strategy by searching in 12 electronic databases and also including studies that addressed the core elements of ACP without explicitly mentioning the term 'advance care planning'. However, if ACP was part of a larger palliative care programme and it was not possible to answer our research questions regarding specific ACP elements of the programme, we had to exclude the respective paper. This may have affected our results to some extent. Second, since the studies were mainly descriptive, statements of causality cannot be made. Finally, our search was limited to published articles in English language, which creates the possibility of publication bias.

Conclusion

This systematic review, summarising findings of 21 studies, provides, for the first time, an in-depth picture of ACP practice in chronic respiratory disease, summarising findings on how ACP is defined in chronic respiratory disease, the experiences with and attitudes towards ACP of patients and HCPs, the barriers and facilitators related to engagement in ACP and the effects of ACP programmes. ACP seems to be acceptable and desired, by both patients and HCPs, while the occurrence of ACP appears to be low. The complex disease course of chronic respiratory diseases and hesitance of both patients and HCPs to engage in ACP as well as system-related factors create barriers to engagement in ACP. These barriers could be overcome by, first, identifying trigger points throughout the disease course to discuss ACP and second, training HCPs on how to communicate sensitive topics such as end-of-life care. Finally, making system-related adjustments, such as enabling continuity of care, allowing the initiation of ACP in appropriate healthcare settings and taking away time pressure from HCPs can help to take away barriers preventing engagement in ACP.

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SUPPLEMENTARY MATERIAL

S-Box 1. Search strategy in Medline for the current systematic review

(exp "Advance Care Planning"/ OR (((("Decision Making"/ AND Patients/)) AND ("terminal care"/ OR "palliative care"/ OR "Terminally Ill"/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR "end of life" OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (Pulmonary Medicine/ OR exp "Respiratory Tract Diseases"/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((exp child/ OR exp infant/ OR (child* OR infan* OR adolescen* OR pediater* OR paediatr*)).ab,ti.) NOT (exp adult/ OR (adult OR older OR elder*)).ab,ti.)

S-Box 2. Search strategy in Embase for the current systematic review

('living will'/exp OR (('patient decision making'/exp) AND ('terminal care'/exp OR 'palliative therapy'/exp OR 'terminally ill patient'/exp OR 'terminal disease'/de)) OR (((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR 'end of life' OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))).ab,ti) AND (pulmonology/exp OR 'respiratory tract disease'/exp OR 'lung surgery'/exp OR lung/exp OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))).ab,ti) NOT ((juvenile/exp OR (child* OR infan* OR adolescen* OR pediater* OR paediatr*)).ab,ti) NOT (adult/exp OR (adult OR older OR elder*)).ab,ti)

S-Box 3. Search strategy in PsychINFO for the current systematic review

(exp "Advance Directives"/ OR (((("Decision Making"/ AND Patients/)) AND ("Terminally Ill Patients"/ OR "Palliative Care"/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR "end of life" OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (exp "Lung Disorders"/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((100.ag. OR 200.ag. OR (child* OR infan* OR adolescen* OR pediater* OR paediatr*)).ab,ti.) NOT (300.ag. OR (adult OR older OR elder*)).ab,ti.)

S-Box 4. Search strategy in Cochrane Library for the current systematic review

(((((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR 'end of life' OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))).ab,ti) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))).ab,ti) NOT (((child* OR infan* OR adolescen* OR pediater* OR paediatr*)).ab,ti) NOT ((adult OR older OR elder*)).ab,ti)

S-Box 5. Search strategy in Web-of-science for the current systematic review

TS=(((Advance) NEAR/2 (plan* OR directive*)) OR ((living) NEAR/2 (will*)) OR (patient* AND ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 (terminal* OR "end of life" OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 life NEAR/2 (saving OR saver* OR sustain*)))) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/2 (disease* OR disorder*)))) NOT (((child* OR infan* OR adolescen* OR pediater* OR paediatr*))) NOT ((adult OR older OR elder*)))

S-Box 6. Search strategy in Scopus for the current systematic review

TITLE-ABS-KEY((((Advance) W/2 (plan* OR directive*)) OR ((living) W/2 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 (terminal* OR "end of life" OR palliati*))) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 life W/2 (saving OR saver* OR sustain*)))) AND (((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) W/2 (disease* OR disorder*)))) AND NOT (((child* OR infan* OR adolescen* OR pediater* OR paediatr*)) AND NOT ((adult OR older OR elder*))))

S-Box 7. Search strategy in Cinahl for the current systematic review

(MH "Advance Care Planning+" OR (MH "Decision Making, Patient+" AND (MH "terminal Care" OR MH "Palliative Care" OR MH "Terminally Ill Patients+")) OR (((Advance) N3 (plan* OR directive*)) OR ((living) N3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) N6 (terminal* OR "end of life" OR palliati* OR (life N3 (saving OR saver* OR sustain* OR Prolong*)))) AND (MH "Respiratory Tract Diseases+" OR MH lung+ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) N3 (disease* OR disorder*)))) NOT ((MH child+ OR MH infant+ OR (child* OR infan* OR adolescen* OR pediater* OR paediatr*)) NOT (MH adult+ OR (adult OR older OR elder*))))

S-Box 8. Search strategy in PubMed publisher for the current systematic review

("Advance Care Planning"[mh] OR (((("Decision Making"[mh] AND Patients[mh])) AND ("terminal care"[mh] OR "palliative therapy"[mh] OR "Terminally Ill"[mh])) OR (Advance care plan*[tiab] OR Advance directive*[tiab] OR living will*[tiab] OR (patient*[tiab] AND (decision*[tiab] OR decid*[tiab] OR preference*[tiab] OR dilemma*[tiab] OR refus*[tiab] OR choos*[tiab] OR choice*[tiab])) AND (terminal*[tiab] OR "end of life" OR palliati*[tiab] OR life saving*[tiab] OR life saver*[tiab] OR life sustain*[tiab] OR life Prolong*[tiab]))) AND (Pulmonary Medicine[mh] OR "Respiratory Tract Diseases"[mh] OR lung[mh] OR (copd OR bronchi*[tiab] OR pulmon*[tiab] OR ((lung*[tiab] OR respirat*[tiab]) AND (disease*[tiab] OR disorder*[tiab]))) NOT ((child[mh] OR infant[mh] OR (child*[tiab] OR infan*[tiab] OR adolescen*[tiab] OR pediater*[tiab] OR paediatr*[tiab])) NOT (adult[mh] OR (adult OR older OR elder*[tiab]))) AND publisher[sb])

S-Box 9. Search strategy in Google scholar for the current systematic review

"Advance directive|directives"|"advance * plan|planning"|"living will|wills" copd|pulmonary|lung|respiratory

S-Box 10. Search strategy in Scielo for the current systematic review

("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills") AND (copd OR pulmonary OR lung OR respiratory)

S-Box 11. Search strategy in ProQuest for the current systematic review

(ti("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills") OR ab("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills")) AND (ti(copd OR pulmonary OR lung OR respiratory) OR ab(copd OR pulmonary OR lung OR respiratory))

S-Table 1. Results of the risk of bias assessment of the quantitative studies

1 st author (year)	Au (2012) ¹⁸	Heffner (1997) ²¹	Heffner (1996) ²²	Janssen (2011) ²³	Sawicki (2008) ²⁶	Janssen (2011) ²⁴	Knauff (2005) ²⁵	Gaspar (2014) ¹⁹	Heffner (1996) ²⁰	Smith (2014) ²⁷
Research hypothesis	1	1	1	1	1	1	1	0	1	0
Study population	1	1	1	1	1	1	1	1	1	0
Selection bias	1	1	1	?	1	1	0	0	1	0
Exposure assessment	1	1	1	1	1	1	1	1	1	1
Outcome	1	1	1	1	0	1	1	1	0	1
Confounding	0	?	?	1	0	1	1	1	?	0
General opinion	1	1	0	1	1	1	1	1	0	0
Total quality score	6	6	5	6	5	7	6	5	4	2

1 = Criterion has been met sufficiently

0 = Criterion had not been met sufficiently

? = Information for rating the criterion was lacking

S-Table 2. Quality evaluation of included studies according to the COREQ checklist

1 st author (year)	Brown (2012) ³⁰	Dellon (2010) ²⁸	MacPherson (2012) ³⁶	Seamark (2012) ³⁴	Simpson (2011) ³⁵	Nguyen (2013) ³³	Burge (2013) ³⁷	Bejwah (2012) ³⁸	Hajizadeh (2014) ³⁹	Crawford (2010) ³¹	Gott (2009) ³²
Domain 1: Research team and reflexivity											
Interviewer/ facilitator	+	+	+	-	-	-	-	-	-	-	-
Credentials	+	+	-	-	-	-	-	+/-	-	-	-
Occupation	+	-	+	+	-	-	-	-	+/-	-	-
Gender	+	+	+	-	-	-	-	-	-	-	-
Experience & training	+	-	+	+	-	-	-	-	+	-	-
Relationship established	-	-	+	-	-	-	-	-	-	-	-
Participants knowledge of the interviewer	-	-	+	-	-	-	-	-	-	-	-
Interviewer characteristics	-	-	+	-	-	-	-	-	-	-	-
Domain 2: Study design											
Methodological orientation and theory	+	-	+	+/-	+	+	+	+/-	+	+	+/-
Sampling	+	+/-	+	+/-	+/-	+/-	+	+	-	+	+
Method of approach	+/-	+	+	+	+	+	+	+	-	-	-
Sample size	+	+	+	+	+	+	+	+	+	+	+
Non-participation	-	+	+	+/-	-	-	+	+	+	-	-
Setting of data collection	+	+	+	+	+	+	+	-	+	+	+
Presence of non-participants	-	+/-	+	+	+	+	+/-	+	-	+/-	+
Description of sample	+	+	+	+	+	+	+	+	+	-	+
Interview guide	+/-	+/-	+/-	+	+	+	+/-	+	+/-	+/-	+/-
Repeated interviews	+	-	-	-	+	+	-	-	-	-	-
Recording	+	+	+	+	+	+	+	+	+/-	+	+
Field notes	+	-	+	+	+	+	-	-	-	-	+
Duration	-	+	+	-	-	-	-	-	+	+	-
Data saturation	-	-	+	-	-	-	+	-	-	-	-
Transcripts returned	-	-	-	-	-	-	-	-	-	-	-
Domain 3: Analysis and findings											
Number of data coders	+	-	+	+	-	-	+	+	-	-	+
Description of the coding tree	-	-	+/-	-	-	-	+/-	+/-	+/-	+/-	+/-
Derivation of themes	+	-	+	+/-	+/-	+/-	+	+	+	+/-	+
Software	-	-	+	-	-	-	-	+	+	+/-	+
Participant checking	-	-	-	-	-	-	-	-	-	-	-
Quotations present	+/-	+/-	+/-	+	+	+	+	+	+	+	+
Data and findings consistent	+	+	+	+	+	+	+	+	+	+	+
Clarity of major themes	+	+	+	+	+	+	+	+	+	+	+
Clarity of minor themes	+/-	-	+	+	+	+	+	+/-	+	+/-	+/-
Total +	17	12	25	15	14	14	15	14	13	9	13
Total +/-	4	4	3	4	2	2	3	4	4	6	4
Total -	11	16	4	13	16	16	14	14	15	17	15
Total score	19.0	14.0	26.5	17.0	15.0	16.0	16.5	16.0	15.0	12.0	15.0

+ = Criterion had been properly described
 +/- = Description of the criterion was incomplete
 - = Description of the criterion was unclearly

S-Table 3. Incidence of and attitudes towards ACP: patient perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Au (2012) ¹⁸	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 68% would like to discuss EOL care preferences with their HCPs. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 15% had EOL discussions.
Heffner (1996) ²²	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 69% wished to learn more explicit details about life-sustaining treatment options. - Most patients wished to actively participate in decisions about life support. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 89% were interested in learning more about ADs. - 78% found discussions about ADs informative. - 22% found discussions about ADs anxiety provoking but worthwhile. - 99% found discussions with HCPs about ADs acceptable. - 86% wanted to learn more about ADs, 12% had initiated these discussions. - 51% felt that physicians should initiate discussions about ADs. <p>68% found that discussions about ADs and life-support should occur in the outpatient setting.</p>	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 15% had discussions about life-support. - 14% believed physicians understood their wishes. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 95% heard of ADs. - 42 % completed ADs. - 19% had discussed ADs with HCPs.
Janssen (2011) ²³		<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 12-18% discussed life-sustaining treatments with HCPs. - Quality of EOL care communication was rated very low (median score 1.1 (IQR 0.0-2.9) for patients with mild to moderate COPD and median score 1.4 (IQR 0.0-3.4) for patients with severe to very severe COPD). - HCPs did not ask about: <ul style="list-style-type: none"> o feelings about getting sicker (53-73%) o important things in life (85-80%) o what dying might be like (89-92%) o spiritual, religious beliefs (87-91%). - 69-84% reported no involvement in treatment discussion.

S-Table 3. Incidence of and attitudes towards ACP: patient perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
Sawicki (2008) ²⁶	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 50% thought that the clinician should initiate the discussion on EOL care. - Patients felt necessity of considering their treatment options, vast majority considered treatment preferences. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 74% spoke to someone about treatment preferences. - 13% talked with their CF clinician about treatment preferences. - 28% were asked by their CF clinicians if they would want to make decisions about their medical care if they became too ill to make their own decisions. - 79% felt comfortable talking to a CF clinician about EOL care preferences. <p><u>Clarifying values & goals</u></p> <ul style="list-style-type: none"> - 58% had specific wishes about medical treatment.. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 30% completed an AD. <p><u>Involving a personal representative</u></p> <ul style="list-style-type: none"> - 65% thought about whom they would like to make their healthcare proxy.
Janssen (2011) ²⁴		<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Quality of EOL care communication was rated very low (median score 0.0). <p><u>Clarifying values and goals</u></p> <ul style="list-style-type: none"> - Patients reported that HCPs did not address religious beliefs (93%) or important things in the patients' life (83%). - 85% of patients reported no involvement in treatment discussions.
Knauff (2005) ²⁵		<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 32% were involved in treatment discussions. <p><u>Clarifying value sand goals</u></p> <ul style="list-style-type: none"> - 75% thought physicians probably/ definitely knew their treatment preferences.
	Qualitative study design	
Brown (2012) ³⁰	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Patients would like to discuss EOL care preferences, if sensitively introduced by well-informed HCP. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 2 out of 15 patients had conversations with HCPs about resuscitation. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 11 out of 15 patients had not seen ADs before.

S-Table 3. Incidence of and attitudes towards ACP; patient perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
MacPherson (2012) ³⁶	<p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - Patients had doubts about documenting 'preferred priorities of care' due to uncertainty about stability of preferences. - Patients had doubts on usefulness of ADs. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Most reported perceived lack of communication around time of diagnosis. - 2 out of 10 patients reported some discussion about future. - 1 out of 10 patients had discussed ACP with HCPs. - 14 out of 10 patients described consultations with HCPs being very focused on the present/ current problem; future/ treatment preferences were never discussed. - Participants had not discussed general care preferences with HCPs, but all stated they would be comfortable with doing so when asked.
Seamark (2012) ³⁴	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - All patients were willing to discuss ACP and related issues such as resuscitation. - Discussing ACP was seen as a difficult but worthwhile. - Having to make concrete decisions about EOL care was perceived as being hard. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - No one recalled discussion in hospital about life prolonging treatment. - Patients recalled admission as being hurried with minimum of discussion with the ambulance crew or attending GP. - Actual inpatient stay was seen as chaotic by most patients with lack of recall about where care took place and by whom. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 1 out of 16 patients had a DNR order at home, however form did not accompany patient to hospital.
Bajwah (2012) ³⁸	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Patients would like to discuss EOL care preferences. - Patients felt a need for further information on e.g. prognosis. - All realised importance of discussions about EOL care preferences, but did not know how to initiate them. - Patients felt that HCPs should be able to best judge when discussions about EOL care preferences should take place. 	<p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - No patients had formulated EOL plans or considered EOL preferences.

S-Table 3. Incidence of and attitudes towards ACP: patient perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
Hajizadeh (2014) ²⁹	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Those who had not discussed EOL decisions with their physicians were willing to do it. - Most agreed that their physicians should be involved in the EOL decision-making process. - 8 out of 11 patients found that physicians should talk about their patient's chance of dying from their disease. - 10 out of 11 patients found that physicians should talk about patients' EOL treatment options. - Patients felt that conversations should take place in advance of acute disease. - Importance of EOL decision making mostly related to experience with a family member. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - Most expressed desire to complete an AD. - 7 out of 11 patients found that physicians should help patients to make ADs. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 8 out of 11 patients knew that they have the right to say no to a breathing machine. - 9 out of 11 patients knew that they have the right to say no to be taken to the hospital. - 1 out of 11 patients had ever talked with HCPs physician about chance of dying from the disease. - 4 out of 11 patients had ever talked about EOL decisions with HCP. <p><u>Involving a personal representative</u></p> <ul style="list-style-type: none"> - All patients had heard of a health-care proxy. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 3 out of 11 patients had heard of an AD.

ACP = advance care planning
 AD = advance directive
 EOL = end-of-life
 HCP = healthcare professional
 COPD = chronic obstructive pulmonary disease
 CF = cystic fibrosis
 GP = general practitioner
 DNR = do-not-resuscitate

S-Table 4. Incidence of and attitudes towards ACP: healthcare professional perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Janssen (2011) ²⁴		<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 6% of both patients and physicians reported having discussed preferences regarding life-sustaining treatment. - 20% talked about life-sustaining interventions with their patients.
Gaspar (2014) ¹⁹	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 77% found it very important to discuss EOL care preferences with advanced COPD patients. - 89% found it (very) difficult to discuss EOL care preferences with their patients. - 99% would like EOL care preferences to be further discussed in scientific meetings. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 62% rarely/ never initiated EOL communication. - 68% rarely/ never suggested patients to make decisions about invasive mechanical ventilation/intubation. - 81% rarely/ never suggested patients to indicate preferences about cardio-pulmonary resuscitation. - 76% rarely/ never suggested patients to make decisions about place of death. <p><u>Clarifying values and goals</u></p> <ul style="list-style-type: none"> - 82% rarely/ never addressed spiritual/ religious beliefs. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 80% never suggested ADs. <p><u>Documenting patients' wishes:</u></p> <ul style="list-style-type: none"> - 33% asked patients about ADs. - 33% presented educational sessions on ADs. - 42% gave written materials on ADs. - Most rehabilitation programmes had no knowledge of their patients' ADs.
Heffner (1996) ²⁰	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - 42% programmes affirmed obligation of HCPs to inform patients regarding all aspects of health care. <p><u>Documenting patients' wishes</u></p> <ul style="list-style-type: none"> - 86% would initiate educational sessions on ADs into their programmes if supplied with appropriate teaching materials. 	

S-Table 4. Incidence of and attitudes towards ACP: healthcare professional perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
Smith (2014) ²⁷	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - 66% thought that most patients with advanced COPD wanted to know about their diagnosis, prognosis, and available care options - 41% thought that most patients with advanced COPD, if asked, wanted to discuss their wishes for EOL care. - 76% thought all adult patients with COPD should be offered the opportunity to discuss ACP. - 94% thought that ACP can improve patients' and families' satisfaction about EOL care. - 77% felt comfortable discussing issues related to death and dying with patients with advanced COPD and their families. - 71% thought it is appropriate to discuss ACP with seriously ill patients who may recover. - 35% felt that ACP could destroy a patients' sense of hope. - 12% were concerned that having ACP discussions with COPD patients would lead to them not returning for further follow up. - 18% felt that ACP conflicted with other chronic disease management goals. - 18% felt that discussing ACP conflicts with responsibility to advocate for ICU levels care/ intubation for COPD patients. - 81% felt comfortable discussing ACP with patients with advanced COPD. - 77% thought it is essential to discuss ACP after recovery in patients with respiratory failure requiring non-invasive ventilation. - 94% felt comfortable discussing DNR orders with patients. - 59% found that ACP should be discussed as a routine outpatient visit. - 71% thought that ACP is a specialist physician's responsibility. - 82% felt supported by colleagues in discussing ACP with patients and families. - 71% felt sufficiently knowledgeable about how to conduct ACP conversations with patients and their families. - 81% reported interest in further ACP education. 	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - 13% discussed ACP with most patients, 56% with few/ (almost) none. - >50% discussed most/ all of the time diagnosis, incurability of disease, purpose of medical treatment, symptom management options. - 47% preferred discussing ACP in outpatient setting, 80% discussed it in hospital. - 6% felt that ACP makes patients losing confidence in physicians' care. <p>Clarifying values & goals and involving a p</p> <ul style="list-style-type: none"> - <30% discussed most/ all of the time appointment of health-care proxy, palliative care options, patients' goals, values and beliefs. - 65% had previous ACP education, 81% learnt ACP skills by adopting ACP skills from others.
Bejwah (2012) ²⁸	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - HCPs did not know when to best initiate discussions about EOL care preferences. - Recognized complexities of delivering information while preserving balance between hope and realism. 	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - Frustrations about poor communication among HCPs and recognition for needed improvement to ensure adequate coordination of end of life care.

Qualitative study design

S-Table 4. Incidence of and attitudes towards ACP: healthcare professional perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
Hajizadeh (2014) ²⁹	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - All interviewees endorsed the need of having discussions about EOL care preferences, most expressed discomfort and/ or resistance discussing prognostic estimates such as life expectancy with their patients. - 4 out of 5 doctors found that physicians should be involved in decision making about EOL care preferences. - 3 out of 5 doctors found that physicians should be required to initiate discussions about EOL care preferences with their patients. - 3 out of 5 doctors believed that discussions about EOL care preferences should take place during outpatient clinic visits. <p><u>Clarifying values and goals</u></p> <ul style="list-style-type: none"> - EOL discussions should address the following topics: patients' possible outcomes and their impact on their quality of life, patients' treatment preferences in term of treatment, patients' preferences in the case of no reasonable chance of recovery, whether patients would like to identify a health-care proxy or surrogate, whether they have previous ADs and the option of not receiving treatment. 	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - All doctors had discussions about EOL care preferences with patients, mostly in the context of intensive care. - All doctors discussed decision-making or preparation for EOL with patients with severe chronic diseases.
Crawford (2010) ³¹	<p><u>Discussing EOL care</u></p> <ul style="list-style-type: none"> - Timing of EOL discussions was crucially dependent on patients' disease pathway. - Language distinctions: 'cancer' has terminal associations; COPD is a medical label with little meaning to patients. - Avoidance of 'death' and 'dying' words from staff and tendency to soften impact of information given to COPD patients, when patients directly asked about death, physicians were unprepared and described anxiety and discomfort. - Lung cancer patients were usually prepared for discussing EOL care preferences by 'planting a seed in their mind'. - COPD patients were not provided with the opportunity for discussing/to discuss EOL care preferences; rather HCPs look for 'cues' to start the discussion. - Patient-initiated discussions were perceived as easier. - Moral and ethical dilemmas were reported: what, who, how, when to tell, while maintaining balance between truth and hope. 	

S-Table 4. Incidence of and attitudes towards ACP: healthcare professional perspective (continued)

First author (year)	Attitudes towards ACP	Experiences with ACP
Gott (2009) ³²	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - Not discussing EOL could limit patient choice. - No consensus on appropriateness of rarely discussing EOL. - Majority thought that whilst they might be the right person to initiate the discussion on EOL care preferences (due to long standing relationship with the patient), there were factors identified preventing them from fulfilling this role. - Practice nurses did not feel that it was their responsibility to start the discussions on EOL care preferences, some reporting that they did not see the very 'terminal' COPD patients because these patients received home visits from the GP, and that they had never received any training in breaking bad news and therefore were ill equipped to manage such discussions. - Respiratory nurses did identify that they often 'knew' patients well and acted as a more constant point of contact in secondary care than medical staff. - Acute admission was not seen as a good time for EOL issues to be discussed. 	<p>Discussing EOL care</p> <ul style="list-style-type: none"> - Discussions about EOL care preferences were rare. - Small minority of GP participants initiate discussions about EOL care preferences earlier in the disease process; typically it was 'too late' for patient to be well enough to make care choices. <p>Most felt that people with COPD receive inadequate information about their condition. HCPs often use euphemisms when disclosing a diagnosis of COPD.</p>

ACP = advance care planning

EOL = end-of-life

COPD = chronic obstructive pulmonary disease

AD = advance directive

ICU = intensive care unit

HCP = healthcare professional

S-Table 5. Effects of ACP programmes: Outcomes from the interventional studies (n = 6)

First author (year)	ACP programme	Study groups (n = participants)	Behavioural outcome
Quantitative study design			
Au (2012) ¹⁸	Based on a patients' questionnaire responses, the HCP and the patient received a one-page patient specific feedback form to stimulate an ACP conversation	Intervention group (n=151) vs control group (n=155)	<ul style="list-style-type: none"> - Intervention group: threefold rate of EOL discussions with physicians (absolute difference 18.6%, $p < .001$), higher quality of EOL communication (difference 5.7 points (scale 0-100), $p = .03$; Cohen effect size 0.21) - No significant effect on number of discussions about patients' feelings about getting sicker, prognosis, what dying might be like, family involvement, asking about things important to patient.
Heffner (1997) ²¹	Educational workshop on ADs and other EOL topics	Patients receiving workshop vs care as usual	<ul style="list-style-type: none"> - Educational group: significant increase ($p < 0.05$) in number of completed living wills (OR=3.6, 95%CI 1.1,12.9), AD discussions (OR = 2.9, 95% CI 1.1,8.3), discussions with physicians about life-support (OR=2.7, 95% 1.0,7.7) and assurance that physicians understand their preferences (OR=3.7, 95%CI 1.3,13.4).
Qualitative study design			
Simpson (2011) ³⁵	Two loosely structured sessions based on a conversation guide. Each family also got the local health district's brochure on ACP	n=8 (+ 7 informal caregivers)	<ul style="list-style-type: none"> - 1 patient expressed appreciation for the sessions in terms of social interaction and opportunity for learning. - 1 patient found that the AD template offered a way to ensure that her family member, spouse and very uncertain substitute decision-maker, would have a tangible guidance about the wishes. - Between study visits 1 patient used the template to develop an AD and planned to follow-up by talking about it with her children. - 1 patient pointed out the appreciation for the facilitator's approach.
Nguyen (2013) ³³	A DVD movie to help build patients' knowledge about EOL options and to facilitate patient-physician discussion	n=12	<ul style="list-style-type: none"> - Most felt DVD did a good job of fulfilling information needs. - Words as 'scary' and 'shocking' were used to describe the visual portrayal of the intubation and tracheostomy processes. Nevertheless most agreed that it was necessary to gain a thorough understanding of the reality of these treatments. - Those who struggled with their diagnosis and prognosis tended to dislike the DVD and not wanting to watch it at all. Generally, the further the participant had progressed in their stages of readiness, the more they expressed that the DVD met their needs.
Burge (2013) ³⁷	ACP sessions	"attendees" (n=44) vs "non-attendees" (n=23) of the ACP sessions	<ul style="list-style-type: none"> - 17 described PR&M programmes as appropriate to receive information about ACP and preferable to an acute hospital setting. - 38 patients found information valuable and gave 'peace of mind' in relation to future care. - 34 patients felt that information about ACP is best presented in a group. - No consensus on which health professional should present the ACP information. <p>12 patients of the community-based group and 8 of the hospital-based group followed up with the ACP facilitators, 21 participants went on to complete documentation.</p>