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Pulmonary rehabilitation for interstitial lung disease: Referral and patient experiences

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Abstract

Objectives: The objectives of this study were to determine the proportion of patients with interstitial lung disease (ILD) referred to pulmonary rehabilitation (PR) and to understand their experiences of participation or non-participation. **Methods:** Adults (>18 years old) with a diagnosis of ILD were identified from the Alfred Health ILD registry in Melbourne. Information regarding PR referral and attendance were collected from medical records. Semi-structured interviews with open-ended questions were conducted with patients who had been referred to PR. **Results:** Of 336 patients eligible for inclusion, PR referral was identified in 137 patients (40.7%). Patients referred to PR had worse respiratory function than those not referred (forced vital capacity mean 64 (SD 23) vs 79 (19) % predicted) and more desaturation during a 6-min walk test (86.6 (7.8%) vs 88.5 (7.0%)). Semi-structured interviews identified three major themes: valued components of PR (supervision and individualization, improved confidence with exercise, education and peer support); limited knowledge about PR prior to attendance and barriers to attending PR (lack of perceived benefits, fear of exercise and accessibility). **Discussion:** Over 40% of patients who attended a specialist ILD clinic were referred to pulmonary rehabilitation, with higher referral rates in those with more severe disease. There are opportunities to improve patient knowledge regarding the role and expected benefits of PR in people with ILD.

Keywords

Rehabilitation, interstitial lung disease, referral and consultation, qualitative research

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Introduction

Interstitial lung disease (ILD) is a group of acute and chronic pulmonary disorders characterized by scarring and fibrosis of lung tissue with or without identifiable cause.[1] Although there is a considerable variation in terms of clinical course and prognosis, most ILDs are characterized by severe dyspnoea, debilitating fatigue and reduced exercise capacity.[2,3] Clinical practice guidelines across the world suggest pulmonary rehabilitation (PR) as an important component in the treatment of people with ILD.[1,4,5] Pulmonary rehabilitation is an interdisciplinary intervention that could be initiated at any stage of the disease and

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Table 1. Interview questions for participants.

1	Can you tell me about any experiences you have had with pulmonary rehabilitation? Follow-up questions as required - can you tell me what you knew about PR before you attended? If the person tells you they did not enrol or did not complete – can you tell me more about that?
2	Can you tell me how you came to be referred to pulmonary rehabilitation?
3	Can you tell me more about your experiences during pulmonary rehabilitation?
4	Sometimes people with ILD who start a pulmonary rehabilitation programme are not able to complete it – they do not attend all the sessions, or they drop out altogether. What do you think makes it difficult for some people with ILD to attend pulmonary rehabilitation?
5	What do you think would make it easier for people with ILD to complete Pulmonary Rehabilitation?
6	Sometimes people with ILD who are referred to pulmonary rehabilitation choose not to attend at all. Why do you think this might happen?
7	What would make it easier for people with ILD to enrol in pulmonary rehabilitation?
8	That was my last question. Do you have anything you would like to add or to ask before we finish this interview? Are you interested in receiving the transcripts of the interview and or summary of the results of this study via mail?

includes exercise training and education aiming to promote adherence to health-enhancing behaviours.[4] Recent research trials in people with ILD have shown improvements in functional status (measured by the 6-min walking distance- 6MWD), quality of life (evaluated with the Saint George Respiratory Questionnaire -SGRQ) and dyspnoea (measured using the MRC scale) after 8–12 weeks of PR.[6] Data suggest that PR when delivered in early stages of pulmonary fibrosis promotes greater improvements in functional exercise capacity and in other ILDs promotes significant gains in dyspnoea and exercise capacity, regardless of disease severity.[7]

Despite the benefits of PR, little is known regarding referrals and attendance of ILD patients to PR and the experiences and barriers encountered by patients to adhere and complete PR have not been explored.

Thus, the aims of this study were 1) to determine the proportion of patients with ILD referred to PR at a tertiary ILD clinic in Melbourne, Australia; 2) to understand the experience of these patients regarding their participation in the programme and the reasons of their non-participation or non-completion of the programme.

Methods

The ILD registry data from the Alfred Hospital was used to identify adults (>18 years old) with a diagnosis of ILD from 2015 until 2019. The ILD registry is approved by the hospital human research ethics committee and patients have given consent to be included in the registry. This study was approved by the Human Research Ethics Committees and of Alfred Health and La Trobe University (402/19). To address Aim 1, medical records were audited to identify information about PR referral and attendance, including whether a referral had been made, location of the programme, date of enrolment, programme completion and any reasons for non-completion. Demographic information including age, diagnosis, lung function tests and exercise capacity tests (6-min walk distance, 6MWD) were also collected from medical records. To address Aim 2, all patients who had been referred to PR were sent a letter with an invitation to participate in a phone interview. Interested candidates were invited to call the principal researcher who obtained verbal consent for participation and audio recording of the interview. Semi-structured interviews with open-ended questions were conducted via telephone with participants who were located at home. A series of eight open-ended questions were created by the researchers based on previous similar studies developed in patients with COPD to investigate the participant's experience with PR (Table 1).[8] The interview was piloted in three patients and questions adjusted to avoid closed follow-up answers and better personal description of PR experiences. Interviews were conducted by a researcher with a background in physiotherapy who was not previously known to the participants (MH) and at a time chosen by the participant. Participants were offered to receive the transcripts of the interview if required. Recruitment continued until data saturation was achieved.[9]

Quantitative data for PR referral were presented using frequencies and percentages. Differences in demographic characteristics between those with and without a PR referral were analysed using the Mann–Whitney U test. The predicted distance of the 6MWD was calculated according to the equation developed by Jenkins et al.[10] For qualitative data, recordings were transcribed verbatim. Two researchers independently analysed the transcripts using deductive thematic analysis following the six steps described in the study of Nowell et al., 2017[11]: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report. The transcripts were read separately by two researchers and emerged themes were initially coded independently. A consensus was reached after data interpretation and discussions between the two researchers to establish initial themes. The preliminary concepts and themes were compared and pooled in predominant themes and subthemes.

Results

Participants

The search of the ILD registry resulted in 336 patients eligible for inclusion, and from those, a PR referral was identified in the medical records for 137 (40.7%) of participants. Patients' diagnosis is described in Table 2. Patients referred to PR had worse respiratory function than those not referred to PR and more desaturation on 6MWD (Table 3).

Of the 137 patients with PR referral, 87 patients were alive at the time of the study and were invited to participate in an interview and 21 patients agreed to participate and gave verbal consent over the phone. Twenty-one interviews were conducted and transcribed for analysis. Data saturation was achieved after 19 interviews (no new themes emerging from the interviews) and confirmed in the final two interviews. From the patients that accepted to perform the interviews, 60% were referred to PR by respiratory physicians, 14% were referred to PR after being an inpatient in the hospital, 10% were referred to PR because they were participating in a research trial, 10% because they were included on the transplant list and 6% were referred to PR via ILD nurse. Seven participants completed one PR programme, nine participants completed two or more PR programmes, two were referred but did not complete the programme and three were referred but did not begin the

Table 2. Participants diagnosis.

	Referred	Non-referred
Diagnosis (*n*)	Idiopathic pulmonary fibrosis (51) Chronic hypersensitivity pneumonitis (26) Combined pulmonary fibrosis and emphysema (17) Connective tissue disease associated ILD (15) Unclassifiable ILD (9) Pneumoconiosis (4) Sarcoidosis (2) *Rare idiopathic interstitial pneumonia* (pulmonary lymphogioleiomyomatosis (1), langerhans histiocytosis (1), lung involvement vasculitis (1), pleuroparenchymal fibroelastosis (1), lymphocytic interstitial pneumonia (1) and follicular bronchiolitis (1) NSIP (3) *Other* Multiple pulmonary nodules (1), bronchiectasis (2) and familial interstitial pneumonia (1)	Idiopathic pulmonary fibrosis (72) Chronic hypersensitivity pneumonitis (24) Combined pulmonary fibrosis and emphysema (17) Connective tissue disease associated ILD (27) Unclassifiable ILD (11) Pneumoconiosis (6) Sarcoidosis (13) *Rare idiopathic interstitial pneumonia* (lymphocytic interstitial pneumonia (2), langerhans histiocytosis (1), lung involvement vasculitis (2) and interstitial pneumonia related to Sjorgen's syndrome (2) NSIP (13) Cryptogenic organizing pneumonia (1) *Unclassifiable idiopathic interstitial pneumonia* – interstitial pneumonitis (3), organizing pneumonia (2) and post infective scarring (1) Drug-induced ILD (2)

Table 3. Demographic characteristics.

	All patients (*n* = 336)	Referred to PR (*n* = 136)	Not referred to PR (*n* = 200)	*p*-value
Age, years	67 (12)	67 (13)	66 (12)	.73
Gender (M/F)	214/122	91/45	123/77	.22
FVC (L)	2.7 (0.91)	2.56 (0.94)	2.82 (0.86)	.044
FVC (%)	73.2 (21.58)	63.72 (22.65)	78.89 (19.42)	.004
FEV_1 (L)	2.14 (0.7)	20.02 (0.7)	2.23 (0.61)	.037
FEV1(%)	77 (21.83)	70.95 (22.26)	82.73 (19.59)	.003
TLCO (ml/mmHg/min)	12.6 (6.78)	10.37 (6.17)	14.1 (7.18)	<.001
TLCO (%)	52.62 (25.11)	41.81 (19.55)	59.78 (25.15)	<.001
6MWD (m)	415.04 (138.18)	393.15 (140.46)	431.86 (134.44)	<.01
6MWD (% predicted)	69.9 (24.9)	64.68 (21.38)	73.35 (27.9)	.1
Nadir O_2 on 6MWD (%)	87 (9.4)	86.64 (7.15)	88.49 (7.02)	.017

Data expressed as mean and standard deviation. FVC, forced vital capacity; FEV1, forced expiratory volume in one second; TLCO transfer factor for carbon monoxide; 6MWD, 6-min walk distance. *p* value represents comparison between those referred and those not referred to PR.

programme. Included participants in the qualitative study were mean (SD) 71 (6) years old range (22–91 years old) with FVC 74.3 (22.8) %, FEV_1 77.38 (24.48) %, TLCO 43.8 (15.91) % predicted value. Participants' diagnosis included: IPF (9 participants), chronic hypersensitivity pneumonitis (4), unclassifiable ILD (2), smoking-related interstitial lung disease combined pulmonary fibrosis and emphysema (2), scleroderma associated ILD (1), rheumatoid arthritis related ILD (1), bronchiectasis (1) and sarcoidosis (1). Their 6MWD was on average 442 (81) metres with nadir desaturation of 88 (6) % and their referral/attendance date to PR programme varied between 1.5 and 4 years prior to study participation.

Three major themes and eight subthemes were derived from the interviews (Box 1).

Valued components of pulmonary rehabilitation

Participants discussed a number of valued components of the PR programme. Individualized programmes with constant supervision by health professionals made an important contribution to a good experience with PR. Most participants reported feeling safe to exercise because of the presence of the physiotherapist and the constant monitoring of their oxygen saturation levels and heart rate. There was a common positive belief that having a personal and individualized programme was important to tailor the exercise to the individual's physical capability.

Participants reported that after PR they were more confident to exercise and had less fear to exercise without supervision. They described how they had learnt to exercise safely and how to self-monitor during exercise. Some of the interviewees had established a new exercise routine at home or in their community centres, increasing the long-term benefits of PR.

Participants reported the relevance of the educational sessions to understand the importance of exercise as well as address common issues such as dealing with depression and symptom management.

Almost all participants reported the interaction between attendees of the PR programme as a motivational factor to completing the programme in full. Exercising with peers who also had lung disease was reported as an extra support to perform the activities during the sessions and allowed them to exchange experiences regarding symptoms and disease management. There was only one participant that reported the presence of peers during exercise as a negative impact. This participant felt that the presence of people with worse symptoms or at a more advanced stage of the disease could make others feel uncomfortable or depressed.

Knowledge about pulmonary rehabilitation

All the participants reported little knowledge about PR before they were referred. Some participants suggested that leaflets or pamphlets would make it easier to understand and increase knowledge about the programme.

Barriers to attending pulmonary rehabilitation

Reports from the participants have also demonstrated some difficulties and challenges encountered to attend or complete PR. Some participants reported they had not completed or attended PR because they did not feel that it would help them to improve their capabilities. Some reported a disbelief that anything could improve their condition since they have a progressive disease. Others reported a lack of benefits because they felt they were not pushed hard enough during the programme, or they found the sessions too easy compared to what they were able to perform. On the other hand, some participants referred to the fear of feeling breathlessness or fear of exercise as a potential reason for lack of attendance or enrolment in PR.

The accessibility of the PR centre was mentioned in almost all of the interviews. This included the distance participants had to travel from their home to the centre, as well as the use of public transportation or parking. Some participants also mentioned the time schedule of the sessions did not suit their routine, especially those still working. Lastly, there were a few participants that mentioned not being able to leave home because they were the primary care provider of either their partner or other relative, so they could not make time to attend the sessions. Some interviewees reported being too sick to attend the sessions. This was mainly described as worsening of their symptoms (persistent cough or breathlessness), disease exacerbations or side effects of medications (Tables 4–6).

Discussion

This study explored the referral of people with ILD to PR programmes and their experiences of participation. Forty

Box 1. Themes and subthemes associated with experiences with PR programme.

Theme	Valued components of PR programme	Limited knowledge about PR	Barriers to attending PR
Subthemes	Supervision/individualized programme		Lack of perceived benefits
	Build confidence in exercising		Fear of exercise
	Education sessions		Accessibility
	Peer support		Too sick to attend

percent of identified participants had received a PR referral. Quantitative data results suggested that patients referred to PR had worse respiratory function and lower functional capacity evaluated by the 6MWT when compared to the non-referred group. Qualitative interviews showed that valued features of PR were the constant supervision and individualization of the programme, the increase in confidence and in exercising and the educational sessions. However, barriers to attendance such as lack of perceived benefits, fear of exercise and accessibility were also identified, which are similar to barriers identified in previous studies of participants with obstructive lung disease.[11] Participants also demonstrated limited knowledge about PR before receiving a referral.

Results showed that the referral rate, although based on a single centre, seems to be higher than referral rates previously demonstrated in people with COPD.[12,13] This can be potentially explained by the fact that PR has been included in the IPF management guidelines since 2011 and many updated guidelines after that recommend PR as part of the treatment of people with ILD.[1,4,5] This higher rate can be related to the fact that participants were part of a specialist ILD service and many of them have limited treatment options, leaving PR as one of the few effective disease management choices. Nevertheless, we still have to acknowledge that less than 50% of patients in a specialist ILD clinic were referred to PR. It is a limitation to this study that we only documented the percentage of the patients who received a PR referral and were not able to document the percentage of patients who were offered PR referral and chose to decline, as this was not routinely included in the medical record. This important group of patients may experience different barriers to PR participation and this should be investigated in future research. Besides, some of the participants (n = 8) had their referral more than 2 years prior their interview, which could potentially have influenced the recall of their PR experience. The finding that patients referred to PR had lower respiratory function and worse functional capacity than those who were not referred also requires further exploration. It is possible that this may reflect a greater disease burden in these patients, and the perception of health professionals that this could be addressed by PR. Literature shows improvements in exercise tolerance and relief in symptoms after PR and no evidence of adverse events related to it.[14,15]

According to the European Respiratory Society Guidelines published in 2013, PR is part of an integrated care for people with chronic lung conditions and should include exercise training, education and behaviour change.[4] The important part of this definition is the inclusion of PR as a key-factor to enhance long term health behaviours. Participants in this study reported positive impacts of PR on health behaviours such as keeping an exercise routine and an active life style after completion of a PR programme. It is possible that part of the interviewees not only obtained the physical benefits of the PR programme but also understood the importance of an active lifestyle and changed their behaviour to improve their physical condition considering this aspect as a valued component of the programme.[4] Another positive aspect revealed by the interviews was the importance of the peer support and the social interaction during the sessions. The possibility of sharing experiences with others under the same conditions as well as the sense of belonging to a group have been previously described as an important aspect to increase adherence and maintenance of PR sessions in patients with COPD.[16] This is a very important aspect since increased attendance has been shown to be directly associated with social support received in the sessions and group cohesion.[17] Besides, a study from Young et al. has shown that most of non-adherent individuals with COPD to PR programmes were socially isolated, less compliant with other healthcare activities and lacked disease related social support. Thus, it is also important to enhance the social aspect between participants to try to increase adherence by group cohesion and social support.[18]

Most of the participants described a lack or no knowledge about PR before they received a referral or started the first session. Increasing the awareness of PR to patients with chronic lung conditions such as ILD is crucial to enhance programme uptake. Circulating the knowledge of the potential benefits of PR can also lead to better adherence to the programme.[19] Innovative approaches such as a welcome session or a 'tester' session prior to enrolment in PR as well as educational and testimonial videos have been described as strategies to increase awareness of PR in COPD patients.[20] More studies need to investigate the role of testimonial videos on increasing adherence in PR but it appears that if we try to improve patient's knowledge about the benefits and components of the programme we could potentially increase the opportunity for them to advocate for their enrolment and discuss their participation with their doctor.

Participants reported increased confidence to exercise alone at home after the programme, which could be seen as an opportunity for home-based programmes with less supervision by the physiotherapist. Home-based PR in patients with COPD has shown to be as effective as centre-based PR in improving short-term outcomes such as health related quality of life and functional exercise capacity, even when using minimal supervision and resources.[21] Technology-enabled PR may also enhance outcomes, although this has rarely been tested in ILD.[22] However, it is important to consider some aspects of PR in people with ILD that could challenge but not prevent home-based programmes, such as the use of oxygen during exercise and the constant need for monitoring oxygen levels on exertion. Home-based programmes could increase accessibility for patients who cannot travel and allow greater accommodation to the patient's daily routine; however,

Table 4. Valued components of PR – representative quotes.

Supervision/individualized programme	P16: 'They teach you a number of things and there were people with lot worse condition than me at the time, but […] they sort of tailor it to what you can do and I thought it was good cause it gets you into the spirit of doing something um under sort of protected environment too'. P15: 'I found helped build up my confidence to do the other exercise because I was being monitored, [..] I was getting oxygen and they were measuring what I was doing and that means that if anything if I had any problems it would be better'.
Build confidence in exercise	P4: 'Since I did the first lot of rehab I've bought myself a second-hand treadmill and I walk everyday now at home. So yep, so I hop on the treadmill every day'. P13: 'The first programme at [...] was excellent, it improved my physical fitness immensely and over the 8 weeks [...]my breathing, my exercise capacity and consequently my just wellbeing, my confidence in my fitness improved immensely and the people were exceedingly helpful'.
Education sessions	P09: 'They also had some educational sessions on you know, how to breathe when you got into trouble and that sort of thing and different other lifestyle issues and I found most of them pretty interesting'.
Peer support	P20: 'You're motivated there, you go out with other people doing those things, the same problems you're more motivated to go and do that where you've got people with the same problem, you can talk to them and all that and the people you have running all these programmes are very good'. P10: [...] there were times when you had a break and being able to talk to other people who you know, no matter how, no matter how good your family are nobody can quite understand how you feel or whatever compare with somebody else with similar illness, so that was, I felt very useful

Table 5. Knowledge about PR – representative quotes.

P15: 'I did not know much about pulmonary rehabilitation at all actually. I was put on a trial while I was up in the in the ward. I was on oxygen and they were monitoring me with some exercise and that and I did that for a while. And then I also, I was given some advice on what and what not to do sort of thing'.
P9: 'Uh nothing, it was just the specialist… at the lung clinic, I obviously had a drop in what they call your gas transfer, which is the amount of oxygen getting through your lungs and your bloodstream that collapsed and uh I was starting you struggle a bit and he said oh it's about time you did some pulmonary rehab and till that point I did not even know it existed…. I knew nothing about it till the doctor suggested that I do it'.
P3: 'What you need to have, something that's describing what the programme is and maybe just a little leaflet. If they do not want to take up the programme then you could sort of put well your local council may have senior classes, senior exercise classes if you do not want to be in a medical setting, so maybe a little pamphlet with the options available could be made up so people are not only made aware of the pulmonary fibrosis programme but other options that are available'.

Table 6. Barriers to attending PR - representative quotes.

Lack of perceived benefits	P12: 'It's a I would do it but I think it's only on certain diseases, you know like I had the pulmonary fibrosis and it was just gonna get worse, it did not you know it was alright for a bit and then it just gets worse and worse so really it did not matter what I do it was not gonna make it better'. P1: 'Previous ones that I've had (PR) seemed to be in amongst a group of people that seemed to be a lot older than me and seemed to be a lot more unwell than I was. And the programmes in it, I think I found them too easy'.
Fear of exercise	P6: 'Fear, uhm just uh do not want to expose themselves to others, that they feel inadequate about their own state, embarrassed by it. It might just be the feel that it's going to be too hard, I suppose that's the embarrassment side again uhm'.
Accessibility	P3: 'I was working at the time too. I since retired, and with the working sometimes it's difficult getting time off work'. P21: 'I've got my wife she's been, had to be put in uh aged care and uh in a home she's got Parkinson's and uh Alzheimer's and that's probably the main reason why I havenot done any of these things'. P11: 'I believe that if a person's carrying an oxygen tank with them or uh has a difficulty in travel therefore it certainly will play a part in attendance and continuing with their physical rehab'. P15: 'Well I was on pred at the time and being on prednisolone it's very easy to get a cold or flu so attending uh using public transport is a no. So, it becomes a bit expensive getting a taxi, I do not have a car, getting a taxi there and back that sort of thing and it adds a bit of money onto the session'.
Too sick to attend	P15: 'I did it for about 3 or 4 weeks and then became very sick at home with um a cold or something, I cannot remember what it was and then I could not participate anymore'. P13: 'Oh once I took the Nintendanib I have diarrhoea so badly it was such um such dreadful side effects that I was home bound'.

there are few studies in the literature demonstrating the benefits of home-based PR programmes in people with ILD.[23,24] Centre-based PR provides social connection and peer support, which was highly rated by our participants; it may also be possible to provide this with virtual group PR programmes. By making the PR structure more flexible and increasing awareness of its benefits, it is likely that people with ILD would be more willing to attend.

This study was the first study to use an ILD registry to elucidate referral rate and participation in PR by people with ILD including a large number of patients. Although we consider this as a strength of this study, data regarding referral were assessed using medical record audit, which may not have included all PR referrals. Because the study was performed at a specialist ILD centre, many patients were referred to PR programmes closer to home and outside our healthcare network, and thus information regarding uptake, completion and characteristics of PR programmes attended was not available. As a result, it was not possible to confirm the proportion of referrals that resulted in attendance at PR. Demographic information for referred and non-referred patients was collected from the time of the most recent medical consultation during the data collection period, which may not have reflected demographics at the time of referral in the PR group. This limitation means that differences between the groups should be interpreted with caution. Many of the interviewed patients had performed at least one course of PR, so our data may not fully reflect the experiences of patients with ILD who choose not to attend PR. Besides, it is not possible to draw definite conclusions regarding the difference in demographic characteristics of patients referred and non-referred to PR once, although the most updated lung function tests and 6MWT were used there was no standardized time point of this assessment in regards to patient's diagnosis or referral. Another strength of this study is the inclusion of 21 interviews, which is considered an acceptable size for qualitative research and in this case was sufficient to achieve data saturation, providing valuable information regarding experiences and attendance at PR programmes.

Conclusion

Referral of people with ILD to PR programmes was relatively common at a tertiary ILD centre. Valued components of PR included the individualization and supervision of sessions, the educational component as well as the peer support provided by the programme. Most barriers identified were accessibility and inadequate knowledge. Strategies to enhance the knowledge of patients with ILD regarding the potential benefits of PR are needed, along with more diverse PR models that could increase programme accessibility and uptake.

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