

Access to specialist palliative care services for people with interstitial lung disease: a systematic review

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Abstract

Background: Current guidelines recommend palliative care based on individual needs for patients with idiopathic pulmonary fibrosis (IPF). However, patients with interstitial lung disease (ILD) are less likely to receive specialist palliative care services compared with patients with malignant disease. The aim of this review is to summarise recent studies addressing barriers to referring patients to specialist palliative care services. **Methods:** PubMed, Embase, Medline and Web of Science were reviewed to identify relevant publications. Studies were selected if they examined the frequency of specialist palliative care referral and/or addressed issues surrounding access to palliative care services for patients with ILD. **Results:** Ten studies with a total of 4073 people with ILD, 27 caregivers, and 18 healthcare professionals were selected and analysed. Frequency of palliative care referrals ranged from 0% to 38%. Delay in palliative care referrals and end-of-life decisions, patients' fear of talking about the future, prognostic uncertainty, and confusion about the roles of palliative care were identified as barriers to accessing palliative care services. **Conclusion:** Further research should concentrate on the early identification of patients who need specialist palliative care possibly with establishment of criteria to trigger referral ensuring that referrals are also based on patient's needs

Keywords: idiopathic pulmonary fibrosis, interstitial lung disease, palliative care, supportive care, end-of-life

Introduction

Interstitial lung diseases (ILDs) have a significant detrimental impact on patients' independence and mental well-being. Idiopathic pulmonary fibrosis (IPF), the most common form of ILD, is a life-limiting condition that causes 5000 deaths each year, and the incidence is increasing in the UK (1, 2). Despite emerging new therapies, notably pirfenidone and nintedanib, IPF remains a progressive and incurable disease for the majority of patients who are not suitable for lung transplantation. Management involves mostly supportive measures, including pulmonary rehabilitation, oxygen therapy and the treatment of acute exacerbations (3). The median survival length of IPF patients is 2 to 5 years, which is comparable with that of malignant lung diseases (4, 5). Non-IPF fibrotic ILD also carries a poor prognosis (6). New antifibrotic agents do not reverse existing fibrosis and there are no effective treatments for end stage disease.

ILD patients report impaired quality of life secondary to poorly controlled symptoms, including breathlessness, coughing, sleep disturbances, and exhaustion (7). The physical symptoms frequently result in emotional stress, including depressed mood, fear, frustration and anger (8, 9). Compared with

lung cancer patients, patients with ILD have a high symptom burden with breathlessness and cough being the most prevalent (10, 11).

Palliative care aims to improve patients' quality of life by reducing suffering and supporting spiritual and psychological needs. Several studies have shown that specialist palliative care significantly improves quality of life in patients with malignant diseases and with non-cancer respiratory diseases (12, 13). In addition to symptomatic benefits, early integrated palliative care is associated with improved survival in advanced cancer patients (14). Palliative care services improve patients' quality of life and facilitate better symptom management in patients with non-malignant diseases (13). Current guidelines recommend palliative care in conjunction with disease-focused care based on individual needs for patients with IPF (15, 16). However, ILD patients are less likely to receive specialist palliative care services compared with patients with malignant lung diseases (11). Specialist palliative care refers to the care provided by professionals who have undergone recognised specialist palliative care training and who are members of specialist palliative care team whereas generalist palliative care refers to the care provided by other healthcare professionals (17, 18).

Patients' access to a specialist palliative care team is often dependent on the physician's judgement in the absence of automatic referral systems. Focusing on intervention without addressing the barriers to referring patients to specialist palliative care services may not be successful in improving palliative care access, leaving the majority of patients without access to palliative care services. This study aimed to explore current evidence of the utilisation of palliative care services in the management of interstitial lung disease by examining (1) specialist palliative care referral rates, (2) timing of referrals and (3) barriers and facilitators to specialist palliative care referrals. Previous reviews have considered symptom prevalence and symptom control in ILD, and palliative care in non-malignant lung conditions (10, 19, 20). Therefore, we wished to focus on access to specialist palliative care services in management of ILD.

Methods

Study design

The systematic review is registered with PROSPERO, registration number: CRD42017077494. We followed Cochrane methodology Version 5.1.0 (21) and PRISMA reporting standards (22). The initial search was conducted between August 2017 and September 2017 and an update search was conducted in June 2018.

Entry criteria

Studies were included if (1) they examined people with a labelled diagnosis of any form of interstitial lung disease without necessarily making any reference to diagnostic criteria (2) discussed barriers, facilitators or issues about accessing palliative or supportive care. Both qualitative and quantitative studies were considered. Studies reporting the views and behaviours of relatives of people with interstitial lung disease and health care professionals were considered. Review articles, conference abstracts, case studies, comments and editorials were excluded. Manuscripts written in non-English language were also excluded (Table 1).

Search strategy

Four electronic databases (PubMed, Embase, Medline, and Web of Science) were reviewed to identify relevant publications. They were chosen as they encompass the majority of the medical literature. Grey

literature was not searched. Search terms included (“Lung Diseases, Interstitial”[Mesh], “interstitial lung disease” OR “interstitial lung diseases” OR “interstitial pneumonia” OR “interstitial pneumonias” OR “idiopathic pulmonary fibrosis” OR “pulmonary fibrosis” OR “fibrotic lung” OR “usual interstitial pneumonia”) combined with (“Palliative Care”[Mesh] OR “Terminal Care”[Mesh] OR “palliative” OR “palliation” OR “end of life” OR “end-of-life” OR “terminal care” OR “supportive care” OR “hospice care”). We screened the reference lists and citations of relevant studies to identify additional studies and searched for studies referencing the identified articles.

Data collection and quality assessment

The search results were screened independently by two reviewers (JK and CA). Any disagreement was resolved by a third party (AMW). Data were extracted independently by two reviewers (JK and CA) using a structured data extraction form. Any disagreement was resolved by discussion. Quality assessment was performed by two reviewers (JK and CA). The Newcastle-Ottawa scale adapted for cross-sectional studies was used for quality assessment of quantitative studies (23). It scores studies out of 10 by assessing the quality of study in three domains: selection (maximum five stars), comparability (maximum two stars), and outcome (maximum three stars). Qualitative studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (24). It entails 10 questions encompassing topics of validity, results, and value of study.

Results

Characteristics of the studies

The search identified 645 publications with 37 full text articles reviewed. Of 37, ten studies were selected (figure 1). Of these, eight studies involved ILD patients or caregivers of ILD patients. Two studies not specific to ILD population were also included as they included people with ILD (25, 26). Two studies were qualitative, and the remaining studies were quantitative. In this review, narrative analysis was used given the heterogeneity of the included studies. Table 2 describes the characteristics of the included studies. Most the studies were based in the USA or in Scandinavia with one study evaluating carers and healthcare professionals from Northern Ireland.

Quality assessment

Convenience sampling was used in both of the qualitative studies, therefore there may have been a selection bias. Data were analysed using thematic analysis of semi-structured interviews and focus groups. In both studies, there was no discussion whether number of focus groups and interviews were sufficient to reach data saturation.

The quality of the eight quantitative studies ranged from four to six stars (Table 3). All eight studies were retrospective in nature, with the potential for record bias. The majority of the studies were of a small sample size although two studies reviewed large databases; the sample size ranged from 13 to 3166 people. Three of the studies including people in an intensive care setting and are therefore not likely to be generalizable to the ILD community as a whole. Five studies defined the provision of palliative care based on database records. However only one of those studies reported the validity of those database records (11). Three studies did not report the prevalence of any comorbidities,(11, 27, 28) and one study reported the prevalence of cancer but no other comorbidities (29). Five studies involved data from deceased IPF or ILD patients. However, only one of these studies examined the cause of death (30).

Referral rates

The frequency of specialist palliative referrals ranged from 0% to 38% (26, 27, 29-32). Bajwah et al. reported that of 38% of patients received palliative care input, only four (9%) had access to both hospital and community palliative care services (31). Two studies explored palliative care access for ILD patients compared with lung cancer patients (11, 28). In both studies, there was no statistically significant difference in specialist palliative care referral rate for consultation between ILD patients and lung cancer patients.

Timing of referral

One study described a correlation between the time of palliative care referral and the time of death ($r=0.99$; $p<0.001$) (27). In this study, only 13.7% of patients received referrals, and 71% of these referrals were made in the last month of life, suggesting that the referrals are late in the disease course.

Rajala et al. described significant delays in end-of-life care decisions; with 32% having documented end-of-life decisions (30). A total of 74% of end-of-life decisions were made in the last 3 days of life. Life-prolonging treatments such as antibiotics (66%) or non-invasive ventilation (29%) were frequent during the last week of life, and 25 (42%) patients had laboratory tests during the last 24 hours of life (30).

Deaths of ILD patients were more likely to be 'unexpected' compared with lung cancer patients (15% vs. 4%, $p<0.001$) and end-of-life discussions with patients and their families were less likely to occur (41% vs. 59%, $p<0.001$ and 52% vs. 73%, $p<0.001$) (11).

Barriers

Hesitancy to engage in palliative care due to fear of talking about the future, the wish to focus on positive aspects, prognostic uncertainty, and confusion about the roles of palliative care were observed as barriers (25, 33). Palliative care referrals were negatively associated with Hispanic race in a US database review (29).

Facilitators

Patients who received palliative care team input had more ILD specialist centre visits than patients who did not (27). The author suggested that patients who had more clinic visits had more opportunities to establish rapport with health care professionals, facilitating the discussion of palliative care options and subsequent arrangement of a formal palliative care referral. Older age, urban teaching hospital settings, and "do not resuscitate" (DNR) status were associated with increased palliative care access for patients with IPF undergoing mechanical ventilation in the USA (29).

Discussion and future perspectives

Reviewing the available literature on palliative care for ILD confirmed a low percentage referral to specialist palliative care services and also a late referral with many people being referred in the late stage of their disease. Our review identified that the main barriers to referral to palliative care included attitudes to palliative care from both patients and healthcare practitioners, difficulty estimating prognosis, as well as circumstantial factors. Despite thorough searching, our findings are based on limited data as we only identified ten papers. This highlights the research need in this area given the importance of ensuring people with ILD have appropriate access to specialist palliative care services.

The low referral rate data presented in this review are in keeping with the findings of the British Thoracic Society interstitial lung disease registry, which previously demonstrated that only half of centres assessed palliative care needs at each clinic visit, and that only 3% of patients referred at first visit (34). Low referral rates and late referrals to specialist palliative care team have been observed in the management of COPD patients compared with people with heart failure, severe dementia or cancer (35). A literature review of qualitative studies on different chronic conditions described that most people with advanced lung diseases did not perceive their condition as life-threatening (36). From our search, there are no published data reporting specialist palliative care referral patterns for ILD patients compared with people with other non-malignant chronic conditions. A further study on this topic may help us to understand unknown barriers.

The death of people with ILD were more likely to be “unexpected” compared to those with cancer and, concurrent life-prolonging treatment and end-of-life treatment was frequent, suggesting physician’s potential struggle in identifying patient reaching the end of life (30). Previous studies have reported that prognostication difficulties due to unpredictable disease trajectory form a barrier to providing adequate specialist palliative care services to patients with non-malignant conditions (37). One qualitative study described how health care professionals have difficulties in deciding the optimal time to make specialist palliative care referrals when the prognosis is uncertain (25). In contrast with other chronic respiratory conditions such as COPD, bronchiectasis and asthma, which have an episodic pattern with exacerbations and frequent near full recovery, people with ILD and in particular IPF have more of a steady prognosis and rarely recover from exacerbations. It is therefore surprising that we identified difficulty in estimating prognosis to be a key barrier for ILD patients.

Improving accuracy of prognostication may improve confidence of physicians in deciding to refer to palliative services, as well as allowing patients and families to plan for the future (38). However, palliative services should be provided based on patients’ needs rather than an arbitrary estimated life expectancy (39). Physician decision aids such as the Need Assessment Tool: Interstitial Lung Disease (NAT-ILD) (40) may be helpful. However, even with the NAT-ILD, time constraints and inadequate skills for exploring non-medical aspects have been shown to be barriers to palliative care referral. Automatic referral systems based on pre-defined criteria have been proposed for cancer patients (41, 42). Such systems could be adopted for ILD patients, and, for example, commencing long-term oxygen therapy (LTOT), or other criteria to trigger referral could be established. Standardised criteria can regulate access to specialist palliative care. Robust studies have been conducted and implemented in oncology and further research might adopt successful strategies performed in other specialties.

Our review highlighted the poor understanding of the roles of palliative medicine by patients and healthcare professionals. Despite increasingly integrated palliative care services, patients’ perceptions of palliative care have not changed considerably (43). There is a common misconception that palliative care is equivalent to end-of-life care. This misconception has led to negative perceptions of palliative care associating it with the loss of hope and dying. Patients receiving life-prolonging or curative treatment fear that they may be abandoned by physicians if they require palliative care (44). This fear is not limited to patients. Physicians also fear that the introduction of palliative care may destroy patients’ hope (44). Barriers observed when providing palliative care for lung transplant candidates reflects a misconception and poor understanding of the roles of palliative medicine (44). Palliative care referrals should be based on patients’ needs, and lung transplant candidates should not be disadvantaged in their access to palliative care services, as transplant candidates also have palliative care needs (45).

The physician's understanding of palliative medicine could be enhanced by expanding collaboration between ILD specialists and specialist palliative care teams via joint clinics, MDT meetings, and educational meetings. In addition to the gap in understanding of the roles of palliative care, one qualitative study identified that there were issues surrounding inadequate knowledge and experience in the management of ILD patients among non-ILD specialists including specialist palliative care team (46). This reflects the necessity to provide additional support to both respiratory and palliative care teams in the decision making and management of ILD patients. Additionally, increasing exposure to palliative medicine in medical school can introduce the importance of integrated palliative care to medical students at an early stage of their career (47).

Urban teaching hospitals setting was associated with better palliative care services (48). Teaching hospitals are likely to have an established integrated palliative care system and higher availability of specialist palliative care services (49). Further studies are needed to achieve equity of access to specialist palliative care and adequate care transfer between different clinical settings for people with ILD.

Limitations

The main limitation of this review is that the included studies were performed in different settings, limiting accurate comparison of the studies. The review is based on a small number of studies and all quantitative studies were retrospective in nature. Additionally, we included studies of people with a concomitant significant medical condition and also studies that evaluated people with non-ILD respiratory conditions to maximise the potential of identifying possible barriers and facilitators. These alternative diagnoses may have influenced the patient's management plan, including specialist palliative care referrals and end-of-life decisions and a careful approach needs to be taken when interpreting our results. This review was limited to published scientific articles and we did not attempt to evaluate the grey literature and conference abstracts or seek data from unpublished sources because they had not undergone adequate peer review but we may have missed some additional barriers or facilitators. Furthermore, we did not include studies written in non-English language also potentially limiting the findings. We did not employ a librarian to generate the search terms, however we used a broad range of terms and did not identify papers in forward or backward searching so we believe our searching was complete.

Conclusions

This review has highlighted the low referral rates of people with ILD to palliative care. We identified that the main barriers to referral to palliative care were fear of talking about future, patients' wish to focus on the positive, unpredictable disease trajectory, and poor understanding of the roles of specialist palliative care. The main facilitators were more contact with healthcare professionals, teaching hospital settings, older age, and advanced care planning. Further research should therefore concentrate on the early identification of patients who need specialist palliative care possibly with establishment of criteria to trigger referral ensuring that referrals are also based on patient's needs. Additionally, further education on the roles of specialist palliative care is required to inform patients and physicians about the purpose of specialist palliative care referral so that it is not associated with a sense of abandonment or loss of hope.

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Inclusion criteria	
Participants	<ul style="list-style-type: none"> ▪ Studies of adult participants with interstitial lung disease ▪ Studies of participants who are family caregivers and/or healthcare professionals caring for patients with interstitial lung disease
Outcomes	<ul style="list-style-type: none"> ▪ Any outcomes which reports issues surrounding access to specialist palliative care services, including referral rates, timing of referrals and barriers and facilitators to referring patients
Study designs	<ul style="list-style-type: none"> ▪ Both quantitative and qualitative studies
Publication types	<ul style="list-style-type: none"> ▪ Full texts and English language
Exclusion criteria	
Conference abstracts, review articles, comments, and editorials Studies written in non-English language	

Table 1 Inclusion and exclusion criteria

Author, Year	Aim	Sample	Design	Method	Key finding of the study
McVeigh, 2018(25)	To explore generalist and specialist palliative care for people with non-malignant lung diseases.	Bereaved carers n=17; Health care professionals n=18 (Northern Ireland)	Qualitative	Semi-structured interview and focus group	<ul style="list-style-type: none"> Barriers: poor understanding of the roles of palliative care from healthcare professionals and prognostic uncertainty Variations in generalist and specialist palliative care provision
Rush, 2017(29)	To explore palliative care access for IPF patients undergoing mechanical ventilation compared with lung cancer	IPF n=3166 (USA)	Quantitative	Retrospective analysis of database	<ul style="list-style-type: none"> 408 (12.9%) had a palliative care input Older age, urban teaching hospital settings, DNR status and West and Midwest areas were associated with increased palliative care access Factors associated with less PC access: Hispanic race and missing race were associated with less PC referrals compared with white race Significant increase in number of PC referrals from 2006 to 2012
Lindell, 2017(33)	To understand the palliative care needs in IPF patients and their caregivers	IPF patients n=5 Family caregivers n=5; Family caregivers of deceased IPF patients n=3 (Pittsburgh, USA)	Qualitative	Thematic analysis of focus group	<ul style="list-style-type: none"> There is a high symptom burden (psychological and physical) for both patients and caregivers Hesitancy to engage in palliative care due to fear of talking about future, wish to focus on the positive, confusion about roles of palliative care
Liang, 2017(32)	To examine frequency and timing of palliative care referral in IPF patients admitted to ICU	IPF n=106 (USA)	Quantitative	Retrospective review of patients' medical records	<ul style="list-style-type: none"> 84% of ICU admission were due to acute respiratory deterioration. 27 (25%) patients received a formal palliative care referral. Of 27, four referrals made prior to ICU admission. 82 (77%) patients died in ICU
Ahmadi, 2016(11)	To examine end-of-life care and symptom prevalence in oxygen-dependent fibrotic-interstitial lung disease compared with lung cancer patients.	ILD n=285 Lung cancer n=10,822 (Sweden)	Quantitative	Retrospective analysis of the database	<ul style="list-style-type: none"> Death of ILD patients were more likely to be 'unexpected' (15% vs. 4%, p<0.001). EOL discussion with patients and their families were less likely to occur (41% vs. 59%, p<0.001 and 52% vs. 73%, p<0.001). The difference in palliative care team consultation between IPF and lung cancer patients was not statistically significant (6% vs. 19%, p=0.655). An infrequent usage of validated symptom scale for pain and other symptoms (13% vs. 28%, p<0.001 and 8% vs. 14%, p=0.004, respectively) in ILD patients IPF patients were more likely to have unrelieved breathlessness, pain and anxiety
Rajala, 2016(30)	To examine end of life care in patients with IPF	Deceased IPF patients n=59 (Finland)	Quantitative	Retrospective healthcare documentation review	<ul style="list-style-type: none"> No documented specialist palliative care was identified. Only 1 patient was referred to a hospice Concurrent life-prolonging treatment and EOL treatment 19 (32%) had documented EOL decisions. 74% of EOL decisions were made in the last 3 days of life
Brown, 2016(28)	To explore palliative care for patients with ILD and COPD who die in intensive care unit compared with lung cancer	ILD n=79; COPD n=592; Lung cancer n=158 (Seattle, USA)	Quantitative	Retrospective review of patients' medical records	<ul style="list-style-type: none"> No statistical difference in palliative care consultation (OR 0.87, 95% CI 0.33-2.28, p=0.771). An inadequate documented pain assessment (OR 0.43, 95% CI 0.19-0.97, p=0.043) in the last 24 hours of life. DNR order and documented discussion of prognosis were less likely to occur (OR 0.40, 95% CI 0.19-0.86 and OR 0.36, 95% CI 0.19-0.66, respectively) compared with cancer patients

Lindell, 2015(27)	To investigate timing of palliative care referrals in patients with IPF	Total n=404 Known location of death n=277; unknown location of death n=127 (Pittsburgh, USA)	Quantitative	Retrospective analysis of a clinical database	<ul style="list-style-type: none"> ▪ 13.7% of patients who died in hospital received a formal palliative care consultation. ▪ A correlation between the time of PC referral and the time of death ($r=0.99$, $p<0.001$), indicating that palliative input occurred close to time of death. ▪ Deceased people who received palliative care team input had more ILD specialist centre visits (mean: 8.0 visits [SD±6.1]) than patients who did not (mean: 5.2 visits [SD±5.4]). ▪ Patients seen by palliative care were more likely to die in an academic medical centre or hospice.
Colman, 2015(26)	To investigate outcome of lung transplant candidate referred to palliative care services	Total n=308 People referred to palliative care n=64 (Ontario, Canada)	Quantitative	Retrospective analysis of healthcare records	<ul style="list-style-type: none"> ▪ 64 (20.7%) was referred to palliative care services ▪ Of 64,51 (80%) had a diagnosis of ILD ▪ The median timing of palliative care referral from transplant listing was 65 days. The median timing of referral from delisting or death was 32 days.
Bajwah, 2012(31)	To understand the palliative care and end-of-life planning needs in patients with fibrotic ILD	ILD n=45 (London, UK)	Quantitative	Retrospective review of patients' records	<ul style="list-style-type: none"> ▪ 17 (38%) had specialist palliative care input. 4(9%) had both hospital and community palliative care. 28 patients (62%) did not have any palliative care input in their last year of life. ▪ Few patients had a preferred place of care (8/45) or place of death (6/45) ▪ 34 (76%) patients died in the hospital.

Table 2 Characteristics of the Included Studies

First Author, Year	Selection of participants	Confounding measurement	Outcome measurement
Rush, 2017(29)	★ ★ ☆ ☆ ☆ IPF patients undergoing mechanical ventilation.	★ ☆ No comorbidities recorded other than malignancy Cause of death not recorded	★ ★ ★ Sensitivity and specificity of palliative care codes are unknown in patients with IPF (coding error)
Liang, 2017(32)	★ ★ ☆ ☆ ☆ IPF patients who was admitted to an ICU. Single centre study	★ ☆ Reasons for hospital and ICU admission explored.	★ ★ ★ Outcome collected retrospectively. Palliative care defined as documented evidence a formal consultation.
Ahmadi, 2016(11)	★ ★ ☆ ☆ ☆ Only oxygen dependent ILD patients, may represent more severe disease only Of 490 deceased people with IPF, 205 patients were excluded as data missing from the SPRC registry	☆☆ No comorbidities recorded	★ ★ ★ SPRC collect data retrospectively after patients' deaths (recall bias) No statistically significant difference in specialist palliative consultations. However, ILD population (n=285) was significantly smaller than the population of lung cancer (n=10,822). Therefore, it seems possible that these results are due to small sample size of the ILD group.
Rajala, 2016(30)	★ ★ ★ ☆ ☆ Includes all patients recruited to a prospective, national clinical registry (2012 to February 2014). Unclear if national registry collects all patient diagnosed with IPF. Likely representative but small sample size.	☆☆ Comorbidities recorded. 17% of study population had cancer. Cause of death was IPF in 42 (71%) of patients. 29% died of other causes including cancer (10%) and cardiovascular disease (12%)	★ ★ ☆ Access to individual notes of all patients in registry available as well as death certificates. Outcomes collected retrospectively and required accurate records.
Brown, 2016(28)	★ ★ ☆ ☆ ☆ IPF patients who died in intensive care unit only. Small ILD sample size	★ ☆ Reasons for hospital and ICU admission not explored Comorbidities not recorded but excluded patients with more than one of COPD, ILD, or lung cancer	★ ★ ★ No statistically significant difference in specialist palliative care consultations. However, ILD population (n=79) was smaller than the population of lung cancer (n=158)
Lindell, 2015(27)	★ ★ ☆ ☆ ☆ Exclusion of patients where place of death unknown may affect generalization to all IPF patients Single centre study	☆☆ No comorbidities recorded Cause of death not recorded	★ ★ ★ Death notifications within an 18-hospital network allowed location of significant number of deaths to be identified. Palliative care input defined as a dictated palliative-care consultation.
Colman, 2015(26)	★ ★ ☆ ☆ ☆ Included candidates for lung transplant from multiple respiratory conditions. Includes ILD patients but does not specify whether IPF or alternative diagnosis. ILD responsible for majority of palliative care referrals (51 patients; 80%). Single centre study	☆☆ No specific analysis of ILD (or subgroups) Comorbidities only recorded for people referred to palliative care	★ ★ ★ Assessment of the outcomes not described – data extracted by appropriately trained member of the team. Appropriate statistical methods employed

Bajwah, 2012(31)	★★☆☆☆ Two large London (UK) tertiary centres with demographic variation (cultural and socioeconomic) Small sample size	☆☆ Comorbidities recorded but not controlled Cause of death not recorded	★★☆ Pre-specified data-extraction sheet collected outcomes from individual patient note sets. Data collected retrospectively.
Qualitative study			
McVeigh, 2018(25)	Not specific to IPF population (ILD cause of death for 4 out of 17 bereaved carers). Included health care professionals and care givers, taken from 2 sites (1 rural, 1 urban) each in Republic of Ireland and Northern Ireland.	More health-care professionals (18) than care givers (17) Specific IPF/ILD carers not identified in results	Semi-structured interviews with carers. Focus groups undertaken with health care professionals. All data were audio-recorded and then transcribed, analysed using thematic analysis with coding software used to aid analysis.
Lindell, 2017(33)	May not representative of general IPF population – convenience sampling (selection bias) Single centre study	More care-givers (8) than patients (5)	Audio recording of focus groups; appropriate size (3-5 participants per group). Coding software used to identify major concepts/themes, multiple coders used to identify themes. No discussion of whether number of focus groups was sufficient to identify all themes (saturation).

Table 3 Quality assessment of included studies

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