Article

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Article

"Exercise….to Me, It's Freedom": Motivation, Support, and Self-Management to Keep Physically Active with Parkinson's Disease: A Qualitative Study

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Abstract: Objective: To explore motivation to exercise, support, and self-management needs among people with Parkinson's (PwP), family-members and physiotherapists. **Methods:** Purposeful and maximum difference sampling methods (age, sex, geographical setting, and disease severity) were employed. PwP and family-members were recruited through physiotherapy services and local support groups. Semi-structured interviews with 12 PwP, focus groups with four family-members, and five physiotherapists were conducted. Interview guides were informed by patient-public input, and a recent systematic review. Interviews were recorded, transcribed, and analysed using thematic analysis. **Results:** Four common themes emerged: *1) The value of an intrinsic connection with exercise: but there are challenges.* A greater connection to exercise led to long-term compliance. *2) Tailoring exercise is essential.* Preferred exercises and environments were mixed, with differences emerging between sexes. *3) Physiotherapists' aim to only maintain physical function led to frustration.* Limited self-management opportunities, stigma and dehumanisation were discussed. *4) Non-motor symptoms, stigma, fear, and determination.* Apathy, pain, and low mood were discussed. **Conclusion:** Exercise provided physical, emotional, and social rewards. Supports are necessary; however, challenges arise when PwP's motivation are mismatched to family-members' and physiotherapists' goals. Co-created goals, tailored to their preferences, and exercise plans with supported self-management are recommended.

Keywords: Parkinson's disease; exercise; physiotherapists; social stigma; qualitative research

Impact Statement

Despite considerable barriers to exercise, the PwP interviewed were committed to exercise to improve function. However, mismatches between PwP's goals and level of support provided by their family-members and physiotherapists' were common, leading to frustration. Co-created exercise plans and goals, tailored to the person's preferences, can help maintain sufficient exercise intensity and safety.

Implications for Rehabilitation

- We recommend considering differences in exercise patterns and preferences between sexes when designing exercise programs (targeting individual's intrinsic motivators and perceived needs).
- Family-members are crucial to support exercise and physiotherapists rely on them especially in cognitive decline. However, frustration can arise when they are "pushing" exercise, rather than supporting exercise.
- Explaining the rationale for tailored exercises is important, but people value having ownership and independent self-management of their exercise programs.
- Exercise intensity is often under prescribed, missing the opportunity to guide people to high intensity exercise, which may have a neuroprotective effect, slowing disease progression.

- Highly functioning, motivated people feel excluded from challenging exercise. They are signposted to community-based classes or neurological gyms, where they feel underchallenged.

Introduction

Alongside pharmacological management, exercise is important for people with Parkinson's (PwP) to attenuate motor and non-motor symptoms [1], improve sleep, mood, and memory. Some indications of slowing disease progression exist, especially in the early stages [2,3]. The positive effects are detected across a wide spectrum of exercise types and intensities, high-intensity aerobic exercise, high-intensity balance training and unstructured physical activity have all shown attenuated motor symptoms and improved function [4], irrespective of nigrostriatal degeneration [5].

However, adherence to exercise is challenging. Despite growing evidence of its value, as few as 30% of PwP with mild disability achieve the World Health Organisation recommended activity levels [6,7]; with some inactive for 70% of the day; considerably less active than age-matched peers [8]. Ellis et al.[9] has identified self-efficacy and outcome expectations as strong predictors of exercise adherence in PwP. Similarly, Dobkin [10] recommends self-management strategies in all neurological rehabilitation, to improve exercise adherence, optimise motor learning, and improve long term outcomes. Recently, we systematically reviewed the effects of behavioural change (BC) interventions to improve exercise self-efficacy and adherence in PwP [11]. We mapped the BC interventions to the Theoretical Domains Framework [12], which helped identify effective core components across the interventions [12]. Most were small exploratory studies, and interventions were multi-component, including education, behavioural techniques, and support groups. While exercise self-efficacy or adherence remained unchanged, QoL and physical function improved [11]. The most effective TDF domains were Behavioural Regulation, Belief about Capabilities, Social influences, Reinforcement, and Goals [11]. Heterogeneity between studies prevented a meta-analysis, highlighting the novelty of the topic and need for further exploration [11].

While self-efficacy and exercise adherence seem to be difficult to change, qualitative evidence suggests that social and physical environment [13,14], and family support [13–15] are important in sustaining physical activity. Early physiotherapy involvement, daily exercise, and support from both clinicians and family empower PwP to stay motivated and involved in activities [16]. Many PwP look forward to engaging with their therapists, exercise instructors and fellow classes members [17]. While many studies have explored barriers and enablers of PwP, they have not provided insight into their support systems; their physiotherapists and family-members' experience of supporting exercise and activity to PwP.

Therefore, by interviewing PwP, family-members and physiotherapists, we will PwP's motivation to exercise, and the challenges that arise between all involved. To gain insight into the relationship between their experiences, this is a sequential qualitative interview study with the first phase informing the subsequent phases. In Phase 1, through semi-structured one-to-one interviews with PwP, we identified the main supports and motivation needs of the PwP. We brought these to the subsequent Phase 2 group interview with their family-members, and Phase 3 group interview with their physiotherapists.

The findings will inform a behavioural change intervention to improve exercise self-efficacy and exercise adherence in PwP.

Methods

Design and Ethical Considerations

The study was conducted between November 2022 and January 2023, and is reported following the consolidated criteria for reporting qualitative research (COREQ)[18]. Local ethical approval was received [ECM 4 (d) 11/1/2022].

Recruitment and Study Sample

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Purposeful and maximum difference sampling methods were employed to recruit PwP, of varying age, sex, geographical setting, and disease severity. Posters were used in urban primary care centres and local support groups to recruit participants and their family members. Interviews were offered in person, by phone and online. A convenience sample of local community/hospital (public healthcare) physiotherapists with a minimum of three years' experience of working with PwP were recruited by email.

Data Collection

The topic guides were informed by our systematic review [19], clinical experience, and patient-public involvement group (PPI)(See supplemental data). In line with our systematic review, the Theoretical Domains Framework was used to structure the topic guide, to explore barriers to exercise [12].

The interviews were conducted by a registered physiotherapist (LA) with qualitative research training. All interviews lasted up to one hour and were conducted in a quiet, private room at the physiotherapy department. At the end of the interviews, all participants briefly reviewed the interview for verification. Between interviews, the data was checked for emerging themes and to allow self-reflection. Phase 1 was terminated when data saturation based on *code meaning* [20] (no new themes emerging and the data was beginning to repeat), was reached. All interviews were audio-recorded, transcribed, and checked for verification. The transcripts were used for analysis.

Data Analysis

The data were analysed using a grounded theory approach, using Braun and Clarke's reflexive thematic analysis [21]. (1) The data were reviewed with reflexivity, highlighting the key notes (LA). (2) Text was coded and highlighted data was extracted (LA). Codes were reviewed by a second experienced qualitative researcher (CC). An integrated code and corresponding list of quotations was completed. (3) Subthemes and themes were developed (LA). (4) The themes were independently reviewed for overlap and sense-making (RMC, ST). (5) Refinements were made (LA), similar topics were merged, and large topics were split repeatedly until all authors reached a consensus, with no new themes. (6) Finally, all authors examined the relationship between the themes, and finalised the report with supporting illustrations.

Results

Participants

Forty-two people were contacted (n=20 PwP, n=12 family-members, n=10 physiotherapists); twenty-one were interviewed, (n=12 PwPs (6 females), n=4 family-members (1 female) and n=5 physiotherapists (5 females)) (see Table 1). Two PwP completed a dyad interview, (one online) and one interview was completed by telephone. Neither dyad-interviewed family-member participated in the family-member group interview. All physiotherapists were at senior grade (Table 1). Eleven PwP self-reported that they engage in regular physical activity; the twelfth self-reported that they exercise infrequently. Eight were urban dwellers, while four were rural dwellers.

Table 1. Clinical characteristics of participants.

Phase 1 participants: People with Parkinson's							
Code	*Interview performance method*	*Age (years)*	*Sex (M/F)*	*Years Since Diagnosis*	*Geographical setting*	*Mobility*	*Family-member*

P1	In-person	57	F	4	Rural	Independent (no aid)	None
P2	Phone interview	-	F	12	Urban	Independent (no aid)	None
P3	In-person	57	M	17	Urban	Independent (no aid)	None
P4	In-person	62	F	2	Urban	Independent (no aid)	None
P5	Online dyad interview (spouse present)	68	M	6	Rural	Independent (with walking aid)	Spouse
P6	In-person	52	F	2	Urban	Independent (no aid)	None
P7	In-person	84	M	8	Urban	Independent (no aid)	Daughter
P8	In-person	82	M	11	Urban	Independent (with walking aid)	Spouse
P9	In-person	76	F	6	Rural	Independent (no aid)	Spouse
P10	In-person	73	F	8	Urban	Independent (no aid)	None
P11	In-person	73	M	1	Rural	Independent (no aid)	Spouse
P12	In-person dyad interview (spouse present)	76	M	6	Urban	Independent (no aid)	Spouse

Phase 2 participants: Group interview with family-members (of participants from phase 1)			
Code	*Sex*	*Relationship with phase 1 participant*	*Phase1 participant code*
FM1	F	Spouse	P8 (11 years diagnosed)
FM2	M	Spouse	P4 (2 years diagnosed)
FM3	M	Spouse	P10 (8 years diagnosed)
FM4	M	Spouse	P9 (6 years diagnosed)
Phase 3 participants: Group interview with physiotherapists			
Code	*Sex*	*Years working years with PwP*	*Work Location*
PT1	F	14	Residential care
PT2	F	7	Urban Primary Care
PT3	F	5	Urban Primary care
PT4	F	15	Outpatient department
PT5	F	12	Rural Primary care

Data analysis led to four themes across PwPs, family-members and physiotherapists. Each theme is presented as PwPs' perspectives, then family-members' perspectives and finally physiotherapists' insights. The subthemes and representing quotes, are displayed in Table 2.

Table 2. Themes, Sub-themes, and Quotations.

Theme 1: The value of an intrinsic connection with exercise: but there are challenges	
People with Parkinson's	
Subtheme	Quotation
Meaning of Exercise	*P3: exercise is **anything and everything** you know, it can literally be a walk to the shops, getting up and walking up and down the stairs.*
	P9: ………as long as you are moving its exercise.
Physical and Mental Benefits of exercise	*P11: I believe a good workout sorts a **lot of other problems**. It flushes out the system, it rejuvenates it. If I don't get out for three or four days with three or four weeks, my **mental health** and everything starts and **slide**.*
Exercise was essential to 'fighting' Parkinson's.	*P3: I would try to **combat** it [Parkinson's] through exercise. Doing the exercises isn't necessarily for fitness, it's about **not letting it take control** over you. You're both there under sparing of each other, who's **going to win**? Who's gonna last the longest?*
	*P2: I'm **still able** to do the things I want to do, and I believe it's just because I exercise regularly.*
Intrinsic motivation leads to long-term adherence	*P11 (male): …. I **always like** to exercise; I think it is just a gene you are born with.*
	*P4 (female): I **always prided** myself on having the insight to know that we need to keep fit.*
Family-Members	
Subtheme	Quotation
Reluctance to suggest exercise	*FM3: It depends. She's always saying, **I'm tired** and I have something else to do. And she'll always **find an excuse**.*

	*FM4: I **had it out with Julie** three weeks ago, four weeks ago. ….. Because I felt that, I was taking over all that and I suppose, you see, if [she is] the recipient of that, [she] can say "I'll **sit back for a session**, he is going to remind me to do those things.*
	*FM1: Tom gets irritated with me; he gets mad says **I'm nagging him**.*
Physiotherapists	
Subtheme	Quotation
Emotional burden on family-members	*PT1: Yeah, I I agree. I guess over the years I felt sometimes not like a **referee**…and then the wife's like 'I'm always telling him that.'. And they like 'he gets cross when I remind him' you know.*
Theme 2: Tailoring exercise is essential.	
People with Parkinson's	
Subtheme	Quotation
Exercise should be personalised and adapted to each individual	*P11: Well, what works for me doesn't work for a lot of people. But there is a lot more to it than that you have to check the **individual** and design a program **that suits him**.*
Exercise preferences varied per individual	*P4: I would have always been a very **outdoorsy person**…..So, like, if the sun is shining …. natural vitamins that are out there.*
	*P1: People with Parkinson's should be **outside**; they should be outside and getting the natural vitamins from the sunlight rather than kept indoors and dark places.*
Group exercise created a sense of belonging	*P11: **camaraderie** is a great thing if, if you can inject, you can inject that into your group. They, they help each other then and it's, it's **comforting**.*
Exercise preferences varied among sex	*P2 (female): Even though the exercise may not be enjoyable, that **social** event is very important to keeping people going. … These social events should allow for a social discussion. **Don't make it medical**.*
	*P4 (female): I find I like to exercise in the **group** setting like a, so I don't really fancy the walking. I walk with anybody. But I don't like doing it on my own. And it just being part of a group.*
	*P10 (female): The. There's good **camaraderie**… In the group. That are in there with me and…. The **craic**, as they say (giggles). It's the social aspect of it that's it.*
	*P3 (male): It's not the kind of thing that I would enjoy (group classes), and I think there's a degree that you can put yourself under too much pressure to participate you know? **I prefer to do it myself**.*
	*P12 (male): [For] someone who needs it to be fun, I think group exercise would work. **But I am happy exercising just me**.*
Mindfulness	*P6: My joints were sore. Every part of me. Do you know? **I know my body** and I just knew, like, this is my Parkinson's. So just take a break this week.*

	*P4: And, I started looking into **mindfulness**, and I then realized it's so important to have a plan, to be able to know, I **didn't even know my body**.*
Family-Members	
Subtheme	Quotation
Benefit of social element	*FM4: She is very happy about that, and I think it's as well the **meeting other people**.*
	*FM4: She **needs to be mixing**. She used to get into the car and visit her sister's every Thursday night and a couple of jazz get a taxi home and that kind of thing, so I think when she is **exercising the socialising** in a group is **good** for her.*
Physiotherapists	
Subtheme	Quotation
Adapting exercise to the patient	*PT3: we have to look at what we're actually giving the patient, **taking time** to go through that with them and I suppose finding out **what works for them** what doesn't work for them.*
	*PT2: The other thing then would be, I, when they can't access it, 'well then what **exercise can you access**?' And saying that **anything** is better than **nothing**.*
Theme 3: Physiotherapists' aim to only maintain physical function led to frustration.	
People with Parkinson's	
Subtheme	Quotation
Physiotherapists should be encouraging not authoritative	*P1: Just say "you know what you're **doing brilliant** now, come back in a month time I know better you'll be after improving, we'll see now, I bet **you will be better**"', **not** "you **must** do this, and you **must** do that."*
Under prescribing – intensity too low, lack of exercise progression	*P3: being told what you can do and can't do. People telling me that I **shouldn't** do this then I shouldn't do that or I **need** to slow down or I need to stop……….if I can cycle nine kilometres there and I'm going to cycle nine kilometres back, but my chart says I'm only supposed to do so many minutes so I **can't do any more than that**…..like I find it **frustrating**.*
	*P1: I have asked and asked and asked and **I'm not being assessed**. I shouldn't have to ask to be assessed I should be assessed naturally; **my exercises should be progressed as I get better.***
	*P12: the classes **aren't hard enough** for me. I'm not saying it is beneath me, don't get me wrong, **but I just need harder to be beneficial***
PwP want more responsibility, independence to progress	*P3: being told what you can do and **what you can't do**. And I'm constantly trying to break the system you know. People telling me that I **shouldn't** do this then I **shouldn't** do that, or I **need** to slow down, or I need to **stop**.*
	*P3: but I jump on it, and I hop straight up to level 18 **because I'm capable of this**, and then he (physiotherapist) has a hernia.*
Family-Members	

Subtheme	Quotation
Mismatch between need and the service provided	*FM4: She has [Parkinson’s Disease] for about **7 years**, and slowly but surely the deterioration, even though [the doctor] don’t notice it (speaking to interviewer), because [they are] not living with the person. Her **strength** is quite **good**, but a **dexterity is awful**, she can’t open the tops of bottles. She can’t put on her bra. Like you said (speaks to FM1) **[I’m] actually caring for the person**…. if I leave the house, I have to leave something for her to eat. And I wouldn’t want to be going out too much like (laughs), because again it’s the dexterity issue**….but everytime I mention it to a doctor, I’m told she is doing well**….all because she can walk perfectly.*
Physiotherapists	
Subtheme	Quotation
Education is the first step	*PT1: but I think it’s taken the time to actually **teach** them the **right way to exercise**, teach them **what this is and like, try and get them started** on that and look into the **barriers** that might be there.*
	*PT2: It’s a **cultural** thing. And a **health literacy** thing as well. They might **have never exercised a day** in their lives. Now they are being told they have a engage in regular exercise – that’s **difficult** for anyone.*
	*PT4: If the GP hasn’t accessed the service, people could have never accessed the services nor seen a neurologist, and **they haven’t been educated** so they **don’t actually know that exercise is good**.*
Focus is to maintain function	*PT2: **introducing** them to exercise and showing them and how they’re going to **maintain** themselves.*
	*PT4: I suppose we see a lot of them when in with early (stages). You know, they’ve just been diagnosed with Parkinson’s. And I suppose the, your **education** component would be **huge** in that. They might be functioning at a very high level but just to **educate on the progression of Parkinson’s** and the **importance of exercising** at every stage and you know, the **problems associated with progression**.*
Lack of resources and expertise, poor awareness	*PT5: **it’s really hard** to give patients the amount of **time** they need and maybe the number of **sessions** they need to set them up.*
	PT1: Not every therapist will have expertise in the area.
	*PT2: GPs not thinking I should get them into physio now, because they’re not bad, they are relatively high functioning…And I think it **often boils down to resources** as well because … if somebody’s **functioning** well, there’s no resource there to look at **that prevention piece**.*
Theme 4: Non-motor symptoms, stigma, fear, and determination	
People with Parkinson’s	
Subtheme	Quotation

Non-motor barriers	*P11: unfortunately, I **had to stop** because when you're racing you to make some very **quick decisions** and I that side [thinking and concentration] just **doesn't work right**.*
	*P5: Well, I think it's it's important not to try and do your exercises **when you're tired**. Because if you do, **you're more inclined to make mistakes** or twisting the knee or, you know, like.*
	*P4: Anxiety, **anxiety is a big one**.*
Stigma	*P6: Well for me. People have said to me, God, you don't **look like** a person to have Parkinson's. And my answer is, what does a person look like that has Parkinson's. Maybe in the elderly 70, 80 he would walk in frame and bent over their limbs and stuff, you know and. But for a young person, what? **What's a young person supposed to look like with Parkinson's**?*
	*P4: It's just the fact that when I say (about diagnosis) **they're probably expecting me to be doddering over** or whatever.*
"Being a burden"	*P2: but maybe people have had to stop driving for one reason or another. **Asking for lifts can prevent people from going to classe**s. feels that they are in the way. Not only are people asking for lifts but during the class **the driver must wait for an hour** outside.*
Exercise to fight against Parkinson's	*P4: OK, I have to give up my body to this disease at some stage and give more than I ever want, but it would take me **kicking and screaming**.*
Exercise to maintain	*P12: I would seize up. You know now when I say seize up, **I would be stiff and slow**.*
Family-Members	
Subtheme	Quotation
Non-motor barriers	*FM1: He can do it (exercise). He can do it. But he's suffering very badly **from mood swings,** and he did before and then it got a bit better, and he exercised a little bit more. Mood swings and **mood swings are a terrible thing** because you don't know when you have them.*
	*FM4: She knows what to do but she finds it **very frustrating** that she can't do those things.*

Theme 1: The value of an intrinsic connection with exercise: but there are challenges.

A common consensus among **people with Parkinson's** was that exercise was wider than just planned or structured activity. An intrinsic connection with exercise was linked with long-term exercise adherence. Those with a deeper connection viewed it as a relationship rather than a task (*'it's freedom'*), and while personal, it was portrayed as a pleasant experience providing physical and mental benefits (*P1: 'it invigorates me, it makes me feel brave, it **lifts** me'; 'It's just **my time** and my space').* Overall, it appeared that those intrinsically motivated to be active prior to diagnosis, displayed stronger exercise self-efficacy and self-motivation, important predictors of long-term adherence. Importantly, exercise seemed to provide a sense of control and empowerment, bringing greater beliefs about their capabilities, especially that exercise was essential for "*fighting*" Parkinson's.

Family-members understood its value and often attempted to motivate PwP to exercise. Sometimes their attempts worked, but other times it led to disagreements, thus leaving them

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reluctant to suggest exercise. Some described the emotional burden as they felt pushed by health professionals to encouraging exercises, rather than supporting the PwP's intrinsic motivation to exercise *(FM1 'Tom gets irritated with me, I have, you know all the [exercise] posters up…he gets mad, says I'm nagging him')*. Similarly, **physiotherapists** acknowledged the value of family to support and promote exercise *(PT1: '…I think it's really important that they're involved in the whole…physio treatment with the patient')* and relied on family-members especially in cognitive decline (*PT5: 'they might need prompts…the carers are kind, of your source of information')*. Ultimately, the turning point from supporting, to pushing, is to be respected. This finding suggests that family-members can be guided to give support and companionship in exercise, rather than rely on them to be the (external) motivator at home.

Theme 2: Tailoring exercise is essential.

Most **PwP** felt that exercise should be fun and enjoyable; if personalised, were more appealing and effective. People were more motivated to embed simple exercise into daily life, (*P1: '…..when you are standing at the sink lift your legs, move them up and down'), (P5: 'Walking it's movement like- it's not all about the machines, like')*

All the **family-members'** understood that exercise was important (FM3: '…last year...[I] bought the bike…. The greatest thing I ever bought for exercise, and she uses it. That's if she can't get out on a day like today… So, I think exercise is paramount'). (FM1: 'if I can get my husband just even walking. So, he's not sitting in his chair all day'). **Physiotherapists** agreed, stressing the importance of accessible exercises, easily embedded into daily lives (PT2: 'To try and make this a more normal part of their lives'), and adapting the exercises to the patient's ability and environment.

Discussions revealed diverse exercise preferences, and settings for exercise among **PwP**. Many were motivated to exercise **outdoors** (*P4: 'we need to keep fit, and we need to keep outdoors'*) while others liked a local supervised gym with fully accessible equipment (*P5: 'you are around other people with … similar ailments like stroke')*. Being able to exercise created a sense of belonging and support among **PwP,** promoting community engagement.

Men and women's opinions about exercising in groups were different. All the women appreciated the **peer support** of a sociable group. Conversely, men either stated no preference, or preferred to, exercise alone, suggesting stronger intrinsic motivation. The benefit from a socialising through exercise was also expressed by the **family-members,** while this did not come up in the **physiotherapists'** group interview. Four women discussed the value of mindfulness, describing how it helped self-manage their condition by allowing a deeper physical and mental connection with exercise, supporting long-term adherence (*PT 4: 'I started looking into mindfulness, and I then realized……I didn't even know my body')*.

These findings revealed that all participants value exercise. Taking time to consider unique exercise preferences could motivate engagement and enjoyment of exercise.

Theme 3: Physiotherapists' aim to only maintain physical function led to frustration. (this theme was not expressed by family-members).

Conversations revealed frustration and dissatisfaction amongst **people with Parkinson's** when the support they receive does not match their needs. While people were motivated to *improve* function through exercise, they were frustrated with the physiotherapists' primary goal to *maintain* function. Many PwP felt that physiotherapists were overly authoritative rather than supportive.

Those with fewer motor symptoms felt particularly excluded by physiotherapy services. They were rarely offered physiotherapy, but rather were signposted to other community-based exercise classes, which did not seem to be a good fit for their needs. At most, they were offered physiotherapy-led exercise classes, were they felt that the condition of Parkinson's was seen rather than them, and their broader needs. They perceived that exercises' dosage and intensity were too low to make a difference. A community-based gym (providing accessible equipment, physiotherapy-prescribed programmes, and supervision) was offered frequently, where, they again felt underchallenged, or exercises were not progressed sufficiently to be challenging (*P3: 'but why can't exercise help me get better; why did it have to be at best a flat liner')*. A common assumption was that physiotherapists were overly concerned about potential adverse events with exercise progression.

Most **PwP** wanted to have some control and responsibility of their own exercise programs, with the freedom to progress and adapt exercises *with the guidance* of the physiotherapists. They wanted to learn *how* to exercise with the view of developing self-management and independence.

Physiotherapists too expressed frustration. They believed they need to educate people how to exercise *safely* and correctly in the early stages, and motivate people to exercise. Equally, the physiotherapists described that some **PwPs** need a lot of education to even begin exercising. Physiotherapists's discussions showed that their focus is to *maintain* function as the disease progresses, conflicting with the PwP's motivation to *improve* rather than maintain function. Resources issues frustrated the physiotherapists: lack of accessibility, staffing and expert knowledge among available staff. One physiotherapist recognised these high-functioning individuals were not being referred to physiotherapy and resource issues. Family-members did not voice any concerns about physiotherapy services – repsonse bias may have influence these findings.

These findings revealed that people were motivated to exercise to *improve*, and to be more responsible for their own exercise programs. Conversely physiotherapists felt their primary obligation was to *keep* people active, rather than to progress exercises, and were frustrated with resources.

Theme 4: Non-motor symptoms, stigma, fear and determination

People with Parkinson's described how the non-motor features associated with Parkinson's including pain, fatigue, apathy, cognition and sleep disturbance prevented exercise considerably. **Family-members and physiotherapists** were aware of this phenomenon also.

Stigma was a real issue by the **people with Parkinson's**. (P1: 'I'm walking in and I'm thinking the whole place is looking at me'; 'I don't go out for people to see me walking'). A feeling of "being a burden" was common when PwP needed support to exercise.

Conversely, anxiety, fear of progression, and a determination to stay well and independent were strong motivators to exercise. Some **people with Parkinson's** and their family-members spoke about 'not giving up' (*P1: 'I can't give up...'; P3: 'refusing to give in'),* or were more explicit in the perceived *"fight"* against Parkinson's disease, while others spoke more in terms of maintaining function.

Physiotherapists recognised additional barriers to exercise, including fear of falling/injury non-motor symptoms such as mood *(PT4 'the apathy, the depression like all that that can exist in the absence of …motor problems'),* and transport.

Discussion

We aimed to explore motivation, support, and self-management to keep physically active among people with Parkinson's, and to discuss these further with family-members and physiotherapists. Four themes emerged:

- *An intrinsic connection with exercise provides physical and mental benefits, which family and physiotherapists are keen to support, but it can be challenging when they are mismatched.*
- Tailoring exercise is essential.
- Individuals were frustrated by physiotherapists' lack of exercise progression and guidance on self-management, while physiotherapists were frustrated with resource issues.
- Non-motor symptoms and social stigma are considerable barriers, while fear and determination are motivators to exercise.

Many participants agreed across themes: the value of exercise in Parkinson's, the need for accessible exercise, and non-motor symptoms as a barrier to exercise. However, some conflicting opinions arose around the motivation to exercise, to *improve* function, to *"fight"* Parkinson's (PwP), or to *maintain* function, or prevent deterioration. There was frustration among PwPs who were motivated to exercise more intensely, and among physiotherapists who prioritised safe exercising and fair use of limited resources.

This research identified three key considerations for exercise services for PwP. These include careful tailoring in exercise prescription, including sex considerations, the importance of creating shared responsibility for exercise progression, and preventing the exclusion of higher-functioning

PwP in exercise classes. Although data saturation was achieved in this high-functioning cohort there is a need to explore whether these findings/issues are similar in people with limited function.

Considering Sex in Tailoring Exercise Prescription

Sex specific exercise preferences in our study included types of motivation, the ideal exercise environment, and mindfulness. Women with Parkinson's appeared to be motivated to exercise with peer support and company, while men with Parkinson's engaged in exercise for the physical and/or mental benefits. Family-members also valued the social aspect of exercise for the PwP. van Uffelen et al.[22] similarly found that older women were more motivated by spending time with others, meeting friends or improving appearance, while older men were motivated by managing stress, preventing health problems and the "feel good" factor associated with exercise [22].

We found that women consistently reported enjoying exercising outdoors, while men did not express a preference. However, this does not seem to be universal. Older men were found to prefer outdoor activities than older women [22,23], and described it as a "spirit lifter" [24] (p. 9). Generally outdoor activity was preferred among both male and female Swedish and Irish seniors [25,26]. The importance of being outdoors with nature was highlighted in this study.

Other "spirit lifters" mentioned were music, enjoyment, fun and mindfulness. We found that mindfulness motivated some women to self-manage and adhere to exercise; this was not the case among men. Blair Kennedy *et al* have reported improved exercise adherence and self-efficacy when mindfulness is integrating with exercise [27]. An emerging area of research, Nymberg et al.[28] in Sweden, are currently examining the impact of mindfulness on motivation and adherence to physical activity in middle-aged to older adults [28].

Shared Responsibility to Tailor Exercise Type, Dosage, and Intensity

Importantly, we found that PwP want to share responsibility for their exercise progression. Patient-centred care is at the forefront of our practice [29], however, when we prescribe exercises, this principle can be inadvertently de-prioritized. PwP felt unheard and frustrated with little shared ownership of their exercise programs.

Noting that our interviewees were active exercisers, the PwP believed that they were capable of more challenging exercise, which they felt was largely overlooked. Instead, they perceived that physiotherapists were afraid to progress exercises; that exercises were prescribed "for the Parkinson's disease" rather than for the person (physical and mental health), potentially missing the opportunity to support high intensity, potentially neuroprotective exercise. People lacked a sense of belonging when they were directed away from physiotherapy, to community-based classes or gyms, leaving them feeling disengaged from physiotherapy and their Parkinson's community. These findings highlight the need for patient-led, tailored exercise, adapted and progressed to cater for the individual, mindful of the wider social, physical, and mental health benefits of exercise and its settings.

Exercise can improve balance, strength, gait, and physical function [30], and non-motor features including quality of life and depression [31]. Emerging evidence suggests that high-intensity exercise (65-85% max heartrate) is associated with neuroprotective effects, slowing disease progression and appears to be feasible and safe [4], but more research is required. Thus, healthcare professionals should consider higher intensity exercise initially for PwP and keep informed of emerging evidence.

We believe that the mismatch between the goals of the physiotherapists and PwP through exercise emerged by using the sequential interviewing method and focussed our exploration on the interviews. Initially, we identified "under-prescribing exercise" as important to PwP from their interviews, which then, informed the topic guide for the physiotherapists' interview group.

Strengths and Limitations

A few factors hinder transferability of the findings. Firstly, the study mostly represents high-functioning PwP. Although we followed the recommendations provided by Mutrie *et al* [32] and every attempt was made to recruit people with varying exercise adherence and by, the sample included participants who were more interested/already engaged in exercising only. Secondly, the sample size of PwP is small [33], however guided by information power versus data saturation [34], we gathered rich data from twelve high-functioning PwP with varying gender, years since diagnosis, and living circumstances. We believe that data saturation was achieved with no new emerging themes in the final interviews. Finally, the findings only represent physiotherapists worked in the Irish National Public Health system. All were women; recruiting male physiotherapists was challenging as 74% of physiotherapists in Ireland are women [35].

The interviewer (LA) is a registered physiotherapist, whose special interest and clinical expertise in Parkinson's may have led to better iterative questioning and credibility. While all participants were encouraged to be open and honest during the interviews, an existing physiotherapist-patient relationship between the interviewer and three PwP and the family-members, may have affected open dialogue and participants responses. Every attempt was made to minimise this, including keeping the conversation on *"exercise"* rather than physiotherapy services. Data analysis was completed by three team members, improving credibility and the interviewer completed a reflective diary between interviews.

Conclusion

To our knowledge, this is the first study exploring motivation, support and exercise self-management needs in Parkinson's disease through multiple viewpoints. An important finding is the mismatch between physiotherapist and PwP goals with exercise. Physiotherapists were perceived to focus on the condition rather than the physical, social, and mental wellbeing of the individual. Higher-intensity exercises were sought by PwP, and early evidence suggests that it can be neuroprotective and safe. Exercise preferences appeared different between sexes and could be considered to make exercise more enjoyable. Women were more motivated by external factors such as social interaction, while men had higher intrinsic motivation to exercise. Most importantly, this study highlights the welcome of a shared responsibility between therapist and patient, as part of overall disease self-management. Family-members play an important role in supporting exercise, but an expectation to drive or coach exercise can be detrimental.

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