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Peer Connect Service for people with pulmonary fibrosis in Australia: Participants' experiences and process evaluation

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Summary at a glance

The Peer Connect Service initiated by Lung Foundation Australia, provides a model of support for people with a rare disease such as PF who are widely dispersed geographically.

The service provides a unique opportunity for people with PF to connect and share experiences and offer mutual support.

ABSTRACT

Background and objective: People living with PF report unmet needs for information and support. Lung Foundation Australia developed the Peer Connect Service to facilitate telephone support for people with PF across Australia. This project documented the experiences of participants and the resources required to support the service.

Methods: Consenting participants took part in semi-structured interviews by telephone. Primary peers (peers who agreed to initiate contact) and secondary peers (eligible patients who sought a peer match) were interviewed. Thematic analysis was undertaken by two independent researchers. Data were collected on the number of matches and contacts required to establish each match.

Results: Interviews were conducted with 32 participants (16 primary peers, 15 secondary peers and one who was both), aged from 53 to 89 years with 56% being male. Major themes included the value of shared experiences, providing mutual support, and the importance of shared personal characteristics (e.g. gender, hobbies) in allowing information and emotional support needs to be met. Participants saw face-to-face contact with peers as highly desirable whilst acknowledging the practical difficulties. Primary peers were cognisant that their role was not to provide medical advice but to listen and share experiences. In the 12-month period, 60 peer matches were made, each match requiring a minimum of seven staff contacts.

Conclusion: The Peer Connect Service provides a unique opportunity for people with PF to share experiences and offer mutual support. This telephone matching model may be useful in providing peer support for individuals with rare diseases who are geographically dispersed.

Short title: Connecting people with pulmonary fibrosis

Keywords: pulmonary fibrosis, qualitative research, lung diseases, evaluation, service delivery

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INTRODUCTION

Pulmonary Fibrosis (PF) encompasses a group of disorders characterised by scarring of the lung tissue. Amongst the most prevalent is idiopathic pulmonary fibrosis (IPF), a progressive condition with a median survival of 2-5 years from diagnosis. ¹ People with PF live with distressing breathlessness that limits exercise capacity and restricts participation in valued activities. Many patients experience a relentless increase in symptoms that become distressing to themselves and their caregivers, and present a challenge in maintaining quality of life. ²

The patient experience with IPF often involves a protracted route to diagnosis, high-volume symptom burden and inadequate disease information. ³ Whilst the emergence of disease-modifying anti-fibrotic treatments (pirfenidone and nintedanib) ⁴ has provided hope, patients and their caregivers still report significant anxiety and unmet support needs. ⁵ Such needs include managing dyspnoea, cough, fatigue, low mood, psychological distress and loss of autonomy. ⁶ Reducing physical and psychological burden, decreasing social isolation, and support from family and peers were rated as “very important” in the ability to accept and cope with the disease. ^{7, 8} In a recent qualitative study, 100 people recruited from the Australian IPF Registry were interviewed to gain insights into the critical unmet needs of people with IPF and their carers. ⁹ A strong emerging theme was the compelling desire to speak to others with IPF, particularly in the early stages following diagnosis as they came to terms with the disease and its prognosis. The establishment of peer support groups for a rare disease such as PF presents challenges for peer matching including geographical dispersion of patients and variability in disease prognosis.

To address the urgent support needs voiced by people with IPF, Lung Foundation Australia has developed a peer support service known as **Peer Connect Service**.¹⁰ This Service involves connecting eligible PF patients with other PF patients, by telephone or email. The objective of this paper is to report the experiences of people who participated in Peer Connect Service and to document the resources required to support such a service.

METHODS

Study setting

The Peer Connect Service aims to bring together people with PF in a mutually supportive environment. The Service is managed by Lung Foundation Australia (LFA), a national organisation established in 1990 to provide support to people with a lung disease and to ensure lung health is a priority for all in Australia.¹¹

The Peer Connect Service

The Peer Connect Service matches eligible people with PF to others going through a similar experience in order to provide mutual support. LFA maintains a contact list of primary peers (eligible patients who agree to initiate contact) to be matched with referred PF patients, known as secondary peers (eligible patients seeking a peer match). Secondary peers connect with the service via several routes including the LFA website, the PF Connect flyer distributed to clinical networks and health professionals, Australian IPF Registry staff, and the LFA Information and Support Service toll free number. Primary peers are matched to secondary

peers by a dedicated staff member within 5-7 days of referral. Matching is based on residential location, age, gender, family status, disease progression and treatment. Primary peers are provided with a contact number for the secondary peer to enable initial contact. LFA does not monitor or facilitate the peer support relationship, but does contact both peers to ensure a successful match has been established. Most people with PF are eligible for the Peer Connect Service, except those diagnosed with severe mental health issues (aside from well managed anxiety and depression), those with advanced disease being considered for end stage palliative care, and those requiring specialised support services.

Study design

A mixed-method design was used to evaluate participants' experience with the Service and the resources associated with its operation. The study was approved by the La Trobe University Human Ethics Committee (#HEC18023). The evaluation of participants' experience involved qualitative, semi-structured interviews conducted by telephone with primary and secondary peers who were registered users of the Service and consented to participate.

Participants

Eligibility for this study included being a primary or secondary peer involved in the PF Peer Connect Service and having completed the first contact match. Primary peers were required to have been involved in the Service for at least three months and secondary peers at least one month. Potential participants were informed about the study by mail after completion of peer matching. Peers interested in participating were asked to contact research personnel by

telephone. Verbal consent was obtained and audio recorded at the commencement of each interview.

Semi-structured interviews

Semi-structured interviews were conducted by telephone from May 2018 to September 2018. Interviews were conducted by JL, a study researcher trained in qualitative methods. Semi-structured interview questions for primary and secondary peers are detailed in **Box 1**. The interviews were audio-recorded and transcribed verbatim using a professional transcription service. Basic demographic and clinical information including age, gender, postcode, living status (alone or with others), and current treatments for PF were collected as part of the evaluation.

Box 1: Semi-structured interview questions

Semi-structured interview questions for primary peers.

1. Could you tell me about why you decided to take part in the LFA Peer Connect service?
2. Could you tell me about your experience of contacting a peer for the first time?
3. Can you tell me about your experience of ongoing contact with your peers?

Follow-up if required: Can you tell me about the way you've been in contact (e.g. phone, email, social media) and which you preferred?

4. In your experience, what type of support are people with PF seeking from the LFA Peer Connect service?
5. Can you tell me about any ways in which you feel well equipped to deliver this support?

6. Can you give me any examples where you may have felt unable to address the needs of your peer?
7. What do you think makes a good 'match' in a peer?
8. If you could change one thing about the LFA Peer Connect service, what would it be?

Semi-structured interview questions for secondary peers.

1. Could you tell me how you heard about the LFA Peer Connect service?
2. Could you tell me why you decided to take part in the LFA Peer Connect service?
3. Could you tell me about the first conversation with your peer?
4. Could you tell me about any other contact you've had with your peer?
Follow-up if required: Can you tell me about the way you've been in contact (e.g. phone, email, social media) and which you preferred?
5. Could you tell me about anything you found helpful about the LFA Peer Connect service?
6. Could you tell me about anything you found difficult or unhelpful about the LFA Peer Connect service?
Follow-up if required: Can you give an example where you felt that your peer was unable to address a need or concern you had?
7. Can you tell me about any plans for future contact with your peer?
8. What do you think makes a good 'match' in a peer?
9. If you could change one thing about the LFA Peer Connect service, what would it be?

Process evaluation

The process evaluation utilised the information collected in the LFA Client Management System. This included: the total number of referrals, route of referral, number of peer matches made, number of PP, number of SP, and number of SP assigned to each PP.

Data analysis

Deductive thematic analysis of the transcribed interviews was undertaken by two independent researchers (AH, JL). The transcripts were first read line-by-line and fragmented into descriptive codes to represent the data (open coding).¹² Codes were organized hierarchically to form themes and the original transcripts were searched to refine the relationship between themes and codes (axial coding). The final themes were agreed through iterative discussion between the two investigators. Data for the process evaluation were reported descriptively as n (% of group).

RESULTS

In the 12-month period reported on, the total number of primary and secondary peers was 91 from which, 60 peer matches were made and 32 peers consented to be interviewed. The characteristics of the 32 peers who participated in the qualitative study are summarised in **Table 1**. The majority were male, with an average age of 71 years, resided in either Victoria or Queensland and almost two-thirds were using anti-fibrotic therapy.

Table 1: Characteristics of the 32 peers involved in the evaluation of the Peer Connect Service.

CHARACTERISTIC	n (%) of TOTAL
Primary peer	16 (50)
Secondary peer	15 (47)
Both primary and secondary peer	1 (3)
Gender, male	18 (56)
Age (years), mean \pm SD, range	71 \pm 7, 53 – 89
Residential state in Australia	
ACT	2 (6)
NSW	6 (19)
NT	0 (0)
SA	1 (3)
TAS	0 (0)
QLD	8 (25)
VIC	9 (28)
WA	5 (16)
Not stated	1 (3)
Living status	
Married or living with others	28 (88)
Living alone	4 (12)

Current pharmacological treatment	
None	6 (19)
Anti-fibrotic therapy	21 (66)
Other	5 (15)

Five major themes were identified consistently across primary and secondary peers, plus two additional themes that emerged from interviews conducted amongst the primary peers (Table 2).

Table 2: Summary of major and minor themes emerging from interviews with participants with PF (n=32) involved in the Peer Connect Service evaluation.

	PRIMARY PEERS	SECONDARY PEERS
MAJOR THEMES	Value of shared experience	Value of shared experience
	Mutual support	Mutual support
	Importance of shared personal characteristics	Importance of shared personal characteristics
	Face-to-face meetings desirable	Face-to-face meetings desirable
	Ongoing contact not needed	Ongoing contact not needed
	Role is not to give medical advice	---
	Setting limits	---
MINOR THEMES	Unmet support needs of primary peers	---
	Death of a peer	Death of a peer

MAJOR THEMES: PRIMARY AND SECONDARY PEERS

Value of shared experience (Box 2: 2.1)

The positive value of sharing experiences with someone on the same journey was a strong theme expressed by both primary (PP) and secondary (SP) peers. Many highlighted the isolation and very lonely journey that people with PF experience due to the lack of knowledge, understanding and empathy about the disease. Peers found the shared experience provided them with a more comfortable environment in which to talk about their fears and concerns, that at times, was difficult to do with partners or friends.

Mutual support (Box 2: 2.2)

Both primary and secondary peers found that sharing their experiences and concerns with others provided mutually beneficial moral support and positivity. Many peers expressed the value of others being the source of new information and insights into the disease that was often more reliable than sources such as the internet.

Box 2: MAJOR THEMES:

Primary and secondary peers

2.1 Positive value of shared experience

“Doctors and nurses can tell us what our journey is to be, but they can’t tell you how you’re travelling. That, you can only get from your fellow travellers”. (PP18)

“It’s just about sharing your experience; having somebody that’s empathetic because most of the community is apathetic.” (PP01)

“I just needed, really needed somebody to talk to that knew exactly what I was going through.” (SP28)

“...I can’t say it to my friend, I’ve got this, this and this, but I can tell it to someone else who has experienced it and probably knows all about it”. (PP20)

2.2 Mutual support

But it’s not one way, I mean I get an awful lot out of it as well, even though I’m the one who made the initial contact, you know. (PP19)

I’ve provided him with some information perhaps that he didn’t have; and I certainly got some information that I didn’t have. (SP25)

Importance of shared personal characteristics

(Box 2: 2.3)

Personal characteristics and shared common interests were highly important in ensuring a positive experience and in establishing a rapport with another peer. Many peers indicated that being matched with the same gender allowed them to feel more comfortable and less embarrassed about discussing personal aspects of the disease (such as bringing up phlegm) or other gender-specific issues such as 'women problems'. Peers indicated that the success of the match relied on finding common ground based on age, family, similar interests, occupations or life experiences, in addition to the disease itself. Similar interests were more important than having the opportunity to meet face-to-face if there was little in common. Peers acknowledged that not all matches were successful and building rapport was sometimes difficult due to differences in personalities, "not being on the same wavelength", or SP not being receptive to the calls.

Box 2 cont. MAJOR THEMES:

Primary and secondary peers

2.3 Importance of shared personal characteristics

"...I think it's probably a little more awkward if it's male to female or female to male, because, ah, men approach these things differently to women." (PP33)

"I was quite a keen motorcycle rider and so was he, so we joked that when we come good, we'll go for a bike ride together." (PP32)

2.4 Face to face meetings desirable

"It would be nice to meet someone face-to-face, I think but, um, that's not always possible, because they're so far away..." (SP29)

2.5 Ongoing contact not needed

"I've spoken to someone and I'm not going mad, because she's got the same sort of thing, and I guess didn't feel the need to speak to anyone again." (SP36)

Face-to-face meetings desirable (Box 2: 2.4)

A commonly stated limitation to the Peer Connect Service was that contact was only by phone primarily due to geographic distances. The majority of peers, regardless of geographic location, indicated they would prefer the option of having at least one face-to-face meeting as this would make things more personal and make a bigger difference. However, other participants felt it was not necessary or practical to meet in person.

Ongoing contact not needed (Box 2: 2.5)

Primary and secondary peers agreed that the initial contact provided the major benefit as it offered the opportunity for the most important questions to be answered. Some peers did not feel the need for ongoing contact, whilst others perceived a natural conclusion to the relationship after a small number of phone calls.

MAJOR THEMES: PRIMARY PEERS ONLY

Role is not to give medical advice (Box 3: 3.1)

Primary peers were cognisant of their role being primarily one of listening and talking about their experiences rather than providing any medical or psychological advice. They encouraged secondary peers to raise questions regarding treatment decisions with their physician.

Setting limits (Box 3: 3.2)

Primary peers reported that their role could potentially be all-consuming, affecting them emotionally, physically and psychologically. For some this meant delaying contact or limiting frequency of contacts or the number of peers they took on.

BOX 3 MAJOR THEMES:**Primary peers only****3.1 Role is not to give medical advice**

"I can't take the place of the medical specialist, but I can talk about the experiences that I've had. There's a real mental side to that as I said earlier that's not recognised. And I think we fill that gap not as psychologists or mental specialist but just as somebody that listens." (PP01)

3.2 Setting limits

"I try not to dwell on her too much because she puts very negative feelings on Facebook, letting everybody know how she feels. She's got a negative attitude and I don't think I can – I can't cope with that sometimes." (PP03)

MINOR THEME: PRIMARY PEERS ONLY

Unmet support needs of primary peers (Box 4)

A minor theme emerging from the interviews with primary peers was their need for more emotional support. While they were happy to provide support to others, some felt the desire to be contacted themselves to be able to discuss their own issues.

Box 4 MINOR THEME:**Primary peers only****Unmet support needs of primary peers**

"It was always me ringing him... so that's a little bit annoying because, I need the support too." (PP07)

MINOR THEME: PRIMARY AND SECONDARY PEERS**Death of a peer (Box 5)**

Managing the psychological effects following the death of a peer emerged as a concern for both primary and secondary peers. Most experienced a sense of 'shock' and the harsh realisation of their own future journey.

Box 5 MINOR THEME:**Primary and secondary peers****Death of a peer**

"I felt really sad, and it made me, a bit down for a while, and you know you just wonder you know, if it will be you." (SP29)

"Oh, it upset me. It was quite a loss actually." (PP03)

PROCESS EVALUATION OF THE PEER CONNECT SERVICE

Over a period of 12 months during which the evaluation was undertaken, there were 60 peer matches. The largest source of referrals (44%) came from the LFA Information and Support Service, with 15% coming from health professionals. Primary peers (n=30) were matched with between one and five secondary peers, with a minimum of seven contacts (interchanges)

required from LFA staff to establish each match. The majority of contacts (64%) between LFA staff and peers occurred by telephone, with a smaller number by email.

DISCUSSION

The objective of the Peer Connect Service is to provide a means for people with PF to connect with each other, provide mutual support and understanding, and to reduce the isolation and loneliness that commonly accompanies the disease. Qualitative interviews with 32 Service users indicated that overall the model was well understood. Primary peers clearly articulated that their role was not to provide medical advice, but to listen and share their experiences of living with PF. Both primary and secondary peers expressed the positive value of making contact with people on the same journey, allowing them to share common experiences that alleviated some of their uncertainty and emotional distress and acknowledged their symptoms and feelings in a more comfortable environment. There was a general consensus that having things in common was the most important criterion in determining the success and continuity of the connection. However, peers acknowledged that not all contacts were successful, particularly if one side was not interested.

Peer Support programs have been reported for people with a number of health conditions including cancer.¹³ Telephone based peer support services have been particularly effective for geographically and socially isolated patients.¹⁴ This mode was found to be confidential, inexpensive and a relatively simple method of allowing patients to be supported by a peer and could be a satisfactory substitute for face-to-face interaction.¹⁵ Evaluation of the programs report similar findings to our study in that the majority of participants found the experience

positive and mutually beneficial. However, the monitoring and evaluation of different models of peer support programs remains challenging, but are needed to better support and adapt programs to meet the needs of participants.¹⁴

The interviews identified several challenges to implementing and sustaining the Service. These included the desire to meet face-to-face with their peer, which was logistically difficult in the majority of matches due to geographical distances and presents a common challenge for PF support services given the uncommon nature of the condition. Primary peers reported the need for more emotional support, with this expectation not always met in their interactions with secondary peers. Presently, the model is being refined to address the identified challenges. This includes exploring options for establishing PF-specific face-to-face support groups, providing peers with guidelines about the scope of the service and expectations of the roles. Supportive documents including referral pathways are being developed to assist peers in connecting with other peers and to aid in dealing with difficult conversations and circumstances. A three-call limit will be introduced to support the wellbeing of primary peers, ensure sustainability of the service, and encourage independence for the secondary peers.

The evaluation of the resources required to deliver the Peer Connect Service suggests that a significant amount of time is required by dedicated LFA staff to establish a match. At least seven contacts were required for each match with LFA staff estimating at least 2.5 hours was needed. Additional resources include dedicated staffing (LFA has a Peer Connect Coordinator), as well as time to establish standard operating procedures and promote the service to people with PF and health professionals. This has implications for establishing and sustaining similar services. As only 15% of referrals to the Service are made by health

professionals, this is an area that could be improved to allow a greater pool of more diverse peers to be established. Further data relating to the resources required for such a service are needed to provide a more detailed cost-effectiveness evaluation.

The strength of this study is that it provides an evaluation of participant experiences with a model of support specifically designed for people with a rare disease such as PF who are widely dispersed geographically. Such insights have the potential to guide the development of disease-specific models of care and support. Given that the service is unique to PF patients, the generalisation of these findings may be restricted to the volunteers who participated in the evaluation study. These may differ from others who did not participate, as well as those in more remote areas of Australia such as the Northern Territory.

In conclusion, the Peer Connect Service provides a unique opportunity for people with PF share experiences and offer mutual support. This telephone-based matching service may be useful to establish peer support for individuals with rare diseases who are geographically dispersed.

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Author contributions:

Abbreviations:

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