

**Participant expectations and experiences of a tailored physiotherapy intervention for people with Parkinson's and a history of falls**

Alison Rowsell<sup>1</sup>, Ann Ashburn<sup>1</sup>, Carolyn Fitton<sup>1</sup>, Vicki Goodwin<sup>2</sup>, Sophia Hulbert<sup>2</sup>, Sarah Lamb<sup>3</sup>, Emma McIntosh<sup>4</sup>, Alice Nieuwboer<sup>5</sup>, Ruth Pickering<sup>6</sup>, Lynn Rochester<sup>7</sup>, Kim Seymour<sup>1</sup>, Claire Ballinger C<sup>6</sup>

<sup>1</sup>Faculty of Health Sciences, University of Southampton

<sup>2</sup>Medical School, University of Exeter

<sup>3</sup>Oxford Clinical Trials Research Unit

<sup>4</sup>Institute of Health and Wellbeing, University of Glasgow

<sup>5</sup>Rehabilitation Sciences, University of Leuven, Belgium

<sup>6</sup>Faculty of Medicine, University of Southampton

<sup>7</sup>Institute of Ageing, University of Newcastle

Contact: Alison Rowsell, Faculty of Health Sciences, University of Southampton, SO17 1BJ,  
Tel: 02380592360, [acoc@soton.ac.uk](mailto:acoc@soton.ac.uk)

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## **ABSTRACT**

### **Purpose**

People with Parkinson's are twice as likely to fall as older people within the general population. This longitudinal qualitative study was part of a larger programme of research including a randomised controlled trial to test the effectiveness of a tailored physiotherapy intervention. Specific qualitative aims focused on a subsample of trial participants in the intervention arm of the trial, and comprised the following:

- To explore the expectations of participants about the intervention
- To investigate participants' experiences of the intervention, and its perceived impacts
- To understand the facilitators and barriers to engagement

### **Methods**

Two semi-structured interviews were completed with a theoretical sample of people with Parkinson's from the intervention arm, initially after randomisation but before the intervention commenced, and then again six months later.

### **Results**

Forty two participants out of a large clinical trial were interviewed initially, with 37 agreeing to a second interview at six months. Prior experience of rehabilitation plus information accessed through the trial consent procedure informed participants' realistic expectations. Most found the level of the intervention acceptable, and perceived a range of benefits. However, views about equipment provided were more equivocal. The biggest barriers to participation were time and motivation, whilst social support facilitated engagement with the intervention.

## **Conclusion**

This study is the first to capture expectations about participation in a programme of exercises and strategies. It highlights that previous challenges to engagement in physical exercises and activities are not a barrier to future participation and provides new insights into the role of equipment and technology in programmes of physical activity for people with Parkinson's. The challenge of ensuring that programmes of exercise and strategies become an embedded feature of everyday life is highlighted, particularly alongside busy social engagements and leisure pursuits.

**Keywords** Parkinson's, falls prevention programmes, adherence, qualitative research, expectations, experiences, facilitators, barriers.

## **Background**

Parkinson's is a common, progressive neurological condition with symptoms resulting from cognitive, motor and non-motor dysfunction. The mean age of onset is 60 years and around 50% more men than women are affected [1]. Problems with balance and cognitive impairment contribute to an increased risk of falls amongst people with Parkinson's [2,3] with those with Parkinson's being at least twice as likely to fall as older people within the general population [4].

Parkinson's can have a significant impact on the everyday lives of both those with the condition and the people who live with and care for them. Motor symptoms such as rigidity, bradykinesia and tremor can have a profound influence on quality of life, for example, through reduced mobility and loss of physical abilities [5,6,7,8]. Psychological and social factors in Parkinson's including depression, cognitive changes and anxiety and apathy are also negatively associated with quality of life [9,10,11] and a number of studies have also highlighted the impacts of Parkinson's for families and carers including stress, burden and financial strain [12,13,14,15].

The body of qualitative research exploring the illness experiences of people with Parkinson's highlights the nature of uncertainty about the illness and the future, and the impact of Parkinson's on identity and sense of self [16,17]. The challenges for families and carers are also apparent in this literature, with uncertainty and changes to roles and relationships [18,19] also featuring prominently, highlighting the need for support for carers and family.

There is a growing body of evidence around the effectiveness of non-pharmacological interventions in PD, with exercise being a particular focus in rehabilitation research. A meta-

analysis exploring the impact of exercise on falls, balance and gait for people with Parkinson's identified 25 randomised controlled trials of moderate quality and found small but inconsistent impacts on fall rate ratios, favouring exercise [20]. However, the number of people with Parkinson's who fell was not significantly reduced, and recurrent falls were not impacted.

Research exploring people with Parkinson's experiences of exercise interventions highlight both perceived benefits and potential barriers. Strength, fitness and maintenance of independence and function were identified as important outcomes from participation in exercise by people with Parkinson's [21,22,23]. Perceived improvements in physical abilities were also a motivating factor for continued participation in exercise hydrotherapy for this group [24]. Different facilitators and barriers to participation in individual home-based exercises and community group exercises have been identified. Amongst people with mild to moderate Parkinsons, the provision of a secure and supportive group exercise environment, with groups facilitated by caring and compassionate trainers with expertise in Parkinson's was highlighted as a benefit [24, 25, 26]. Similarly, Parkinsons' participants enjoyed the positive social experience of community exercise groups, where symptoms of Parkinsons were understood and accepted [21, 24, 27]. However, transport to and the accessibility of venues and the scheduling of community exercise programmes within the context of other health issues and doctors appointments can act as barriers to participation in community exercise groups for people with Parkinsons [22, 26].

A recent meta-analysis [28] comparing home-based exercises to 'centre-based exercise' for people with Parkinsons reported similar benefits from both types of programmes on balance related activities and quality of life (although not sustained in the longer term). The authors

suggest that this equivalence should enable clinicians to choose optimal location, based on the preference of the individual person with Parkinsons, and resourcing. However, it is important to note that in this review, the ‘centre-based exercise’ was conducted with both individuals and groups. Consequently, the meta-analysis does not analyse the impact of the social environment.

Increasingly, randomised controlled trials of health interventions are including embedded qualitative studies designed to explore the subjective experiences of trial participants [29]. A recent example within the field of Parkinson’s research is the study by Canning [30]. The inclusion of such embedded qualitative studies can help make sense of trial findings when exploring complex health interventions, for example, shedding light on mechanisms of effect or explaining negative results [31]. The context for this qualitative study was a UK multi-centre single blind randomised controlled trial, designed to establish the effectiveness of a novel, home-delivered physiotherapy intervention (PDSAFE) compared with usual care, on risk of falling for PwP who have a history of falling [32-33].

Four hundred and seventy-four participants were randomly allocated to either physiotherapy or control groups and were followed to the primary outcome of risk of repeat falling, collected by self-report monthly diaries, 0 to 6 months post-randomisation. 238 were allocated to a physiotherapy programme and 236 to control. All participants had routine care and the intervention group (PDSAFE) had an individually tailored progressive home-based fall avoidance strategy training programme with balance and strengthening exercises. The treatments were personalised to individual needs with 12 supervised sessions spread over six months and daily practice encouraged. PDSAFE did not reduce falling across the whole heterogeneous sample of Parkinson’s however; the trial confirmed that exercise and strategy

training are not uniformly effective across all presentations and disease severity. Reduced fall rates were apparent among those with moderate disease while those at the more severe end of disease had an opposite response.

The embedded qualitative study comprised a series of longitudinal qualitative interviews with participants recruited to the intervention arm of the trial; the overarching aim of this longitudinal study was to explore the understandings and experiences of participants in the intervention arm of the trial, with specific research questions comprising the following:

1. What were the expectations of participants about the tailored physiotherapy intervention?
2. What were participants' experiences of the intervention, and what were the perceived impacts?
3. What were the barriers and facilitators to participating in the intervention?

## **Methodology**

This longitudinal qualitative study involved semi-structured interviews informed by the principles of grounded theory, including the use of 'intensive interviewing', iterative development of themes, the use of reflective memoranda to assist analysis and employing theoretical sampling [34]. Borrowing elements of grounded theory is not uncommon in health research [35-39], as it sensitises the researcher to rigorous, data collection and analysis methods, which are grounded in the data and inform understanding; in this case of participants' experiences of the PDSAFE intervention (Appendix 1 for details).

Longitudinal qualitative studies are comparatively rare in health research, although have been identified as particularly useful when exploring conditions of change such as for those with long term and progressive conditions [40-42].

Participants in the intervention group of the first four sites of the PDSAFE trial (all in the Southern counties of England) were invited to take part in two qualitative interviews. Eligibility for the trial meant that the study participants had a confirmed diagnosis of Parkinson's, lived in their own home and had experienced one or more falls in the twelve months leading up to recruitment. Participants were identified through a priori purposeful sample, to reflect as equal distribution as possible based on four criteria: disease severity, age, time since diagnosis and gender and recruited from each site. As the study progressed, under-represented groups for each of the four criteria above were targeted. They were first screened for cognitive impairment in the trial [43] and again through a process of providing informed consent in the presence of a researcher (AR) and were able to understand and use English, and were able to get around indoors independently, either with or without use of a walking aid. Theoretical sampling by trial site, age, gender, disease severity, number of falls prior to trial entry, time since diagnosis, and living status ensured participants had a range of demographic characteristics.

Qualitative semi-structured interviews were chosen to research the experiences of participants in the intervention arm of the PDSAFE trial [32-33] because they facilitate in depth exploration about situated, contextual perspectives, with a focus on nuance and complexity [44]. Qualitative interviews therefore provide data to augment and complement trial findings.

Initial interview guides were informed by scoping relevant literature and through referring to study protocols for primary questions of interest. Interview guides were next developed iteratively, in collaboration with the main study team and stakeholders (including trained



physiotherapists, rehabilitation experts and qualitative researchers), other clinical and academic experts (two qualitative researchers, two social networks experts) and two people with lived experience of Parkinson's. Both interview guides were then piloted with people with Parkinson's to ensure questions made sense and revised as necessary.

Initial interviews (T1) took place after recruitment and randomisation within the main trial, but prior to starting the treatment programme. The first set of interviews explored the impact of Parkinson's on the daily lives of participants, as well as their expectations and hopes for participation in the PDSAFE programme. Follow-up interviews (T2) were then conducted at six months following completion of the treatment programme (Appendix 1 for details) explored participants' experiences of the PDSAFE intervention. The interviews were all carried out, transcribed and analysed by the first author (AR), who was not involved in the delivery of the interventions. In introducing the qualitative element of the study, the interviewer made it clear that she was interested in all comments, both positive and negative. Additionally, she clarified that participants' feedback would not impact on their involvement in the trial, subsequent research or receipt of clinical interventions. All interviews were conducted with participants in their homes.

An overview of the initial and follow up interview guides is provided in table 1.

INSERT TABLE 1 ABOUT HERE

Interviews were transcribed verbatim and then checked for accuracy by a member of the research team who had carried out the data collection. Two researchers carried out analysis of interview transcripts independently (AR, CB), using inductive thematic analysis [45-46]. Dominant themes were identified through close examination of the data and during an iterative process, refining, confirming or refuting areas of interest, until the point of data saturation. Themes were crosschecked and verified by comparing transcripts directly, using inter-rater agreement and final themes agreed. Interview transcripts were read and re-read to ensure a high level of familiarity with the data before line-by-line coding, developing themes iteratively and recording them in a coding manual. The coding manual was discussed and agreed by two members of the research team (AR, CB) at key points through the coding process.

Full ethics and governance approvals were received from the relevant NRES committee (REC reference 14/SC/0039) and NHS Trusts.

## **Results**

A total of forty two participants completed interviews at T1, of whom thirty seven completed interviews at T2, although two of these had withdrawn from the main trial at T2.

Consequently, thirty five participants remained in the trial and completed interviews at T1 and T2. Table 2 provides demographic details of participants.

INSERT TABLE 2 ABOUT HERE

The group at T2 was comparable to T1 and participant characteristics in the qualitative sample were comparable to the overall study sample. All transcripts were included in the thematic analysis.

Thematic analysis of the data from the first interviews (T1) generated thirteen main themes, including forty subthemes and 104 codes. From the second set of interviews (T2), 75 codes and 33 sub themes (see Supplementary Figure 1) were generated and organised into seventeen main themes. Some themes had been reported in previous literature and since the themes were varied and broad (e.g., Theme 7; ‘losses attributed to Parkinson’s’) and often overlapped, for coherence they were summarised, organized and presented below to address our three study questions. In the excerpts following, ‘I’ designates Interviewer, ‘P’ participant and ‘C’ carer; TSD designates time since diagnosis and number of falls in the previous 12 months (NF12M). We have also reported H&Y status, gender and above/below mean age.

### **1. Expectations of participants about the PDSAFE intervention**

In order to contextualise participants’ expectations of the physiotherapy intervention, PDSAFE, their previous experiences of physiotherapy and rehabilitation therapies were explored at T1. Nearly all had experienced physiotherapy in the past and just under half had experienced other forms of rehabilitation and complimentary therapies (including reflexology, acupuncture, speech therapy and massage). Around half of the participants had taken part in structured exercise, such as classes at their local Parkinson’s group.

In the initial interviews, the majority of participants correctly anticipating that the PDSAFE intervention would include an element of exercise, which could be done at home and was designed to help them with their mobility. This could be attributed to information included in the Participant Information Sheets, the consent process for participation in the main trial plus wide experience of rehabilitation both for Parkinson's and other conditions. A smaller number of participants talked in greater detail about what this might involve; including tailored exercises, stretching and exercises for balance, co-ordination, posture, freezing, stiffness and muscle tone. Occasionally participants talked about being 'assessed' or 'monitored'.

P: Well as I said, hopefully they will come up with a series of exercises that I can do, hopefully every day, or most days, which will keep me a bit mobile and stop me getting stiff. I dread the thought of being really really stiff and not being able to move and get around; I don't want that to happen. [Female; over mean age; TSD  $\leq$  5 years; H&Y2; NF12M =1 fall]

The majority of participants were pleased that the PDSAFE programme was home-based; reasons for this included convenience, problems travelling due to mobility, not having to visit hospital sites or clinics or park a car.

In terms of anticipating benefits from the programme, most participants placed particular emphasis on projected improvements in physical functioning and mobility, including improved balance, increased strength, enhanced co-ordination, stability and posture. Participants described expecting to be provided with strategies to help them manage their Parkinson's:

I: What is your understanding of what might happen when the physiotherapist comes to see you tomorrow and over the course of the next few months when you are working with the physio?

P: Now you've frightened me (laughs) ... I haven't really thought about it sufficiently. I'm hoping that they will give me some useful exercises that will deal with, well the balance, now the question in my mind, is whether they will go on from that and talk about also posture, which is something I desperately need and general muscle tone I suppose, so I'm sort of hoping that they will cover all three things. [Male; under mean age; TSD 11-15 years; H&Y3; NF12M =2-10 falls]

In addition to the general improvements as described above, some participants spoke of very specific things they wanted help with or to achieve; for example, everyday activities such as putting on their socks, manipulation of buttons, getting up from a chair, crossing the road or getting in a lift.

Finally participants hoped the programme would help boost their confidence, and support their social contacts, for example with family:

P: Yes, so, that's really why I put my name down for it, because I thought, well anything that can help me keep going as long as possible, because I have got one daughter in [place] and one daughter in [place], so, and no daughters in England [laughter] and they are not likely to be coming back, so a, I want to keep going. [Female; over mean age; TSD 6-10 years; H&Y1; NF12M =2-10 falls]

In general, participants at the initial interview were looking forward to taking part in the programme and valued the opportunity to learn from a trained Parkinson's physiotherapy specialist about suitable and tailored exercises for them.

P: Oh I am pleased actually because I am never quite sure what exercises are beneficial and what are not. I mean I used to go to a Pilates class and I was beginning to find it really hard to do and I wasn't sure if I should keep going and sort of push through it, even if it was hurting, or whether that was telling me I ought to stop, I don't know. So I am really pleased to speak to somebody and have some exercises that are actually tailored to suit the condition. [Female; over mean age; TSD  $\leq 5$  years; H&Y2; NF12M =1 fall]

A small minority of the sample expressed feelings of anxiety about the early therapy sessions, in part related to perceived anxieties about what the programme might involve and the intensity of the sessions. Others said they had not previously experienced success with physiotherapy and so wondered how beneficial it might be this time round. There were also a few participants who did not know what to expect from the PDSAFE programme and had little idea about what it might involve for them.

## **2. Experiences and perceived impacts of the PDSAFE intervention**

At T2, in addition to introductory questions exploring any changes in their condition, participants were asked about the content of the PDSAFE programme. Many of the participants focused on the exercises and strategies, sometimes describing these in great detail. Exercises discussed included rising from a seated to a standing position, walking, lunges, walking in figure of eight, step ups, strengthening and balance exercises, as well as

exercises specifically concentrating on individual problem areas, sometimes explained with reference to the PDSAFE programme booklet. Some participants described the process of negotiation with the physiotherapist to determine the content and intensity of the exercise programme:

I: How did the therapist know where to start with the sort of programme, was it literally following the booklet or did she start or did you decide where to start ...?

P: Well I think we had, it was a matter of discussing it and trying and seeing what I could do and what I couldn't do; what I sort of largely said was that I did not want to do a lot of exercises which weren't demanding and did not actually achieve anything.

[Male; under mean age; TSD 11-15 years; H&Y3; NF12M =2-10 falls]

Most people found the level of the programme acceptable and generally recognised the progressive nature of the programme (i.e. increased in intensity and number of repetitions).

A small minority of participants found the exercises too easy (especially younger participants) or too challenging (particularly older participants); or occasionally felt they were aimed only at older people. Most acknowledged that there was an expectation for them to carry out the exercises and programme almost daily (or as agreed with their therapist); this was challenging for a number of participants.

P: Well I mean, the idea is to do the exercises everyday, she (*i.e. the physiotherapist*) said, um, 'If you could do them three or four times a week that would be sufficient, not ideal, but it would be sufficient', so I did try to do them three or four times. [Female; over mean age; TSD ≤5 years; H&Y2; NF12M =1 fall]

The PDSAFE intervention introduced participants to a range of different items of equipment depending on their needs; including a DVD, a weighted vest, a step, a blue folder detailing the individualised exercise programme and providing a log sheet and a metronome. Among the minority who used the weighted vests, there were mixed views; some users ‘loved it’, found it useful and felt it made the exercises more challenging for them; this was especially true for younger people and those whose Parkinson’s was not severe. Others disliked the weighted vests, describing them as not being very practical, not coping with them, or not being useful.

Participants commonly described being filmed as part of the intervention, or using the DVD supplied as part of the PDSAFE programme, which included a metronome. A minority of participants felt that the DVD prompted or helped them to engage in the exercises. More commonly they described at least one problem with the DVD, metronome or filming; the metronome particularly was found to be hard to use, with participants experiencing difficulties in keeping in time. Older people found the metronome particularly difficult to use. On a few occasions participants accessed the metronome on an app on a portable device (such as a mobile phone), which was more acceptable and easier to use. Although participants made reference to being filmed (excerpts from which were then used within the DVD to educate and prompt), they did not tend to use these DVDs at home. A sizeable minority of participants expressed dissatisfaction that the equipment (other than their personal log sheet) was reclaimed at the end of the programme.

Most participants felt they had experienced benefits as a result of engaging in the PDSAFE programme including enhanced mobility through use of strategies such as slowing down and use of swaying to initiate movement, functional gains, psychological and social benefits such



as improved confidence, prevention of falls and increased awareness of limitations and triggers for falls. People valued the personalised nature of the PDSAFE intervention:

P: 'Best thing that came out of it is that I found out more about my Parkinson's as a personal thing to me and I found out that it didn't mean that the person I saw walking past with Parkinson's was one who was like I am going to be, because it is all different, so don't be sitting here thinking 'Oh god, I am going to end up like that' because you might not, and I found it has definitely made me better' [Female; under mean age; TSD  $\leq$ 5 years; H&Y1; NF12M =2-10 falls]

A minority of participants commented that the benefits they had experienced were limited, with some reporting no subjective change to their balance, mobility or falls. Several questioned whether the intervention could make any difference to them in the face of a deteriorating condition, even if they felt the programme was in itself well designed.

### **3. Barriers and facilitators to participation in the PDSAFE programme**

A number of barriers to participation in the PDSAFE programme were described, with limited time and motivation proving the biggest challenges. Participants described the programme as being time consuming or requiring a big commitment, which proved difficult for those with busy lives, often comprising those with less severe Parkinson's. People found the decline in visits by the physiotherapist as the programme progressed problematic. Visits ceased on completion of the programme, and the sample found it more difficult to continue practicing the exercises and strategies in the PDSAFE intervention without the support, encouragement and feedback the therapist provided. Some participants described

experiencing boredom as the programme progressed, and found it difficult to remain engaged:

I. What would you say was the most difficult or challenging thing that has come out of the physiotherapy treatment?

P. It would be trying to do it every day. But that day, I know that if I do it I would be better and more flexible and more coordinated but it is just motivating myself to do it sometimes. It's the hardest, that's...it's the hardest thing to do. [Female; under mean age; TSD 11-15 years; H&Y2; NF12M =1 fall]

As previously mentioned, the technology and equipment proved challenging to many, and some highlighted these as a barrier to participation, including technical issues with playing the DVD (including the metronome) or feeling limited because the exercises and strategies were not accessible on a portable device. Some found the use of equipment to increase the intensity of the exercises a disincentive:

P: I was doing stepping on that and that was fine, um, and then she put little feet on it (*i.e. the portable step*) to make it harder, but every time she came, she made it a little bit more difficult and the real shock was when she came with the weighted vest. Have you seen the weighted vest? It's a torture chamber honestly. [Female; over mean age; TSD  $\leq 5$  years; H&Y2; NF12M =1 fall]

During the course of the programme, some participants experienced other illness, an injury or other life events, which meant that it was difficult, or in two cases impossible, to continue

with the programme. Some participants also experienced ‘off’ or ‘bad days’ with their Parkinson’s when it proved too challenging to exercise:

P: ... And sometimes, you know with Parkinson’s you have your off periods where your drugs haven’t kicked in and there are times when I am having an off evening and I try and do my exercises, but the off spell seemed to be longer than normal, so I might have to miss it then, so it’s just choosing the time of day. [Male; under mean age; TSD 16+ years; H&Y3; NF12M= 2-10 falls]

Occasionally participants offered ‘poor memory’ as a barrier to recalling the exercises and strategies correctly, and anxiety about falling prevented a few who lived alone from engaging with the exercises. Occasionally they also described feeling embarrassed or self-conscious about exercise.

Our sample also identified some of the facilitators for continued involvement in the PDSAFE programme. Participants expressed greater effort and commitment in knowing that the physiotherapist would be returning, expressing the view that they did not want to disappoint her.

C: Also having the physiotherapist visiting regularly; that gives you something to aim for, like, when you know that she is coming next week and you want to make sure that everything is up to date and that you are doing the exercises properly, so having that sort of check and balance if you like helps to keep and it ran very smoothly. [Male; over mean age; TSD 6-10 years; H&Y3; NF12M= >10 falls]

Support and encouragement from one's partner, spouse or carer was another important facilitator. This could take several forms; for example, the partner or carer completing the exercises alongside the participant, or reminding them to complete them:

I: How was that when she (*i.e. the physiotherapist*) wasn't here? How was it doing the exercises?

P: Fine.

I: Were you doing them with (partner)?

C: Yes, we had our little routine every morning, dancing around in the kitchen.

I: Brilliant. (laughter)

[Male; over mean age; TSD 6-10 years; H&Y3; NF12M = >10 falls]

Whilst participants identified the written material about the PDSAFE programme provided in the 'blue folder' as helpful, they also felt that it was easier to complete the programme when they had learnt all the information by heart, and no longer needed to make reference to the written material.

For some, particularly those with other commitments, the intervention was easier to follow if integrated into their daily lives. Participants found novel ways of employing the strategies into their daily routines; for example when walking the dog, playing golf or shopping.

P: I even tried it down the rec (*recreation ground*), didn't I, we have got some posts and I tried the figure of eight around that, and that was different from....

C: The post are on the edge of the car park, the posts are six foot apart and we used to weave in and out doing your figures of eight.

P: So, we did try

21/053 [Female; under mean age; TSD 11-15 years; H&Y2; NF12M =1 fall]

## **Discussion**

PDSAFE is the largest trial of physiotherapy for fall prevention among PwP, it was more than double the size of the previous largest trial by Canning et al [30]. The novel intervention was personalised and home-based. The non-significant result was similar to that found by previous researchers but the large size of the trial demonstrated a diverse response to exercise and strategy training; those with milder disease responding better than those with a more severe condition profile. In extrapolating findings from this study to other research and clinical contexts, it is therefore important to be aware of the prior knowledge and experiences of potential participants with Parkinsons of exercise programmes, as these may influence engagement and adherence. It may be necessary to provide more information prior to commencement of the programme, in order to reassure or address unrealistic expectations (which could in turn impact on adherence).

This study is one of the first to explore longitudinally the expectations and perspectives of people with Parkinson's participating in an exercise based physiotherapy intervention as part of a randomised controlled trial. The realistic and well informed expectations of many of the participants about the PDSAFE programme was reflective of both prior experience and information gleaned from the Patient Information Sheets. Most had had previous experience of physiotherapy and a variety of other rehabilitation interventions, including experience of exercises classes in Parkinson's UK groups, and drew on these experiences to talk about their expectations of PDSAFE.

Also evident in the initial interviews were suggestions that some had found adherence to exercise or rehabilitation challenging previously. For example, some talked about not having had time to continue with their previous programme, or that they found the therapy a lot to cope with. However, participants seemed well motivated to embark on the programme for a variety of personal reasons, included anticipated benefits relating to improved mobility and function, and more general improvements in confidence and independence.

Participants recalled the exercise programme well at the time of the second visit, and were able to describe in some detail specific components. They recognised that the exercise programme was graded, becoming more intense as it progressed, and acknowledged that their programmes were individually tailored. Several also highlighted the strategies in describing the programme, and understood better the process of discussion and negotiation whereby exercises and strategies were designed to meet individual needs and expectations. This may have been as a result of the personalized and interactive nature of the intervention design, which was specific to each participant's mechanism of fall. The PDSAFE programme also required a strong element of self-directed and self-progressed activity.

The mixed reactions to the use of equipment were impacted by the value which participants placed on the increased intensity which they afforded. For example, whilst some could understand the increased demands which the weighted vest offered for their physical activity, others seemed surprised and shocked by how much more difficult the vest seemed to make their exercises. This reaction might also reflect a historical expectation that exercise should be easy, although evidence suggests that high intensity, moderately hard exercise is required to drive physiological change [47]. Clearer explanations and description by the therapists about how equipment like the weighted vest was designed to impact might prepare

participants better, and facilitate their acceptance of equipment as part of their programmes. This suggestion is supported by Quinn et al. [22], who found in their study of client and therapist views about exercise in early to mid-stage Parkinson's, that an understanding of the relevance and usefulness of exercises was the most important factor influencing their participation.

The varied responses to the technology used within PDSAFE reflected a continuum of familiarity and use amongst participants. There were some problems with the technology offered within the programme, for example, some of the DVDs didn't seem to work well. However, some who were familiar with computers and smart phones felt that the visual images should be offered in alternative formats (for example as an application, or app) which they could download and keep with them (e.g. on a tablet). These findings highlight a need to be creative and flexible when using technology, in order that the means of delivery can likewise be tailored to suit individual participants.

Most participants felt that the PDSAFE programme had been of some benefit, when reflecting on its impact, whether in mobility, balance, strength or freezing, more general functional activities or improved confidence and independence. Similar views were expressed by participants with Parkinson's in the study by Quinn and colleagues [22], who believed that exercise would keep them 'strong, functional and fit'. A minority of our participants mentioned that they experienced fewer falls, or were more aware of triggers for falls. A wide variety of benefits were highlighted, not all of which were captured by outcome measures used within the main trial which has also been reflected in previous research [21].

In terms of barriers to participation, lack of motivation was highlighted as a specific challenge, both whilst the PDSAFE programme was being actively tailored and supervised by the physiotherapist, and after. Participants valued the encouragement, monitoring and feedback provided by the therapists, and missed this once visits became less frequent and eventually stopped, again reflective of previous research in this field [24,48]. In our study, those who continued to exercise recognised that this might not be at the intensity or frequency suggested, which could have adversely affected the effectiveness of the programme.

Another barrier was the time required to complete the individualised programmes, and several participants mentioned their other competing commitments, and difficulties in carrying out the PDSAFE programme, either in full or in part. Many participants had busy lives including leisure activities, Parkinson's groups and family commitments, particularly those whose symptoms were not so severe.

Challenges with equipment have already been explored, and other barriers to participation included other illness or injury, and life events such as bereavement. With advancing age, people increasingly experience multi-morbidity, a finding reinforced by O'Brien et al. [48]. Specific reference was made in the PDSAFE booklet encouraging participants to reflect on how they were feeling, prior to commencing exercises, with alternative actions recommended. However, it might be useful additionally to include some discussion about exercising specifically within the context of multi-morbidities pertinent to the individual.

The social support and encouragement provided by both the treating physiotherapists and others such as spouses, carers and partners seemed to be the biggest facilitator for continued



engagement with the programme. Three types of support have been described; instrumental, information and emotional support, with Allied Health Professionals described as providing all three forms of support for engagement in physical exercise in the interviews with seven people with early Parkinsons, who comprised the sample in this study [23]. The positive influence of social support for engagement with physical exercise by both exercising peers and physiotherapists has previously been described by people with Parkinsons, with social interaction supporting the reframing of identity in the face of a progressive disease, providing opportunities for comparison and helping people not to feel alone with their disease [48]. Participants in our study spoke of trying harder, and not wanting to disappoint the therapists by stopping their programme, and partners supported engagement in a number of ways, including doing the exercises alongside the participant and reminders to complete, also reported by Ravenek and Schneider [23]. As highlighted in the Introduction, some group exercise participants with Parkinson in other studies valued the peer support and positive social experience offered by such Parkinsons specific groups [21, 24, 25, 26, 27]. It may be that, within the context of the PDSAFE intervention, it would be advantageous to link programme participants either virtually or in person, in order that they can share experiences and provide mutual support. This in turn might have positive benefits for adherence, particularly once the therapist visits cease.

Other strategies optimising social support include provision of a ‘buddy’ or supporter, who works with the PwP to support the therapist recommendations, regularly enquires about progress, and perhaps exercises alongside the participant. Exercise classes can perform this function for some, but potential disadvantages such as transport to the venue need to be considered, and some of the participants we interviewed clearly didn’t enjoy exercise classes, also found by Quinn et al. [22] and Ravenek and Schneider [23]. In considering how

programmes such as PDSAFE are tailored, it would be useful to include preferences for social support and venue.

Participants mentioned that they found written information about the PDSAFE programme useful, offered in blue folders to which many made reference. However, others highlighted that the integration of the programme into daily life (to the extent that the folders became redundant) also helped facilitate engagement. Both strategies have been found to be associated with increased adherence to exercise within the context of falls prevention within a general older population [27,49-50]. For PDSAFE, the treating therapists could perhaps consider specific use of the folders as reminders of individualised programmes at the start of the programme. However, with later visits, it might be possible to work with participants to commit their programmes to memory, or to use easily accessible means of recalling their programmes, such as sticky notes (for example on fridge doors, kitchen walls and where exercises are performed) or use of mini black or white boards.

Limitations of this study include the pragmatic research design, which militated against the development of a theoretical model with which to explain and interpret participants' accounts. However, our pragmatic orientation ensured that findings remained closely rooted in the experiences of participants, and enabled us to identify practical suggestions which can be implemented in future exercise and strategy interventions for people with Parkinson's who fall.

## **Summary**

This study is important in being among the first longitudinal qualitative enquiries into the expectations and experiences of people with Parkinson's participating in a home based

exercise programme. Of the qualitative research studies exploring the experiences of PwP of exercise and physical activity, our study is also the largest, with forty-two participants. Our findings have confirmed those of others, notably the variety of motivators for exercise [21], variety of perceived benefits [21,22], the importance of support, feedback and encouragement from treating physiotherapists (exercise instructors) and also from spouses, partners and family members [23,24-27,48]. The role of additional illnesses and injuries in creating barriers to engaging in physical activity also echoes findings from O'Brien et al. [48].

This study is the first to capture expectations about participation in a programme of individualised, home-based exercises and strategies for people with Parkinson's. It also highlights that previous challenges to engagement in physical exercises and activities are not a barrier to future participation. Our study provides new insights into the role of equipment and technology in programmes of physical activity for people with Parkinson's, suggesting that the promise of technological advances needs careful consideration before it can be realised. The use of equipment designed to increase exercise intensity also requires careful introduction and explanation to ensure its use. The challenge of ensuring that programmes of exercise and strategies become an embedded feature of everyday life is also highlighted by our study, particularly alongside busy social engagements and leisure pursuits. We have suggested a number of strategies to address these findings.

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**Table 1**      **Outline of initial and follow up interview guides**

<b>Initial interview guide (T1)</b>	<b>Follow up interview guide (T2)</b>
<ul style="list-style-type: none"> <li>• Introduction and impact of PD</li> <li>• Typical day</li> <li>• Managing movement and stability</li> <li>• Experiences of previous therapy and expectations about treatment</li> <li>• Perceived benefits and challenges of treatment</li> <li>• Looking forward to/not about treatment</li> <li>• Anything else</li> </ul>	<ul style="list-style-type: none"> <li>• Introduction and changes</li> <li>• Experience of the intervention</li> <li>• Facilitators and barriers to participation</li> <li>• Perception of falls and mobility since T1</li> <li>• Expectations vs experiences</li> <li>• Anything else</li> </ul>

**Table 2 Participant characteristics**

		<b>Interviewed T1 (n=42)</b>	<b>Interviewed T1 and T2 not withdrawn from trial (n=35)</b>	<b>Interviewed T1 and T2 withdrawn from trial (n=2)</b>	<b>Interviewed T1 and T2 (n=37)</b>
<b>Gender</b>	<b>male</b>	24 (57%)	18 (51%)	2 (100%)	20 (54%)
	<b>female</b>	18 (43%)	17(49%)		17 (46%)
<b>Age in years</b>	<b>mean</b>	71	71	70	71
	<b>min-max</b>	57-84	57-84	68-79	57-84
	<b>≤59</b>	2 (5%)	2 (6%)	0	2 (5%)
	<b>60-69</b>	15 (36%)	11(31%)	1 (50%)	12 (32%)
	<b>70-79</b>	20 (48%)	17 (49%)	1 (50%)	18 (49%)
	<b>≥80</b>	5 (12%)	5 (14%)	0	5 (14%)
<b>H&amp;Y class</b>	<b>1</b>	4 (10%)	4 (11%)	0	4 (11%)
	<b>2</b>	12 (29%)	10 (29%)	0	10 (27%)
	<b>3</b>	23 (55%)	20 (57%)	1 (50%)	21 (57%)
	<b>4</b>	3 (7%)	1 (3%)	1 (50%)	2 (5%)
<b>Time since diagnosis in years</b>	<b>median</b>	10	10	30	10
	<b>min-max</b>	18 months-35 years	18 months-21 years	13-35 years	18 months-25 years
	<b>≤5</b>	15 (36%)	14 (40%)	5 (14%)	5 (14%)
	<b>6-10</b>	7 (17%)	5 (14%)	0	12 (32%)
	<b>11-15</b>	13 (31%)	11 (32%)	0	6 (16%)
	<b>≥16</b>	8 (19%)	5 (14%)	1 (50%)	1 (50%)

<b>Falls in the previous 12 months</b>	<b>median</b>	3	3	3	3
	<b>min-max</b>	1-200+	1-200+	1-4	1-200+
	<b>1 fall</b>	11 (26%)	10 (29%)	1 (50%)	11 (30%)
	<b>2-10 falls</b>	24 (57%)	19 (54%)	1 (50%)	20 (54%)
	<b>&gt;10 falls</b>	3 (7%)	2 (6%)	0	2 (5%)
	<b>&gt;100 falls</b>	4 (10%)	4 (11%)	0	4 (11%)
<b>Living status</b>	<b>alone</b>	13 (31%)	10 (29%)	2 (100%)	12 (32%)
	<b>with partner</b>	27 (64%)	23 (66%)	0	23 (62%)
	<b>with relative</b>	1 (2%)	1 (3%)	0	1 (3%)
	<b>with carer</b>	1 (2%)	1 (3%)	0	1 (3%)

## **Supplementary Figure 1 Themes generated from initial and follow up interviews.**

### Initial interviews

#### Thirteen themes:

- 1) Parkinson's diagnosis
- 2) Parkinson's symptoms and experience of PwP
- 3) Reflections on the forthcoming PDSAFE intervention/therapy
- 4) Previous experience of rehabilitation therapies
- 5) Effect of PD on day-to-day routines and life
- 6) Effect of PD on mobility
- 7) Losses attributed to Parkinson's
- 8) Adaptation
- 9) Falls and risk
- 10) Well-being and Parkinson's
- 11) Other health and social issues
- 12) Trial and study participation
- 13) Importance of social networks.

### Follow up interviews

#### Seventeen themes:

- 1) Activities
- 2) After the sessions ended
- 3) Experience of the assessor sessions

- 4) Barriers to PDSAFE
- 5) Deteriorating mobility
- 6) Equipment or technology
- 7) Experience of physiotherapy and other exercise outside of PDSAFE
- 8) Facilitators for continuing with the PDSAFE programme
- 9) Falls
- 10) Impact and treatment of PD condition
- 11) Impact of health condition
- 12) Impact of condition
- 13) Impact of PDSAFE programme
- 14) PDSAFE physiotherapy sessions
- 15) Strategies
- 16) Therapist input
- 17) Other



## **Appendix 1: Details of the PDSAFE programme**

PDSAFE comprised individually tailored, progressive home-based exercise and strategies to avoid falls.

Registered physiotherapists made visits to the participants' home and provided up to 12 supervised sessions (mean of 11 sessions (standard deviation 2.4 sessions)) of 1–1.5 hours duration over 6 months. Participants received more sessions during the early stages of the programme, with the frequency of sessions being reduced over time.

Participants were also asked to engage in daily-unsupervised exercise for approximately 30 min. They were provided with advice for these sessions and strategies to maximise adherence (e.g., integration into daily routines).

Participants were given a blue folder containing pictures and descriptions of exercises, a rating of perceived exertion scale and an exercise log. They were also given DVDs of both exercise demonstrations and personal videos taken by their physiotherapist recording them completing the exercises. All programmes were tailored based on individualised assessment of fall risk factors.

Exercises included:

- Balance training (including gradual decrease in the area of support and foam pads)
- Strength training (using weight resistance and weighted vests where appropriate)
- Strategies for fall and freezing avoidance

For full details of the PDSAFE intervention see:

Chivers Seymour K, Pickering R, Rochester L., et al., (2019) Multicentre, randomised controlled trial of PDSAFE, a physiotherapist-delivered fall prevention programme for people with Parkinson's. *J Neurol Neurosurg Psychiatry* doi:10.1136/jnnp-2018319448