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Fibrotic interstitial lung disease - palliative care needs: a World-Café qualitative study

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ABSTRACT

Objectives The importance of palliative care in those with advanced fibrotic interstitial lung diseases (F-ILD) is recognised, but the palliative care requirements of patients and caregivers affected by F-ILD regardless of disease course are not established. We set out to explore this and identify optimal solutions in meeting the needs of a F-ILD population in Ireland.

Methods Implementing a World-Café qualitative research approach, we captured insights evolving, iteratively in interactive small group discussions in response to six predefined topics on palliative care and planning for the future. Thirty-nine stakeholders participated in the World-Café including 12 patients, 13 caregivers, 9 healthcare professionals, 4 industry representatives and 1 representative of the clergy.

Results Palliative care emerged as fundamental to the care and treatment of F-ILDs, regardless of disease progression. Unmet palliative care needs were identified as psychological and social support, disease education, inclusion of caregivers and practical/legal advice for disease progression and end-of-life planning. Participants identified diagnosis as a particularly distressing time for patients and families. They called for the introduction of palliative care discussions at this early-stage alongside improvements in integrated care, specifically increasing the involvement of primary care practitioners in referrals to palliative services.

Conclusion Patients and caregivers need discussions on palliative care associated with F-ILD to be included at the point of diagnosis. This approach may address persisting inadequacies in service provision previously identified over the course of the last decade in the UK, Ireland and European F-ILD patient charters.

Key messages

What was already known?

- ▶ Palliative care (PC) needs in advanced fibrotic interstitial lung disease (F-ILD) are documented.
- ▶ Timeliness of PC in F-ILD is suboptimal.

What are the new findings?

- ▶ Stakeholders consider PC fundamental in all F-ILD stages.
- ▶ PC is required from F-ILD diagnosis onwards.

What is their significance?

- ▶ (a) Clinical.
- ▶ PC from diagnosis may address F-ILD service inadequacies.
- ▶ (b) Research.
- ▶ World-Café approach is valuable in PC stakeholder engagement.

INTRODUCTION

The term fibrotic interstitial lung disease (F-ILD) describes a number of parenchymal lung disorders associated with lung fibrosis. Idiopathic pulmonary fibrosis (IPF), the most prevalent F-ILD, is estimated to affect around 33 500 patients across UK and Ireland and is characterised by disabling breathlessness, cough and fatigue.^{1 2} Disease progression incrementally and significantly limits physical activities impacting patients' quality of life (QOL), with a median survival of 4.5 years postdiagnosis reported pan-Europe.^{3 4} The morbidity and mortality associated with living with IPF significantly impacts psychosocial functioning in both patients and caregivers.⁵

Pharmacological treatments available for F-ILD may prolong life but are associated with side effects impacting health-related QOL.⁶ The main goal of palliative

care in F-ILD is to improve or at least maintain QOL for the patient and their caregiver.⁷ Evidence suggests that patients with F-ILDs do not always have access to palliative care expertise and for those that do the timeliness of palliative care interventions is rarely optimal.^{8,9} The European Patient IPF Charter, and the Irish Thoracic Society Position Statement on the Management of IPF identified an urgent need to involve palliative care in F-ILD.^{1,9}

Prior research has explored the unique palliative care needs of people living with advanced F-ILDs.^{10–12} This is the first study to explore the palliative care needs of patients with F-ILDs at earlier stages of the disease process, prior to the end-of-life pathway. Implementing a novel World-Café approach we report on palliative needs of patients living with F-ILD and their informal caregivers, regardless of disease course, in Ireland.

METHODS

Aim and study design

This research was conceived and sponsored by the Irish Lung Fibrosis Association (ILFA), a not-for-profit patient advocacy organisation. Formal ethical approvals were not sought. None-the-less principles of Good Clinical Practice defined by the UK Policy Framework for Health and Social Care Research were adhered to protect the rights, safety and well-being of participants.¹³ A core study team (NC, TS and A-MR) was established for study oversight, adherence to protocol and governance.

Our aim was to gain a better understanding of palliative care and future health and social care planning needs of individuals and families living with F-ILDs in Ireland, to inform meaningful care pathways and resources. To address this goal we undertook qualitative research, consistent with a constructivist paradigm, specifically selecting a World-Café approach.

The World-Café participatory method enables a structured conversational community-centred approach to gather perspectives of key stakeholders and is gaining global traction as a qualitative method.¹⁴ Inclusive by default, it maximises individual participation, capturing interactive discussions through evolving rounds of dialogue. Similarly to focus group discussions, the World-Café approach is a discursive method in that it facilitates collaborative dialogues in which knowledge is both gained and shared. It has advantages over more traditional qualitative approaches as it documents dialogues from a larger sample size in a more timely and efficient manner than focus groups, while increasing individuals' participation compared with a large group discussion. The approach thus ensures that each delegate has the opportunity to share their experiences and ideas.¹⁵

Participants and procedure

Patient and caregiver participants self-selected to attend the World-Café via an open invitation in the

ILFA newsletter. A purposive heterogeneous sample of healthcare professionals (HCPs) working in hospital, hospice and community settings, clergy, pharmaceutical, oxygen companies and Irish Hospice Foundation representatives were selectively invited to participate on the basis of their interest in the field. This approach was selected in order to gain understanding of issues and potential solutions from both 'user' and 'provider' perspectives. Participants' demographic profile or severity of disease did not present a barrier to inclusion.

Six discussion topics were predefined by consensus of a nominal group of expert HCPs working in F-ILD, and validated by an ILFA patient group: (1) practical planning, (2) palliative care and symptom management, (3) end-of-life considerations, (4) psychological support needs, (5) acute exacerbation management and lung transplantation and (6) legal matters.

Participants received an information pack notifying them of the topics prior to attending the World-Café to enable preparation and informed choice to participate. Written signed consent was obtained on the day prior to commencement of the event. The World-Café event was held in a hotel-based conferencing suite, selected for ease of access both in terms of geographical location and needs of delegates. Participants were advised that they could withdraw at any stage without having to give a reason and exits from the room were clearly identified. Ground rules were established at the outset. Each group conversation was hosted by a group leader, supported by a note-taker. Group leaders were professionals with specialist knowledge of the discussion topic, with minimal previous interactions with majority of participants. Note-takers were a heterogeneous group, comprising ILFA committee members (n=4), one ILFA volunteer and one HCP, with whom participants may have had some previous contact through other ILFA activities. Such interactions are unlikely to have significantly impacted data collection given the participatory nature of the World-Café approach. Each conversation lasted 12 min. Once the allotted time had passed, the leaders and note-takers for each topic rotated to the next group. The discussions were summarised and presented to participants for verification. Given the sensitivity of the discussion, psychological and emotional support was available to participants throughout the meeting. Subsequent in-depth qualitative interviews with three pairs of patients and caregivers were conducted to affirm and evaluate their experiences of the World-Café approach. Here, we report primarily on the World-Café. All participants were invited to complete a formal evaluation.

Data collection and analysis

Complimentary literary and artistic summary approaches relay our findings. During the World-Café event a note-taker captured individual contributions and insights on each discussion topic while an

illustrator captured emerging themes from each discussion expressed as 'live art'. The group leaders' summary discussions of each topic were audiorecorded and later transcribed. All data sources were anonymised and reviewed by the core research team. The source materials were thematically analysed by predefined topic, taking a deductive approach. This methodology was selected in order to provide a detailed and nuanced account of the data on each individual topic, as opposed to a more generalised overview of key themes from the entire data set.¹⁶ Within-topic themes were then subcategorised according to issues and solutions. Group discussion and cross referencing to source material determined that themes generated were true to the topic discussions. The emerging themes from this analysis were subsequently verified by the event group leaders and a small cohort of patient and caregiver participants.

RESULTS

The World-Café was held mid-2018. Sixty delegates attended with 39 stakeholders participating in discussions: 12 patients (5 males), 13 caregivers (6 males) median age 60 years, 9 healthcare and adjunct professionals, 4 industry representatives and 1 clergy member supported by 6 discussion group leaders, 6 note-takers and 3 facilitators. Six patients required continuous oxygen therapy; two patients had undergone single lung transplantation. We present the results of our thematic analysis by topic.

Practical planning for living with F-ILD

Issues

Participants identified a lack of 'quality' disease-specific information for patients and carers, delays in oxygen services, mismatch of devices and inadequacies in support for daily living (eg, delays in home

adaptations). Receiving a diagnosis of F-ILD was identified as a very emotionally distressing time. Participants expressed frustration with the lack of integrated services, resulting in disjointed care, for example, cardiovascular comorbidities treated separately to F-ILD; repetitive history taking (a theme reoccurring in discussions on exacerbations). See figure 1 for the group's proposed solutions.

The role of palliative care

Issues

Palliative care has not been seen as a fundamental part of treatment for those with F-ILDs. Delays in being given information with family members/significant others excluded from important discussions was reported. A stigma surrounding the terminology of palliative care, with many associating it only with care in the final days of life, was recognised as a potential barrier to engaging palliative care services. See figure 2 for the group's proposed solutions.

End-of-life considerations

Issues

A failure to elicit the patient's personal choices and a failure to recognise individual's spiritual beliefs, emotions and ideas about their end-of-life care options which are inherently different. Many people are unaware of support services available to them when considering end-of-life care, impacting the ability to make informed decisions. See figure 3 for the group's proposed solutions.

Psychological needs and support for living with F-ILD

Issues

Living with F-ILD causes emotional distress for patients and caregivers. Care for the carer was often lacking and caregiver stress often overlooked. Specific education

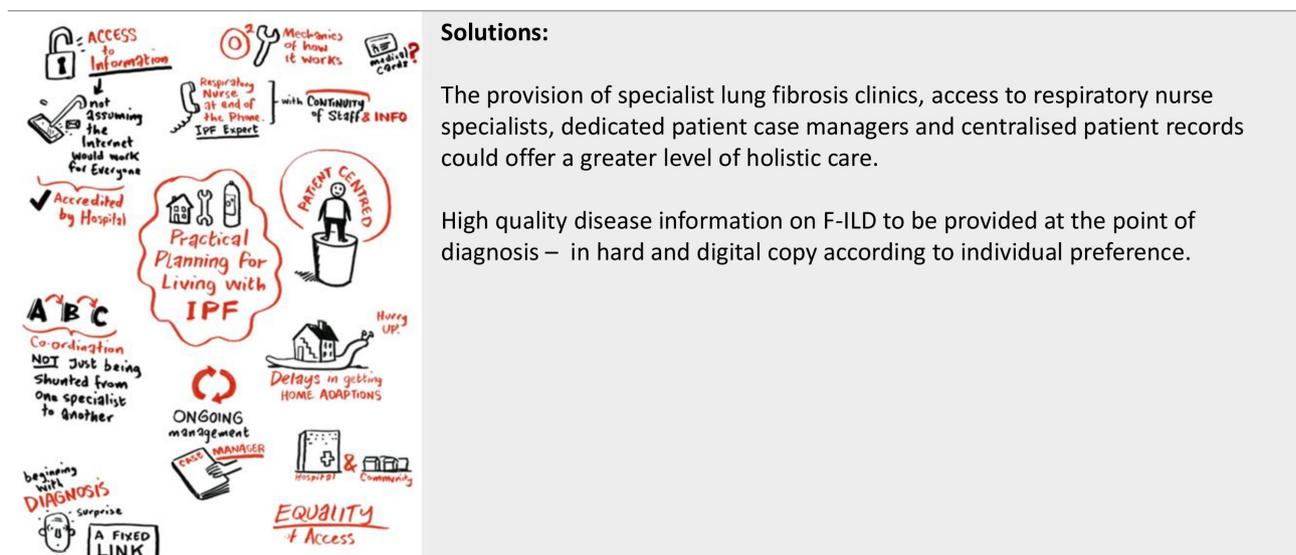


Figure 1 What practical solutions would help you cope better with the challenges of living with F-ILD? F-ILD, fibrotic interstitial lung diseases.



Solutions:

Continuing use and explanation of the term PC across the ILD community. Easy to read information on PC to be provided at the time of diagnosis with the inclusion of family members / significant others in care planning where appropriate. Primary care practitioners to have a greater role in referring patients to PC services.

Figure 2 In what ways do you think PC can help you the patient, carer or healthcare professional to manage F-ILD symptoms? F-ILD, fibrotic interstitial lung diseases; PC, palliative care.

and support for carers was not readily available. Diagnosis was considered to be a particularly stressful event for patients and families, with the initiation of oxygen, transplant-related issues and the end-of-life period being subsequent distressing transitions. There was a lack of psychological support at these touchpoints. Some HCPs were reluctant to open up time to discuss palliative care due to fear/lack of training. See figure 4 for the group’s proposed solutions.

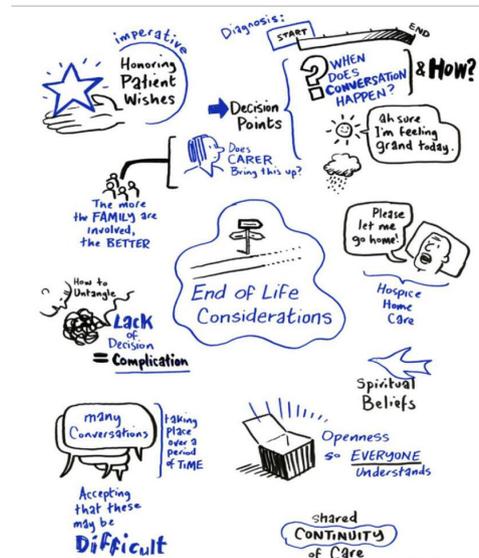
breathlessness and is difficult for those with F-ILDs to repeatedly provide a verbal medical history to each HCP they see giving rise to frustration. Participants raised concerns regarding a perceived lack of equality in transplantation services, for example, geographical differences in access criteria or waiting times for transplant assessment in public vs private healthcare, and the timeliness of referral for lung transplant assessment. See figure 5 for the group’s proposed solutions.

Acute exacerbations and transplantation concerns
Issues

A lack of education for patients, families and HCPs on how to optimally manage exacerbations, including definition, prevention and treatment was a great concern. HCPs can often forget that talking causes

Legal matters
Issues

The need for early and ongoing conversations on this topic were identified. Patients, family members and HCPs did not have enough information on Advance Healthcare Directives* and how to set up an enduring



Solutions:

Personal choices and beliefs should be elicited and understood by both HCPs and family members so that optimal individualised care can be provided.

A training needs analysis might identify unmet professional needs. Participants acknowledged that these are difficult conversations to start. A conversation guide on this topic was proposed which ILFA is currently developing.

Figure 3 What are the most important care elements to support patients and their families at end of life? HCPs, healthcare professional; ILFA, Irish Lung Fibrosis Association.



Solutions:

Information on how to make a will and advice on the practicalities of this could be available in the clinic and through patient advocacy groups. Supporting patients with a life limiting illness who would like to make an Advance Healthcare Directive* will help patients feel in control.

This documents an individual’s wishes for their treatment in the event they can no longer communicate for themselves.

Accessing critical illness medical insurance payments, as F-ILD must be recognised as a critical illness by insurance companies; advocacy groups have a role to play here.

Figure 4 What coping mechanisms do you draw on to manage your thoughts and feelings associated with your experiences of living with F-ILD? F-ILD, fibrotic interstitial lung disease; ILFA, Irish Lung Fibrosis Association.

power of attorney. See figure 6 for the group’s proposed solutions.

DISCUSSION

World-Café participants agreed that palliative care should be a fundamental part of management for all people with F-ILD, specifically calling for early referral to specialist palliative care services. While the need for the involvement of palliative care in the management of F-ILD has been previously discussed patients typically experience considerable delays in accessing services.^{5 7 11 17} The need for holistic care, disease education and early referral for palliative care in F-ILD, as identified at our World-Café, has also

been highlighted in the ILFA and EuropeanIPF patient charters.^{9 18}

A recent European survey reported that palliative care discussions in IPF remained largely synonymous with dying and end-of-life care; HCPs reporting that palliative care was initiated in advanced stages of the disease and a fifth of HCPs surveyed stating it was only initiated at the end-of-life.¹⁹ Our research supports a preference for greater involvement of primary care practitioners in the referral of patients to specialist palliative care services, as well as specific education to tackle the stigma associated with palliative care. Integrated care pathways for those with F-ILDs may help to address some of the barriers to palliative care. A



Solutions:

Rapid access to specialists in exacerbation diagnosis and management is needed alongside telephone access to respiratory nurse specialists or rapid access clinics.

The introduction of a “health passport”, providing details of a patient’s conditions, medications and hospitalisations, would reduce the need for a verbal history when presenting to the hospital or to a HCP unfamiliar with patient’s case and could improve the management of exacerbations alongside increasing awareness of what an acute exacerbation entails.

A mentoring system wherein patients and families who have gone through lung transplantation support those considering it, was proposed as an adjunct support mechanism.

Figure 5 (A) How can the treatment of acute exacerbations be managed better? (B) Lung transplantation may be a treatment option for some people diagnosed with F-ILD; do you have any concerns in relation to lung transplant? F-ILD, fibrotic interstitial lung diseases; HCP, healthcare professional.

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Solutions:

Information on how to making a will and advice on the practicalities of this could be available in the clinic and through patient advocacy groups. Supporting patients with a life limiting illness to have an Advance Healthcare Directive* will help patients feel in control.

This documents an individual's wishes for their treatment in the event they can no longer communicate for themselves.

Accessing critical illness medical insurance payments, as F-ILD must be recognised as a critical illness by insurance companies; advocacy groups have a role to play here.

Figure 6 What legal matters are important to you to help you make good decisions in managing a life limiting condition such as pulmonary fibrosis? Have you made or considered making a will or Advance Healthcare Directive? F-ILD, fibrotic interstitial lung diseases.

UK study into a model of integrative care for patients with advanced F-ILDs, involving palliative care and community services, reported a positive impact on QOL, anxiety and palliative care concerns by participants and their caregivers.²⁰ Recent studies have examined other novel models of providing palliative care in F-ILD, including nurse-led early intervention and comanagement across the ILD and palliative care teams.^{21 22} While these studies reported positive findings in terms of disease knowledge and preparedness, the persistence of some barriers to palliative care such as misperceptions and access, was also noted. This indicates further research is needed to identify strategies for the optimal provision of palliative care in F-ILD. Unlike other respiratory conditions including asthma, chronic obstructive pulmonary disease (COPD) and cystic fibrosis, there is no national clinical care programme for F-ILD in Ireland, despite frequent calls from patient and professional organisations. A clinical care programme for ILD could avert some of the inadequacies in service provision that we have identified, providing a framework for care integration and palliative care involvement.

This is the first study which has examined the palliative care needs of those living with F-ILDs regardless of disease stage, and thus explores issues not typically associated with end-of-life care such as diagnosis and lung transplantation. It is evident that receiving a diagnosis of F-ILD is associated with a great deal of emotional distress for both patients and caregivers. The lack of high-quality disease information at this time, and the paucity of palliative discussions at the time of diagnosis, suggests that unmet needs go far beyond those recognised in treatment provisions.²³ Lung transplant is recognised as a highly effective treatment for IPF, however, not all IPF patients will meet

the criteria.^{1 24 25} Given the unpredictability of disease progression and potential for comorbidities, it has been suggested that referral for transplant assessment be considered early, and that the clinician, in discussion with the patient, should consider the optimal timing for transplant assessment.^{24 26} The timeliness of referral for lung transplant assessment was identified as an issue in our research, indicating that earlier assessment is required.

Although a substantial need for improved education for patients about IPF, to assist them to better manage the disease, was identified as early as 2007 we and other authors have identified these needs persist and extend across F-ILDs.^{9 27–30} While patients and caregivers differ in when and how much information they require over the course of the disease, access to information and education, from multiple sources, enhances coping approaches for patients and carers.^{29 31–33} Information should be tailored to individual patient's needs³⁴ offering practical help on 'living with IPF'.^{28 31}

Carers cope better when informed and participate more actively in the patients' healthcare management.^{30 31} A proactive individualised approach to supporting carers physically and emotionally with the burden of care is needed. While our World-Café event indicates that carers gain a great deal of support through sharing experiences with others in a similar role, this cannot be a replacement for professional advice and education for caregivers.

There is a growing body of international research into the significant psychological, social and physical impact of F-ILD on QOL.^{5 30 34 35} Our findings demonstrate that living with F-ILD is associated with a range of psychological issues for both the patient and the caregiver. Participants expressed a need

for professional support from the time of diagnosis throughout the disease course.

We identified a significant need for education on the practicalities and legalities of end-of-life planning for people with F-ILDs in Ireland. The Irish Hospice Foundation (www.hospicefoundation.ie) has developed high-quality, country-specific support materials to guide people through end-of-life planning, including a People's Charter on Death, Dying and Bereavement in Ireland. The lack of awareness of these materials among patients and family members in our research is a marker for the paucity of end-of-life planning. The difficulties expressed in having conversations on this topic indicate that specific personalised support and interventions are needed to meet end-of-life care needs. This includes education/training for HCPs on end-of-life planning and a conversation guide for patients and family members.

There is a lack of research exploring the practical issues of living with F-ILDs, in contrast to other long-term life-limiting illnesses such as COPD, multiple sclerosis and motor neuron disease.^{36,37} Collaborations between patient support groups representing these conditions with the Irish Hospice Foundation (COPD Support Ireland & Irish Hospice Foundation, 2018 and The Neurological Alliance of Ireland and The Irish Hospice Foundation, 2018) has shown that many people with life-limiting illnesses value the opportunity to put their affairs in order. Much of the information and resources developed as a result of these collaborations may be useful in the context of F-ILD.

As the first study to specifically focus on palliative care needs of F-ILD patients in Ireland, our findings lend support to the need for a more structured approach to palliative care in this population. There are limitations to our research, specifically with regard to selection bias. Patients and caregivers self-selected to participate in this research, having been initially identified via their membership of a patient support group. Similarly HCP and industry stakeholders were invited to attend the World-Café event based on their interest in the fields of ILD or palliative care. This favours participation from stakeholders who are likely to be highly engaged in this topic compared with a general population.

The World-Café provided an innovative and dynamic approach to engage with stakeholders and discuss the topic of palliative care in a positive and meaningful way. The inclusions of visual art to capture the round table discussions complemented the narrative and provided a medium for further exploration of topics. Our methodological approach lends itself to other conditions and geographical locations.

The approach has highlighted several unmet needs of patients with F-ILDs in Ireland, and generated ideas for solutions. Our experience indicates that patient organisations can play an important role in engaging patients and family members on sensitive issues such

as palliative care and end-of-life planning. ILFA facilitated a national patient information day in 2019 dedicated to palliative care and planning for the future, attended by more than 80 patients and caregivers and is continuing to develop a series of educational, awareness and advocacy activities to respond to needs identified in this research. Please see www.ilfa.com for further information and to access the ILFA Patient Charter.

* An Advance Healthcare Directive documents an individual's wishes for their treatment in the event they can no longer communicate for themselves.

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