Modified interstitial lung disease (ILD) pulmonary rehabilitation programme

Patients’ perceptions

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Acknowledgements

• Academic Supervisors:
  • Prof Joy Conway
  • Dr Rachel Summers

• ILD Clinical Lead
  • Dr Sophie Fletcher

• UHS Physiotherapy Team
  • Claire Cobbett
  • Dr Denise Gibson
Background

Value of PR in ILD

The burden of living with IPF

ILD patients want to be educated
Interstitial Lung Disease (ILD)

Identify known cause or association
- Drug induced ILD
- Connective tissue disease (CTD)
- Occupational ILD
- Familial or inherited

Idiopathic Interstitial Pneumonias (IIP)
- Idiopathic Pulmonary Fibrosis (IPF)
- IIP other than IPF
- Unclassifiable
  - Respiratory Bronchiolitis associated ILD (RB-ILD)
  - Non-specific Interstitial Pneumonia (NSIP)
  - Lymphocytic Interstitial Pneumonia (LIP)

Granulomatous Disorders
- Sarcoidosis
- Hypersensitivity Pneumonitis (Extrinsic allergic alveolitis)

Cystic Lung diseases
- LAM (Tuberous Sclerosis Complex)
- Langerhans Cell Histiocytosis (LCH)
Idiopathic Pulmonary Fibrosis (IPF)
Pulmonary Rehabilitation for ILD

Robust evidence for **short-term benefits** of rehabilitation in people with ILD

Improvements as large as those in other groups

Standard rehabilitation format works for most

Majority of **data in IPF**
Short Term Benefits of Pulmonary Rehabilitation
IPF versus COPD

**IPF**

- **Quality of Life**
  - N=3 studies, 92 patients
  - SGRQ -8.3 points

- **Exercise capacity**
  - N=4 studies, 113 patients
  - 6MWD +44m

**COPD**

- **Quality of Life**
  - N=19 studies, 1146 patients
  - SGRQ -6.9 points

- **Exercise capacity**
  - N=65 studies, 3822 patients
  - 6MWD +44m

*Minimal clinically important difference*

Gomes-Neto et al. 2018 J Cardiopulm Rehabil Prev
McCarthy et al. Cochrane Database 2015
The patient perspective

Living with idiopathic pulmonary fibrosis: an in-depth qualitative survey of European patients

Gadi Schoenheit¹, Ian Becattelli¹, and Alan H Cohen²

Be honest and help me prepare for the future: What people with interstitial lung disease want from education in pulmonary rehabilitation

Anne E Holland¹,²,³, Julio F Fiore Jr², Nicole Goh³,⁴,⁵, Karen Symons³, Leona Dowman³,⁴,⁶, Glen Westall³,⁷, Anita Hazard⁸ and Ian Glaspole³,⁷
Objectives

To explore patients’ perception of:
1. Prior expectations
2. The content
3. Perceived utility
4. Expectations met?

Ethical approval was granted by the North-West Lancaster Research Ethics Committee
### Methods

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<th>Session</th>
<th>Topic</th>
<th>Delivered</th>
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<tbody>
<tr>
<td>1</td>
<td>What is ILD</td>
<td>ILD Consultant Lead</td>
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<td>2</td>
<td>Benefits of Exercise &amp; Breathlessness</td>
<td>Physio Team</td>
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<tr>
<td>3</td>
<td>Pharmacological Management &amp; Research</td>
<td>ILD Clinical and Research Team</td>
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<td>4</td>
<td>Fatigue Management &amp; Goal Setting</td>
<td>Physio Team</td>
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<tr>
<td>5</td>
<td>Palliative Care &amp; Psychological Support</td>
<td>Psychologist</td>
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<tr>
<td>6</td>
<td>Q&amp;A session</td>
<td>Physio &amp; ILD Clinical Team</td>
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- 60 minutes of exercise
- 30 minutes of education
- Home exercise plan
- 6 sessions, once weekly
Data collection & analysis

**Qualitative Data Collection**
- Focus group interviews
- Telephone interviews
- Thematic analysis

**Clinical Assessment Data**
- Demographics
- Outcome Measures:
  - SGRQ-I
  - K-BILD
  - 6MWD
  - Baseline, Immediately post PR
  - 3 months post PR

Descriptive analysis of means
Findings

all participants’ identities have been protected and are referred to by pseudonyms
Engagement with PR

Knowledge
Desire for physical gains

Perceived benefit of PR

Physical Gains
Emotional & Social Interaction
Self Management
Empowerment

Important components of ILD specific PR

Education
Course Structure
Exercises
Group Dynamics
Accessibility
Engagement with PR

I was hoping I could find some answers. How I could control it more. there was no information whatsoever, you know they’d show you an x-ray. Well that’s ok but, give me a bit more information, why is this happening?

Susan

The physios down there don’t realise I’m a different disease to COPD, they just don’t have an understanding of IPF. Bill

I was hoping I could find some answers. How I could control it more. there was no information whatsoever, you know they’d show you an x-ray. Well that’s ok but, give me a bit more information, why is this happening?

Susan

I realised I knew absolutely nothing about my condition so I was keen to learn. Susan

with sarcoidosis you do get breathless and you have the cough [...] and you do get anxious at times with the breathlessness, you know and I hoped the exercise would really, really help. Mary

I was hoping I could find some answers. How I could control it more. there was no information whatsoever, you know they’d show you an x-ray. Well that’s ok but, give me a bit more information, why is this happening?

Susan

wasn’t quite certain what I could cope with in terms of exercise, so the easiest way was to have some supervised exercise, and as far as I was concerned, it met the bill. Fred

I realised I knew absolutely nothing about my condition so I was keen to learn. Susan
Perceived benefit of PR

we had a breathless management talk, they give you certain things to do if you feel you are getting anxious and one of them was to look at the hands, so that one sticks out in my mind so I do quite often do that, so brilliant, and I wouldn't have known that before. Mary

exercises really helped me, you know the strengthening and also mentally as well, I felt happier in myself. It gave me confidence. Mary

I wouldn't have gone up the gym before, erm, partly because I wasn't certain how much I could do. In the past I'd think I don't know what that means so perhaps I won't ask. Bill

I've spent the last 6 months learning how to pace myself instead of trying to do everything flat out, so I don't get distressed about it. Peter

I'm more inclined to do things but on the other hand I know more what my limitations are, and I have learnt to pace myself a bit...When you're doing it on your own you've got no one to chat to, if you've got someone else in the same situation there is more of a purpose for doing it. Susan

I wanted to find out what I was capable of doing and the exercises proved that to me, and err, the fact that we progressed each week and did slightly more, I certainly felt a lot lot better at the end of it. Fred
Important components of ILD specific PR

**Breathlessness one was really beneficial** and it should be added to not taken away from. Bill

(discussing education on **palliative care**), I find that depressing, but that’s my initial reaction. Depressing, because I’m not thinking in terms of me getting much worse. I’m actually still in the process of thinking I can cope with this and I’m not getting any worse. Fred

[...] you provided us with the information, you provided us with the exercise routines, you provided us with the where with all to do it, **it’s down to us to do it**. I think that’s one of the benefits that it was a small group. The physios were able to give us personal attention, very beneficial. Peter

Mine was definitely a **distance issue as I can’t walk very far**, so even parking in the disabled car park I can’t walk down to the rehab area. Peter

I found **all but the psychology very helpful**, but I think it’s so personal, not that you can’t talk about it but you can’t generalise with one person. Susan

So **you didn’t feel like a group setting was the appropriate**? [Interviewer]

No, not at all. Susan

No I’d agree with that. Bill
### Clinical Outcome Data

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<thead>
<tr>
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<th>Mean Scores</th>
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<tr>
<td></td>
<td>SGRQ-I</td>
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<tr>
<td><strong>Baseline</strong></td>
<td>54.7</td>
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<tr>
<td><strong>Immediately Post PR</strong></td>
<td>59.7</td>
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<tr>
<td><strong>3 Months Follow Up</strong></td>
<td>52.5</td>
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**Key:**
- Red: Worst Score
- Purple: Best Score

Higher score depicts worse outcome in SGRQ.
Lower score depicts worst outcome in KBILD.

Minimal clinically important difference from baseline.
Conclusions

- Desire for knowledge key to engagement
- Increased control over symptoms
- Strong satisfaction from improved functional activity
- Trust in PR clinicians ILD knowledge
- Increased engagement with leisure & physical activities
- Conflict of opinions on psychologist involvement & palliative care topics
- Home exercise plans facilitate upkeep of activity
- Desire for more education: cough, pacing, ACT, oxygen
- Combination of strength and endurance training
Clinical Outcomes

Optimal Timing
- Early disease to promote self mx
- Later disease to optimise function

Optimal exercise prescription
- Endurance
- Strength
- Aligned to hobbies/interests

Non exercise components
- Guidelines for education delivery
- Palliative care

Setting
- Community
- Home-based Remote Intervention
- Hospital Setting

Generic, ILD or Disease Specific
- Generic with separate education
- IPF specific
Many thanks for listening

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https://www.blf.org.uk/ipf-support-service