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INTERSTITIAL LUNG DISEASE

# Specialist Palliative Care is More Than Drugs: A Retrospective Study of ILD Patients

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**Abstract**
*Background* This study aimed to assess the palliative care needs of progressive idiopathic fibrotic interstitial lung disease (PIF-ILD) populations in two London ILD centres.
*Methods* Patients' records from Royal Brompton Hospital (RBH) and King's College Hospital (KCH) were extracted to assess palliative care needs, use of palliative treatments, and whether end-of-life preferences were documented and achieved.
*Results* Forty-five PIF-ILD patients were identified (26 RBH, 19 KCH). Patients at RBH were younger (37–81 years, median = 61 years) and predominantly white British (23/26) compared to KCH's older, more racially diverse population (70–99 years, median = 82 years, 6/19 nonwhite). Seventeen of 45 patients had specialist palliative care team involvement. Nearly all patients (42/45) experienced breathlessness in their last year of life. Additional symptoms included cough, fatigue, depression/anxiety, and chest pain. All patients given opioids (22/45) or benzodiazepines (8/45) had documented benefit. Nonpharmacological treatments were rarely used. Few patients had preferred place of care (8/45) or preferred place of death (6/45) documented.
*Conclusions* Despite demographic variation, the patient populations at the two hospitals experienced similar symptoms. There was use of standard pharmacological treatments with symptom benefit. Nonpharmacological interventions were seldom used and documentation of preferred place of care and preferred place of death was poor.

**Keywords** Cough · Dyspnoea · Lung disease · Interstitial · Pain · Palliative care · Pulmonary fibrosis

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## Introduction

There are at least 2,000 new cases of progressive idiopathic fibrotic interstitial lung disease (PIF-ILD) each year in England and Wales, with a similar number of deaths [1, 2]. There is evidence from death certificate data that the incidence is increasing [1, 2]. Median length of survival from diagnosis in the UK is ~3 years [3, 4] which is not dissimilar to that of lung cancer. Only a minority of patients are suitable for lung transplantation and there are no other significant treatment options once the disease has become advanced and irreversible [5].

The World Health Organisation defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening

illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual''. The treatments involved in specialist respiratory palliative care contain both pharmacological (e.g., opioids, benzodiazepines and $O_2$ therapy) and nonpharmacological methods (e.g., counselling, relaxation/breathing therapies, use of hand-held fans, and spiritual care). When appropriate, specialist palliative care teams routinely address end-of-life planning needs. This includes assessing and documenting a patient's wishes on preferred place of care (the setting in which care should be delivered in the last days/weeks of life) and preferred place of death (where the patient prefers to die). Palliative care aims to facilitate the achievement of preferred places of care and death.

Palliative care has traditionally focused on improving quality of care in cancer. UK government strategies for individual disease groups [6, 7] and the recent End-of-Life Care Strategy [8] have highlighted the importance of developing effective palliative care interventions for patients with nonmalignant diagnoses. In addition, there is an increasing recognition of the need to improve palliative care currently available to nonmalignant respiratory diseases such as COPD [9]. To date there has been a paucity of research that has explored the palliative care needs of patients with PIF-ILD [10–13].

This study forms part of a larger project to develop evidenced-based palliative care guidelines and a complex end-of-life intervention for patients with PIF-ILD. The aims of this study were to compare the palliative care needs, treatments, and end-of-life preferences of PIF-ILD patients.

## Methods

Two large London hospitals that regularly treat PIF-ILD patients were approached to take part. Royal Brompton Hospital (RBH) is a specialist ILD centre in central London. The unit has one of the largest diffuse lung disease patient populations in the world with over 500 new referrals a year for patients with ILD from across London and the surrounding counties. Patients come from areas with varying palliative care services and community support teams. King's College Hospital (KCH) is a tertiary hospital with a specialist ILD clinic in the southeast of London. KCH serves a geographical area characterised by material and social deprivation in addition to a large population of black and minority ethnic communities. The area has a network of palliative care services, including inpatient hospices, community services, and hospital support teams, coordinated through the South London Palliative Care Network and other regionally based networks. The two very different study settings were chosen to allow assessment of palliative care needs and end-of-life preferences of PIF-ILD patients from different cross-cultural, socioeconomic groups and two distinct ILD centres.

Retrospective assessment of case notes of PIF-ILD patients who died between January 2009 and May 2010 was carried out using a data extraction sheet noting demographics and type of disease. PIF-ILD diseases included nonspecific interstitial pneumonia (NSIP), idiopathic pulmonary fibrosis (IPF), usual interstitial pneumonia (UIP), and idiopathic interstitial pneumonia (IIP) as classified and diagnosed by ATS/ERS criteria [14, 15]. We have concentrated on diagnoses that are idiopathic in nature and excluded pulmonary fibrosis related to drugs and occupational exposure.

The following specialist palliative care domains were used: palliative care needs (shortness of breath, cough, fatigue, insomnia, depression/anxiety, spiritual, and other), palliative treatments (opioids, benzodiazepines, steroids, antireflux agents, antidepressants, fan, relaxation therapy, counselling, referral for spiritual care) palliative care involvement, and end-of-life planning (preferred place of care and death). The data extraction sheet was piloted on ten sets of notes. The data were transferred to Statistical Package for the Social Sciences (SPSS; IBM, Chicago, IL) for analysis. The general practitioner was contacted for clarification of demographic information when necessary.

## Results

Forty-five PIF-ILD patients were identified (26 RBH, 19 KCH). Clinicians had diagnosed PIF-ILD using ATS/ERS criteria 2002 [15] and IPF using ATS/ERS 2000 criteria [14]. The diagnoses were made initially on history, physical examination, chest radiograph, and lung function tests. Patients with possible IIP underwent high-resolution computed tomography (HRCT). If the HRCT test was consistent with features of IPF, then a diagnosis of IPF was made. If HRCT was inconsistent with IPF or inconclusive, surgical lung biopsy was performed. Overall, 34 patients underwent diagnostic biopsy.

Patients at RBH were younger (range = 37–81 years, median = 61 years) and predominantly white British (23/26) compared to KCH's older and more racially diverse population (range = 70–99 years, median = 82 years, 6/19 nonwhite).

The majority of patients had IPF (62% RBH, 90% KCH). Nine patients at RBH and 11 patients at KCH did not have any other significant comorbidities. Of the remaining patients, many had multiple comorbidities (Table 1).

There were no significant differences in other results between the two hospitals and the remaining data are therefore given for the total cohort.

**Table 1** Characteristics of ILD centres and demographics of patients (obtained from records and clarified where necessary with general practitioner) with type of ILD and comorbidities documented

| | RBH | KCH |
|---|---|---|
| Geographical catchment | London and surrounding counties | South East London |
| No. of referrals per annum | 500 | |
| Sex | | |
| Male | 14 (54) | 10 (53) |
| Female | 12 (46) | 9 (47) |
| Age | 61 ± 11 | 83 ± 8 |
| Ethnicity | | |
| White British | 23 (88) | 13 (69) |
| Indian | 2 (8) | 1 (5) |
| Bangladeshi | 1 (4) | 0 |
| Black African | 0 | 1 (5) |
| Black Caribbean | 0 | 4 (21) |
| Type of ILD | | |
| NSIP | 8 (31) | 1 (5) |
| IPF | 16 (62) | 17 (90) |
| UIP | 0 | 1 (5) |
| Other[a] | 2 (8) | 0 |
| Comorbidities | | |
| Heart failure | 2 (8) | 4 (21) |
| COPD | 4 (15) | 3 (16) |
| GORD | 8 (31) | 1 (5) |
| Lung cancer | 1 (4) | 1 (5) |
| Renal failure | 1 (4) | 1 (5) |
| Pulmonary embolism | 3 (12) | 1 (5) |
| TB | 2 (8) | 0 |

Data presented as *n* (%) and mean ± SD

*RBH* Royal Brompton Hospital, *KCH* King's College Hospital, *ILD* interstitial lung disease, *NSIP* nonspecific interstitial pneumonia, *IPF* idiopathic pulmonary fibrosis, *UIP* usual interstitial pneumonia, *COPD* chronic obstructive pulmonary disease, *GORD* gastro-oesophageal reflux disease

[a] One patient had a diagnosis of pleuroparenchymal fibrosis of unknown aetiology and one patient had a diagnosis of diffuse fibrotic lung disease on a background of serological autoimmune features

**Table 2** Documentation of symptoms and psychological and spiritual needs

| | |
|---|---|
| Shortness of breath | 42 (93) |
| Cough | 27 (60) |
| Fatigue | 13 (29) |
| Insomnia | 3 (6) |
| Depression/anxiety | 10 (22) |
| Spiritual distress | 0 |
| Anorexia/weight loss | 8 (18) |
| Chest pain | 13 (29) |
| Generalised pain | 4 (9) |
| Dyspepsia | 2 (4) |
| Polyuria/polydipsia | 2 (4) |
| Headaches | 1 (2) |
| Diarrhoea | 1 (2) |
| Dysphagia | 1 (2) |

Data presented as number of patients experiencing (%)

**Table 3** Documentation of possible palliative treatments given and their effectiveness

| | Patients receiving | Documentation of effectiveness | | |
|---|---|---|---|---|
| | | Effective | Not effective | No documentation |
| Opioids | 22 (49) | 21 (95) | 0 | 1 (5) |
| Benzodiazepines | 8 (18) | 7 (88) | 0 | 1 (12) |
| Steroids | 37 (82) | 22 (59) | 10 (27) | 5 (14) |
| Antireflux agents | 3 (7) | 2 (67) | 1 (33) | 0 |
| Antidepressants | 2 (4) | 2 (100) | 0 | 0 |
| Fan | 0 | 0 | 0 | 0 |
| Relaxation therapy | 1 (2) | 1 (2) | 0 | 0 |
| Counselling/ psychological support | 3 (7) | 3 (100) | 0 | 0 |
| Spiritual care support | 0 | 0 | 0 | 0 |

Data presented as *n* (%)

Thirty-three of 45 patients had pulmonary function tests recorded. Percentage predicted transfer factor values were recorded, with a mean of 28% and a standard deviation of 12%. Patients had both a mean and median number of three symptoms. Nearly all patients experienced breathlessness in their last year of life (42/45, 93%). Additional symptoms included cough, fatigue, and depression/anxiety. Just under one third of patients experienced chest pain (Table 2).

The majority of patients received steroids, with symptomatic benefit documented in two thirds of patients. Opioids or benzodiazepines were given less frequently (22/45 opioids, 8/45 benzodiazepines). However, when drug use was documented, they were found to be 100% effective, i.e., there was a documented improvement in symptom response. Nonpharmacological palliative treatments (fan, complementary therapy, but not oxygen) were rarely used (Table 3).

Few patients had a preferred place of care (8/45) or a preferred place of death (6/45) documented. The majority of patients died in the acute hospital setting (34/45). 17 (38%) patients had some sort of specialist palliative care team (PCT) involvement. Of those, 4 (9%) had both hospital and community palliative care teams involved in their care. 28 (62%) did not have any palliative care input in the last year of life (Table 4).

**Table 4** Documentation of preferred place of care and death compared to actual place of death with specialist palliative care involvement

| | |
|---|---|
| Preferred place of care | |
| Home | 5 (11) |
| Hospice | 2 (4) |
| Hospital | 1 (2) |
| Not documented | 37 (82) |
| Preferred place of death | |
| Home | 1 (2) |
| Hospice | 4 (8) |
| Hospital | 1 (2) |
| Not documented | 39 (87) |
| Actual place of death | |
| Home | 4 (8) |
| Hospice | 5 (11) |
| Hospital | 34 (76) |
| Unknown | 2 (4) |
| Palliative care involvement | |
| No palliative care | 28 (62) |
| Hospital palliative care only | 5 (11) |
| Community palliative care only | 8 (18) |
| Both hospital and community palliative care | 4 (9) |

Data presented as *n* (%)

## Discussion

This study allowed the palliative care needs and treatment of patients with PIF-ILD to be examined. Patients from the two hospitals were very different demographically, with older and more ethnically diverse patients at KCH. Patients from KCH were more likely to have received a diagnosis of IPF than at RBH. This may reflect an increased tendency at RBH to confirm PIF-ILD diagnosis via lung biopsy. Despite the demographic differences, there was very little difference in the palliative care needs of these patients.

Previous literature has noted that PIF-ILD patients suffer from many symptoms, including shortness of breath, cough, low mood, and fatigue [10–13] and this was supported by our study. Unsurprisingly, shortness of breath was the most prevalent symptom. However, the prevalence of chest pain in these patients was unexpected. It is not clear whether these symptoms are directly related to ILD or the comorbidities such as pulmonary embolisms experienced. In our study, even though the mean number of palliative care needs experienced in the last year of life is small, it is likely that this has been underestimated. Justice et al. [16] found that compared to self-report, clinicians significantly underreport the presence and severity of symptoms. Pulmonary function tests were carried out. However, as this was a retrospective review of case notes, it is not possible to relate pulmonary function tests more closely to severity of symptoms.

There appeared to be a failure to consider wider issues in the palliation of these patients. There was no documented assessment of spiritual needs and rarely documentation of assessment for depression and anxiety. It is unlikely that these issues do not occur in this group of patients. A previous study by Edmonds et al. [17] suggests that patients with chronic lung disease at the end of life have physical and psychosocial needs at least as severe as patients with lung cancer. A systematic review by Solano et al. [18] found a similar prevalence of patients experiencing pain in cancer, heart disease, and COPD compared to our study population. In addition, comparable levels of fatigue and insomnia were found in cancer populations and anorexia in heart disease (HD) patients compared to our PIF-ILD patients (Table 5). Of note, our study population experienced more breathlessness than that experienced in the cancer, AIDS, heart disease, COPD, or renal disease (RD) population reviewed by Solano et al. [18]. Our study is limited by the reliance of health professionals recognising the importance of asking about wider palliative care needs, patients reporting them, and health professional documentation. It is likely that the palliative needs of these patients are actually greater than reported in our study and span a much wider range.

The paucity of documented use of nonpharmacological therapies such as counselling and relaxation therapy was marked. It is possible that there is little recognition of the effectiveness of these interventions in improving symptom control. Alternatively, this may reflect a "sticking-plaster" palliative approach in which there is an earnest attempt by the respiratory teams to deal with the cardinal and expected symptoms (i.e., dyspnoea) with standard pharmacological intervention (opioids and/or benzodiazepines in addition to oxygen therapy). In our study, both units have been attempting to address this, although the approach appears

**Table 5** Prevalence of palliative care needs of both hospitals compared to cancer, AIDS, HD, and RD as found by Solano et al. [18]

| | Combined RBH + KCH | Cancer | AIDS | HD | COPD | RD |
|---|---|---|---|---|---|---|
| Shortness of breath | 98 | 10–70 | 11–62 | 60–88 | 90–95 | 11–62 |
| Fatigue | 29 | 32–90 | 54–85 | 69–82 | 68–80 | 73–87 |
| Insomnia | 7 | 9–69 | 74 | 36–48 | 55–65 | 31–71 |
| Anorexia/ weight loss | 18 | 30–92 | 51 | 21–41 | 35–67 | 25–64 |
| Pain | 36 | 35–96 | 63–80 | 41–77 | 34–77 | 47–50 |

Data presented as %

to be far from systematic. Expert palliation or specialist palliative care aims to use both pharmacological and nonpharmacological therapies in a systematic way in the palliation of both expected and unexpected symptoms. However, there is a need for clear evidenced-based guidelines on how the palliative care needs of patients with PIF-ILD should be managed.

Recent governmental strategies [8] have encouraged the achievement of preferred place of care and death for patients at the end of life. However, our study shows poor documentation of both. It is difficult to comment on whether preferred place of death is achieved. However, previous studies have shown that the majority (49–78%) of patients would rather die at home [19]. In our study, the majority of patients died in hospital. It is possible that discussions on end-of-life preferences are occurring with the patients, although Curtis et al. [9] found that patient—physician communication about end-of-life care was unlikely to occur in COPD patients. Without clear documentation and communication across primary and secondary healthcare settings, achievement of preferred place of care and preferred place of death is unlikely to occur in PIF-ILD patients. Only when end-of-life preferences are clearly documented and assessment of whether these are achieved is conducted will we be able to start to investigate and rectify possible contributing factors.

The majority of PIF-ILD patients did not have any palliative care input in their last year of life. However, our study may highlight and reflect the previous difficulty of defining when these patients were entering the preterminal phase. Respiratory physicians may have found it difficult to address end-of-life issues without an accurate poor prognosis. However, future development of effective staging instruments [20] should allow physicians to identify PIF-ILD patients in the last year of life.

Very few patients had both community and hospital palliative care team support. These patients often had multiple admissions to the acute setting in the last year of life (RBH inpatient records 2009) and it is possible that they may have benefitted from both community and hospital palliative care input in addressing symptom control, preventing hospital admission, and achieving end-of-life preferences. There is evidence that palliative care teams improve outcomes (symptoms, therapies offered) for patients with cancer and may reduce healthcare costs by transferring care from acute hospital to community settings [21]. We advocate a proactive approach for PIF-ILD patients that involves systematic and holistic palliation by respiratory physicians whilst supported by specialist palliative care teams. However, access to such support is not routinely offered to patients with conditions other than cancer, where the effects of palliative intervention are not well understood and indeed the models for cancer may not directly apply. In addition, it is not clear whether other reasons such as monetary, religious/cultural, or health professionals' perceptions of palliative care may prevent referral in this group and it was beyond the scope of this study to assess this. There is an urgent need for further research into the palliative care needs and preferences of the ILD population and to develop interventions that enable patients to die in their preferred place of death.

There are a number of limitations to our study. As it is a retrospective review of case notes, we are reliant on health professionals recording symptoms and the effectiveness of palliative interventions. It is likely that symptoms have been underreported. On the other hand, effectiveness of interventions was recorded in our study only when there was a clear positive effect documented in the clinical notes. It is possible that interventions were being used without being recorded or they were effective and it was not documented. In addition, there were no validated outcome measures used in the assessment of the palliative care needs of these patients which is a clear learning point. It is difficult to believe that we will be able to deliver effective interventions to improve symptom control when they are not being assessed using a systematic and validated method. Finally, even though palliative care involvement was noted, the level of palliative care input was not recorded for this study. It is possible that some patients had more intensive palliative care support than others and more detailed recording of this should be considered in any similar future studies.

## Conclusion

Despite demographic variation between sites, the patient populations were documented as experiencing similar symptoms. Pain was more prominently documented than previously noted in the literature. There was documented use of standard palliative pharmacological treatments with symptom benefit despite limited specialist palliative care involvement. The numbers documented as having a beneficial response to symptoms with these interventions is encouraging and needs further quantification. Nonpharmacological interventions were seldom documented as being used, and documentation of preferred place of care and preferred place of death was poor.

These results may reflect difficulty in identifying and managing a preterminal phase in this group of patients and/or a need for increased access to specialist palliative care services.

**Conflict of interest** The authors have no conflict of interest to disclose.

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