

## Healthcare professionals' perspectives on access to specialist palliative care services for people with interstitial lung disease: a questionnaire survey

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Word count: 1508

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## Abstract

**Background:** Fibrotic interstitial lung disease is an incurable disease with poor prognosis. We aimed to understand factors affecting decisions regarding referrals to specialist palliative care services and to address barriers and facilitators to referrals from healthcare professionals' perspectives.

**Methods:** A survey study of healthcare professionals, including respiratory physicians, interstitial lung disease nurse specialists, respiratory nurse specialists and palliative care physicians, was conducted using a questionnaire, entailing 17 questions.

**Results:** Thirty-six respondents, including 15 interstitial lung disease nurse specialists completed the questionnaire. Symptom control, psychological/spiritual support, general deterioration and end-of-life care were the most common reasons for referrals to specialist palliative care services. Most respondents felt confident in addressing palliative care needs and discussing palliative care with patients. A few participants emphasised that experienced respiratory nurse specialists are well placed to provide symptom management and to ensure continuity of patient care. Participants reported that access to palliative care could be improved by increasing collaborative work between respiratory and palliative care teams.

Conclusions: Most respondents felt that enhancing access to specialist palliative care services would benefit patients. However, palliative care and respiratory care should not be considered as mutually exclusive and multidisciplinary approach is recommended.

## Background

Idiopathic pulmonary fibrosis (IPF) is an incurable lung disease that causes 5000 deaths each year in the UK <sup>1</sup>, and non-IPF fibrotic interstitial lung disease also carries poor prognosis with no effective treatment <sup>2</sup>. People with ILD carry a high burden of physical and psychological symptoms and supportive measures such as oxygen therapy are the mainstream of treatment <sup>3</sup>.

Palliative care aims to improve the quality of life by preventing and reducing suffering of patients and their families through symptom control and supporting the psychological and spiritual needs <sup>4</sup>. Specialist palliative care is shown to improve patient satisfaction, reduce inpatient hospital stays and improve survival in cancer patients <sup>5</sup>, and improve quality of life in people with non-malignant chronic respiratory diseases <sup>6</sup>. There is variation in the palliative care services for people with non-malignant respiratory diseases in the United Kingdom <sup>7</sup>. Our previous systematic review described delay in referrals to specialist palliative care team (SPCT) and low referral rate, patients' fear of talking about the future, uncertainties about prognosis and the roles of palliative care were identified as barriers to accessing palliative care services <sup>8</sup>. Most studies addressing issues surrounding access to palliative care in people with ILD were based on retrospective analysis of medical records and only one study included healthcare professionals <sup>9</sup>.

By contacting ILD and palliative care professionals, we aimed to understand factors affecting decisions regarding SPCT referrals and to address barriers and facilitators to referring patients to SPCT from healthcare professionals' perspectives.

## Methods

### *Study design*

The questionnaire was developed after literature review and in consultation with people with ILD and respiratory and palliative care nursing and medical professionals. The questionnaire had two parts. The first part relates to access to SPCT and the second part relates to current specialist palliative care provision and available services in participants' practice. All responses were anonymous. At the end of the survey, participants had the opportunity to provide free text suggestions. The study was approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at University of East Anglia (Reference number 201819-016) and had Health Research Authority (HRA) approval (IRAS ID 248634).

### *Participants*

Participants were identified by the following routes; (1) ILD clinical service leads (2) Members of the East Anglia Interstitial Lung Disease Network (3) Members of the ILD-interdisciplinary network (4) Local palliative care professionals. Consent was implicit in undertaking completion of the questionnaire.

### *Data collection and analysis*

The survey was conducted from March 2019 to April 2019. Questionnaires were completed electronically on a web-based system: Research Electronic Data Capture (REDCap, Harvard College, Boston, USA). Data were analysed using descriptive statistics using SPSS (v. 25.0). Free text comments were analysed using thematic framework analysis.

## Results

### *Reason for referrals*

The response rate is estimated to be approximately 15%. Thirty-six respondents completed the questionnaire (Specialist ILD respiratory nurses n=15, Specialist respiratory nurses n=8, Specialist ILD physician n=5, General respiratory physician n=5, Specialist palliative care physician n=3). Most respondents from respiratory team felt confident in discussing palliative care (97.0%), making decisions to refer to SPCT (93.9%), addressing palliative care needs (81.8%), providing generalised palliative care (87.9%) and understanding in roles of SPCT in management of ILD (90.9%). The most common disease triggers for referral were end of life care, general deterioration, poorly controlled symptoms and hospital admissions. Only a quarter used physiological measures such as forced vital capacity and diffusing capacity for carbon monoxide to guide referrals to SPCT. The GAP (Gender, Age, and Physiology) index, a validated tool for predicting mortality risk in IPF <sup>10</sup>, was rarely used.

	Most common						Least common
	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Rank 6	Rank 7
Symptom control	29 (80.6)	2 (5.6)	4 (11.1)	1 (2.8)	0	0	0
Psychological/spiritual support	1 (2.8)	20 (55.6)	4 (11.1)	4 (11.1)	3 (8.3)	3 (8.3)	1 (2.8)
To support maintaining activities of daily living	2 (5.6)	7 (19.4)	12 (33.3)	4 (11.1)	8 (22.2)	0	3 (8.3)
Care in the last days/weeks of life	2 (5.6)	5 (13.9)	9 (25.0)	9 (25.0)	5 (13.9)	5 (13.9)	1 (2.8)
To support family & bereavement	0	1 (2.8)	4 (11.1)	8 (22.2)	14 (38.9)	7 (19.4)	2 (5.6)
On patient's request	1 (2.8)	0	3 (8.3)	7 (19.4)	4 (11.1)	19 (52.8)	2 (5.6)
Other	1 (2.8)	1 (2.8)	0	2 (5.6)	1 (2.8)	0	6 (30.6)

*Table 1. Reasons for referrals to specialist palliative care team. Respondents were asked to rank, from the most to the least common, reasons for referrals to specialist palliative care team from a pre-specified list of options. The table shows the results in order of commonality from the top row to the bottom row.*

### *Barriers to SPCT referrals*

Respiratory professionals concerned that transferring care to palliative care team could result in patients feeling abandoned by respiratory team and concerned about loss of continuity of care. Approximately half (57.5%) of respiratory healthcare professionals felt that SPCT was unlikely to add additional benefits to the patient's management. Respiratory specialist nurses perceived that ILD team were skilled to support ILD palliative patients with better understanding in respiratory support and ILD management. The majority were aware of patients who did not wish to see SPCT and reported common negative perceptions concerning terms “palliative care” by patients. Limited resources (e.g. long waiting list, limited beds) were considered as main barriers to access SPCT.

### *Improving access*

Eighty percent (n=29) agreed that ensuring access to SPCT would benefit ILD patients. Respondents highlighted that joint clinics and training are important methods to improve access to specialist palliative care services. A few respondents suggested that ILD nurse palliative care training would maintain continuity of care but would require increasing the number of ILD nurse specialists. Use of patient-reported outcome measures and a consultation guide to identify palliative care needs, automated referral based on pre-defined criteria or SPCT attending ILD MDT at diagnosis were not felt to be useful.

### **Discussion**

Respiratory healthcare professionals valued continuity of care throughout patients' journey and concerned that transitioning patient care from respiratory care team to SPCT could potentially

exert a detrimental impact. A few respondents emphasized that experienced ILD nurse specialists are ideal to provide optimal symptom management as they have more experience in dealing with respiratory support, and an interdisciplinary approach was a common suggestion to improve delivery of palliative care.

Although, most respondents were confident in assessing palliative care needs, self-reported confidence may not relate to clinical performance and competence <sup>11</sup>, and generalist palliative care may be prone to focus on the physical aspect of symptoms <sup>12</sup>. The British Thoracic Society (BTS) ILD registry illustrated that 57% of IPF patients' palliative care needs were assessed <sup>13</sup>.

This suggests that palliative needs assessments are not frequent. The oncology version of the End-of-Life Nursing Education Consortium (ELNEC-Oncology) training programme not only improved the perceived effectiveness in providing end-of-life care, but also inspired oncology nurses to participate in other palliative care activities such as attending further palliative care courses <sup>14</sup>. An ILD version of a palliative care education programme could be developed and implemented to support respiratory teams.

Expanding the collaboration between palliative and respiratory team via joint clinics and training was identified as the most favourable method to improve access to SPCT in our study. Indeed, in previous studies of advanced lung disease, the integrated care have shown to improve access to SPCT and breathless management <sup>15</sup>, and symptom control guidelines developed between SPCT and respiratory team, joint breathlessness clinics and joint workshop were described as examples of good practice <sup>16</sup>. The positive effect of a respiratory palliative care clinic run by a respiratory physician with special interest was illustrated by one



respondent. This could be adopted to bridge the gap of limited resources and facilitate efficient transition of care from respiratory team to SPCT without leaving patients feel abandoned by specialist team.

Limited resources in palliative care form a barrier to providing specialist palliative care.

Additionally, there are insufficient specialist nurses to provide generalist palliative care by ILD team. National Institute for Health and Care Excellence (NICE) guideline for the diagnosis of management of suspected IPF recommends an ILD specialist nurse should be available at all stage of the care pathway <sup>17</sup>, but the BTS ILD registry reported that only 61% of centres have a dedicated ILD nurse specialist, suggesting needs for expanding ILD specialist nurses. Strategic plans such as education programme, hospital policy, implementation of palliative care delivery model for people with ILD, need to be established to provide high quality care within finite resources.

### ***Strength and limitation***

The advantage of this study was it was completely anonymous and therefore we believe the answers are genuine and true. We allowed free text to explore the reasons behind the quantitative findings. The main limitations were the low response rate and the imbalance of different disciplines. We do not know the exact denominator. Although we forwarded the questionnaire to the gate keepers of the networks, we do not know how many people were on multiple mailing lists nor how many people received the questionnaire from onward mailing. The response rate is therefore an estimate. Hence, our findings should not be considered as a representation of ILD healthcare professionals' views.

## Conclusion and recommendation

Palliative care and respiratory care should not be considered as two separate entities and a multidisciplinary approach is recommended. Maintaining respiratory/ILD nurse specialists as the first port of call and training respiratory/ILD team in various aspects palliative care such as psychosocial aspects could bring additional benefits to patients by ensuring continuity of care and allow early recognition of patients who need SPCT input. Further qualitative evaluation of healthcare professionals would allow us to gain better understanding of respiratory professionals' opinions on establishing a structured palliative care framework tailored to people with ILD. A larger survey could allow us to examine variation in services across the UK and produce more generalizable results. We also recommend further research of people with ILD and their carers to understand their preferred mode of palliative care delivery.

## Acknowledgement

We thank all medical and nursing staffs for their time and support.

## Competing Interest: None declared

## Funding

This questionnaire survey was funded by Norfolk and Norwich University Hospital Respiratory Research Funds.

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