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“It is the fear of exercise that stops me” – attitudes and dimensions influencing physical activity in pulmonary hypertension patients

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Abstract

Pulmonary hypertension is a progressive cardiorespiratory disease that is characterized by considerable morbidity and mortality. While physical activity can improve symptoms and quality of life, engagement in this population is suboptimal. The aim of this study was to explore attitudes towards exercise and the dimensions that influence physical activity participation in individuals with pulmonary hypertension. Virtual, semi-structured interviews were conducted with individuals, with a formal diagnosis of pulmonary hypertension. Participants were recruited through the Pulmonary Hypertension Association of Ireland. Interviews were transcribed and analysed using thematic analysis. Nineteen patients were interviewed ($n = 19$). There was a female preponderance ($n = 13$) and the mean age was 50 ± 12 years. Three themes were identified and included fear, perceived value of exercise and environmental factors. Fear was the primary theme and included three sub-themes of fear of (i) over-exertion, (ii) physical damage and (iii) breathlessness. The perceived value of exercise encompassed two distinct sub-themes of perceived (i) exercise importance and (ii) benefits of exercise. Environmental factors included the terrain, weather conditions and location. Fear of overexertion, harm and dyspnoea strongly influenced attitudes to and engagement in physical activity. This study revealed heterogeneous patient perspectives regarding the importance of physical activity and exercise. Future interventions that mitigate fear and promote the value of physical activity for individuals with pulmonary hypertension may have considerable benefits in promoting physical activity engagement. Such interventions require multidisciplinary involvement, including specialised pulmonary hypertension clinicians and exercise and behaviour change specialists.

Keywords

exercise, perceptions, participation, barriers, behaviour change

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Introduction

Pulmonary hypertension (PH) is a rare and incurable cardiorespiratory disease that is characterized by premature morbidity and mortality.¹ Progressive remodelling and luminal narrowing of distal pulmonary vessels results in increased pulmonary vascular resistance and right ventricular afterload and manifests as progressive dyspnoea, fatigue and right heart failure if left untreated.² Although the expansion of treatment options in the preceding two decades has resulted in improvements in life expectancy, patients continue to experience considerable physical and

psychological symptoms that impact quality of life. In recent years, there has been a greater appreciation of non-pharmacological interventions with strong emphasis on the role of exercise in PH management.

Exercise limitation in PH is common and multifactorial in nature and reflects a combination of physical and

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psychological factors. Until recently, consistent evidence and clear recommendations for exercise in PH were lacking and in many instances exercise was discouraged.³ The significant advances in research and a shift towards encouraging exercise among PH patients is highlighted by the recent European Respiratory Society statement on exercise training and rehabilitation in patients with severe chronic pulmonary hypertension³ which summarised the numerous beneficial effects of exercise training in PH, including potential improvements in prognostic markers such as functional class and cardiac index. Supervised specialized low-dose, individually adjusted training is now recommended for patients with PH.³ However, physical activity (PA) levels among this cohort still remains low and the research has shown that reduced PA levels in patients with pulmonary arterial hypertension (PAH) has been correlated with more severe disease-related symptoms.^{4,5} Despite the recognition of the importance of PA for optimal PH management, there is a paucity of information regarding patient attitudes and barriers to PA and exercise, and the dimensions that influence exercise engagement. Furthermore, there is a tangible lack of data derived using qualitative methods.

To date, only two studies have explored barriers to exercise in PH. The first found lack of self-discipline, lack of energy and lack of interest as the main exercise barriers.⁶ In a recent international survey of exercise attitudes among PH patients, Chia et al.⁷ found that most patients reduced their PA post diagnosis. Furthermore, many expressed uncertainties regarding the importance and safety of exercise. A number of barriers were identified such as breathlessness, fatigue and psychosocial barriers including embarrassment, anxiety and social isolation.⁸ To our knowledge, no study has used a qualitative approach to explore the dimensions influencing exercise engagement in individuals with PH. Qualitative approaches that adopt inductively derived patient perspectives are likely to yield rich data that may broaden and deepen our understanding of perceptions of and engagement in PA among PH patients. Further, this is a necessary first step to develop patient-centred interventions aimed at increasing PA levels. The aim of this study was to explore attitudes towards exercise and the dimensions that influence PA participation among PH patients.

Materials and methods

Participant recruitment

Convenience sampling was used to recruit participants for this study. A formal invitation email was disseminated via the Pulmonary Hypertension Association of Ireland mailing list of subscribed PH patients (n=105). This included a patient information leaflet. Following an expression of interest, written informed consent was obtained. A formal diagnosis of PH (using right heart catheterisation), age of ≥ 18 years, fluent English and informed consent were required for study inclusion. Ethical approval for this

study was granted by the Dublin City University Research Ethics Committee (DCUREC/2020/155).

Data collection

Semi-structured interviews lasting between 35 and 55 min were conducted virtually via video-conferencing applications. An interview guide was developed by the lead author with guidance based on previously published work,^{9,10} regarding the factors that may influence PA and patient perspective in PH. Open ended questions were employed, such as “*Could you speak to me about your current physical activity levels?*”, and “*Could you say a few words about how important or not physical activity is to you?*”. Interviews were co-lead by (CMcC & SH), digitally recorded, transcribed verbatim and subsequently analysed. The aim was to achieve a sample size of 15–20 based on similar qualitative studies^{9–11} that have achieved data saturation. Data saturation was achieved after 15 interviews; however, a decision was made to interview the remaining four eligible participants to encapsulate a more diverse sample (i.e., a greater age range and diverse geographic location).

Data analysis

Data were analysed using the six-step approach to thematic analysis that was described by Braun and Clarke.¹² Thematic analysis was utilised because it can be widely used across a range of epistemologies and research questions and it not wedded to a particular approach or theory. It is a broad qualitative method for identifying, analysing, describing and reporting themes found within a data set.¹³

Step one of six involved multiple readings of patient interview scripts, in order to gain an in-depth understanding of the data. Step two involved systematic data coding regarding perceptions of physical activity and the dimensions that influenced PA engagement. The third step involved the collation of coded data into potential themes and sub-themes. In step four, a “thematic map” was created to ensure that themes accurately and coherently reflected the opinions and experiences of the participants. Step five involved refining and defining of themes, to identify the essence of each theme. Step six involved the final opportunity for analysis, selecting appropriate extracts, discussion of the analysis to ensure themes are distinct and ensuring all coded data related to the research questions is included in the finalised themes before final report was completed. Although it is recognized that there is the potential for biased interpretations of data since the researchers are actively involved in the process, steps were taken to enhance the credibility in data analysis. The primary strategy to alleviate the potential for bias was the use of two researchers (with insider and outsider perspectives) to conduct the interviews and independently analysis the data. The primary

researcher (CMcC) has experience and knowledge in qualitative research with a particular focus on exercise and PH which allowed for a mutual understanding of disease, limitations and terminology used by participants (insider perspective). The second researcher (SH) has a wealth of experience and knowledge in qualitative research and also knowledge of exercise and health psychology and behaviour change but had no prior or direct link with the cohort included in this study (outsider perspective). In the process of data analysis, there was an attempt to bracket pre-existing academic knowledge. As there were no predetermined themes prior to data collection, inductive inference was used in the identification of themes and data interpretation. To further demonstrate credibility, a rigorous approach to data analysis was ensured by the following steps: (i) a detailed description of the steps taken to conduct the thematic analysis, (ii) independent and comprehensive coding by two researchers thereby broadening the possible interpretations and (iii) providing “thick description” via the use of extensive quotations to allow readers to evaluate the credibility of the interpretation. Confidence of the existence of a theme is established when a number of instances of the theme are identified across the data set.¹² In the present study, it was not the intention of the authors to quantify the data. Qualitative researchers working within the interpretive paradigm are broadly against using quantitative methods to illustrate qualitative data. In the present study, the use of pronouns was adopted as suggested by Sandelowski, to provide an indication concerning the prevalence of the theme or sub-theme within the data.¹⁴ In this way, “most” implies approximately 75%, “several” implies approximately 50% and a “few” implies approximately 20% of the sample.

Results

Twenty-six patients initially expressed interest in study participation. Two individuals did not meet the inclusion criteria, two were unavailable on specific interview dates and three did not respond to the confirmation email. A total of 19 interviews were subsequently conducted and included in the final thematic analysis. The baseline demographic data are summarized in Table 1. Thirteen participants were female (68%), with an average age of 50 (± 12) years old and a mean duration of PH of 8 years (± 4). Table 2 outlines individual participant characteristics (Table 2). Data analysis identified three themes relating to factors that influence attitudes towards PA engagement. The primary theme was fear with three sub-themes of fear of (i) over-exertion, (ii) physical damage and (iii) breathlessness. The second theme was perceived value of exercise and had two distinct sub-themes including (i) perceived importance of exercise and (ii) perceived benefits of exercise. The third theme was environmental factors.

Table 1. Baseline characteristics of the participants included in this study.

Baseline demographics: N (%)	19 (100)
Age (years), mean $\pm$ SD	50 $\pm$ 12
Gender: male, N (%)	6 (32)
PH WHO Group, N (%)	
Group 1 PAH	15 (79)
Group 4 CTEPH	4 (21)
Duration of diagnosis (years): mean $\pm$ SD	8 $\pm$ 4
Emphasis-10 score: mean $\pm$ SD	32 $\pm$ 11
Highest level of education, N (%)	
Primary school	1 (5)
Secondary school	4 (21)
Diploma/certificate	10 (53)
Undergraduate	3 (16)
Postgraduate	1 (5)
Current employment status, N (%)	
Unemployed due to medical illness	13 (68)
Retired	3 (16)
Full time employment	3 (16)

SD: standard deviation; PH: pulmonary hypertension; WHO: World Health Organization; PAH: pulmonary arterial hypertension; CTEPH: chronic thromboembolic pulmonary hypertension.

Table 2. Participant pseudonyms and individual characteristics.

ID code	Gender	Age	PH group	Years since diagnosis	6MWD (m)	Emphasis-10 score (total)
01	Male	36	CTEPH	8	340	34
02	Male	66	CTEPH	5	510	8
03	Female	61	PAH	16	420	17
04	Male	44	PAH	10	335	34
05	Female	39	CTEPH	7	490	23
06	Female	51	PAH	6	275	42
07	Female	39	PAH	5	309	43
08	Male	47	CTEPH	7	497	14
09	Female	67	PAH	15	330	26
10	Female	54	PAH	3	320	41
11	Male	52	PAH	6	355	33
12	Female	38	PAH	7	416	35
13	Female	43	PAH	4	217	36
14	Female	48	PAH	15	285	36
15	Female	44	PAH	10	458	24
16	Male	76	PAH	4	295	44
17	Female	63	PAH	7	290	37
18	Female	40	PAH	4	435	36
19	Female	57	PAH	11	227	44

PH: pulmonary hypertension; PAH: pulmonary arterial hypertension; CTEPH: chronic thromboembolic pulmonary hypertension; 6MWD (m): six-minute walk distance in meters.

Fear

Fear associated with PA and exercise was a central theme and was expressed by all participants: “*There’s always a fear factor*” (PH-05), “*I don’t exercise specifically because I’m afraid*” (PH-14), “*I see people walking or cycling and my*

husband would say, why don't we do a walk or cycle but I'm too scared to" (PH-08). The theme was multidimensional and encompassed three sub-themes of fear of (i) overexertion, (ii) physical damage and (iii) breathlessness.

Fear of overexertion. Fear of overexertion was described by most participants and was associated with perceived negative consequences of exercise. Several participants described finite energy levels and expressed concern regarding the conservation of energy for essential daily tasks:

I would have always found that whenever I overdid it in terms of physical exertion, I would pay the price. I felt like I couldn't really do my exercise and live my life as normal at the same time if that makes sense. (PH-05)

Since being diagnosed with PH, I tend to try and save my energy... I'm kind of like a phone. I use my phone battery or the battery in myself for my day-to-day activities. (PH-06)

For many, this meant PA was not included in their daily schedule: "I have to structure my day, if I have anything else on I can't really [go for a walk]. I have X amount of energy and stuff to accomplish each day so I have to work it out that way" (PH-01).

Several participants reflected that the perceived risks of exercise engagement outweighed potential benefits: "I'm not going to waste my time doing a half an hour walk if I'm going to lie in bed for three days afterwards" (PH-06). Prior negative experiences relating to overexertion were described and identified as a barrier to subsequent PA and exercise engagement, with a few participants showing resistance towards engagement:

I bought an exercise bike about five or six years ago and I tried that a few times... the room was spinning after I got off it and I had oedema in my legs and if I overdo the exercise, that comes back... I just say to myself that this is not worth it because I'm not getting anything out of it, I'm just making myself feel worse. So, I don't bother. (PH-04)

This included overexertion in the context of pulmonary rehabilitation (PR) or community chronic illness exercise classes that were not specifically designed for individuals with PH: "What I found was it wasn't particular to PH. It was for people with COPD. I could see those people really improving and I was doing the exercises as hard as I could, but as the course went on I declined during the exercises I would be fainting and that kind of thing because it wasn't specific to PH" (PH-09) and in some cases turned them off exercise: "When I was on that [treadmill] she kept putting it up higher and higher. I kept saying I can't do that and she kept saying you can. So that turned me off" (PH-12).

Study participants reported suboptimal knowledge regarding their individual exercise capacity: "The risk is

that I won't know it's too much until I have gone too far. That's always the fear. I can never measure how much is too much" (PH-05) and "Well I would definitely be fearful... I would be afraid to walk somewhere with the fear that I wouldn't be able to come back" (PH-13). Furthermore, participants expressed uncertainty regarding appropriate exercise intensity: "There is always the question of how hard you should push yourself" (PH-02), and "I don't know whether I'm at the limit of how much more active I could be, I'm not sure" (PH-17).

Fear of overexertion appeared to be sometimes reinforced through encounters with PH clinicians and ambiguous communication regarding specific PA and exercise prescription: "When I asked about exercise, that was kind of always the answer. Do take exercise, it's important, do exert yourself but don't over-do it" (PH-02).

Fear of physical damage. A common concern among interviewees was fear that PA could result in irreversible physical damage. This concern was often driven by their personal understanding of the disease and the perception that exercise could aggravate this: "It would be lovely to be able to do it [exercise], but I don't want to damage myself any further" (PH-13) and "When I do the exercises, I make this pressure even higher and because of that my lungs are getting damaged... I might harm my heart, my lungs, if I push, I try not to... in my head I think if push too much then I might do more damage" (PH-07). Furthermore, disease descriptions provided by medical professionals may also contribute to this fear and exercise avoidance:

But they [clinicians] describe it and your lungs are putting all this pressure and can't get enough blood through your lungs and have to put all this pressure on your heart. So, psychologically I think you are always thinking about that description if that makes sense... I am always thinking about how my heart must be struggling when I'm breathless. (PH-05)

The fact that the doctors said well you won't be playing golf and you won't be doing this... I actually was afraid to move. (PH-03)

Historical perspectives regarding the potential dangers of exercise in individuals with PH were reiterated by patients:

In terms of exercise at the time, the theory was that no it wasn't written down anywhere, but you don't actually move. Or you moved a little as you possibly could. With the result I was nearly frozen in time. I was afraid to do anything. (PH-03)

For many the lack of formal PA guidance or disease specific information concerning appropriate exercise intensity contributed to this fear: "Definitely not knowing... I hope it's not going to give me a heart attack. It just how many do you

do and when do you stop” (PH-10) and “So I would just be afraid of heart problems or I’d get dizzy and could faint. I would be nervous to do a workout, as I don’t know what to do” (PH-14), but many patients expressed a desire to be more active: “But I would love if there was something I could do that I felt safe doing” (PH-14) and “I wish, I want to be more active” (PH-07).

For several, this fear influenced the type of exercise they chose to engage in: “I suppose I shied away from that (weights) thinking I might harm myself or damage myself in some way so I don’t lift any weights or do anything other than the walking” (PH-08) or impacted the duration of activity: “The worry is that I was putting my heart under severe pressure by doing that [walking] long distance” (PH-13).

Fear of breathlessness. The debilitating effects of dyspnoea was highlighted as a common barrier to PA by most participants: “It’s just the breathlessness. I can’t move very far, I’m sitting down most of the time. So it’s just very debilitating, breathlessness” (PH-16) and “Doesn’t matter what I try to do, my breathing affects me” (PH-19). The fear of and the unpleasantness of this symptom was frequently communicated and many patients limited their activities to avoid this: “Becoming so breathless... It’s the fear of getting really bad... It makes me so distressed and then I’m trying to recover, you feel like you are going to drown” (PH-17); “I don’t push myself to get out of breath, I just do it until I start to feel a little bit uncomfortable and then I take a rest and then I get back up” (PH-11) and “I wouldn’t push myself. I relate breathlessness to not a very positive feeling” (PH-05).

The fear and the unpleasantness of the feeling of dyspnoea deterred some participants from engaging in any form of PA: “No, I used to be active now I’m not anymore, because if I do something I’m going to get breathless” (PH-07) and “It turns you off doing things when you get so out of breath. You just think why do I bother” (PH-12). This heightened awareness of over-exertion and previous adverse exercise experiences led to avoidance of exercise: “I would fear that I know in the past that I got really breathless, I have fainted and I suppose that has frightened me” (PH-15), and “So, if I exert myself in any way at all my breath goes against me. So in order for me not to have that happen to me well then, I don’t exercise, and it doesn’t happen” (PH-11).

Perceived value of exercise

Participant opinions on the value of exercise was diverse across the sample. This appeared to be influenced by personal beliefs concerning exercise, past experiences, motivation, PA knowledge and subsequently shaped PA attitudes and exercise engagement. The theme of “perceived value of exercise” had two distinct sub-themes of (i) perceived exercise importance and (ii) perceived benefits of exercise.

Perceived exercise importance. For a few participants, the incurable nature of their condition appeared to lead to

acceptance of the disease and pessimistic views regarding the value of exercise. Some participants indicated that exercise was not a priority: “I want to make the best of the time that I have so spending time with my family is more important to me than being able to walk to the shop...?” (PH-13) or unimportant: “I think I have got used to not being active. So it’s less important than what it used to be” (PH-17).

Others were more optimistic and conveyed satisfaction with independence in daily activities:

I’m lucky that I am able to do what I can do. I could be 20 times worse. I have seen the people with oxygen that they do go to exercise classes and all but that is because they’re sitting down all day and they can’t do anything. They can’t even walk up a flight of stairs. I’m alright. I can do that. So, it’s not one of my priorities. (PH-04)

Others displayed more fatalistic attitudes toward exercise engagement: “It’s just when you’re out walking and you’re killing yourself and then you think when you get back sure... what’s the point in that it won’t make my PH go away” (PH-01). Another lacked confidence to exercise and took the view that it was “too late” to engage in exercise: “Well you see the problem is I think it’s too late for me... I’d say I couldn’t do it” (PH-16).

Interestingly, those who did not value or prioritise PA suggested that if they were provided with evidence of benefit, they would be willing to try it:

If I thought that being able to do that would improve my disease, then 100% I would be willing to try it. If I thought it was going to make an improvement to my general health and well-being and my ability to have a relatively normal life. (PH-13)

I suppose if I thought I would stay well longer, that would certainly motivate me. (PH-03)

An interviewee with a diagnosis of PH for over 10 years, highlighted the evolution of her views on the value of exercise over time:

I think all of the years up until recently I actually didn’t think I’d be alive, and I thought sure what would I be exercising for. I had that completely wrong mindset and here I am. I’m still here and I feel good if I got this far, maybe I’d get another ten years and if I do, my husband will be retired at 65 so wouldn’t it be nice to be able to not play golf but at least walk with him. So, I see my mindset changing that I’m still here... and I feel in a better place in that regard, in so far as I want to try. (PH-03)

Perceived benefits of exercise. Patients that were actively engaged in PA or reported previous positive exercise experiences, identified the physical and psychological beneficial

effects of exercise, conveyed more positive attitudes towards exercise and were more motivated to engage in PA and exercise. Several participants cited the physical benefits including improvement in respiratory symptoms and exercise tolerance: *“I think it’s helping me breathing...when I walk every day, I feel that I can do more after a while”* (PH-18); *“If I get a regular amount of exercise within my limits it definitely helps me”* (PH-08), and increased energy levels: *“I feel good, I feel like I have more energy”* (PH-05). Many participants alluded to the psychological benefits, which included improvements in self-esteem and a sense of achievement:

For physical and my mental health, I find it makes a huge difference. (PH-06)

I’m enjoying my walk and I feel better when I come back. (PH-05)

Yes because you’d feel good after it that you had done something. I think it makes you feel better. (PH-12)

I think I feel a bit of achievement. (PH-03)

Engagement in PA empowered patients to take ownership of their health:

I feel like I have accomplished something for the day. I have not let it [PH] rule me if that makes sense. (PH-15)

It gives you independence. (PH-17)

Environmental factors

Environmental factors were also implicated in PA engagement and included practical considerations such as the terrain, the weather and participant location. Most participants reported difficulty walking on an incline:

On the flat I can walk but slowly...If there is a little hill, I need to slow down and I need to sometimes stop and rest. (PH-18)

If I walk up a hill and it doesn’t have to be too steep, I would be breathless. (PH-02)

Several participants reflected on the negative effects of specific weather conditions on PA engagement. Some participants struggled with the cold: *“In the winter I hate it. The cold weather would definitely affect me more. If it was raining there is no way I would go out”* (PH-14); for others it was the heat: *“It’s very difficult on hot days”* (PH-09) and the wind: *“In the winter I can’t walk with the breeze and the rain, I can’t. I can’t breathe when the breeze is on my chest”* (PH-16). This had subsequent implications on individual

motivation and highlights potential seasonal variations in PA engagement, influenced by weather conditions: *“I know I’m much more motivated to walk when the weather is good. It’s easier to get out when it’s bright”* (PH-15).

Participant location was an additional barrier to PA in some cases, where the physical environment was not conducive to physical activities such as walking: *“Where I live now there is nowhere I can go walking, I don’t drive”* (PH-12) and *“Well I don’t drive so I can’t go to the gym and where I live is very hilly”* (PH-06).

Discussion

To our knowledge, this is the first study to examine in depth, attitudes toward and the dimensions influencing PA among PH patients. Fear was the primary influence on attitudes towards and engagement in PA. The central role of fear in exercise avoidance in PH patients is a new finding and an important contribution to the literature. Fear was also reported as a barrier to exercise in one of the two previous PH surveys. However, it was a less commonly reported barrier (30% of respondents) compared to tiredness/fatigue (77%) and dyspnoea (71%).⁷ The other study in PH⁶ reported the primary exercise barriers as motivational (i.e., lack of self-discipline, lack of energy and lack of enjoyment). Fear was not cited as a barrier to exercise participation in the latter study. Although there are some similarities between the present findings and previous research (i.e., PA barriers such as fatigue, breathlessness and lack of energy), the inductive approach of the present study has enabled a deeper understanding of the nature of exercise related fear and the various components that give rise to fear among PH patients including fear of overexertion, fear of damage and fear of breathlessness. For example, fear of overexertion is different to the barrier of fatigue. In the present study, fatigue in itself was not a barrier to exercise nor did participants relate their fear to fatigue. Instead, participants reported a fear that exercise engagement may lead to over-exertion which in turn may adversely impact their energy levels, hindering their ability to complete other necessary daily activities or tasks.

The overarching theme of fear was subdivided into three distinct sub-themes, fear of (i) overexertion, (ii) damage and (iii) breathlessness. The three dimensions of fear are important in understanding the role of fear in exercise attitudes and engagement, and also in the development of appropriate PA interventions. Much of the fear described by participants (with the exception of damage) was associated with a previous bad experience (e.g., event of overexertion and the consequences or the physical unpleasantness of breathlessness as a distinct memory) that in turn negatively impacted participants attitudes of and/or engagement in exercise. The association between previous adverse events during exercise and exercise-related concerns or anxiety has been reported previously.⁷

Many participants believed that exercise may cause physical damage (i.e., damage to their heart muscle and/or lungs) and this appeared to be influenced by personal beliefs concerning exercise, understanding of the disease and the description of PH provided by their clinicians upon diagnosis. The latter is concerning, and clinicians may inadvertently be contributing to patient fear of exercise among PH patients. Participants in the present study also reported fear of exercise due to physical sensations caused by exercise (i.e., breathlessness). In many cases, fear of breathlessness appeared to lead to the avoidance of activities that elicited these physical sensations or termination of PA (e.g. aerobic exercise at the first sign of discomfort such as dyspnoea).

Our results demonstrated the link between fear and exercise avoidance. Previous work in chronic obstructive pulmonary disease (COPD) cohort also found that exercise avoidance was related to dyspnoea-inducing PA.¹⁵ Avoidance of PA due to fear of breathlessness may affect uptake of exercise training or rehabilitation programmes or reduce the effectiveness of interventions due to training at a suboptimal level. However, the research has shown that exposing patient groups to PA in the form of graded activity or exposure to treatment to disconfirm fearful expectancies plays an important role in the treatment of fear-related avoidance behaviour.¹⁶ The use of exposure as a way to reduce fear is a well-established behavioural technique.¹⁷ Previous research in COPD has demonstrated that exposure to exercise training reduces dyspnoea-related anxiety^{18,19} and that part of the reason PR is effective may be due to the exposure of exercise-induced dyspnoea which in turn alters the distressing effects of dyspnoea experienced by patients.^{18,20} A structured exercise programme, with education on the benefits of exercise, training and guidance on appropriate exercise intensity including grading and progression to avoid overexertion may be the optimal way to reduce fear-avoidance of exercise. Fatigue has also been commonly reported in PH patients²¹ and a structured, progressive exercise programme could assist with fatigue management. A recent meta-analysis concluded that exercise training may reduce fear-avoidance beliefs.²²

The present study found mixed views concerning the importance of exercise. Participants perceived exercise to be of low importance either because they did not hold positive exercise outcome expectancies or held more fatalistic attitudes concerning PH. Research in other patient cohorts, e.g., cancer patients²³ has also observed such fatalistic beliefs and that those with such fatalistic attitudes are less likely to engage in health-promoting behaviours such as exercise.²⁴ Participants that were physically active or had an activity history appeared to express more positive attitudes towards exercise, similar to previous findings in PH patients.²⁵ Addressing patients concerns highlighted in this study and fostering the importance of exercise for improved quality of life and functional capacity²⁶ will likely be useful to promote patient engagement with PA.

Practice implications

The predominant factors influencing PA attitude and engagement include fear, perceived importance of exercise and confidence. These dimensions are modifiable and could be addressed within the clinical setting. PH clinicians may be unaware of exercise-avoidance due to fear in patients and how descriptions of the disease may inadvertently heighten fear perceptions. Clinicians may also lack confidence to counsel patients and provide appropriate exercise prescription. Indeed, previous research among PH clinicians⁸ and physiotherapists²⁵ has reported uncertainty regarding appropriate exercise prescription in PH. Other research identified the lack of exercise guidance available for clinicians to provide to their patients.³ First, PH clinicians may benefit from further education to more fully understand the benefits of exercise for PH, and training to enhance confidence to discuss PA with patients, reassure them on the safety of exercise and provide appropriate exercise prescriptions. Second, educational PA resources for patients could be provided within the clinic setting. Third, future PA interventions that address exercise barriers foster the importance and value of PA and provide clear guidance on how to assess and control appropriate exercise intensity and manage energy, fatigue and breathlessness would be worthwhile. A multidisciplinary team approach with the inclusion of physiotherapists, PH nurses, psychologists and exercise specialists could be worthwhile to provide support in expertise-related areas (i.e., psychologist may assist with overcoming fear of exercise). Patients may also benefit from the establishment of exercise referral pathways for more specialist support from exercise specialists with expertise in both appropriate exercise prescription for PH and in behaviour change to support PA adoption and adherence.

It would be a value for further research to explore how prevalent “fear of exercise” is among this cohort, with the inclusion a newly diagnosed PH patients and those with severely impaired exercise tolerance. Interventions to alleviate such fears and enhance confidence to exercise would also be worthwhile. Furthermore, there is a need for more research on PH clinicians and the wider PH team (i.e., PH nurses) regarding their attitudes towards exercise for patients and dimensions influencing PA promotion in order to inform optimal future interventions.

Strength and limitations

The generalisability of the study findings may be limited due to convenience sampling and the self-selection of participants. The recruitment process via email invitation may have favoured those with internet access, higher levels of health literacy and those who are more engaged with the PH association and have strong views on PA. Further, since 68% of the sample were female, the dimensions and perspective unique to men may be under-represented. The study included participants with established PH of

minimum three years and reasonable exercise capacity (i.e., 6MWD ≥ 217 m) and therefore may not represent those earlier in the disease process or those with severe exercise limitation. Strengths of the study include a national sample of PH patients, and an in-depth inductive methodological approach to understanding PA engagement that has provided novel insights concerning the nature of and dimensions of fear in exercise-avoidance behaviours.

Conclusions

Fear related to overexertion, physical harm and dyspnoea was the primary influence on attitudes towards and engagement in PA in individuals with PH. The influence of fear and the dimensions of fear in exercise-avoidance behaviours in PH patients is a novel and important finding. The study also found mixed views concerning the importance and value of exercise, with some expressing fatalistic views concerning the utility of PA in PH which was influenced by their current levels of engagement. Future PA interventions that alleviate fear and promote the importance of PA for PH, and foster confidence would be worthwhile. Such interventions are likely to require the involvement of PH clinicians, particularly in the alleviation of fear. Future interventions will also need to consider the environment and strategies to foster exercise participation regardless of environmental factors. Removing the identified barriers and developing an integrated, multidisciplinary team approach to PA promotion has the potential to lead to more widespread adoption of a physically active lifestyle among PH patients.

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Conflict of interest

The author(s) declare that there is no conflict of interest.

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Ethical approval and consent

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Authors' contribution

CMcC and SH: conceptualization, methodology, investigation, formal analysis, writing original draft. SH, NMM, and BK: supervision, writing-review, and editing. SC, SG, BM, and NM: funding

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