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Access to Specialist and Multidisciplinary Healthcare for Pulmonary Fibrosis

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Abstract

Aim

To gain a quantitative understanding of patients' access to specialist and multidisciplinary healthcare services for pulmonary fibrosis (PF) in Ireland, and to understand patients' preferences regarding models of service delivery.

Methods

Patients with pulmonary fibrosis (including post-lung transplantation) were invited to participate in a quantitative survey, either online or by telephone.

Results

112 patients participated; 13 post-transplant for PF and 99 with current PF. 58% of patients had access to a clinical nurse specialist (n=65, comprising 12 post lung transplant and 53 with current PF), with variable access by patients' geography. 38% of patients had ever been referred to a physiotherapist, 25% to a dietician, 9% to a social worker, 8% for occupational therapy, 6% for clinical psychology and palliative care and 3% for speech therapy, with 45% never referred to any of these services. Majority of referrals were more than 12 months after diagnosis. Most wished to access services through combined virtual and face-to-face care, with the exception of palliative care.

Discussion

Patient access to specialist and multidisciplinary healthcare for PF is poor. A national approach to care provision in PF is needed. Improved recognition of patients' needs, earlier referral, patient education and greater use of virtual care may also improve care access.

Introduction

Pulmonary fibrosis (PF) describes a number of fibrotic respiratory disorders and is characterised by progressive breathlessness, cough, and fatigue. The most prevalent form, idiopathic pulmonary fibrosis (IPF), is estimated to affect around 1,000 patients in Ireland, with median survival from diagnosis of 4.5 years.[1,2] The Irish Thoracic Society (ITS) Position Statement on the Management of IPF serves as a guideline for optimal patient care.[2] It recognises the importance of specialist and multidisciplinary care to manage the many different aspects and impacts PF, recommending that patients should have access to an interstitial lung disease (ILD) nurse specialist, physiotherapy, palliative care, a medical social worker as well as psychological and dietetic supports.

Previous research conducted by Irish Lung Fibrosis Association (ILFA), the national support association for patients and caregivers affected by PF, has documented the high unmet care needs of individuals with PF. Difficulties in obtaining timely diagnosis, unmet needs around palliative care, concerns regarding care access during the COVID-19 pandemic, and poor access to healthcare supports have all been noted.[3-6] However, such research has largely been qualitative to date, and information on the numbers of patients referred to healthcare services versus those requiring support is lacking. ILFA therefore conceived this research to gain a quantitative understanding of patients' access to specialist and multidisciplinary healthcare services recommended for optimal management of PF. We also sought to understand patients' preferences regarding the way they access services, to inform proposals for care delivery improvement.

Methods

This quantitative research was conducted in patients with PF, including those who had received a lung transplant due to PF, using an online survey questionnaire. Individuals with PF were invited to participate in an online survey via an email from ILFA to its members and postings on ILFA's social media. Patients were also provided with the option of accessing the survey via telephone. The survey was designed to collect information on respondents' demographics, patients' experiences around referral or access to healthcare services for PF, patients' perceptions around the quality of such services, and patients' preferences regarding the different approaches for service delivery. The full survey questionnaire may be accessed via the ILFA website.[8]

Results

The survey research was conducted from 19th July to 2nd August 2021. Survey responses were gathered from 112 patients, comprising 99 patients with current pulmonary fibrosis and 13 patients post-transplant. All responses were submitted via the online platform.

Demographics

Table 1: *Patient Demographics*

	N	**%**
	All Patients (n=112)	
Current pulmonary fibrosis	99	
Post-lung transplant for ILD	13	
Male		53
Age category		
31-60 years	26	23
61-70 years	41	37
71-80 years	37	33
81+ years	8	7
Patient location by region		
Dublin	38	34
Munster	31	28
Rest of Leinster	22	20
Connaught	10	9
Ulster	10	9
Time since diagnosis (current PF cohort)	**n=99**	
<12 months	6	6
1 – 2 years	21	21
2-3 years	21	21
3-5 Years	25	25
>5 years	26	26
Time since transplant (transplant cohort)	**n=13**	
<12 months	1	8%
1 – 2 years	0	0%
2-3 years	4	31%
3-6 Years	5	38%
>5 years	3	23%

Access to a Clinical Nurse Specialist

Of the total patient cohort, 58% (n=65) had access to a clinical nurse specialist, comprising 54% (n=53) of patients with a current diagnosis of PF compared to 92% (n=12) post-lung transplant. In patients with current PF, analysis of specialist nurse access according to patients' geographical location showed considerable variation. By region, access ranged from 37% for patients located in Leinster (excluding Dublin) to 80% for patients in Connaught (n=7 of 19 versus n= 8 of 10, respectively), with no patients located in Kilkenny, Laois, Longford, Wicklow, and Wexford having access to a nurse specialist.

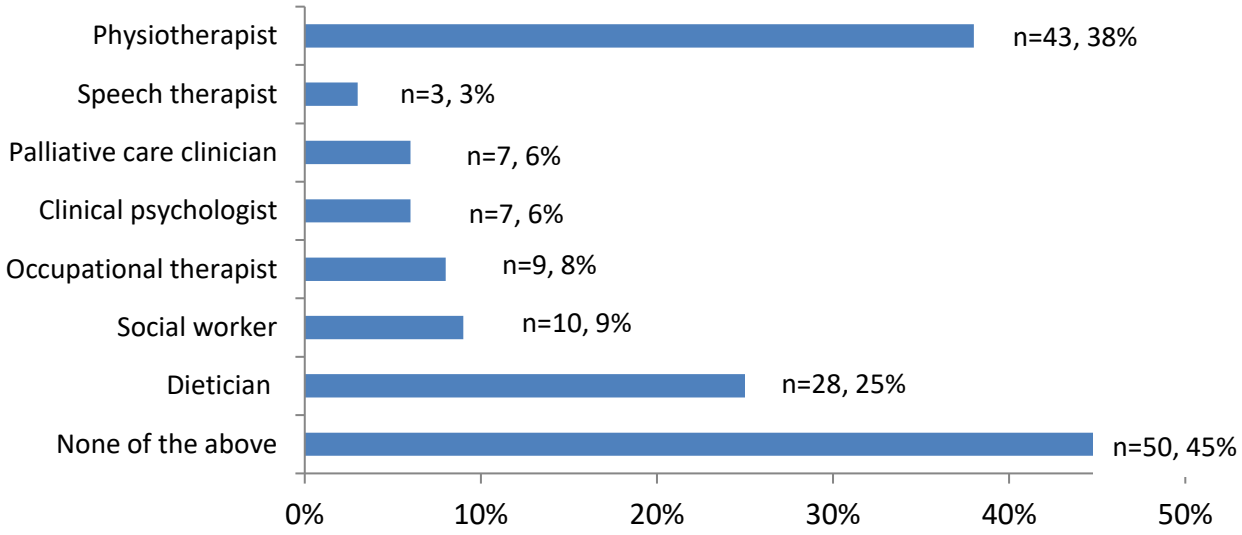
Within region differences by county were also apparent, most notably in Munster where almost all patients in Kerry had access to a nurse specialist (n=6 of 7) compared just 12% (n=2 of 11) of those in Cork.

Comparison of the demographic data from PF patients according to their nurse access showed a greater amount of those without access had been initially diagnosed by someone other than a consultant in the public healthcare sector, i.e. by a GP or a private consultant, (60%, n=27 of 45 versus 42%, n=21 of 53) and more had been diagnosed over 5 years ago (36%, n=16 versus 19%, n=10).

Healthcare Services and Supports: Access, Source of Referral and Quality

The percentage of patients who had ever received a referral to a specified healthcare service or support for PF is shown in figure 1. Almost half of all patients (n=50, 45%) had not received a referral to any of the specified services.

Figure 1: *Percentage of patients surveyed who had ever been referred to a specified healthcare service or support in relation to their pulmonary fibrosis.*



For patients who had received referrals to individual healthcare services, the timeliness of referral, source of referral and perceived quality of each service is discussed below.

Physiotherapy/pulmonary rehabilitation*:* Referrals were mainly via patients' consultant (n=31, 70%), or less frequently by their nurse specialist (n=10, 23%), and majority more than 12 months after diagnosis (26 patients, 63%). The service quality was rated as excellent or good by 95% of patients (n=38).

Dietician: Over half of referrals were via the patient's consultant (n=16, 57%), 21% (n=6) via their nurse specialist, with 21% (n=6) accessing this service privately. The time from diagnosis to referral was more than 12 months for 57% (n=16) of patients. Over half of patients rated the service received as excellent (n=15, 54%), 29% (n=8) as good and 14% (n=4) stating it was "ok".

Social Worker: Referrals were mainly via patients' consultant (n=7, 70%), the remainder via their nurse specialist (n=3, 30%). Majority of referrals (n=7, 70%) were more than 12 months after initial diagnosis. Ninety percent of patients (n=9) rated the service quality as good or excellent.

Occupational therapy: Sources of referral to this service were varied, with 56% (n=5) referred by their consultant, 22% (n=2) by their GP, 11% (n=1) by their clinical nurse specialist and one patient accessing services privately. Majority (n=7, 78%) were referred more than 12 months after diagnosis. An equal number of patients (n=3, 33%) rated the service as excellent, good, and ok.

Clinical Psychology: All referrals were via the patient's consultant, all more than 12 months after diagnosis. The service quality was rated as good or excellent by 86% of patients (n=6).

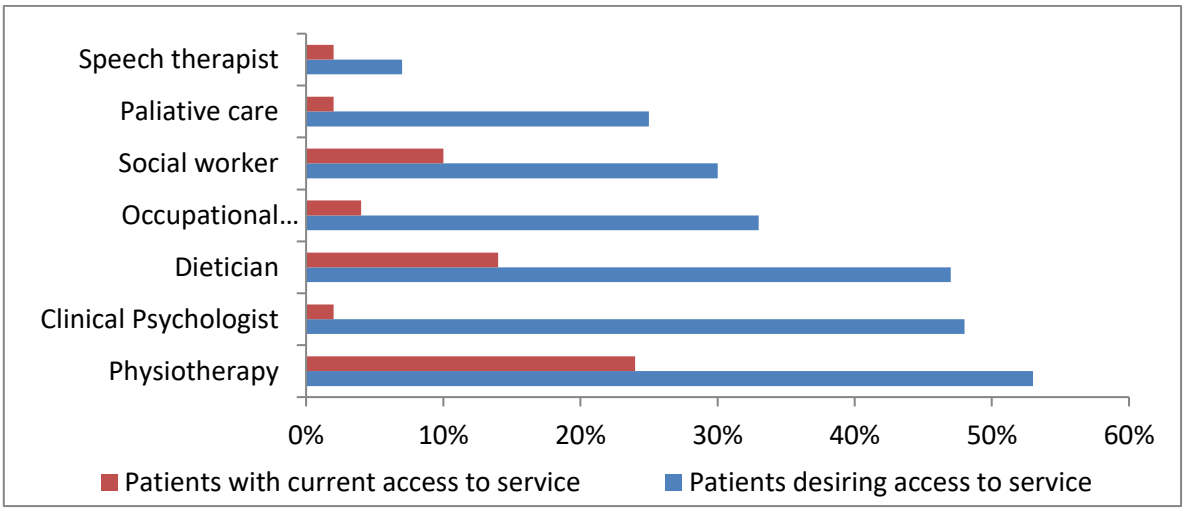
Palliative Care: This service showed greatest heterogeneity in referral source, with 43% (n=3) of patients referred by their consultant, 29% (n=2) by their GP, 14% (n=1) by their nurse specialist and 14% (n=1) referred privately. Majority were referred more than 12 months after diagnosis (n=6, 86%). Three patients rated the service quality as "excellent", whilst an equal number rating it as "ok".

Speech Therapy: All referrals were made by the patient's consultant (n=3). Time from diagnosis to referral was 2-6 months for one patient, and greater than 12 months for the remaining two (67%). All patients rated the service quality as excellent.

Patient-Identified Healthcare Needs

Figure 2 shows the percentage of patients who believe they would benefit from referral to a healthcare service versus patients that had service access at the time of the survey.

Figure 2: *Patient-identified need versus current access to healthcare services.*

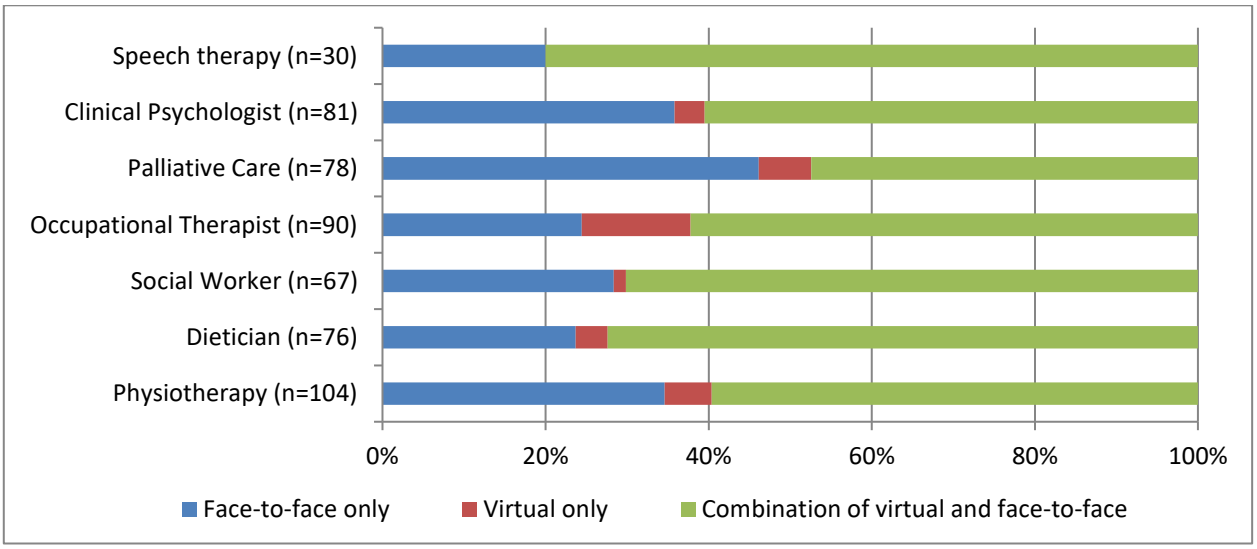


Anticipating future need, 88% (n=92) of patients envisaged benefit from future referral to a physiotherapist, 67% (n=75) to a dietician, 67% (n=75) to a clinical psychologist, 65% (n=73) for palliative care clinician, 56% (n=63) for occupational therapy, 44% (n=50) to a social worker and 12% (n=13) for speech therapy.

Patients' Preferences for Future Healthcare Service Delivery

For patients who wished to access a specified service, majority preferred a combination of virtual and face-to-face care, with the exception of palliative care (see figure 4). Majority of patients expressed a preference for one-on-one versus group care for all services, with the exception of physiotherapy which patients wished to access either solely as a group activity (25%, n=36) or in combination with individual care (45%, n=62).

Figure 4: *Patient preferences for virtual versus face-to-face models of care for each healthcare support.*



Discussion

This is the first quantitative data on patient access to specialist and multidisciplinary healthcare for PF in Ireland. Whilst qualitative research had previously identified unmet needs in PF patient care[4-7], this survey shows the magnitude of the gap between optimal and actual access to care across multiple services is considerable. Whilst there is little international data on care access for PF, the British Thoracic Society ILD registry indicates Ireland compares poorly to UK in this regard, with higher rates of both specialist nurse access (77% versus 54%) and physiotherapy referral (60% versus 38%) reported in the UK.[8] Undoubtedly, COVID-19 has impacted access to healthcare in Ireland across all services in recent times, but as 73% of PF patients surveyed had been diagnosed for over 2 years the pandemic alone does not explain our findings.[9]

Whilst this data indicates poor provision of care for PF across all services, the lack of specialist nursing is of particular concern. ILD nurse specialists are critical to the delivery of patient-centred care, yet almost half of all PF patients surveyed did not have access to this speciality.[10.11] The ITS recommends all IPF clinics should be supported by a ILD nurse specialist.[2] The UK's National Institute for Clinical Excellence (NICE) quality standard for IPF similarly recommends all patients should have an ILD specialist nurse available to them.[12] Given the fundamental importance of this specialty for patient care, and the sheer scale of unmet need, the provision of ILD nurse specialists in Ireland requires urgent attention.

Research indicates that a key barrier to ILD nurse specialist access, and indeed to other required services, is the absence of a national approach to PF care. Unlike other serious lung conditions, including asthma, cystic fibrosis, and chronic obstructive pulmonary disease (COPD), there is no clinical care programme for PF in Ireland.[13] Our survey demonstrated notable regional and inter-county differences in patients' access to a nurse specialist. This is consistent with previous qualitative research which indicated geographical care inequality is a significant issue in PF care in Ireland.[6] Geographical disparity in the availability of physiotherapists, occupational therapists, speech therapists, counsellors and psychologists and social workers has been previously documented.[14] We also note patients without access to a nurse specialist were more likely to have been diagnosed outside of the specialist public healthcare system, and to have been diagnosed over 5 years ago, suggesting that lack of a national programme and defined patient pathway means some patients may simply "fall between the cracks" following diagnosis. The importance of a national strategy in improving care access for PF cannot be underestimated; following the 2015 publication of the NICE quality standard on IPF care access to specialist nursing in the UK has consistently improved year-on-year, with 100% of newly diagnosed patients being offered access to an ILD nurse specialist in 2021 versus just 36% in 2014.[8,12] A national clinical care programme for PF in Ireland could similarly ensure all PF patients, regardless of location, have access to specialist nursing and other key services.

Our findings indicate that where referrals to services for PF are provided, the care received is of high quality. However, the timeliness of patient referral remains a concern. Majority of patients were referred to services more than 12 months after diagnosis, a considerable delay f**o**r a rapidly progressive disease.[1] In particular, the importance of early palliative care, to improve symptom management and quality of life, has been much documented.[15-19] In particular, qualitative research previously conducted by ILFA in mixed group comprised of patients, caregivers and healthcare professionals found stakeholders consider palliative care fundamental in all stages of PF, is that it is required from the point of diagnosis onwards.[19] Paradoxically, only 25% of patients surveyed here self-identified a current need for palliative care versus 65% who anticipated future need. Stigma and patients' misperception of palliative care as end-of-life care are known to barriers to palliation, and findings suggest further patient education is needed in this area.[19-21]

In terms of patients' self-identified healthcare requirements, there was significant unmet need across all services, most notable for clinical psychology. Depression and anxiety are frequent co-morbidities in patients with ILD, with the prevalence reportedly as high as 49% and 60%, respectively, yet only 6% of patients surveyed had been referred to a clinical psychologist.[22] The magnitude of this unmet need suggests there are more barriers to access for mental healthcare for PF than service provision alone. Poor recognition of depression and anxiety in PF patients may also contribute; one study found a 23% prevalence of depression in an ILD population following use of a formal questionnaire despite less than 2% having a previous diagnosis.[23] All patients surveyed who had accessed a psychologist were referred by their consultant, suggesting other healthcare professionals, including GPs, could play a greater role in recognising the mental health impacts of PF.

Majority of patients surveyed wished to access most services through a blended approach of virtual and face-to-face care. Majority also wished to access physiotherapy as a group activity, either alone or combined with individual care. A hybrid model of virtual care and face-to-face care, with group activities where appropriate, could potentially increase service capacity and care access as well as optimising patients' care experience. Previous patient engagement indicates use of online group classes had significantly increased access to pulmonary rehabilitation during the pandemic.[6]

As an online patient survey this study has a number of limitations. We recognise that patients self-selected to participate in this research and were recruited and responded to the survey through ILFA communications using electronic media. This introduces bias in favour of patients who are aligned with our organisation and have electronic device access and knowledge. We also recognise that a sample size of 112, whilst we believe sufficient to make inferences regarding the whole cohort, results in small patient numbers in sub-group analyses. We did not enquire to some elements of patient care, such as access to anti-fibrotic treatment or oxygen therapy. Furthermore, whilst we asked patients to state their location by county, we did not ask them to identify if and where they received specialised management for their PF.

We therefore cannot conclude from this research alone whether the limited access to services is due to the lack of such provision at specialist ILD centres, or because patients are managed elsewhere (i.e. privately, at a general respiratory unit in secondary care, or in primary care). Whilst not the aim of this survey, which was to capture quantitative data on patients' experience of accessing care, follow up research on the availability of services at ILD speciality care centres would be highly valuable.

In summary, this research shows the access to specialist and multidisciplinary healthcare for PF is poor and reveals significant unmet needs across all services. A national approach to the provision of ILD nurse specialists is required, ensuring all patients regardless of location have access to this specialty. Improved recognition of patients' needs, earlier referral, and patient education may also improve healthcare access. Changes to service delivery, including greater use of virtual care and the option of group care, could potentially increase service capacity whilst also improving patient experience.

Declaration of Conflicts of Interest:
The authors have no conflicts of interest to declare.

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