European Respiratory Society Clinical Practice Guideline:

Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

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Abstract

There is increased awareness of palliative care needs in people with chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD). This European Respiratory Society (ERS) task force aimed to provide recommendations for initiation and integration of palliative care into the respiratory care of adult people with COPD or ILD.

The ERS task force consisted of 20 members, including representatives of people with COPD or ILD and informal caregivers. Eight questions were formulated, four in the 'Population, Intervention, Comparison, Outcome' (PICO) format. These were addressed with full systematic reviews and application of Grading of Recommendations Assessment, Development and Evaluation (GRADE) for assessing the evidence. Four additional questions were addressed narratively. An 'evidence-to-decision' framework was used to formulate recommendations.

The following definition of palliative care for people with COPD or ILD was agreed: A holistic and multidisciplinary, person-centred approach aiming to control symptoms, and improve quality of life of people with serious health-related suffering because of COPD or ILD, and to support their informal caregivers. Recommendations were made regarding people with COPD or ILD and their informal caregivers to: consider palliative care when physical, psychological, social, or existential needs are identified through holistic needs assessment; offer palliative care interventions, including support for informal caregivers, in accordance with such needs; offer advance care planning in accordance with preferences; and integrate palliative care into routine COPD and ILD care. Recommendations should be reconsidered as new evidence becomes available.

INTRODUCTION

Chronic lung diseases are major causes of long-term disability and premature mortality worldwide.[1, 2] Chronic obstructive pulmonary disease (COPD) is a leading cause of death and is predicted to be the fourth cause of death in 2030 worldwide.[1, 3] Although interstitial lung disease (ILD) is less prevalent than COPD, for example idiopathic pulmonary fibrosis is associated with high symptom burden, reduced quality of life and short survival.[4, 5] The present guideline focusses on people with COPD and ILD with serious illnesses, defined as carrying a high risk of death, a negative impact on quality of life and functioning in life roles, and is burdensome in symptoms or caregiver stress.[6] People affected have palliative care needs in physical, psychological, social and spiritual/existential domains, equal to or greater than people with cancer.[5, 7-11] Informal caregivers (any relative, partner, friend, neighbor, or significant other with personal relationship with the person cared for and who provides a broad range of unpaid assistance to the person with COPD or ILD[12]) have a major and complex role. They fulfill many tasks (Online supplement 1),[13-19] and are therefore the main, although often "hidden", workforce responsible for providing most of daily care.[20] Nevertheless, they generally receive insufficient support.[13-16, 21] A recent systematic review showed that palliative care interventions offered to people with non-malignant diseases resulted in lower symptom burden, fewer visits to the emergency department and fewer hospitalisations.[22] Despite the mentioned benefits, people with COPD or ILD typically do not have access to the palliative care available to people with cancer.[23, 24] Disease trajectories of people with serious COPD or ILD are highly individual and difficult to predict.[25, 26] In COPD, only one third of deaths are due to a pulmonary cause; about one quarter are due to a cardiovascular cause and about one fifth to cancer.[27] In contrast, ILD is a diverse group of respiratory illnesses associated with different likelihoods of survival.[26] This uncertain prognosis, confusion with end-of-life care and not knowing when to initiate palliative care are barriers towards palliative care.[23, 28] The death of people with COPD or ILD is often perceived as unexpected and they are less likely to die at home than people with cancer[29-31], which may affect the bereavement experience.[32, 33]

Despite inclusion in disease-specific guidelines and some national statements,[34-37] a European clinical practice guideline on palliative care for people with chronic lung diseases is lacking. Therefore, the European Respiratory Society (ERS) task force for palliative care aimed to provide recommendations for initiation and integration of palliative care for adult people with COPD or ILD and their informal caregivers. Our objectives were to raise awareness and assess the effectiveness of palliative care, provide a clinician-guide to palliative care implementation, and identify knowledge gaps to inform future research. The present guideline is not limited to hospice care, which often refers to care for the dying or a location of care in the community.[38] Although for some people *supportive care* has a more positive association than

palliative care, we use the term palliative care, while a well-accepted definition for supportive care is lacking. Moreover, supportive care is sometimes viewed as a component of oncology.[39]

METHODS

We used ERS methodology for clinical practice guideline development.[40, 41] (e-figure 1) (see online supplements for details) Co-chaired by DJAJ and KM, the multidisciplinary ERS task force consisted of 20 members, including three representatives of people with COPD or ILD and informal caregivers, and specialists in nursing, respiratory medicine, palliative care, primary care, internal medicine, old age medicine, pulmonary rehabilitation, physiotherapy, psychology, and methodology. Conflicts of interest were declared and managed according to ERS policies. Representatives of people with COPD or ILD and informal caregivers actively participated in the discussions. One of the co-chairs (KM) held two additional meetings with these representatives: one at the start of the process to discuss the aims of the taskforce and expectations and one to discuss their input for formulating recommendations. Following their input, the task force uses 'person' with illness instead of 'patient' where possible. The senior ERS methodologist (TT) supervised and ensured that all ERS methodological requirements were met, but did not participate in the formulation of questions or recommendations. An information specialist (SG) provided search expertise for all questions. Subgroups of four panellists were formed to work on each question, and the task force held monthly video conferences between November 2020 and September 2022.

Formulation of questions and outcomes

Panellists rated 14 potential topics for inclusion in the clinical practice guideline on a five-point Likert scale using an online survey (Qualtrics [Provo, UT]) to identify the most relevant clinical questions on palliative care for people with COPD or ILD. During three meetings, four questions using the PICO framework were defined as well as four complementary narrative questions.[41] (Table 1 and online supplement 1) Each group member then voted, anonymously, on the importance of outcomes of interest for each PICO question, using an online survey and a scoring system of 0 to 9 (1-3 not important; 4-6 important; 7-9 critical for clinical decision making) following GRADE guidance.[42] Scores for each outcome were averaged, presented and those scored as important or critical further discussed during one meeting until group consensus was reached for the final classification of the importance of outcomes[42] (Online supplement 1). Due to the large number of outcomes, only those deemed as critically important (scoring 7-9) were included.

Literature searches

For each question, a search strategy was designed and executed by the information specialist. See online supplement 2 for a summary of the search process and full search strategies for all databases. Initial searches were conducted between February and May 2021 and updated April 19-22, 2022. A standard set of databases were searched for each question: Medline (OVID), Embase (OVID), Cochrane Database of Systematic Reviews and CENTRAL (The Cochrane Library), CINAHL (EBSCOhost), Scopus, Web of Science Core Collection and Epistemonikos with supplementary searches for systematic reviews undertaken in the online CareSearch systematic review collection resource. Search results were screened independently by two panellists for eligibility (see online supplement 1 for inclusion/exclusion criteria). First, systematic reviews were screened. Systematic reviews that provided evidence for at least one of the outcomes of interest for one of the questions were used as a basis to add later studies. If no relevant systematic review was identified for a question, original studies were screened for inclusion. Whenever there were randomised controlled trials (RCTs) available, those were used as the main body of evidence. Relevant articles not included in the initial search could be added by the task force members. For each question, a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram documented the number of studies included and excluded at each step of screening.[43] For narrative questions seven and eight, task force members identified systematic reviews that had comparable aims and objectives to the questions and extracted relevant themes. Then, primary papers were identified that were relevant but not included in the systematic reviews and these were classified as either adding novel insights not identified in the systematic reviews, or corroborating existing themes.

Evidence syntheses and assessment of the quality of evidence

The literature review and the evidence profile tables for PICO questions three and four were performed by the University of Liège -Epidémiologie et Economie de la Santé. A recipient of the ERS Fellowship in Guideline Methodology with expertise in Public Health (MHB) conducted the systematic reviews, evidence syntheses and GRADE-assessment for PICO questions five and six. Data from included studies for PICO questions three and four were extracted by one panellist and checked by another. Data from included studies for PICO question five and six were extracted by one panellist and checked by two others. Risk of bias was assessed by one panellist and discussed and agreed with two others. Risk of bias was assessed using the Cochrane Risk of Bias tool (version 1) for RCTs and Joanna Briggs Institute (JBI) tools for observational studies. Meta-analysis was not possible for any of the PICO questions because of the limited evidence available. GRADE evidence profiles were created for each PICO question using the GRADEpro Guideline Development Tool (https://www.gradepro.org/), and the certainty of evidence was assessed

based on the GRADE principles: risk of bias, indirectness, inconsistency, imprecision and publication bias.[44, 45] The GRADE evidence profiles were based on RCTs only, except for question six, for which the only included study had an observational design. The final certainty of outcomes for each question was rated as high, moderate, low or very low.[46]

Formulating recommendations

For all questions the evidence-to-decision framework was used to structure the discussions and to document the different factors considered for the recommendations.[47, 48] Apart from the evidence and its certainty other factors considered in this framework included values and preferences of people with illness, resources, feasibility, health equity and acceptability. Draft recommendations were discussed with the task force until consensus was reached. One of the task force chairs (KM), held an additional meeting with representatives of people with COPD or ILD and informal caregivers, and a representative from the European Lung Foundation to discuss in depth their values and preferences concerning each question. Based on GRADE, the strength of the recommendations was rated as either strong (phrased with "We recommend") or conditional (phrased with "We suggest").[49, 50]

For the narrative questions, evidence was reviewed narratively to develop recommendations. For question one (definition), data were extracted for each study concerning: what; what for; to whom; by which means; by whom; where; when; and conditional requirements. (Online supplement 3, adapted from Meyer et al.[51]) For question two (when to start), the framework of Philip et al.[52] was used to extract data on referral criteria. For questions seven and eight (implementation), a whole systems approach was used as a framework for analysis[53], relating the findings of included papers to the needs of people with COPD or ILD, professional requirements and service organisation. Findings were then synthesised in a summary text and key themes illustrated in a schema. For all narrative questions, recommendations for research were drafted by the subgroup and discussed within the task force until consensus was reached.

RESULTS

The number of studies identified and selected is shown in PRISMA diagrams for each question in e-figures 2 to 8. The evidence profile tables and evidence-to-decision frameworks are shown in online supplements 3 (question 1-6), 4 (question 7 and 8 COPD), and 5 (question 7 and 8 ILD). Recommendations are listed in table 1. Table 2 shows recommendations for research.

Question 1. How do we define palliative care for people with COPD or ILD? (narrative)

Recommendation

We suggest to use the definition for palliative care for people with serious illness due to COPD or ILD as shown in box 1. (conditional recommendation for the suggested definition - very low quality of evidence).

Justification

A conditional recommendation was selected based upon the large agreement in the literature on the overall concept of palliative care across the included studies.[54-58]

Summary of main findings

Results included three systematic reviews[54-56], a consensus Delphi study guideline[58], and a study using a summary content analysis, environmental scan and rapid review [57].(See online supplement 3) Studies reported that palliative care is a multidisciplinary approach offered to people with illness as well as their family and aiming to improve quality of life. Palliative care is offered in all settings where a person may have a serious illness and needs.

Other considerations

In a draft definition based on the extracted findings, a definition of specialist palliative care was missing. Therefore, an additional study was sought to define "specialist palliative care". This study used a Delphi procedure and concluded that: "*specialist palliative care is offered by clinicians who have advanced knowledge of identifying dying, skills to assess and manage complex symptoms to improve quality of life, have advanced communication skills and perform distinct clinical practices (e.g., working with the whole family as the unit of care and providing support in complex bereavemen*t)".[59] For the current definition we have combined these skills into: "advanced knowledge of and training in palliative care". ACP is included in the definition and is seen as: "*the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate*".[60] Communication should be both effective (including that what is communicated is received and understood) as well as sensitive (be titrated to the needs of the person with COPD or ILD and informal caregiver). Currently, social equity is not included in the identified definitions of palliative care.

Question 2. When to start a palliative care approach in COPD and ILD? (narrative)

Recommendation

We suggest that a palliative care approach should be considered when people with COPD or ILD and their informal caregivers have physical, psychological, social, or spiritual/existential unmet needs. Needs should be actively sought by asking the person with illness or their informal caregiver, but surrogate markers of disease severity and/or health service utilization may help identify those likely to have needs. (conditional recommendation – low quality of evidence).

Justification

Although the evidence level is low, a conditional recommendation was selected that palliative care should start when an unmet need arises.[52, 61-68]

Summary of main findings

The search retrieved one systematic review[52], one observational study[61] and seven qualitative studies[62-68]. Multiple factors can contribute to late palliative care referral and inequitable variation in care. These include the unpredictable course of chronic respiratory disease, personal views of palliative care, and under-recognition of symptoms and concerns.[69] More standardised criteria for when to start a palliative care approach in COPD and ILD would enhance decision-making and consistency in practice. Available studies describe a range of criteria for when to start palliative care, based on either needs or markers of disease severity and/or health service utilisation review.[52] Referral criteria for palliative care in advanced COPD and ILD across the literature (62 articles: 52 COPD, 4 ILD, 6 mixed) are shown in table 3. The common criteria for starting palliative care include, in order of reporting: hospital use; respiratory status; physical or emotional symptoms; functional decline; use of advanced respiratory therapies; and disease progression [52]. Needs-based criteria function similarly across all diagnoses and can be elicited by asking the person with illness or informal caregiver, or in some cases using objective testing. However, their routine use requires clinicians to identify, assess and then respond to needs.[68] Disease-based criteria, e.g., hospital admissions, are often measured in health systems but their relationship to unmet need is dependent on the disease and service delivery context. For example, a new diagnosis of idiopathic pulmonary fibrosis has been suggested as an appropriate time to start palliative care, yet starting palliative care following a diagnosis of mild COPD may raise undue concern among people with COPD and their families about expected speed of progression.[66]

Other considerations

People with illness and informal caregivers are generally more willing to talk about current needs than potential future ones. They see consultations as about treating the 'here and now' but would like clinicians to initiate discussions about future care.[65] A structured question guide can help the person with illness to bring up symptoms and concerns which they consider 'normal' limitations of disease or which they do not feel can be addressed.[63] Support groups can also help increase readiness for palliative care referral.[61] In primary care, practitioners use verbal and non-verbal indications from people with illness, informal caregivers and health records to identify when to start a palliative care approach. However, without formal screening, recognition of needs may occur late in the disease trajectory by which time it is severe.[64] Most needs will not require specialist palliative care, but potential for benefit depends on the skill-mix and competencies of the care team and delivery structure. The wide range of criteria demonstrates that there is no consensus for when to start a palliative care approach.

Question 3. In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (PICO)

Recommendation

In people with COPD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence)

Justification

In RCTs, palliative care interventions involving caregivers improved the quality of life and well-being[70-74] of people with COPD. Nevertheless, studies were highly heterogeneous, were often applied to mixed populations (not exclusively composed of people with COPD)[70, 73, 75, 76] and the involvement of and support provided to informal caregivers varied. Serious to very serious limitations were found in the GRADE evaluation.

Summary of main findings

In total 28 studies[68, 70-94] were included, nine of which were RCTs.[70-76, 81, 95]. In RCTs, palliative care interventions involving informal caregivers improved quality of life and well-being of people with COPD [70-74] but did not change symptoms of breathlessness[72, 73], anxiety or depression[71-74, 95].

Outcomes in informal caregivers were not assessed in these studies. Hence, the overall quality of evidence was considered very low for all outcomes.

Other considerations

Additional evidence from non-RCTs has shown that palliative care interventions involving informal caregivers: increased satisfaction with care among people with COPD and informal caregivers with care[75, 76, 84, 85, 89, 90, 96]; enhanced quality of communication[96]; raised awareness of proactive care for and involvement of informal caregivers[77]; decreased symptoms in people with COPD[80, 88]; increased confidence in managing symptoms[90, 91, 96] and reduced the mean number of respiratory emergency department visits[75, 97]. There was no evidence of undesirable effects. Strategies such as promoting more involvement of healthcare professionals in identifying eligible candidates for palliative care interventions, initiatives with patients' associations, additional information via technology and peer support, might be needed to facilitate involvement of informal caregivers during the implementation of these interventions to real-world settings, according to the available resources.

Question 4. In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (PICO)

Recommendation

In people with ILD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence)

Justification

The number of available studies is very low, some outcomes of interest were never reported and different instruments have been used to assess the outcomes of interest, leading to very low evidence regarding the use of palliative care interventions involving informal caregivers among people with ILD. Despite this, anxiety and quality of life of people with ILD and burden and depression of informal caregivers was shown to improve with palliative care interventions.[98-100] No serious to very serious limitations were found in the GRADE evaluation.

Summary of main findings

In total 11 studies were included[84, 87, 98-106], three of which were RCTs.[98-100] RCTs with palliative care interventions were few and very heterogeneous, often applied to mixed populations (not exclusively people with ILD) and the support offered to informal caregivers varied and included for example telephone

contacts with a specialized nurse, group sessions, nurse-led support groups or a booklet to address palliative care needs. Nevertheless, anxiety and quality of life of people with ILD and burden/stress and depression of informal caregivers were found to improve. No harmful or adverse events were reported with any of the interventions.[98-100]

Other considerations

Additional evidence from non-RCTs found significant improvements in communication and discussions between people with ILD, informal caregivers and healthcare professionals after palliative care interventions.[84, 101, 102, 105]. Such improvements enabled people with ILD to feel less isolated[99], have better symptom management[101, 103] and, in line with their preferences were less likely to die in hospital[101, 105]. Informal caregivers felt better informed, more prepared, confident and better supported.[100, 103, 105] Satisfaction with care and its acceptability was generally high[98-100], and wishes for earlier access to interventions were expressed. We suggest informal caregivers are involved as early as possible in palliative care interventions implemented in different settings (home, community, hospitals) according to needs and preferences. Strategies such as promoting more involvement of healthcare professionals in identifying people eligible for palliative care interventions, availability of assessment tools, awareness sessions, initiatives with patients' associations, educational programmes, and additional information via technology and peer support, might be needed to facilitate the involvement of informal caregivers during the implementation of these interventions in real-world settings, according to the available resources.

Question 5. In people with COPD, should Advance care planning (ACP) interventions be used? (PICO)

Recommendation

We suggest that ACP should be offered to people with COPD. (conditional recommendation - low quality of evidence)

Remark: ACP should be periodically revised, respecting individual needs and values of people with COPD and their informal caregivers.

Justification

Evidence was limited but demonstrated beneficial effects of ACP for people with COPD as improving quality of communication with healthcare professionals, increasing follow-up ACP discussions, and decreasing anxiety in informal caregivers.[107] Undesirable effects have not been systematically investigated, but they

are considered small and mostly associated with healthcare professionals poorly skilled in ACP undertaking these discussions. The overall quality of evidence was considered as low.

Summary of main findings

Only one study met the eligibility criteria. The selected RCT[107] found that a nurse-led ACP intervention improved the quality of end-of life care communication between people with COPD and their physicians, without causing psychosocial distress in either the person with COPD or the informal caregivers. In addition, the intervention increased the frequency of ACP discussions over the subsequent 6 months.

Other considerations (see also the section in questions 7 and 8 for evidence on implementation)

Nurse-led facilitated ACP is acceptable to people with advanced respiratory disease and is effective in increasing ACP discussions and completion of advance directives. Awareness of symptom burden, readiness to engage in ACP and relevant psychosocial factors may facilitate effective tailoring of ACP interventions and achieve greater uptake.[108] Challenges are how and when ACP should be implemented for people with COPD. The unpredictable trajectory of the disease and the varying readiness of the person with COPD are challenges but also underline the need for timely ACP.[109] Sociocultural factors may play a role in how and when ACP discussions should be conducted. Nevertheless, lack of awareness of culture, religion and spirituality is experienced as a barrier towards ACP discussions with patients with chronic lung diseases.[110] Standardised ACP programmes (e.g., service guidelines and documentation) may facilitate the initiation and ongoing assessment of the plan, but should allow flexibility, respecting personal values and preferences. Healthcare professionals should be trained to conduct ACP discussions including how to address sociocultural factors (such as religion, beliefs and values). Undesirable effects have not been systematically investigated, but mostly appear to be related to poor healthcare professionals' skills in conducting such discussions. As knowledge is still emerging in this area, studies regarding the effects of ACP in people with COPD and their informal caregivers are necessary.

Question 6. In people with ILD, should Advance Care planning (ACP) interventions be used? (PICO)

Recommendation

We suggest that ACP should be offered to people with ILD. (conditional recommendation; very low quality of evidence)

Remark: ACP should be periodically revised, respecting individual needs and values of people with ILD and their informal caregivers.

Justification

There is limited evidence that ACP may decrease dying in the hospital.[101] We consider it likely that the improved quality of communication seen with ACP in COPD would also be seen in people with ILD. Undesirable effects of ACP have not been systematically investigated, but no major concerns have been reported. The included study was an observational study with serious risk of bias and indirectness, so, the overall quality of evidence was considered very low.

Summary of main findings

Only one study met the inclusion criteria.[101] In the selected study a greater percentage of people with ILD who received ACP died at home or hospice compared to those who did not receive ACP.[101]

Other considerations

Two additional studies that considered ACP in people with ILD did not meet the inclusion criteria as they investigated ACP as part of a palliative care complex intervention and the independent effect of ACP could not be disaggregated from results. Qualitative data from one of these studies[98] suggested that people with ILD valued the formal ACP process as it allowed them to have important conversations that might not have otherwise been possible. The second study evaluated an ILD disease management programme that included ACP. The quantitative data from this study suggested decreased quality of life and increased anxiety in the intervention group, but these were not supported by the qualitative results. Qualitative data suggested that people with ILD felt less isolated following ACP discussion.[99] The willingness of people with ILD and informal caregivers to partake in ACP may increase over time.[98] There is limited evidence about how and when ACP should be implemented and any undesirable effects. Sociocultural factors may play a role in how and when ACP discussions should be conducted. Acceptability probably varies across different cultures and religions. As evidence is limited in this area, studies regarding the effects of ACP in people with ILD and their informal caregivers are necessary.

Questions 7 and 8. How do we implement palliative care and ACP with routine clinical care for people with COPD and ILD and their informal caregivers? (narrative)

Note: It became clear that it was not appropriate to separate implementation of palliative care and implementation of ACP because ACP was generally considered as a core component of palliative care and there was considerable overlap in papers. We have therefore combined the findings of the two searches. See online supplement 4 and 5 for further details.

Recommendations

We suggest, with regard to people with COPD or ILD and their informal caregivers, services should:

1. integrate palliative care into routine care, explicitly recognising active disease management and palliative care as complementary;
2. provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs;
3. embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support;
4. foster relationships with trusted healthcare professionals enabling continuity of care;
5. recognise that initiating ACP conversations is challenging and should include analysis of context and timing to offer it. In addition, multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.

(conditional recommendation – low quality of evidence)

Justification

Whilst the lack of rigorous implementation trials mean that the certainty of evidence may be considered as 'low', there is consistency in findings across multiple studies with a broad range of methodologies. Our recommendations build on the key emerging themes from this narrative synthesis.

Summary of main findings

Our COPD evidence-base for this question represents data from 221 original studies (13 systematic reviews reporting 175 original papers, plus 46 primary studies not included in the systematic reviews). The ILD evidence-base represents data from 56 primary studies (four systematic reviews reporting 46 original papers, plus 10 primary studies not included in the systematic reviews). See supplement 4 (COPD) and supplement 5 (ILD) for detailed synthesis of findings. In this summary, we have only included references to the systematic reviews and primary papers with novel findings.

The findings for COPD and ILD are illustrated in figure 1 and key themes of initiating palliative care, holistic needs assessment, integration with respiratory management, communication, and ACP are described below for each condition. In each theme we first describe the findings for people with COPD (which has the more mature literature) and then contrast with the findings for those with ILD. Key priorities for implementation of palliative care in terms of people with COPD and ILD, healthcare professionals and

organisations are shown in tables 4 and 5. These are categorised in terms of people with COPD, healthcare professionals and organisations, a whole systems framework used by five of the systematic reviews in COPD.[68, 111-114]

Theme 1. Initiating a palliative care approach, or referral for palliative care services

Although indicators (e.g., hospitalisation, long-term oxygen therapy, symptom burden) can prompt referral of people with COPD to palliative care services[111-113, 115], some healthcare professionals hesitate to consider a palliative care approach[111, 112] due to the uncertain disease trajectory[111-113, 115, 116], lack of a clear transition to 'end-of-life'[112, 117], normalisation of living with COPD[113], and lack of professional awareness of the potential role of palliative care.[68, 113] This is compounded by some people's reluctance to accept a referral to palliative care because of a misunderstood association with cancer and end-of-life[66, 68, 113], though once referred, acceptability is high.[111] There is limited evidence about optimal timing of referral[113], but 'early' referral has been recommended[112, 115], defined in one study as when the severity of COPD is classified as 'moderate'.[66] Some studies have proactively initiated screening (e.g., during a hospitalisation[111, 118]), or searching for prognostic indicators in primary care records.[84, 111]

Similarly, people with ILD are often not referred to palliative care services, or referred too late to address the high levels of unmet need (e.g., 71% within the last month of life[119]). Suggested triggers for palliative care referral in ILD include: oxygen therapy, ventilatory support, uncontrolled symptoms, functional decline, and opioid consideration[101, 119-122] as well as holistic needs (anxiety and depression, loneliness and isolation, and increasing informal caregiver dependence/burden).[101, 121, 123-125] (Table 3) In contrast to the poor prognosis and downward trajectory over time, albeit still seen as uncertain[120, 122], led to calls for a palliative care approach to be incorporated within usual care from soon after diagnosis.[101, 120, 124, 125]

Theme 2. Holistic needs assessment

Holistic assessment of needs (of people with COPD and informal caregivers[115]), is widely described as a crucial first step[68, 111, 113-115, 126], with practical advice that arrangements should be comprehensive[112, 114], accessible (including home-visits)[111], interdisciplinary[114], and coordinated to avoid duplication between support agencies.[127] A multidimensional assessment should not only consider the needs of the person with COPD, informal caregivers and family, but also the timing of support.[114, 128] The validated Support Needs Approach for Patients (SNAP) tool asks people with

advanced COPD to identify their support needs[129], but is not yet evaluated clinically. Another available tool is the Integrated Palliative care Outcome Scale (IPOS)[130] to assess physical and emotional symptoms and communication/practical issues. IPOS is used in COPD across diverse settings and is suggested to be valid, reliable and responsive to change.[130]

Similarly for people with ILD, multidisciplinary, holistic needs assessment is preferable to a prognosis-based approach[101, 120, 121, 123, 125], with care plans and goals discussed whilst ambulatory rather than during an acute crisis. Three systematic approaches are described in the literature: a validated needs assessment tool to guide consultations (NAT-ILD)[123], a bespoke clinician supportive care decision aid (SCDAT)[125], and a multidisciplinary collaborative ILD-palliative care bundle.[101] IPOS can also be used in people with ILD.[130]

Theme 3. Integrating palliative care with respiratory management

Several studies in COPD addressed service models in which palliative care was integrated into routine care.[68, 111, 117, 127, 128, 131] This approach recognises disease-modifying management and palliative care as complementary[117, 126], and facilitates early discussions of prognosis, ACP, and holistic care.[66] Strategies to promote integration include joint respiratory/palliative care clinics[84], providing respiratory clinicians with palliative care skills[68], regular inter-professional communication[112, 127], and involvement of a key professional to coordinate multidisciplinary working and information transfer between sectors.[117, 126, 131] Raising awareness amongst professionals and the public was important[113, 115], normalising a palliative care approach.[128] Healthcare policy enables these initiatives by supporting organisational change and re-alignment of services.[113, 132, 133]

A needs-based approach was similarly recommended for people with ILD[101, 120, 121, 123, 125], with care coordinated across primary, respiratory (including pulmonary rehabilitation) and specialist palliative care settings, with adequate allied health support to enable care at home (if preferred).[101, 120, 121, 124, 125] Palliative care should be part of multidisciplinary case discussion and a palliative approach triggered by unmet needs, and not seen as a “near-death” intervention.[101, 120, 121, 123-125] Ongoing specialist palliative care for every person with ILD is unnecessary and unsustainable,[125, 134] but needs should be identified systematically to ensure appropriate expertise is involved. Holistic needs assessments involves using an assessment tool and clinical conversation[123, 125, 134], preferably in the ambulatory care setting and not during an acute admission, [123, 125, 134] and consideration caregivers’ needs.[101, 120, 121, 123]

Theme 4. Communication

Communication was a key theme not only among people with COPD, and informal caregivers, but also among healthcare professionals. Strategies to overcome fragmented services[135], included allocating an accessible, named professional able to signpost resources[111, 127, 131, 136], regular multidisciplinary team meetings[114, 127], joint consultations[84], and case management.[115] Most people with COPD value open and honest communication about their prognosis.[96, 112, 113, 131, 133, 136] Digital communication may be useful including phone calls[137], telemonitoring[111], teleconsultations[138], and web-based counselling or support for ACP.[115]

Good communication was also emphasised as crucial for people with ILD. Poor communication between sectors and teams was seen as a major obstacle.[119, 121, 122] Inappropriate optimism, perpetuated by poor communication skills and/or confidence was a problem as healthcare professionals avoided talking about goals of care for fear of "taking away hope".[119, 121, 139] The concept of palliative care providing a layer of care alongside active treatment was not commonly understood[119-121], and often referrals were seen as a covert message that death was very near.[120, 121]

Theme 5. Advance Care Planning

ACP was uniformly described as central to a palliative care approach in both COPD and ILD.[113, 115] Decisions regarding preferences for end-of-life management in COPD (e.g., ventilation, resuscitation) were influenced by the individual's prognostic awareness, illness burden, and existential concerns.[140] Systematic ACP provision for people with COPD improved involvement in decision-making[111, 112], and recording of their wishes[135], with the caveat that pre-stated wishes could change[141], and were not always respected.[128, 135] ACP was perceived to be related to improved control, and confidence in self-managing symptoms[111, 112], but associated changes in unscheduled care and quality of life were variable.[111, 142]

In the context of poor public understanding of COPD[143], people with COPD often lacked insight into their likely prognosis[65, 66], and informal caregivers were unprepared for the death.[**Error! Bookmark not defined.**] A core function of ACP was to meet information needs[65, 115, 144, 145], recognising that the needs of people with COPD and informal caregivers may be different.[112, 115, 133, 136] A significant minority avoid discussion about prognosis[112, 115, 143, 145] and, even if they wanted information, rarely initiated the conversation.[144] Group sessions (e.g. within pulmonary rehabilitation) were perceived as less threatening than individual discussions, though a few found them 'depressing' [141, 146].

Professionals acknowledge the importance of ACP but are unsure when, and how, to start the conversation. They were aware that some people with COPD avoid discussing prognosis, and are afraid of destroying hope by doing so.[147] Therefore, ACP conversations are rarely initiated by professionals[66, 109, 112, 117, 147], who prefer people with COPD to initiate the discussion[**Error! Bookmark not defined.**], which rarely happens.[144] ACP discussions are best delivered by a trusted healthcare professional[65, 141, 143, 144, 147], with advanced communication skills[68, 112, 113] and trained in ACP,[109, 112, 114, 126, 137, 143-145], optimally timed for the patient[137, 141, 143, 145, 147] and including informal carers if wished by the patient.[148] The legal context and place of advance directives was highlighted in one paper.[149] Organisational barriers to incorporating ACP into routine COPD care,[109, 128] include lack of capacity[65, 144, 145, 147], and no clarity on who is responsible for initiating ACP[109, 143-145], or triggers (e.g. hospitalisation) that could indicate appropriate timing.[65, 109, 145] Offers of ACP discussions need to be repeated as preferences change.[141, 143, 144] Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.[115]

The findings for COPD were mirrored in the ILD literature.[119-121, 124] Planning for palliative care at an early stage of the disease with a systematic approach to conversations about disease progression, improving communication about end-of-life needs help people with ILD and informal caregivers manage the uncertainty of illness.

Other considerations

Despite some differences (for example, in the duration of the disease trajectory), the challenges in initiating and delivering an integrated approach to supportive and palliative care for people with COPD and ILD share many features. We have illustrated the considerations for a model of care in a single schema (figure 1) with some differences highlighted. It is important to remember that the evidence base in COPD is far greater than in ILD, and some specific features of ILD care may not be represented in the currently available literature. Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD.

DISCUSSION

The ERS task force evaluated eight questions, including four PICO questions and four narrative questions concerning palliative care for people with COPD or ILD, which were not addressed in previous international guidelines. This resulted in eight conditional recommendations (including a definition for palliative care for people with COPD or ILD), which were based on very low to low quality of evidence. Besides quality of

evidence, people with illness and informal caregivers' values and preferences, resources, feasibility, and acceptability were included into the considerations. In addition, recommendations for future research are provided.

Key findings

There was general agreement in literature that a definition of palliative care for people with serious illness due to COPD or ILD should include components such as: a multidisciplinary and holistic approach; the aim to control symptoms and to improve quality of life; the need to support informal caregivers; and the need to provide palliative care in the place of choice. A needs-based approach is suggested to identify people with serious illness who may benefit from a palliative care approach. These include physical, psychological, social as well as spiritual/existential needs. This is in line with the view of the task force of the European Association for Palliative Care concerning initiation of palliative care in people with chronic heart failure[150]. Moreover, the recent Official ATS/AAHPM/HPNA/SWHPN Policy Statement 'Palliative Care Early in the Care Continuum among Patients with Serious Respiratory Illness' also recommends to offer palliative care to people with serious respiratory illnesses using a needs based approach.[151]

Research is needed to explore markers of disease severity and health service utilisation related to palliative care needs and optimal ways to identify and respond to needs. In people with COPD or ILD, we suggest offering palliative care interventions that include support for informal caregivers. These recommendations were based on very low quality of evidence and, unfortunately, meta-analysis was not possible. However, it is important to realise that there was no evidence of undesirable effects of these palliative care interventions. Moreover, meta-analysis of palliative care interventions in a broader population of chronic non-malignant diseases have shown positive effects on symptom burden, reduced emergency department visits and hospitalisations, but no association with quality of life, which was one of our critical outcomes.[22] A recent systematic review of palliative care interventions in COPD, not limited to those including family caregivers, suggested improved outcomes for people with COPD, but again a meta-analysis was not possible and effects were heterogeneous.[111] Studies are needed to establish the effects of palliative care interventions for people with COPD or ILD involving informal caregivers on critical outcomes such as communication, anxiety, depression, burden for informal caregivers and well-being of the person with illness as well as informal caregiver.

We suggest that ACP should be offered to people with COPD or ILD. However, in both illnesses only one study was selected from the literature, so meta-analyses were not possible. A meta-analysis of ACP in a

broader population showed that ACP increased documentation of advance directives and discussions about end-of-life care, but did not include a meta-analysis concerning our other critical outcomes, like experience of end-of-life care, avoidable hospital visits near the end of life, or symptom control at the end of life.[152] Therefore, further research exploring effects of ACP offered to people with COPD or ILD on these outcomes is necessary. Additional research gaps include components of ACP, and cost-effectiveness.

Finally, a schema of components of palliative care services for COPD or ILD was drafted (figure 1), based on a narrative review of the literature about implementation of palliative care and ACP in routine COPD and ILD care. Our 'whole systems' approach classified components as those that directly address the needs of the person with COPD or ILD, those that support or upskill the professionals, and organisational strategies that underpin the multidisciplinary service. Not all components will be relevant in all settings, but policy makers and those developing services may wish to consider the components as a 'pick list' that they can adopt/adapt to suit their context. Specific targets of future research should be clinical evaluation of holistic need assessment tools, interventions to overcome barriers towards ACP, and implementation of models that integrate a palliative care approach into routine care of people with COPD or ILD. There are regional/national/international differences in access to palliative care services [153, 154], which should be taken into account in studying models of palliative care.

Limitations

There are several limitations concerning the present clinical practice guideline. First, all recommendations are conditional and based on very low to low quality of evidence. Nevertheless, values and preferences of people with COPD or ILD and informal caregivers guided formulation of the recommendations in addition to the quality of the evidence. Second, we could only address eight questions, while the task force identified 14 potential topics for inclusion. Examples of topics that were not addressed and may be relevant for future clinical practice guidelines are symptom management such as palliative treatment of breathlessness, existential needs and bereavement support. Third, two PICO questions explicitly focussed on palliative care interventions involving informal caregivers because of the agreement in the literature concerning the definition of palliative care, as well as agreement among the task force members (including representatives of people with COPD or ILD and informal caregivers). To this end, palliative care interventions not involving informal caregivers were not considered in question three and four of the current guideline, and thereby excluded significant literature regarding effectiveness of palliative care in this population. Importantly, we have sought to synthesise the literature on models of care to provide some insights into how innovative approaches can be implemented. Fourth, social equity was not included

in the identified definitions of palliative care. Research among vulnerable people points out that inequity is present in access to palliative care.[155, 156] Surprisingly, social inequity wasn't found in the literature of questions 7 and 8. Therefore, this may be an important factor to consider in future studies and palliative care definitions. Fifth, in the present guideline, we interpreted ACP according to the definition of the European Association for Palliative Care.[60] Nevertheless, more definitions are available, and ACP can have different legal status around the world.[157, 158] Sixth, in the present guideline, we considered specialized as well as primary palliative care interventions. Although outcomes between these interventions might differ[159], we did not take this into account. Seventh, the literature on palliative care for people with ILD is limited. Therefore, at this moment it is not possible to provide separate recommendations for the diverse group of respiratory illnesses categorized as ILD. By recommending the needs approach instead of a disease-specific approach we believe that palliative care can be adjusted to the personalized needs of people with ILD. Eight, most committee members were palliative care experts from Western European countries. Therefore, perspectives of East and Southern European countries as well as perspectives from clinicians with limited expertise in palliative care were underrepresented.

Conclusion

The task force formulated eight conditional recommendations concerning the definition of palliative care for people with COPD or ILD, when to initiate a palliative care approach for people with COPD or ILD and their informal caregivers, palliative care interventions involving informal caregivers, ACP and the implementation of palliative care interventions and ACP integrated with routine COPD and ILD care. These recommendations were based on very low to low quality of evidence, the values and preferences of people with COPD or ILD and their informal caregivers, resources, feasibility, and acceptability. However, given the consistency of the existing evidence, services should consider providing palliative care in line with these recommendations whilst awaiting further research. As new evidence comes available, these recommendations should be reconsidered and the guideline updated.

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CONFLICTS OF INTEREST

DJAJ reports lecture fees from Boehringer Ingelheim (personal), Chiesi (non-personal), AstraZeneca (non-personal) and Abbott (non- personal) within the previous three years outside the submitted work. DC has received intellectual property payments and consultancy fees from Mayne Pharma International Pty Ltd, manufacturers of Kapanol and is a paid adviser to Helsinn Pharmaceuticals. GPK has received grants from Novo Nordisk Foundation, the Danish Cancer Society and European Commission outside the submitted work. HP has received speaker fees from Boehringer Ingelheim, Teva, and Sandoz for non-promotional talks on digital respiratory health and asthma supported selfmanagement. KM reports lectures fees from Astellas Pharma, GlaxoSmithKline, AstraZeneca, Novartis, Boehringer Ingelheim, Kyowa Kirin, Norgine outside the submitted work. All other panellists have no conflicts of interest to report.

FIGURE LEGEND

Figure 1. Schema of components of palliative care services for COPD or ILD

This schema illustrates the consistent themes from the narrative synthesis (Questions 7 and 8). From the left, a range of triggers can help identify people with COPD or ILD who would benefit from a palliative care approach, though there are barriers to be overcome. A standardised, multidisciplinary assessment is the entry point to the palliative care service and an essential prerequisite to planning appropriate care. The components of a palliative care service are classified as relating to the needs and preferences of the person with COPD or ILD and their informal caregiver, the skills and attributes of the healthcare professional, and the organisational considerations. Relief of suffering is the core aim and requires overlap of these three aspects of a palliative care service illustrated as the overlap of the coloured boxes representing components. Communication (between person with COPD or ILD/informal caregiver and healthcare professional, as well as between different professional groups) is a central theme and is illustrated underpinning the whole process. ACP is a key manifestation of the communication between the person with COPD or ILD and their informal caregiver, and the healthcare professional and thus illustrated emerging from the overlap of these two components.

Abbreviations: HCP: healthcare professional; COPD: chronic obstructive lung disease; ILD: interstitial lung disease; ACP: advance care planning; CRD: chronic respiratory disease; LTOT: Long-term oxygen therapy.

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Box 1. Definition of palliative care for people with COPD or ILD

A holistic and multidisciplinary, person-centred approach aiming to control symptoms, and improve quality of life of people with serious health-related suffering because of COPD or ILD, and to support their informal caregivers. Palliative care:

- Is applicable throughout the whole disease trajectory according to need, in conjunction with any disease-modifying therapies.
- Entails symptom assessment and management, psychosocial support for people with COPD or ILD and informal caregivers, addressing spiritual/existential needs, effective and sensitive communication, and determining current goals of care and advance care planning (ACP).
- Is delivered while recognizing and respecting the personal and cultural values and beliefs of the person with illness and their informal caregivers.
- Is offered by healthcare professionals with basic training in palliative care or, if needed, specialists in palliative care at home, in the hospital (in the outpatient clinic, inpatient palliative care unit, ICU, other hospital wards), hospice, long-term care facility or other place of choice of the person with COPD or ILD.
- Is preferably offered by a multidisciplinary team which might include: nurses, social workers, pharmacists, psychologists, physiotherapists, physicians, occupational therapists, and pastoral care workers. Specialist palliative care is offered by clinicians with advanced knowledge of, and training in, palliative care.

Abbreviations: ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ICU=intensive care unit; ILD= interstitial lung disease.

Table 1. Summary of ERS task force questions and recommendations

	Question	Recommendation
2 Narrative	When to start a palliative care approach in COPD and ILD?	We suggest that a palliative care approach should be considered when people with COPD or ILD and their informal caregivers have physical, psychological, social, or spiritual/existential unmet needs. Needs should be assessed using report from the person with illness or their informal caregiver report, but surrogate markers of disease severity and/or health service utilization may help identify those likely to have unmet needs. (conditional recommendation – low quality of evidence?)
3 PICO	In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)	In people with COPD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence).
4 PICO	In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)	In people with ILD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence).
5 PICO	In people with COPD, should ACP interventions be used? (compared with no or unstructured forms of advance care planning)	We suggest that ACP should be offered to people with COPD. ACP should be periodically revised, respecting individual needs and values of people with COPD and their informal caregivers. (conditional recommendation; low quality of evidence)
6 PICO	In people with ILD, should ACP interventions be used? (compared with no or unstructured forms of advance care planning)	We suggest that ACP should be offered to people with ILD. ACP should be periodically revised, respecting individual needs and values of people with ILD and their informal caregivers. (conditional recommendation; very low quality of evidence)
7 Narrative	How do we implement palliative care with routine clinical care for people with COPD and ILD and their informal caregivers?	We suggest, with regard to people with COPD or ILD and their informal caregivers, services should: 1. integrate palliative care into routine care, explicitly recognising active disease management and palliative care as complementary; 2. provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs;

8 Narrative	How do we implement ACP in routine clinical care for people with COPD and ILD?	3. embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support; 4. foster relationships with trusted healthcare professionals enabling continuity of care; 5. recognise that initiating ACP conversations is challenging, and should include analysis of context and timing to offer it. In addition, multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change. (conditional recommendation – low quality of evidence)

Abbreviations: ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ICU=intensive care unit; ILD= interstitial lung disease; PICO= Patient, Intervention, Comparison, Outcome.

Table 2. Recommendations for research

Topic	We suggest:
Definition of palliative care	Research on including social equity in the definition of palliative care.
When to start palliative care	Performing studies to: • identify which markers of disease severity and health service utilization most closely relate to palliative care need; • elicit the optimal ways for services to identify and respond to needs, including implementing and embedding assessment tools into clinical practice. • examine the impact of different models of responding to need using integrated palliative care on people with COPD or ILD and informal caregivers processes and outcomes.
Palliative care interventions	Performing studies to: • establish the effects (short- and long-term) of palliative care interventions for people with COPD or ILD involving informal caregivers on outcomes considered "critical" by the task force members: Communication within the family and/or with healthcare professionals; Anxiety of informal caregivers; Anxiety of people with COPD or ILD; Burden / stress for informal caregivers; Depression of informal caregivers; Depression of people with COPD or ILD; Quality of life / well-being of informal caregivers; Quality of life / well-being of people with COPD or ILD; Grief/ bereavement/loss experienced by the informal caregiver; Breathlessness of people with COPD or ILD. • study effective components of palliative care interventions for people with COPD or ILD and their informal caregivers. • establish the feasibility and effectiveness of implementing palliative care interventions involving informal caregivers of people with COPD or ILD across different settings (e.g., hospital, long-term-facility, home). • define strategies to promote equity of access to palliative care interventions involving informal caregivers of people with COPD or ILD. • establish the cost-effectiveness of palliative care interventions involving informal caregivers of people with COPD or ILD.
ACP interventions	Performing studies to: • establish the effects of ACP interventions for people with COPD or ILD on outcomes considered "critical" by the task force members: Quality of communication between people with ILD and healthcare professionals; Concordance between the wishes of people with COPD or ILD and received care at the end of life; Documented discussions between informal caregivers and health professionals about goals of care / advance care planning; Symptom control at the end of life; Experience of end of life care; Avoidable hospital visits near end of life, measured by emergency department attendance without admission; Informal caregivers' satisfaction with end of life care; • study acceptability and feasibility (how/when initiate) of ACP for people with COPD or ILD and their informal caregivers; • define core and flexible components of ACP for people with COPD or ILD and their informal caregivers; • explore barriers to ACP implementation of ACP for people with COPD or ILD and their informal caregivers; • analyse changes in care preferences and values of people with COPD or ILD over time; • establish cost-effectiveness of ACP for people with COPD or ILD and their informal caregivers.
Implementation of palliative care and ACP	Performing future studies to: • evaluate holistic needs assessment tools in clinical practice; • develop and evaluate interventions to overcome the barriers preventing initiation of discussions about prognosis and ACP • implementation of models that integrate a palliative care approach into routine care of people with COPD or ILD.

Abbreviations: ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ILD= interstitial lung disease.

Table 3. Categories of palliative care referral criteria across literature for people with serious illness due to COPD or ILD (with examples) [52, 62]

Needs-based criteria	Disease-based / health service utilization criteria
Physical or emotional symptoms (e.g. poor symptom control, breathlessness, pain, weight loss, cachexia)	Hospital use (e.g., admission, frequency of admission, admission for exacerbation)
Functional decline (e.g. increasing care dependency, low 6-minute walk test or gait speed, unable to meet ADLs)	Respiratory status (e.g., FEV_1 <30% pred., respiratory insufficiency, GOLD stage 3-4)
Psychosocial (e.g. social needs, supportive counselling, spiritual or existential concerns)	Advanced respiratory therapies (e.g. invasive / non-invasive ventilation, home oxygen use)
Decision support (e.g. advance care planning, hospice referral, care coordination)	Disease progression (e.g. deteriorating lung function, heart failure, low albumin, multimorbidity)
Person with illness or informal caregiver request for palliative care	Prognosis (e.g. “surprise question”[160], life expectancy <6-12 months)
Informal caregiver distress or need for support	Comorbidities (e.g., cancer, renal failure, diabetes)
Other (e.g. ethical concerns)	New diagnosis (ILD specific)
	End stage care (e.g., terminal care, lack of treatment options)
	Other (e.g., frailty)

Abbreviations: ADLs= Activities of Daily Living; FEV_1= Forced Expiratory Volume in the first second; GOLD= Global Initiative for Chronic Obstructive Lung Disease; ILD= Interstitial Lung Disease.

Table 4. Priorities for implementation of palliative care according to people with COPD, healthcare professionals and organisations

People with COPD and informal caregivers
• accessing information about COPD and support services[65, 111, 112, 136] • optimising treatment to reduce physical symptoms[66, 68, 111, 112, 115] • coping with psychosocial challenges, maintaining enjoyable activities[68, 84, 112] • 'being listened to' so that their care is appropriately tailored[111, 115] • empathy[136], • feeling 'cared for'[65] • establishing, maintaining, and in due course closing relationships[**Error! Bookmark not defined.**] • need for information and practical support (e.g. respite care; resources) (informal caregivers)[115, 117, 136]
Healthcare professionals

• trained in respiratory and palliative care and with access to multidisciplinary generalist and specialist expertise[111-114]
• specific skills include:
  ○ ability to optimise treatment[112, 115, 117]
  ○ provide holistic care[68, 112, 114, 115, 117]
  ○ discuss prognosis and ACP [66, 68, 112-114, 126, 133]
• lead/co-ordinating professionals could be from any discipline or setting[111-113, 116, 126]
• continuity of care crucial to build trusting relationships[112, 113, 127, 136]

Organisations
• accessible service (often community-based)[111, 112] • responsive to individual needs and fluctuating clinical condition[112, 117] • adequately resourced with professional time[111, 116] • services to meet physical, psychological, social and spiritual care needs,[111, 112, 115, 128, 136] provided by a team including clinical and social care providers, generalists, disease-specific and palliative care specialists • availability of ACP documentation to front-line clinical staff to guide decisions (including in an emergency) • multidisciplinary teams need to be collaborative, coordinated, with good communication and defined referral channels for specialist support.[112, 113, 116, 117, 127, 131] • encouraging people and their informal carers to foster relationships with one - or a very few - trusted professionals enabling continuity to be maintained despite the multidisciplinary nature of team[65, 96, 111, 113, 127, 136]

Abbreviations: ACP= advance care planning; COPD= chronic obstructive pulmonary disease.

Table 5. Priorities for implementation of palliative care according to people with ILD, healthcare professionals and organisations

People with ILD and informal caregivers

• access to information and palliative care services[101, 120, 121, 123]:
  ○ for symptom control
  ○ to address psycho-social needs
  ○ for provision of practical help in the home
  ○ support for informal caregivers
• clarity about prognosis
• continuity of care from trusted professionals
• informal caregivers' needs should be assessed alongside the needs of the person with ILD (e.g. the validated NAT:ILD [123])

Healthcare professionals

• trained in [119, 120, 134]:
  ○ holistic assessment
  ○ symptom management
  ○ planning current and future goals of care
• access to, and support from, specialist palliative care teams
• using for example [123-125]:
  ○ a needs assessment tool into routine care
  ○ multidisciplinary respiratory/palliative integration with case conferences
  ○ referral checklists/decision aids

Organisations

• service reconfiguration to allow time for:
  ○ holistic assessment and management
  ○ multidisciplinary team discussions
  ○ communication skills training for clinicians, managers and the clinical team
  ○ adequate flexible resources
• possible models:
  ○ linking respiratory/generalists with specialist palliative care teams for mutual education, training and referral[134]
  ○ a fully integrated collaborative ILD-palliative care service.[101, 124]

Abbreviation: ILD= interstitial lung disease.