



# Referral criteria to palliative care for patients with respiratory disease: a systematic review

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This systematic review reveals there are multiple different criteria currently used to prompt referral to palliative care, suggesting a lack of consensus around this practice and highlighting the need to establish agreed criteria going forward <https://bit.ly/38H7W3i>

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## Abstract

**Aims** Advanced nonmalignant respiratory diseases are associated with significant patient morbidity, yet access to palliative care occurs late, if at all. Our aim was to examine referral criteria for palliative care among patients with advanced nonmalignant respiratory disease, with a view to developing a standardised set of referral criteria.

**Methods** We performed a systematic review of all studies reporting on referral criteria to palliative care in advanced nonmalignant respiratory disease, with a focus on chronic obstructive pulmonary disease and interstitial lung disease. The systematic review was conducted and reported according to the PRISMA guidelines, and was undertaken using electronic databases (Ovid, MEDLINE, Ovid Embase and PubMed).

**Results** Searches yielded 2052 unique titles, which were screened for eligibility and resulted in 62 studies addressing referral criteria to palliative care in advanced nonmalignant respiratory disease. Of 18 categories put forward for referral to palliative care, the most commonly discussed factors were hospital use (69% of papers), indicators of poor respiratory status (47%), physical and emotional symptoms (37%), functional decline (29%), need for advanced respiratory therapies (27%), and disease progression (26%).

**Conclusion** Clinicians consider referral to specialist palliative care for a wide range of disease- and needs-based criteria. Our findings highlight the need to standardise palliative care access by developing consensus referral criteria for patients with advanced nonmalignant respiratory illnesses.

## Introduction

Chronic obstructive pulmonary disease (COPD) affects an estimated 328 million people worldwide and is expected to become the leading cause of death by 2035 [1, 2]. Interstitial lung disease (ILD) affects far fewer adults, with the incidence of idiopathic pulmonary fibrosis (IPF), one of the most common of the progressive fibrosing phenotypes of this illness group, reported to range between 2.8 and 19 cases per 100 000 people per year throughout Europe and North America [3], with a median survival from diagnosis of 2–5 years [4].

Together, these advanced nonmalignant respiratory diseases are associated with significant morbidity, with patients reporting a median of 11–14 symptoms including, in up to 98% of individuals, complaints of

dyspnoea and impaired quality of life [5, 6]. This morbidity extends beyond the patient to family carers who provide the majority of physical care in the community, and who describe significant anxiety, frequent exhaustion and uncertainty [7]. Patients and their families require access to information around prognosis and about treatment benefits and burdens, as well as support, as they participate in complex decision making around their care, particularly in the setting of advanced disease.

The needs reported by patients with COPD or ILD and their families, *i.e.* symptom relief, provision of information, discussions around prognosis and future preferences for care, all constitute core tasks of palliative care, which seeks to provide a holistic approach to caring for the person as well as their broader family or community. Palliative care was developed in the context of cancer, but recently the benefits of this approach for people with advanced nonmalignant respiratory disease have been highlighted by professional bodies and international guidelines [8–10]. Yet, currently, access to palliative care for this patient group occurs late in the illness course, if at all. For example, between 2006 and 2012 in the USA, just 1.7% of hospitalised patients with COPD receiving home oxygen had a palliative care contact. While access to palliative care increased over the 6-year time period, markedly fewer patients with COPD received such care compared with a cohort of patients with metastatic cancer (in 2012: 2.56% versus 11.9%) [11]. Similarly, despite international consensus regarding the importance of early palliative care referral for ILD patients, this is not widely practised. For a group of patients who died of IPF, palliative care referral occurred infrequently (13.7%) and late, with most (71%) being referred within 1 month of death [12]. This lack of palliative care utilisation is despite patients with nonmalignant respiratory disease having needs that are reported to be at least as severe as those with cancer [13].

A series of factors have been identified as contributing to this lack of early palliative care referral, with resulting uncertainty and variation in care [14]. These include the unpredictability of the disease trajectory, patient and health professional views of palliative care, and, importantly, the under-reporting, under-recognition and undertreatment of chronic breathlessness and its associated needs and suffering [14, 15]. Adding to this uncertainty is the lack of standardised palliative care referral criteria for this patient group [16]. In lung cancer, the time of diagnosis of metastatic disease is the criterion for clinical trials of palliative care integration [17], a point readily identified and associated with high needs and poor prognosis. In cancer care more broadly, consensus referral criteria for outpatient palliative care have been developed including the presence of severe physical or emotional symptoms, existential crises, request for hastened death, assistance with decision making, specific cancer complications such as delirium and spinal cord compression, prognostic outlook of <12 months and progressive disease despite second-line therapy [18–20]. The relevance of similar criteria to people with advanced nonmalignant respiratory disease is not clear.

The development of criteria to initiate a palliative care referral for people with advanced nonmalignant respiratory disease would: 1) facilitate timely, appropriate access to palliative care and thereby improve patients' quality of life; 2) reduce variation between providers and health services; 3) in turn allow the establishment of clear measures and standards of quality care; and 4) enable benchmarking between health providers to facilitate the development of services including integrated respiratory and palliative care.

We conducted a systematic review of the literature to examine referral criteria for palliative care among patients with advanced nonmalignant respiratory disease, focusing upon COPD and ILD. This systematic review represents the first step towards developing a standardised set of referral criteria.

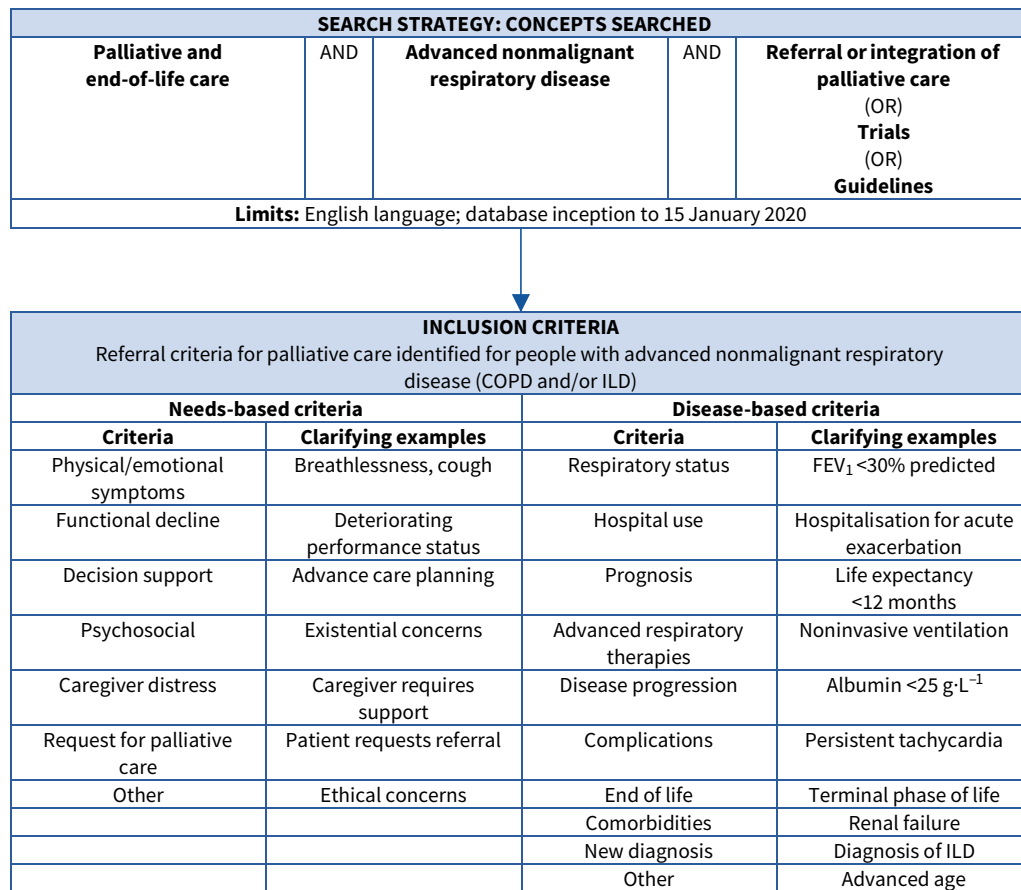
## Methods

### Design

We conducted a systematic review of studies meeting our aim to examine referral criteria for palliative care in advanced nonmalignant respiratory disease, including either COPD or ILD. It was guided and reported by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [21]. The review was conducted as the first stage in a broader programme of work by this team seeking to develop a standardised, consensus-based set of referral criteria, across a series of nonmalignant diagnoses, also including heart failure [22], dementia and renal disease. As this study provided a review of existing literature, ethics approval was not required.

### Search strategy: identification of studies

Ovid, MEDLINE, Ovid Embase and PubMed electronic databases were searched for publications in the English language (due to lack of access to translations), from the database inception to 15 January 2020. A set of key terms and their related synonyms and/or abbreviations were defined (figure 1) and applied to titles, abstracts, key words and subject headings specific to each database. As per figure 1, this included



**FIGURE 1** Search and coding strategy. COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease; FEV<sub>1</sub>: forced expiratory volume in 1 s.

searches combining the following concepts: “Palliative Care” AND “Respiratory Disease” AND “Referral/Integration” OR “Clinical Trials” OR “Guidelines/Consensus Statements”. A manual search of grey literature was also conducted to ensure key papers were included from experts in the field, cross-checking reference lists of key papers for articles potentially meeting inclusion. The complete MEDLINE Search strategy is detailed in the supplementary material.

**Eligibility: inclusion and exclusion criteria**

Studies were eligible for inclusion in this systematic review if they 1) were focused on a) advanced nonmalignant respiratory disease, or specifically identified b) COPD or c) ILD cohorts which comprised >50% of the study population; and 2) detailed a “trigger” or a referral criterion, or set of criteria, for specialist palliative care. Of note, consistent with the aims of this systematic review, we sought a broad overview of the range of referral criteria proposed in the literature. This meant we included referral criteria that were mentioned either directly, arising as a primary result of the study, or as a component of a clinical trial or were recommended as an implication of the study findings, or indirectly as derived from clinical perspectives on triggers not defined based upon research. We included all original studies, reviews, systematic reviews, guidelines, editorials, commentaries and letters, and excluded duplicates, case reports and conference abstracts.

**Data extraction**

The study selection process from the total pool of discrete articles (n=2052) obtained was conducted as follows. First, titles and abstracts for each citation were independently screened by two authors (J.P. and A.C.) and if either of the reviewing authors determined that the study met the eligibility criteria it was included for further review. In the second stage, a full-text review of the sample potentially meeting inclusion (n=124) was again independently conducted by the two authors (J.P. and A.C.) and then

collectively discussed in turn to reach consensus, including the aid of a third author (N.S.) as arbitrator where required (n=1).

### Analyses

Data extracted from the final sample meeting eligibility (n=62) were summarised using descriptive statistics, including counts, frequencies and percentages. The referral criteria identified were thematically categorised according to an established coding framework, consistent with published reviews of referral criteria in other disease settings, including cancer and advanced heart failure [22, 23]. These criteria were classified under two major domains: needs-based criteria (*i.e.* patient/caregiver supportive care concerns) and disease-based criteria (*i.e.* diagnosis, prognosis, progression or utilisation of healthcare resources).

## Results

### Overview of included studies

Our systematic search of the literature identified 2052 articles for potential inclusion (figure 2). Review of titles excluded 1471 articles that were duplicates, case reports, conference abstracts or immediately identified as not meeting the aims of this systematic review. A total of 581 articles were subjected to a detailed abstract review, of which a further 457 were excluded, as they did not discuss referral criteria. The remaining 124 articles were included for full-text review by two investigators, resulting in a final sample of 62 that identified referral criteria to palliative care in advanced nonmalignant respiratory disease (table 1).

Most studies were from the USA (31%), Europe (34%) and the UK (23%), and were published after 2010 (84%) in respiratory (42%) or palliative care (34%) journals. The studies involved a range of methodologies, most commonly narrative reviews (23%), retrospective studies (16%), prospective randomised trials (15%) and prospective nonrandomised studies (13%). Most explored referral criteria in COPD populations (84%), while just four studies (6%) focused on ILD and six studies (10%) included mixed populations of patients most frequently described as having advanced nonmalignant lung disease without further specification.

### Referral criteria

We identified 18 categories of referral criteria, which were broadly grouped according to “needs-based” (n=8) and “disease-based” (n=10) (table 2). Across all included studies, disease-based factors were more prevalent than needs-based factors. The most commonly discussed criteria in order of frequency were:

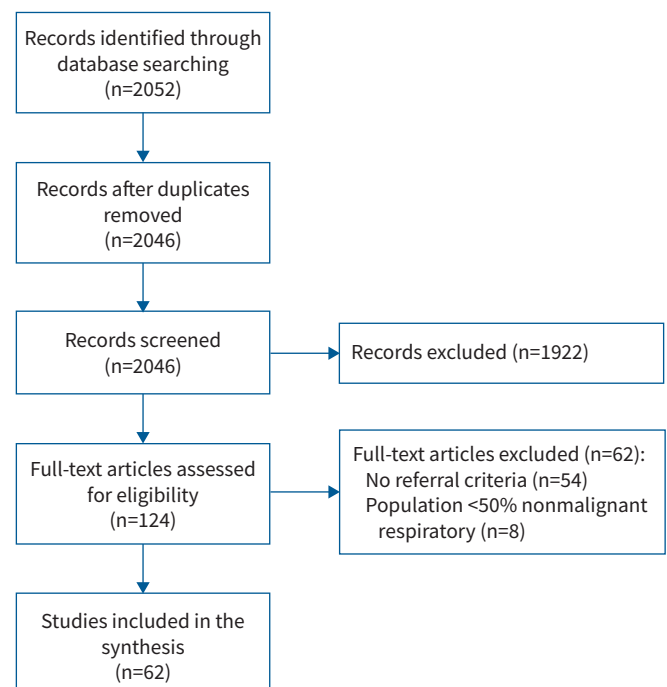


FIGURE 2 PRISMA diagram of the literature search.

**TABLE 1** Publication characteristics

<b>Publications</b>	62
<b>Study population</b>	
COPD	52 (84)
ILD	4 (6)
Mixed population	6 (10)
<b>Article type</b>	
Practice guidelines, expert consensus	5 (8)
Prospective nonrandomised studies and surveys	8 (13)
Prospective randomised trials	9 (15)
Qualitative studies	7 (11)
Retrospective studies	10 (16)
Review (narrative)	14 (23)
Review (systematic)	2 (3)
Trial design	7 (11)
<b>Publication year</b>	
2002–2010	10 (16)
2011–2019	52 (84)
<b>Journal type</b>	
Respiratory journals	26 (42)
Palliative care journals	21 (34)
General medical journals	10 (16)
Other	5 (8)
<b>Country</b>	
Europe	21 (34)
Australia	2 (3)
UK	14 (23)
USA	19 (31)
Canada	3 (5)
Switzerland	1 (2)
New Zealand	2 (3)

Data are presented as n or n (%). COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease.

“Hospital use” (n=43 (69%)) [5, 24–65], followed by “Respiratory status” (n=29 (47%)) [24, 25, 32, 34, 37–42, 44, 45, 47, 52, 56–59, 62–72], “Physical or emotional symptoms” (n=23 (37%)) [16, 24, 25, 27, 32, 37–39, 46, 48, 52, 62, 63, 65–67, 69, 72–77], “Functional decline” (n=18 (29%)) [5, 24, 25, 28, 30, 37–39, 47, 52, 56, 58, 62, 63, 65, 66, 72, 78, 79], “Advanced respiratory therapies” (n=17 (27%)) [5, 25, 27, 31, 32, 34, 38, 42, 46, 47, 52, 53, 56–59, 62, 64, 76] and “Disease progression” (n=16 (26%)) [24, 25, 27, 28, 32, 34, 37, 38, 44, 48, 52, 57, 59, 62, 65–67, 72]. The detailed breakdown of factors coded within the most commonly cited subgroups is given in table 3.

Less commonly mentioned criteria were psychosocial factors [16, 30, 32, 34, 37–39, 43, 46, 48], prognosis [24, 25, 32, 33, 35, 47, 49, 60, 61, 65, 70, 80–82], end of life [46, 47], carer distress [16, 30, 48], request for palliative care [34, 39, 43, 48], support with decision making [16, 30, 43, 72], medical complications of respiratory failure [24, 38, 65], new diagnosis of ILD [79, 83] and comorbidities [5, 25, 32, 34, 44, 52, 62, 63].

Most articles (68%) did not make an identifiable distinction regarding the specific palliative care setting for which the referral criteria were intended. 12 studies (19%) specifically mentioned outpatient palliative care, while just three mentioned home-based care (5%), two mentioned hospice care (3%) and one mentioned inpatient care (2%). Just eight studies (13%) indicated the proposed referral criteria had been tested or implemented in practice.

#### **Referral criteria in COPD**

In those articles focused upon COPD only, the referral criteria from individual studies were summarised and the most commonly cited referral criteria were associated with hospital admission (n=38 (73%)), including recent hospitalisation with exacerbation, two or more hospitalisations in the past 12 months and increased frequency of hospitalisation (table 3). The next most frequently cited referral criteria were markers of respiratory status (n=27 (52%)), including, for example, reduced forced expiratory volume,

TABLE 2 Categories of palliative care referral criteria for advanced nonmalignant respiratory disease

	Descriptive list of criteria <sup>#</sup>	COPD	ILD	Mixed	All
<b>Publications</b>		52	4	6	62
<b>Needs-based criteria</b>					
Physical or emotional symptoms [16, 24, 25, 27, 32, 37–39, 46, 48, 52, 62, 63, 65–67, 69, 72–77]	Poor symptom control, mood disturbance, dyspnoea, refractory pain, weight loss, fatigue, insomnia, physical dependence, level of dyspnoea, SGRQ total score, cough, shortness of breath at rest, daily symptoms limiting daily activities despite optimal standard therapy, complex symptoms, worsening quality of life, cognitive decline	19 (37)	1 (25)	3 (50)	23 (37) <sup>¶</sup>
Functional decline [5, 24, 25, 28, 30, 37–39, 47, 52, 56, 58, 62, 63, 65, 66, 72, 78, 79]	Increasing care dependency, 6-min walk test <300 m, 6-min walk test < gait speed over 4 m, 6-min walk test change in 50 m, BODE score, unable to meet ADLs, housebound, validated performance status scale	14 (27)	2 (50)	2 (33)	18 (29) <sup>¶</sup>
Psychosocial [16, 30, 32, 34, 37–39, 43, 46, 48]	Social needs, supportive counselling, spiritual issues, financial concerns, existential concerns/wanting to talk about dying, need for extra help at home/access to community support, home adaptations, care distress, respite care	9 (17)	1 (25)	0 (0)	10 (16)
Decision support [16, 30, 43, 72]	Advance care planning or goals of care, hospice referral, care coordination, resuscitation preferences, help with treatment decisions	4 (8)	0 (0)	0 (0)	4 (7)
Request for palliative care [34, 39, 43, 48]		3 (6)	1 (25)	0 (0)	4 (6)
Caregiver distress or need for caregiver support [16, 30, 48]		2 (4)	1 (25)	0 (0)	3 (5)
Other	Disabled parking sticker [30], ethical concerns [43], respiratory physician experience [34]	3 (6)	0 (0)	0 (0)	3 (5)
<b>Disease-based criteria</b>					
Hospital use [5, 24–65]	Hospital admission, increasing frequency of hospital admission, length of stay, ICU admission characteristics, emergency department presentation	38 (73)	2 (50)	3 (50)	43 (69) <sup>¶</sup>
Respiratory status [24, 25, 32, 34, 37–42, 44, 45, 47, 52, 56–59, 62–72]	FEV <sub>1</sub> <30% predicted, FEV <sub>1</sub> <50%, hypoxaemia, hypercapnia, mMRC, MRC 5, MRC >4, CCQ, GOLD 3 or 4, COPD score 25+, CAT score >25, BMI <21, BMI <18, unintended loss of weight, chronic lung failure, oxygen increased dependence	27 (52)	0 (0)	2 (33)	29 (47) <sup>¶</sup>
Advanced respiratory therapies [5, 25, 27, 31, 32, 34, 38, 42, 46, 47, 53, 56, 57, 59, 62, 64, 76]	Invasive ventilation, episode of assisted ventilation, NIV, NIV last year, home oxygen, chronic home oxygen	15 (29)	0 (0)	2 (33)	17 (27) <sup>¶</sup>
Disease progression [24, 25, 27, 28, 32, 37, 38, 44, 48, 52, 57, 59, 62, 65, 67, 72]	Cor pulmonale, NYHA level 3, heart failure, anaemia, serum albumin <25 g·L <sup>-1</sup> , maximal oxygen uptake (V <sub>O<sub>2</sub></sub> )	13 (25)	2 (50)	1 (17)	16 (26) <sup>¶</sup>
Prognosis [24, 25, 32, 33, 35, 47, 49, 60, 61, 65, 70, 80–82]	“Surprise question”, life expectancy <12 months, life expectancy <6 months, validated risk score, unspecified prognosis	12 (23)	0 (0)	2 (33)	14 (23)
Comorbidities [5, 25, 32, 34, 44, 52, 62, 63]	Cancer, renal failure, diabetes, worsening comorbidities, severe comorbidities	8 (15)	0 (0)	0 (0)	8 (13)
Medical complications of respiratory failure [24, 38, 65]	Transplant scores, persistent tachycardia	2 (4)	0 (0)	1 (17)	3 (5)
End of life [46, 47]	End-of-life care, lack of treatment options	2 (3)	0 (0)	0 (0)	2 (4)
New diagnosis [79, 83]	Diagnosis of ILD	0 (0)	2 (50)	0 (0)	2 (3)
Other	>6 weeks of systemic steroids in last 6 months [27], advanced age [26, 34, 63, 67], age >70 years [25], unmarried, age >65 years [31], feeding tube, tracheostomy, renal replacement therapy [43]	8 (15)	0 (0)	0 (0)	8 (13)

Data are presented as n or n (%). COPD: chronic obstructive pulmonary disease; ILD: interstitial lung disease; SGRQ: St George's Respiratory Questionnaire; BODE: BMI, airflow obstruction, dyspnoea and exercise; BMI: body mass index; ADLs: activities of daily living; ICU: intensive care unit; FEV<sub>1</sub>: forced expiratory volume in 1 s; FEV: forced expiratory volume; (m)MRC: (modified) Medical Research Council; CCQ: Clinical COPD Questionnaire; GOLD: Global Initiative for Chronic Obstructive Lung Disease; CAT: COPD Assessment Test; NIV: noninvasive ventilation; NYHA: New York Heart Association. <sup>#</sup>: descriptive list of criteria as quoted in studies; <sup>¶</sup>: a breakdown of factors within each of these categories is provided in table 3.

presence of physical or emotional symptoms such as breathlessness (n=19 (37%)), need for advanced respiratory therapies (n=15 (29%)) including noninvasive ventilation, functional decline (n=14 (27%)) and evidence of disease progression (n=13 (25%)) (table 3).

**TABLE 3** Breakdown of individual criteria for the most frequently mentioned categories (cited by >25% of the 62 articles)

Category	Individual criteria	Articles n (% of category)	References
<b>Hospital use</b>	Admission	16 (37)	[25, 27, 28, 32–34, 41, 43, 47–49, 54, 55, 58, 63, 64]
	Hospital length of stay	3 (7)	[26, 35, 51]
	Hospital admission for exacerbation	10 (23)	[5, 29, 36, 40, 42, 44–46, 53, 58]
	Increasing frequency of hospital admission	12 (28)	[24, 30, 31, 37–39, 52, 57, 59–62]
	ICU admission	3 (7)	[43, 50, 65]
	Emergency department use	1 (2)	[56]
<b>Respiratory status</b>	FEV <sub>1</sub>	14 (48)	[24, 25, 32, 34, 37, 45, 47, 52, 56, 62, 63, 66, 67, 69]
	Hypoxaemia	4 (14)	[24, 25, 32, 66]
	MRC	7 (24)	[25, 32, 34, 37, 52, 57, 59]
	Hypercapnia	5 (29)	[25, 32, 34, 65, 66]
	High CCQ (cut-off not specified)	1 (3)	[34]
	BMI	7 (24)	[34, 37–39, 57, 59, 63]
	GOLD 3 or 4	9 (38)	[38, 40–42, 57, 59, 64, 68, 71]
	Unintended loss of weight	3 (10)	[24, 39, 47]
	COPD score 25+	1 (3)	[57]
	Oxygen increased dependence	3 (10)	[52, 57, 59]
	CAT score >25	1 (3)	[59]
	Respiratory accessory muscles, orthopnoea	1 (3)	[72]
	Cough	1 (3)	[24]
<b>Physical or emotional symptoms</b>	Dyspnoea	16 (73)	[16, 24, 25, 27, 32, 39, 48, 52, 62, 65, 67, 72–76]
	Physical dependence	1 (4)	[25]
	Weight loss	1 (4)	[67]
	Poor symptom control	3 (13)	[38, 69, 77]
	Mood disturbance	4 (17)	[38, 46, 48, 66]
	Fatigue	1 (3)	[24]
	Cough	1 (3)	[24]
	Poor quality of life (not further defined)	2 (9)	[25, 63]
	Cognitive decline	1 (3)	[37]
	House bound	4 (22)	[52, 58, 62, 66]
<b>Functional decline</b>	Poor functional status	1 (6)	[37]
	Cognitive decline	1 (6)	[37]
	Unable to meet ADLs	1 (6)	[38]
	Deteriorating performance status	3 (17)	[5, 28, 39]
	6-min walk test	2 (11)	[63, 78]
	BODE score	3 (10)	[25, 38, 44]
	Functional decline	4 (22)	[47, 56, 63, 79]
	Loss of function	1 (6)	[58]
	Increasing dependence, needs assistance	1 (6)	[72]
	Minimal physical activity	1 (6)	[63]
	New dependence in two ADLs	1 (6)	[65]
	Moderately disabled at home	1 (6)	[24]
	<b>Advanced respiratory therapies</b>	Invasive ventilation, episode of assisted ventilation, NIV, NIV in the last year	13 (77)
Home oxygen use, chronic home oxygen		10 (59)	[27, 31, 38, 42, 46, 53, 56, 59, 64, 76]
<b>Disease progression</b>	Cor pulmonale, heart failure, NYHA level 3	12 (75)	[25, 27, 32, 37, 38, 44, 52, 57, 59, 62, 65, 72]
	Albumin <25 g·L <sup>-1</sup> , anaemia	1 (6)	[25]
	Maximal oxygen uptake (V <sub>O<sub>2</sub></sub> )	1 (6)	[67]

ICU: intensive care unit; FEV<sub>1</sub>: forced expiratory volume in 1 s; MRC: Medical Research Council; CCQ: Clinical COPD Questionnaire; COPD: chronic obstructive pulmonary disease; BMI: body mass index; GOLD: Global Initiative for Chronic Obstructive Lung Disease; CAT: COPD Assessment Test; ADLs: activities of daily living; BODE: BMI, airflow obstruction, dyspnoea and exercise; NIV: noninvasive ventilation; NYHA: New York Heart Association.

#### Referral criteria in ILD

Four studies examined referral criteria in ILD. Among these articles, hospital use, evidence of disease progression and functional decline were cited (each category n=2 (50%)), and in addition two articles suggested that time of diagnosis of ILD was their criterion for referral (new diagnosis of ILD) [79, 83].

### *Referral criteria in mixed populations*

Of the six articles involving advanced nonmalignant lung disease without further specification, hospital use and physical and emotional symptoms were the most commonly cited referral criteria (n=3 (50%)).

### **Discussion**

This systematic review has documented those criteria advanced as prompts for initiating referral to palliative care in the setting of advanced nonmalignant respiratory disease, with a focus on COPD and ILD. Our final sample revealed a wide range of reasons that clinicians use to consider referral to specialist palliative care, broadly classified across needs-based and disease-based criteria with further classification into 18 subgroups. In this systematic review, the most common criterion advanced for referral to palliative care was unscheduled hospital admission, followed by respiratory status and physical and emotional symptoms. The increasing body of literature suggests that the clinical community recognises the need for consideration of palliative care and has sought to establish when or under what circumstances this should take place. However, the wide range of possible criteria implies that consensus for the rationale for referral has not yet been reached.

Importantly, we have not sought to evaluate the criteria nor assigned priority in this systematic review. Rather we have mapped the landscape of all those criteria that have been published, with their relative frequencies. These findings will facilitate further research to elucidate the level of priority assigned when considering criteria to trigger a palliative care referral.

As the most common criterion for palliative care referral, hospital admission was understood to cover multiple circumstances. These ranged from unplanned hospitalisation related to exacerbations; to frequency of hospitalisation, ranging from any hospitalisation, to hospitalisation within the last 3 months, to more than one hospitalisation in the past 12 months; to length of stay, again also variously defined. In addition, emergency department presentations, increased health appointments and any intensive care admissions were all cited as criteria within this broader criterion for considering palliative care referral. In this setting, it may be that hospital use is being considered a surrogate for deteriorating respiratory function, poor prognosis, increasing needs, or failure to identify or respond to patient needs. Such needs may include the requirement for symptom relief, or for emotional support, or the need for community support and information or assistance with decision making, or indeed for all of these.

Another possible explanation for this focus on hospital use is because it is objective and easily measured, being readily available through mapping of health service administrative data and thus useful in settings where there may be limited access to comprehensive information such as in primary care or in emergency departments. Another advantage of these markers for referral is their low risk for measurement bias. Used in this way, unscheduled hospital use could be a criterion used as an automatic trigger to inpatient palliative care referral, allowing for some standardisation of referral practices. However, for some patients a hospital admission will occur only very late in the illness and for some this admission will conclude with death, meaning that limiting referral to palliative care to the inpatient setting may not facilitate timely palliative care access. Meanwhile, although unscheduled hospital use is associated with a poorer prognosis [84], there are fewer data demonstrating the link of unscheduled hospital use with needs, *i.e.* fewer correlations between epidemiological and subjective experiential data. This is an important area for future investigation if unscheduled hospital use is being considered a surrogate for these needs.

A referral to palliative care based upon needs (both physical and emotional, and most commonly dyspnoea and mood disturbance) was highlighted in over a third of papers in our systematic review (37%), with slightly fewer highlighting functional decline (29%) and fewer again highlighting psychosocial needs (16%). In cancer care, an international consensus panel of experts determined that needs-based criteria were most highly cited for referral to palliative care [20]. A recent survey of cancer patients also highlighted that they preferred needs-based over time-based referral [85]. The discrepancy between the importance placed on these criteria in oncology and the relatively lower frequency of these as highlighted in nonmalignant respiratory disease deserves comment. Studies consistently highlight that these needs are not routinely assessed in nonmalignant respiratory care [86, 87]. If key symptoms or needs for support are not routinely included as part of the respiratory clinical consultation and instead must be directly asked for by the clinician, this means an additional “step” must occur within a consultation to identify needs in order to prompt palliative care referral. Even in oncology care, which traditionally includes more integrated palliative care, this step does not always occur, with oncologists reporting inadequate time, expertise and clinic space to fully assess needs [88], thus allowing the needs, in some instances, to go unrecognised [89]. If relying upon “needs” as the recommended criterion for referral to palliative care, then training and support for respiratory providers to identify, assess and respond to needs must accompany such a recommendation.



Most articles in our systematic review focused upon COPD, with very few relating to ILD or unspecified diagnoses, meaning that no detailed discussion of differing criteria between diseases is possible. It is interesting to note, however, that unlike in COPD, two of the four ILD articles highlighted the time of diagnosis as prompting palliative care referral [79, 83], likely reflecting the universally progressive nature of IPF, the most common of the idiopathic ILDs. Most of the studies reviewed did not specify the setting in which palliative care should be delivered. In this systematic review, 19% of articles referred to palliative care in the outpatient setting. The outpatient model has been widely adopted as a means of introducing palliative care in oncology care as it is: 1) readily delivered to patients “early” in their disease course, 2) a setting which is familiar to patients and 3) associated with established positive outcomes, including symptom relief, improved support and reduced subsequent unplanned admissions/health service use [90]. While further testing in advanced nonmalignant respiratory disease is required, initial advantages demonstrated in models of care delivered on an outpatient basis include improved mastery of dyspnoea, increased likelihood of advance care planning, fewer emergency department presentations and improved survival [75, 91].

Different key professional bodies have released guidelines to assist clinicians in implementing or providing care in advanced nonmalignant respiratory disease. These guidelines provide important leadership and direction, but there is not yet a commonly agreed approach across organisations. The American Thoracic Society Clinical Policy Statement recommends: “Palliative care should begin when a patient becomes symptomatic and is usually concurrent with restorative and life-prolonging care” and in the executive summary, that “palliative care may be applied to all stages of illness, whether terminal or not” [8]. The British Thoracic Society states “People with end-stage COPD and their family members or carers (as appropriate) should have access to the full range of services offered by multidisciplinary palliative care teams, including admission to hospices” [92]. The joint statement of the European Respiratory Society and American Thoracic Society from 2004 includes a section discussing the role of palliative care, but does not highlight clear indicators for referral other than in the circumstances when a patient chooses “to refuse life supportive care or have it withdrawn” [93]. Finally, the Lung Foundation Australia-produced and Thoracic Society of Australia and New Zealand-endorsed COPD-X 2020 Guidelines state that “Palliative care – ideally from a multidisciplinary team which includes the primary care team – should be considered early, and should include symptom control and addressing psychosocial issues” and the ILD position statement from the same organisations stresses “Palliative care should be viewed as ‘supportive care’, and should be addressed early as pharmacotherapy in IPF remains largely ineffective for the control of symptoms” [94, 95].

The recommendations highlight the importance of palliative care, and broadly suggest that it should be considered early and be considered in the context of symptoms and for delivery of support; however, detail of how these circumstances are defined is limited. Further clarity and agreement around referral criteria would facilitate clinician decision making and practice. Furthermore, such agreement would greatly facilitate standardisation of the design of palliative and supportive care clinical trials.

This systematic review has potential limitations that should be addressed. Our search was inclusive to avoid a bias towards only those studies where palliative care referral had actually occurred. Just a small number of the studies in our review (15% and 13% were randomised and nonrandomised studies, respectively) included the criteria for referral as part of an empirical prospective design. Many articles included were based on expert opinion or retrospective service reviews. Furthermore, we included all published guidelines which detailed criteria for referral. While inclusive, therefore, we are unable to comment on the utility of the criteria discussed since these have largely not yet been subject to evaluation. Such a formal evaluation will be critical to take the field forward.

Notwithstanding the work still required, we suggest the following should be the focus of such work: needs-based criteria of symptoms including chronic breathlessness, psychological distress, existential distress and increasing care dependency, as well as disease-based criteria including at diagnosis of ILD, two or more (COPD) or any (ILD) hospitalisations for exacerbations, or need for advanced respiratory therapies. The role of setting (outpatient *versus* inpatient) and disease (all advanced respiratory disease *versus* COPD or ILD) requires further specific consideration. Importantly, the priority assigned to patient needs as criteria for palliative care referral means that training in identifying and responding to needs for respiratory providers must occur in parallel with dissemination of recommendations.

In conclusion, our systematic review has identified 18 categories of criteria which may prompt a referral to palliative care for people with nonmalignant respiratory disease and which may be broadly understood as needs-based or disease-based. The large range of categories suggests a lack of agreement on the timing, circumstances and for what purpose palliative care referral should occur in this disease setting.

Nevertheless, the increase in literature in the area and the increasing attention palliative care introduction is receiving in guidelines from professional bodies reveal that palliative care is recognised as playing an important role in the holistic care of people with advanced, nonmalignant respiratory disease. We propose further focus should centre upon criteria of symptoms including chronic breathlessness, psychological distress, existential distress and increasing care dependency, two or more hospitalisations for exacerbations, or need for advanced respiratory therapies. In order to progress this field, consensus around those referral criteria considered most important must be established and in turn evaluation of proposed criteria should be undertaken in prospective studies. Our systematic review forms the first step towards this programme of work.

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