

# Patients' Experiences and Opinions on Pulmonary Rehabilitation and Use of It as a Tool of Palliative Care on Idiopathic Pulmonary Fibrosis (IPF)

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## Abstract

**Background:** Idiopathic Pulmonary Fibrosis (IPF) is a chronic, progressive, and life-limiting condition. It has no cure hence it is vital to establish effective methods of improving the quality of remaining life in these patients. One of the key components of improving quality of life is pulmonary rehabilitation. However little research has been conducted to understand the perspectives and lived experience of people with IPF on pulmonary rehabilitation. Hence, we aim to fill this gap in the existing literature. **Methods:** We sought to understand how patients coped with pulmonary rehabilitation. A patient-centred approach was used to explore the physical and psychological impact of pulmonary rehabilitation. Semi-structured interviews were conducted by experienced academics. Interviews used a topic guide but mostly led by the participants. An inductive thematic approach was used to analyse data, allowing us to identify common themes in the participants' experiences. **Results:** Of fifty invited participants, ten took part in the study (aged 53 - 81 years). Inductive analysis of interviews identified seven second-order themes and eleven first-order themes, represented by two General Dimensions: "motivation" and "Advantages and disadvantages". Overall, participants found the pulmonary rehabilitation programme to be useful and they experienced an increase in their quality of life following rehabilitation.

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## Keywords

Pulmonary Rehabilitation, IPF, Patient Perspective, Exercise, Quality of Life

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## 1. Introduction

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, irreversible and progressive disease that causes the development of scars in the lung tissues [1]. The root cause of this is unknown and it causes fibrosis in alveolar walls which leads to gas exchange impairment leading to decline in respiratory function and death from respiratory failure [2]. In the UK there is an increase of IPF cases by 5% per year [3]. Some medications exist for the slowdown of the decline of lung function but no fixed treatment still exist requiring palliative care [4]. One key component of palliative care is pulmonary Rehabilitation (PR). PR can be very effective in managing the symptoms of IPF allowing individuals to have a reasonably normal day-to-day life [5]. PR provides a programme of exercise, education, social interaction, and support to teach people with IPF teaching them how to deal with their condition and maximize their functional capacity [6]. These programmes are typically carried out for a few weeks following the initial diagnosis but the scientific basis underpinning the type, intensity, and duration of the exercise component of these programmes remains under-researched [6]. The British Thoracic Society (BTS) published recommendations on creating PR programmes in the UK, based on NICE (National Institute for Health and Care Excellence) guidelines [7]. According to the BTS, PR is an interdisciplinary programme that is tailored to optimize the performance of physical activity and is a key management strategy in people with chronic pulmonary diseases (COPD) [7]. The American Thoracic Society states that the primary goal of PR is to “restore patients to the highest possible functional state” [8]. According to the BTS, the following are improved in people with COPD as a result of undertaking PR in adults: exercise capacity, dyspnea severity, physical activity levels, muscle strength, psychological status, and self-efficacy [7]. Although there are guidelines for PR programs for people with COPD, no such guidelines exist for people with IPF.

Education is a pillar in PR, which supports behavioural and lifestyle changes to assist the affected people in self-management of the disease. These educational sessions are usually based on topics such as human anatomy/physiology, oxygen therapy, smoking cessation, chest clearance techniques, nutritional advice, goal-setting, confidence-building and self-management which will lead to improvements in quality of life [7].

Studies conducted on the outcomes of PR for people with IPF are limited and studies relating to their perspectives on PR are even less. Hence, in this study, we aimed to explore views and experiences of people with IPF on PR and its different components (for example, education, exercise and support group sessions) through individual interviews. This enabled them to talk freely about their own

experiences they felt during the PR programme and suggest recommendations for improvements of the program in the future.

## 2. Materials and Methods

### 2.1. Design

This is a qualitative, exploratory study, which was a component of a Ph.D. research by the first author. This bigger study looked into the Physical and Physiological changes following exercise rehabilitation among people with IPF. The study was conducted at Swansea University, Swansea, UK.

### 2.2. Participants—Sampling, Recruitment

Participants were recruited from a monthly support group for those with IPF. The first author initially met the potential participants at a support group meeting, following which invitation letters for participation in the study were sent to group members. A total of fifty (50) participants were contacted by post and ten of them volunteered to take part in the interview. Our sampling criteria required that participants must have been diagnosed with IPF through physiological parameters (spirometry) and through a lung biopsy. They must be aged 18 years or older and be able to write and converse in English (to facilitate data collection). The study participants ranged in age from 53 to 81 years old (mean =  $70.5 \pm 10.4$  years), one of whom was female, and one participant used oxygen during the interview. All the participants were Caucasian. **Table 1** presents further details on relevant participant characteristics.

All recruited participants provided their written informed consent to participate in the study. They were then enrolled in the PR programme at Morriston Hospital, Swansea.

### 2.3. Ethical Concerns

Ethical approval for the study was obtained from the School of Sport and Exercise Sciences Ethics, Committee at Swansea University. At the outset of each interview, participants were reminded of the purpose of the study, that participation was entirely voluntary and that they were free to stop the interviews at any point that they wished and decline to answer any question if they wished to do so. Once any queries were addressed, they were asked to provide their written informed consent to participate. To maintain anonymity, pseudonyms are given to individual participants when reporting their responses and all names and locations were redacted from the transcripts.

### 2.4. Data Collection and Data Analysis

All interviews were conducted by the first author who has experience in conducting qualitative research and good knowledge of IPF. This helped to reduce bias in the interview process; participants were put at their ease and, at least from their detailed and in-depth responses, felt comfortable discussing the personal

**Table 1.** Example interview questions.

Question type	Example question	Purpose of the question
Introduction	Can you tell me about the onset of your condition and a little bit about it?	This question aimed to engage the participant with the topic and to allow them to express their personal understanding of their condition.
Transition	How does IPF make you feel on a day-to-day basis?	This question was used to gain an overall impression of the psychological impact of the disease from the participant's perspective, and to link the introductory and main questions.
Transition	How do you make the most of it?	These questions helped to facilitate the flow between topics of interest during the interview. These types of question were followed by the main question, depending on the participant's response.
Main	If you think back to your life before being diagnosed with your medical condition, what are the things that you did before but are prevented from doing now?	This type of question was asked to get an indication of the participant's lifestyle before diagnosis of the disease and how IPF had affected their daily life. This is the key information in which the interviewers were interested.
Summary	Is there any other way that it affects you?	These questions were intended to sum up the main topics of the interview, allowing the participant to summarise their overall experiences and personal perspectives of living with the disease.

aspects of their disease.

The interviews were semi-structured, following the steps outlined by Rubin and Rubin [9]. The interviews started with introductory questions, followed by transition questions, then the main questions and finally summary questions. An exact list of questions asked in this study cannot be provided as the specific questions posed were led by the participants' responses but a general structured overview of questions is given in **Table 1**.

Interviews lasted approximately 45 - 60 minutes and they were audio-recorded to assist with transcription later. The transcripts were either emailed or posted back to the individual participants for a review before data analysis. Following all the interviews the first author transcribed all the interviews verbatim.

An inductive thematic approach [10] was used to analyse the data. Using this approach, notes and initial impressions were recorded by the authors during the interviews. These ideas were tracked and continually revised throughout transcription. The initial data analysis was conducted by the first author of the study starting with reading and re-reading the transcripts and immersing himself in the data before more detailed analysis of the transcripts. This was followed by creation of raw data themes based on the participants' responses to the questions. This analysis was informed by the methods used by Miles and Huberman (1994) [11] where quotes were highlighted, representing raw data, and labelled

with an initial raw data theme that reflected the idea or meaning being conveyed in the quote and the overview of the first and second-order themes are shown in **Figure 1**.

This process continued until all transcripts were completed. After all raw data had been identified and allocated to a raw data theme, authors returned to the transcripts to verify the allocations.

An extended process of peer debriefing was used to establish the trustworthiness of the data analysis where the second author acted as a critical friend to challenge and check the credibility of the data analysis and interpretation.

### 3. Results

#### Demographic Information

All the participants were recruited from the immediate surrounding areas of Swansea, Wales, UK. All the participants were Caucasian. Eight of the participants attended the interview on their own (one of whom was interviewed in his own home) and two attended with their wife. In these latter interviews, the participant's spouse contributed to the discussion, simultaneously offering verification of the participant's responses, but also often encouraging further reflection or interpretation from the participant. All information pertaining to patient socio-demographics and physiological parameters are shown in **Table 2** and **Table 3**.

#### 4. Impact of IPF on Day-to-Day Life

Idiopathic pulmonary fibrosis (IPF) is a life-limiting and untreatable disease [12]. This condition is little recognized and poorly understood in the public. From a participant's perspective, a diagnosis of IPF is therefore often completely unexpected and confusing, provoking a range of psychological responses that cause much anxiety.

Findings report that IPF has affected this group both physically and mentally. IPF was limiting their activity levels, hobbies, daily routines and what they enjoyed doing.

*"I have always exercised. When this condition came along, you start to worry about if exercise good or bad for you."* (Participant E, 60y)

*"I used to play golf and I can't do that anymore. I can't dance."* (Participant A, 73y)

Themes	Impact	Impact of disease			
		Motivation	Advantages	Disadvantages	Programme
Sub Themes	Impact on day-to-day life		Learning importance of exercise	Weight loss	Perception about the programme
			Improvement of QoL		Suggestions to improve
			Togetherness		

**Figure 1.** Overview of the findings.

**Table 2.** Socio-demographic information of the participants.

Pseudonym of the Participant	Age	Gender	Duration of diagnosis	Smoking history (previous)	Work history	Other medical conditions
H	81 years	M	05 years	Yes	Chemical industry/Cleaning industry	Heart conditions
I	80 years	M	03 years	Yes	Motor industry	No
J	81 years	M	01 year	Yes	N/A	Gastric acid reflexes
K	71 years	M	01 year	Yes	Office environment	No
D	65 years	M	08 years	Yes	Steel industry/Graphite industry	No
C	73 years	M	10 years	Yes	Steel industry	No
B	53 years	M	01 year	Yes	Cleaning industry	No
A	73 years	F	01 year	No	Office environment	No
L	65 years	M	01 year	Yes	Military	Heart conditions
E	60 years	M	N/A	Yes	Nickel industry	Gastric acid reflexes

**Table 3.** Participant demographics: FEV1 % = age-predicted forced expiratory volume in one second, FVC = age-predicted forced expiratory volume, DLco = diffusing capacity of the lung for carbon monoxide (conductance of gas transfer to red blood cells), Kco = carbon monoxide transfer coefficient (measure of alveolar transfer of carbon monoxide). 6MWT and VO<sub>2max</sub> values are shown pre- and post-intervention. N/A = data not available.

Participant ID	BMI (kg·m <sup>-2</sup> )	6MWT (m)		VO <sub>2max</sub> (ml·kg <sup>-1</sup> ·min <sup>-1</sup> )		FEV1 (litre [%])	FVC (litre [%])
		Pre	Post	Pre	Post		
H	36.7	370	362	14.9	15.2	1.92 [67]	2.33 [62]
I	47.7	200	304	10.0	8.4	1.46 [82]	1.66 [77]
J	26.3	290	430	18.7	17.1	2.34 [78]	2.78 [63]
K	34	358	373	13.1	12.8	1.48 [75]	1.81 [76]
D	32.7	181	300	14.6	13.5	2.93 [130]	3.95 [131]
C	32	384	480	16.0	12.5	2.73 [88]	3.49 [89]
B	32.3	407	427	18.3	19.3	2.53 [79]	3.22 [74]
A	28.7	300	322	15.1	9.6	2.21 [85]	2.90 [82]
L	23.1	222	N/A	14.3	12.8	1.93 [63]	3.13 [52]
E	20.8	457	440	28.4	26.2	2.22 [93]	3.37 [107]

Many of the participants reported being frustrated and worn out with existing therapeutic practices they were following.

*“I went to a course of physiotherapy and honestly I think it’s too much for me, when I came home, I was knocked out I wasn’t even able to do simplest things. Now my strength is gone and sometimes I feel ashamed about the things I can’t do, perhaps it could be because of getting old.” (Participant H, 81y)*

*“I didn’t feel any better in any other way. Talks afterward, I found it [other ways] stressful. I didn’t find it useful because I wasn’t able to cope with that, the*

*stress I have gone through. The breathing exercise was good. There was a lot of good. The actual gym I enjoyed.” (Participant A, 73y)*

Some participants appeared feeling low mood and frustrated perhaps because they could not cope with certain activities, they would love to do but couldn't enjoy due to their illness.

*“I could probably do biking, walking, or running. But if I am going out, I need to plan a route which I know is flat. I want to get somewhere I can get back and if I can't get back, I want to call somebody to ask come and pick me up. I feel like an old man in 90.” (Participant E, 60 y)*

Some of the participants felt dependent or controlled as the illness was limiting their capacity to do things.

*“If she [wife] see me doing something I shouldn't do, she would ask the girls to do it... and I would say I will want to do it because I need to do it. Eventually, she is talking about us moving downstairs and stays downstairs once it gets to a certain point. Well, I don't want that. I'd rather take 10 minutes to go upstairs to go to bed than staying downstairs all the time.” (Participant E, 60 y)*

It also appeared people need psychological support to cope with the illness.

*“IPF is a disease I can't do anything about. All I can do is to prolong it as much as I can. And whatever I can do to do that I will. I know a few people that are going to the rehabilitation course and they complain about being depressed. Well, I'm not depressed; I've accepted what I have got. And try to be positive.” (Participant C, 73 y)*

The pulmonary rehabilitation exercises appeared to be a good solution for improving their quality of life including their physical and psychological well-being. However, there were a number of internal and external factors that motivated the participants' engagement with RRP.

## 5. Motivation

The theme of “motivation” describes the participants' views and experiences on what factors determined their level of motivation (whether it increased or decreased), or what motivated them to engage in pulmonary rehabilitation exercises.

Some said they continued to exercise to take care of themselves even before they got the illness. Thus, they continued to exercise as a way of keeping their well-being.

*“I've been on the exercise bike, I've been walking slowly and doing gentle exercise. So, I have been taking care of myself.” (Participant L, 65y)*

Factors that increased their motivation include increased understanding, feeling better, opportunity for social interactions with others and family support.

*“You meet people and have cup of tea with them while having a chat. It was nice.” (Participant B, 53y).*

Some preferred doing exercises at the programme rather than doing it by themselves as they felt safer and being guided or supervised.

*“It was good, the one in the hospital. I felt safe. There were people there watching you and when you had enough you could stop.” (Participant A, 73y)*

Many reported their individual preferences for the exercises. Having a number of machines and variety of activities allowed them to choose activities on the basis of their capacity levels, preference and feeling of improvement of physical fitness/breathing capacity/etc.

*“They had the walking machine, the bike. They had starch bands. And I found them helpful in some ways. The bicycle, the walking machine. I like the elastic band, the medicine ball and weights. I found them very helpful.” (Participant A, 73y)*

Many seem to be motivated when they receive good family support. There were situations where the participants felt guilty of being a burden and bothering their loved ones, however, overall, they seemed to enjoy carrying out these physical activities together.

*“My husband had been very protective in a loving way. They want me to do it. My husband thinks it's good. He wants to go on walks and then I worry about him because of his situation. But we do go for walks.” (Participant A, 73y)*

Uncertainty about their capacity to engage in activities as well as lack of awareness about the structure of the programme seems a limiting factor that reduces their motivation. Some requested to be better informed about the activities before they joined the programme.

*“I think if you are going somewhere [rehabilitation programme] the people you are going to should know about the illness and should know how far you could go. I'm waiting to go to one of the programs and I don't know what it's like. The nurses who are sorting this out should check what they do before they push you out.” (Participant A, 73y)*

Short duration of the program affected the continuity of doing exercises. When the programme terminates in six weeks many participants' motivation seems to decline.

*“If they carried on what I was doing with this twice a week, I would have carried on doing it. It was disappointing that it ran for a limited time.” (Participant B, 53 y).*

It appeared that when people are externally motivated adherence lasted only for a short period.

Interviews also explored the effectiveness of the exercise programme and participants discussed the advantages and disadvantages experienced throughout the programme.

## **6. Advantages and Disadvantages of the Exercise Programme**

### **6.1. Advantages**

The most reported advantages include learning new information, increased physical activities, improving physical fitness, breathing capacity and opportunity to socialize.



### 6.1.1. Learning the Importance of Exercise

The participants appreciated the awareness and knowledge increased by participating in exercise programme. It appeared that they were able to change their initial perceptions towards illness and well-being through this programme.

*“They offered me a course at Morriston for 6 weeks where you go twice a week for an hour. Basically, I was doing different exercises. I thought with the work I do I don’t need to do exercises. I got a dog and I walk with him up and down a canal and get quite a distance. At the end of that term my improvement worked out to be 33% in my lung capacity.” (Participant B, 53y)*

*“I also had a few good discussions about what happens, what you get, because there are so many different varieties of it. I learnt a few things like when it comes to climbing steps it’s easier to breathe in when u take off the step and breath out when you land on the step.” (Participant B, 53y)*

### 6.1.2. Improvement of Quality of Life

Some reported improvement in their quality of life because of engaging in the RRP.

*“The breathing exercise was good. There was a lot of good. The actual gym I enjoyed.” (Participant A, 73y)*

Another participant explained what benefits he receives from stretching:

*“My intercostal muscles were very stiff, so I wasn’t able to breathe properly. So, I stretch and eventually I get comfort through that. And the more I did the better it became. [...] Stretching is really good and individual would be better because I can stop and start whenever I want and it would help others too.” (Participant L, 65 y)*

*“I’m sleeping better on the days I was doing it.” (Participant E, 60 y)*

The program along with medication improves the attitude and mood of the patient. Overall, it improved the quality of life of the entire family bringing more good and happiness.

*“Before the summer holidays, there is a big improvement in his attitude. He is positive and I think it’s the new drugs he is taking. During the winter I was worrying that he would go for depression. But it had made a big difference.” (Wife of Participant B)*

A participant shared his thoughts especially about the social interaction session:

*“It was nice to see people, it became a close gathering eventually. At the end we were missing each other. It was about talking the problem with the people who are aware about it. When I talk to people from work, they have no idea what they are talking about, because they don’t have a clue.” (Participant C, 73 y)*

### 6.1.3. Togetherness

Another benefit from the programme was the opportunity for socialization. Many participants reported that they felt together, happy and teamed-up to survive their condition.

*"We have friends coming in as well. So, it is really good." (Participant E, 60 y)*

*"There was company, people with the same disease. I found I was looking forward to going. And I thought it was doing me good." (Participant A, 73 y)*

Witnessing how others go through similar difficulties enhanced their coping. Positive feeling towards illness and feeling "*not isolated*" is an important determinant of psychological well-being of these participants.

*"Lot of people were carrying the bottles around and they had tubes up their nose and they were hardly doing anything. And I told myself I am not that bad yet. That was a bonus." (Participant B, 53y)*

Patient B said he felt good after seeing other people who are doing worse than him:

*"It is a horrible thing to say but it is nice to see there were people worse than I was."*

Some participants seem to enjoy company and they thought sharing experiences will motivate others so continued to attend the programme even though they cannot engage in physical exercises anymore.

*"I can't actually take part in physiotherapy. I thought my input will be valuable because the people there are surprised that I've lasted five years." (Participant J, 81y)*

## **6.2. Disadvantages**

### **Weight Loss**

Some reported difficulties in breathing and or weight loss as negative effects of the programme.

*"I was really getting breathless but I went really hard. Maybe there is something in it. [...] I've lost some weight and I can't seem to put it back on, that seems a problem." (Participant B, 53 y).*

*"Can't put a finger on it, but I feel better in myself. I also lost half a stone." (Participant C, 73 y)*

## **6.3. The Programme**

### **6.3.1. Perceptions about the Programme**

All agreed that programme is good and it brought more benefits (both physical and mental health) for the participants. Most of them who saw the benefits of the programme suggested encouraging others.

*"Some patients are 40 - 50 and most of them are fitter than me. I think it's a good thing and I think people should be encouraged to do it." (Participant H, 81y)*

Exercises improved their sleeping at night, joint flexibility and therefore, people reported they enjoyed taking part in the programme.

*"It's really good. You do half an hour of exercise and then we had lectures on the condition and it was really helpful. I'm still a member of LC2. It benefits physically as well as mentally. [...] I found after exercising I slept better, woke up better and it improved my flexibility. Mentally you are feeling better too and it*

helps.” (Participant E, 60y)

“I’ve been on the rehab programme. I enjoyed it. I thought it was good.” (Participant A, 73y)

Many participants appreciated the social interaction sessions as a part of the programme.

“You met people and after that you got a cup of tea sit down and had a chat. It was nice. But you won’t get that in a gym.” (Participant E, 60 y)

### 6.3.2. Suggestions to Improve

People suggested how the programme would like to be and what exercises they preferred doing.

“As long as it’s not strenuous I can do it. [...] I can certainly go on the exercise bike, nothing hard but I find it useful for circulation on the legs. I find that the stretching is good and the exercise bicycle is wonderful. We also go for walks around the lake.” (Participant L, 65 y)

Some explained their difficulties and suggested removing certain exercises from the programme based on their lived experience.

“Rowing is not good; we did cross trainers and it was a killer because you use so many limbs at the same time. I tried doing that and in 3 - 4 minutes I was done for the day. Bending things up is a problem; carrying things is a problem; heavy weights are a problem.” (Participant E, 60 y)

Uncertainty about their capacity to engage in activities as well as lack of awareness about the structure of the programme seems a limiting factor that reduces their motivation. Some requested to be informed about the activities before they joined the programme to minimize confusion.

“I think if you are going somewhere [rehabilitation programme] the people you are going to should know about the illness and should know how far you could go.” (Participant A, 73y)

They also suggested increasing time for activities rather than talking as well as increasing the duration of the RRP.

“Maybe 15 minutes more on the exercise part would have been better and cut down the talking session. And I would like to carry on the programme for more than six weeks.” (Participant A, 73y)

“I would make it a bit longer. The individual session. Because there was a warm-up and you would lose 20 minutes and it was a lot of time lost. I like to see that extended for a couple of hours.” (Participant E, 60y)

## 7. Discussion

IPF is a disease with three different variants with variable life expectancies [13] and it could affect individual patients in unique ways, hence patient experience with IPF would be different from person to person. This pathological process results in a gradual loss of functioning alveolar units and a decline in pulmonary function. Consequently, people with IPF develop progressive breathlessness and eventually die from respiratory failure. Whilst new therapies which slow the de-

cline in lung function have recently become available, there is still no cure for IPF which has a median survival of three years although the range is wide; some people with IPF follow a slowly declining trajectory over many years whilst others may have a rapidly progressive course [14]. The majority of people with IPF will therefore require supportive care at some point in the course of their disease and national guidelines recommend that oxygen therapy, PR and palliative care should be offered when appropriate (NICE 2013) [15]. With this background, the purpose of this study was to interview people with the disease in order to obtain their opinion on a bespoke pulmonary rehabilitation programme and look into their thoughts on engaging physical activity with the disease and the perceived benefit of exercise. One-to-one interviews were chosen over focus groups because of the subjective nature of the disease. Each individual would be at a different timeline on disease progression hence individual interviews would give the opportunity for them to talk more about their individual experience with the disease. Furthermore, One-to-one interviews give complete privacy to the participants allowing them to express their honest feelings and opinions freely on the topic without feeling judged or intimidated by fellow participants.

Every individual has psychological needs. These needs are described under the self-determination theory put forward by Deci and Ryan [16]. This theory breaks down the psychological needs of individuals into three factors, which are (a) Relatedness, (b) autonomy and (c) Competence. The findings of current study showed that these factors determined the participants' motivation to engage and continue the exercises long-time. Findings also indicated that improved physical abilities along with professional, peer and family support encourage them to take part in the programme. Continuity of the encouragement, therefore, is a must for them to remain in good health.

From the onset of diagnosis, IPF is a disease that affects each of these aspects of psychological and physical health alike, substantially lowering the quality of life of the affected individuals compared to their healthy counterparts. Autonomy is very important to every individual. It gives people control over their own lives and allows them to be independent and act on their free will which develops self-respect, confidence, and ego which in turn builds a personality in all individuals. The debilitating nature of IPF challenges this autonomy by restricting movement and any vigorous physical activity, especially in the long run which affected and changed their lifestyle immensely.

Competence is the ability of a person to control the outcomes of life. This is explained by the cognitive evolution theory, which is a division of a self-determination theory. IPF is a disease that severely affects competence due to the restrictive nature of the disease when it comes to conducting daily activities and this had a substantial negative impact on the psychology of our participants. Not surprisingly, given its physically restrictive nature, IPF had a substantial impact on patients' satisfaction regarding the need to feel competent. This impact was especially apparent in the execution of what were previously simple, taken-for-granted

daily activities. The participants we interviewed often experienced signs of breathlessness and fatigue during the simplest of physical activities like walking or moving an object from one place to another. In addition, most of our participants had previously been involved in sport or other recreational activities such as hiking prior to the onset of IPF and no longer being able to participate in these activities further thwarted their need to feel competent.

Our results indicated clearly that there was an improvement in overall QoL life of our participants. This improvement can be attributed directly to the rehabilitation program. In the program, they learnt different methods of breathing and conducted breathing exercise to improve the strength of the respiratory muscles. This improvement of muscle strength together with the newly obtained knowledge on breathing techniques gave them confidence to conduct their daily activities without help from loved ones. This newly obtained feel of confidence allowed them to do more activities independently which have the sense of regaining autonomy in their lives.

A theme of relatedness or togetherness emerged in the form of peer support they experienced from the rehabilitation programme. This support from others with the disease was perceived as vital in overcoming the physical barriers of the disease which indirectly improved the relatedness of the participants of current study. This was perceived as a vital component of the programme since this interaction acted as an informal educational session among peers. Some of the positives that the participants experienced during the rehabilitation programs include increase in blood circulation on the days that they exercised, and some participants felt that exercising slowed down the progression of the disease. Apart from these physical benefits, there were psychological benefits as well. Some of the participants appeared to feel mentally better after exercise and some slept well during nights after they had exercised. This positivity was boosted when they felt a sense of achievement leading to some hope about the future. These achievements ranged from being able to do something that they did prior to the disease, like exercise, hiking and going for walks and this led to the first steps of having some normality in their lives after the diagnosis. This achieved independency fulfilled the feeling of relatedness of these participants to their loved ones leading to improvement in QoL in both the participants and their loved ones alike.

## **8. Conclusion**

Study participants felt that exercise could benefit them physically, could influence positively on their mental well-being, and help them to deal with their feelings of depression and simply carry on with their daily life. This study has presented the previously unexplored opinions and experiences of patients with IPF on pulmonary rehabilitation programs. This study offers novel findings that will help other IPF patients to change their opinion on exercise and give them information on the benefits of exercise and pulmonary rehabilitation. By interpreting

these experiences within the theoretical frameworks offered by self-determination theory and the transactional model of stress and coping, we add insight into the mechanisms that underpin the impact of pulmonary rehabilitation on the psychological well-being of individuals who are diagnosed with IPF.

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## Declaration of Conflicting Interests

We confirm that all authors had access to the data and a role in preparing this manuscript. The authors declare that they have no conflicts of interest with respect to authorship or publication of this article.

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