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Citation: Baron, F. & Bogosian, A. (2024). Exploring social, cultural and environmental factors that influence attitudes to exercise among people with Parkinson's disease: a qualitative study. *Journal of Health Psychology*, doi: 10.1177/13591053241296647

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Exploring social, cultural and environmental factors that influence attitudes to exercise among people with Parkinson's disease: A qualitative study

Journal of Health Psychology
1–14

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DOI: 10.1177/13591053241296647

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Fred Baron¹  and Angeliki Bogosian¹ 

Abstract

Exercise is recommended for people with Parkinson's (PwP) but clinical exercise-based interventions are generally ineffective. Social, cultural and environmental factors can influence exercise behaviours, but these topics are under-researched. We interviewed 18 PwP using a narrative approach to identify factors influencing their exercise behaviours throughout their lives. Thematic analysis identified three themes: (1) Why I exercise, (2) What helps and (3) Exercise with Parkinson's. Participants had consistent core motivations to exercise: mood and well-being, body image, competition, and camaraderie. Having active partners, supportive work, and varied exercise options were among the important facilitators of long-term exercise. Participants believed strongly in the benefits of exercise for Parkinson's, but experienced guilt about not exercising enough and frustration when symptoms made it harder to continue. This study illustrates how narrative interviews can reveal important social, cultural and environmental influences on exercise behaviour, offering potential to develop more individualised and effective exercise interventions.

Keywords

chronic illness, culture, exercise, exercise behaviour, physical activity, qualitative methods

Introduction

There are over 145,000 people with Parkinson's (PwP) in the UK, and this will increase by 20% in the next 10 years (Parkinson's UK, 2022a). Parkinson's is a neuro-degenerative disease which causes a reduction of dopamine in the brain. This neurotransmitter helps regulate movement, and many symptoms are movement related (Damier et al., 1999). Symptoms usually manifest in people over 50 and progress at a variable rate (Bloem et al., 2021). Many PwP live with a reduced quality of life for years

(Schrag et al., 2000). Pharmacological treatments relieve some of the symptoms but do not affect the underlying neuro-degenerative process (Bloem et al., 2021).

¹City, University of London, UK

Corresponding author:

Fred Baron, Department of Health Services Research and Management, City, University of London, Northampton Square, London EC1V 0HB, UK.
Email: fred.baron.3@city.ac.uk

Exercise and Parkinson's

Exercise is an important non-pharmacological treatment (Bogosian et al., 2020), and is recommended for all PwP (Keus et al., 2014; National Institute for Health and Clinical Excellence (NICE), 2017). Systematic reviews have shown that exercise can reduce falls and improve motor symptoms and quality of life (Allen et al., 2022; Ernst et al., 2024). However, there is considerable variation in effect size, and research is ongoing into different exercise types and doses.

The evidence from *pragmatic* exercise-based studies is less positive, with three large therapist-led UK trials yielding small or non-significant effects (Ashburn et al., 2019; Clarke et al., 2016; Goodwin et al., 2011). PwP face many barriers to exercise, but studies examining these tend to focus on cognitive-behavioural influences such as self-efficacy and knowledge (Ellis et al., 2013; Schootemeijer et al., 2020). A systematic review of qualitative studies on barriers and motivations found that PwP value exercise which is highly individualised (Hunter et al., 2019). One possible reason, therefore, that exercise interventions are ineffective is that they do not align with PwP's individual backgrounds, goals and attitudes (Amateis et al., 2019). This may affect the person's engagement and thereby the efficacy of interventions.

Social, cultural and environmental influences on exercise

By contrast with cognitive-behavioural models, ecological approaches emphasise how behaviours are influenced by a system of social, cultural and environmental factors (Burke et al., 2009; Sallis et al., 2008). Qualitative studies in different populations have shown how childhood experiences, education, ethnicity, religion, gender roles, migration, environmental factors and cultural beliefs can interact and influence attitudes to exercise (Caperchione et al., 2009; Jang et al., 2016; Mahmood et al., 2022; Mayes et al., 2022; O'Driscoll et al., 2014).

Recognising these wider influences, some researchers are now using the COM-B model to understand and map determinants of exercise behaviour among people with neurological conditions (Huynh et al., 2023; Nicholson et al., 2014; Pekmezi and Motl, 2022; Riemann-Lorenz et al., 2021; Silveira et al., 2021). COM-B assesses the *capabilities*, *opportunities* and *motivations* associated with a behaviour, integrating external opportunities (i.e. social, cultural and environmental factors) with intrinsic capabilities and motivations, to establish the most appropriate type of behavioural intervention (Michie et al., 2011).

Very few studies have examined the social, cultural and environmental influences on exercise among PwP. One systematic review of experiences of exercise among PwP (Hunter et al., 2019) found only two studies conducted in Jordan (Khalil et al., 2016, 2017). They noted that stigma can hinder a PwP's disclosure of their diagnosis, limiting exercise options in the early stages, while some PwP may view exercise culturally inappropriate after young adulthood. These studies did not fully explore the variety of influences on attitudes to exercise, nor how they interact and build over time in individuals.

Research aim

Our premise is that deeper understanding of individuals' relationships with exercise could improve clinical interventions. This study aimed to describe how social, cultural and environmental factors influence the meaning of, and attitudes to, exercise among PwP. We used thematic analysis to examine how exercise behaviours develop over time, before and after a diagnosis of Parkinson's.

Materials and methods

This was a qualitative study featuring semi-structured interviews with PwP in the UK. This study is reported using the COREQ criteria

(Tong et al., 2007) (see Supplemental Materials), and was approved by the City, University of London School of Health and Psychological Sciences Ethics Committee (Ref: ETH2223-1452).

Epistemology

The ontological basis for this study was naïve or direct realism, where the emphasis is on enabling the participants to recall, describe and reflect on experiences in their terms (Willig, 2023). The analytic approach was broadly inductive (Braun and Clarke, 2021). However, interviewees were guided (see below) to focus on the external influences on their behaviour, reflecting the ecological approach to the study.

Reflexivity

Reflexivity recognises that the standpoint and values of the researcher will affect all aspects of the study (Berger, 2015). The lead author is a neurological physiotherapist with experience of working with PwP. Interviewees were aware of his profession, which may have shaped their comments about NHS services and exercise. The author completed field notes and reflections after each interview. Where his experiences of exercise aligned with those of interviewees, there is a risk that their comments may have had undue influence in the analysis.

Participants

Participants were recruited by the lead author from Parkinson's UK's support groups and their network of PwP interested in research. Flyers were distributed at a Dance for Parkinson's group, and the study was promoted via *X* (formerly Twitter) and a video on *YouTube*, which was shared with African and Jewish Parkinson's organisations. To increase the diversity of the data, recruitment materials highlighted the desire to recruit Black, Asian and Minority Ethnic (BAME) PwP.

Participants aged ≥ 18 years were eligible if they had a self-reported diagnosis of idiopathic Parkinson's disease, were a UK resident and were able to participate in an interview. Interpreters and translations of study material were available. Participants were excluded if they were unable to consent due to apparent cognitive impairment during initial interaction with the lead author.

A target of 15 participants was established based on resources and the 'information power' of the sample (Malterud et al., 2016). This methodology proposes six dimensions which influence how many participants are needed in qualitative research. Most dimensions suggested a higher number for this study, including a broad topic area, absence of theoretical grounding and predominantly convenience sampling.

Forty-two PwP expressed an interest, of whom one was ineligible due to cognitive impairment. No interviewees declined to participate after reading the information sheet. In response, purposive sampling was introduced to maximise the diversity of the data set. Interested PwP completed a survey, giving their age, gender, ethnicity, education level, employment type, time since diagnosis, use of mobility aid and frequency of exercise. The lead author selected participants to maximise variation in each category.

Written informed consent was obtained. Table 1 shows the interviewee characteristics and method of recruitment. Eighteen PwP (44% male, 56% female) were recruited. The mean age was 68 years, and the majority were white British (78%), with two British Indian, one Portuguese and one Jewish American. Most participants (83%) were Hoehn and Yahr stage ≤ 3 , meaning they could walk without a walking aid. Most participants (83%) were recruited through Parkinson's UK.

Data collection

Interviews were conducted between 16 June and 1 August 2023 by the lead author. The

Table 1. Interviewee demographic, clinical and recruitment characteristics.

Characteristic	Total (N = 18)
Patient reported demographic, n (%)	
Sex	
Male	8 (44)
Female	10 (56)
Age	
Range (mean)	53–81 (68)
UK census ethnic group	
Asian or Asian British Indian	2 (11)
White British	14 (78)
White other	2 (11)
First language	
English	16 (89)
Other	2 (11)
Clinical information, n (%)	
Modified Hoehn and Yahr stage	
Stage 1	2 (11)
Stage 1.5	5 (28)
Stage 2	2 (11)
Stage 2.5	5 (28)
Stage 3	1 (6)
Stage 4	3 (17)
Method of recruitment, n (%)	
Parkinson's UK local group	7 (39)
Parkinson's UK research database	8 (44)
Dance for Parkinson's group	2 (11)
X (Formerly Twitter)	1 (6)

semi-structured format allowed participants to describe experiences in detail while focussing on set of topics (Holloway and Wheeler, 2010). Interviews lasted between 23 and 53 minutes. Seven interviews were conducted in participants' homes, 10 by video, and 1 by phone. No interpreters or repeat interviews were required. The partner of one participant (A) was present during their interview.

Narrative approaches are appropriate to illuminate how individuals' health behaviours build over time, influenced by social relationships and environments (Greenhalgh et al., 2015; Haydon and van der Riet, 2017). This involves collecting and interpreting data from people's accounts of their lives (Anderson and Kirkpatrick, 2016). Interviews were structured to identify childhood, adult and later life

exercise experiences, using a guide adapted from a methodologically similar study (Mayes et al., 2022) (see Supplemental Material). The interview guide was reviewed after two pilot interviews and after the first six interviews. Initial questions encouraged storytelling about exercise experiences and attitudes. Follow-up prompts were open, 'You mentioned X, can you please tell me more about this?'. Specific prompts were used, if needed, to ask participants to focus on social, cultural or environmental influences.

Participants were given diagrammatic hand-outs to explain 'culture' and 'exercise' (see Supplemental Materials). The term 'exercise' was considered simpler for interviewees, though the examples given conform to the broader definition of 'physical activity' (World Health Organisation (WHO), 2022).

Data processing

Interviews were recorded through Microsoft Teams or Zoom or by encrypted digital audio recorder. Participants were assigned lettered study IDs and pseudonymised recordings were professionally transcribed. Verbatim transcripts were analysed using NVivo 14. It was not possible to seek interviewees' comments on transcripts.

Data analysis

The data was analysed using thematic analysis (Braun and Clarke, 2021). This methodology is appropriate for a novice researcher and is compatible with realist approaches (Campbell et al., 2021). It involves discovering patterns of meaning across the interview transcripts and field notes through a multi-staged approach (See Supplemental Materials for description of process and coding tree example).

Patient and physiotherapist advisory groups

Two PwP with research experience were recruited through Parkinson's UK. They

Table 2. List of themes and sub-themes.

Theme	Sub-themes
1. Why I exercise	a. Mood and well-being b. Body image c. Competition d. Camaraderie
2. What helps	a. Active partners b. Flexible and supportive work c. Groups that bring people together d. Access to varied local exercise options e. Pleasant surroundings f. Intergenerational activities
3. Exercise with Parkinson's	a. Taking control through exercise b. Exercise as a cure c. Feeling guilt d. It gets harder to see the benefits

reviewed the information sheet, undertook pilot interviews, commented on interview guides, and reviewed the initial themes. Three physiotherapists were recruited through the Association of Chartered Physiotherapists in Neurology (ACPIN) by invitation to members with an interest in Parkinson's. They commented on the initial themes, relating them to their patient cohorts. Both groups were remunerated according to NIHR guidance (National Institute for Health and Care Research (NIHR), 2023).

Results

Qualitative themes

Three themes and 14 sub-themes were identified, shown in Table 2. Theme 1, 'Why I exercise', describes the differing motivations participants have to exercise. Theme 2, 'What helps', identifies the social, cultural and environmental factors which enabled the participants to exercise throughout their lifetime. Theme 3, 'Exercise with Parkinson's', describes how exercise has a significant role in participants' responses to Parkinson's, but brings with it practical, psychological and emotional challenges.

The three themes can be represented temporally in relation to PwP's lifetimes as shown in Figure 1. In doing so, it is also possible to map the themes against the three dimensions of the COM-B model.

Theme 1: Why I exercise

Interviewees had rich experiences of exercise. They were all active as children, but often in adolescence developed an identity as 'sporty' or not, based on aptitude, opportunities or interests. While this identity persisted into adulthood, being 'non-sporty' did not preclude later life enjoyment of exercise. By early-to-mid

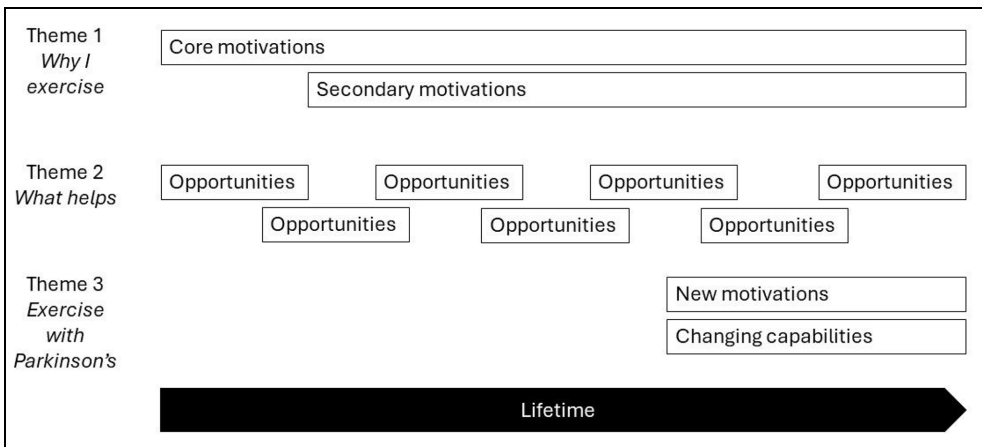


Figure 1. Qualitative themes mapped against COM-B dimensions.

adulthood most interviewees had developed a core reason to exercise, which consistently motivated them from then on. Four types were identified, which were individualistic or more collective in nature.

Mood and well-being. Immediate feelings of wellness were the key motivator for some, while others found that regular exercise stabilised their mood in the long term, counteracting the effects of stressful work or relationships.

It makes you feel good, when you walk and you think about stuff and you go through things in your head and sort them out. And it just makes you feel really good. (Participant J)

For some interviewees, the well-being from exercise came from having time alone. Sometimes this took on a spiritual quality, exercising in a way or place which was important for them.

Body image. For some female interviewees, exercise was a means to avoid gaining weight, and to look good. They articulated the societal pressures for this, which developed during adulthood.

I started doing the gym. I felt I needed to do it, to improve my looks. I think that's probably why I am doing it now, trying to. In my mind it's important to look nice. (Participant E)

No male interviewees expressed an aesthetic motivation to exercise, perhaps reflecting the cultural norms of males in this age group.

Competition. For some interviewees, competition provided an enjoyable sense of achievement, either within team sports, or in beating personal bests.

Well, I used to like being competitive, so if I did well in a competition, that gave me a boost. (Participant K)

Camaraderie. Team or group exercise was often a source of belonging and togetherness, and of long-term friendships.

I had a tennis four. We still call ourselves "the tennis four" . . . We played, we drank coffee, we sorted the world out, helped each other out, forty something years, fantastic. (Participant R)

Some participants held negative views about their non-preferred exercise types, for example competitive sports or gym-based activities.

I can't get up in the morning or go to a gym and do half an hour exercise. That is just not in my psyche. I wish I could, but I can't. But I did play a lot of squash, I did play bowls, so I got plenty of exercise. (Participant M)

Many participants reported knowledge of the health benefits of exercise, but this tended to develop later in adulthood.

I think by that age I was probably beginning to understand that it wasn't just about enjoyability. It was probably still about not putting weight and looking like somebody who worked near Bond Street and liked to kind of present herself in a certain way. But I think I was beginning to understand that this is also something that's good for you. (Participant N)

In this case, the participant had a core, affective motivation to exercise, which was reinforced later by a secondary, reflective reason.

Theme 2: What helps?

Participants were mostly frequent exercisers, before and after their diagnosis of Parkinson's. However, there were periods when they had exercised less, when focussing on careers, during child-rearing, or when recovering from illness. By exploring these times, participants were able to identify people, places and structures around them which provided opportunities or encouragement to exercise.

Active partners. Interviewees' partners were often significant influences. Some joined in their partners' exercise activities; others were brought into new social environments where exercise was integral.

After college, I met my husband who was a very keen rugby player. . . His life was always at the rugby club. So then, bringing up my children in that rugby club scenario, I started playing netball for Leamington ladies as well. And so that was really important to me, so yeah, I discovered sport again. (Participant Q)

However, where individuals' exercise needs did not align with their partners' interests, there were relationship tensions.

They [exercise classes] are in places which are very, very difficult and [my wife] has got her own life. It may be when she has a doctor's appointment or something, or she's got one of her hobby groups. How to get there. . .? (Participant A)

Flexible and supportive work. Work could have positive impacts on exercise behaviour, sometimes instrumentally by providing cycle parking, or by organising sports days which reinforced the social acceptability of exercise. In other cases, work introduced enjoyable physical demands on individuals.

I went to work with horses. . . I was doing a lot of physical activity, there was mucking out and going out to the fields to fetch them in and that kind of thing. . . I loved it, really loved it. (Participant J)

Participants highlighted the importance of autonomy and flexibility in their job roles to undertake exercise. Following their diagnosis, this further enabled them to alter or reduce their hours to focus on their health.

Work is very flexible. . . Today I went in, in the morning, to the office. Came home, brought some

work home, and exercised in the back [garden] and then did some more work. So yeah, a lot of flexibility. (Participant O)

By contrast, some interviewees who were self-employed or were paid by the unit reported working very long hours, which left little time for exercise.

I used to work in the textile industry. I used to work basically, morning, afternoon and night. . . It was hard, there wasn't always time to get it. (Participant G)

Groups that bring people together. Many interviewees participated in group exercise classes. Their comments revealed complexity in group relationships, and the need to find groups which matched their needs. Some participants described a threshold of being ready, or not, to join groups with fellow PwP.

I feel I would like to be part of a group now, people with Parkinson's. . . I feel like I'd like a more intimate discussion group with people I think about things that are important, like how people feel about the future. . . (Participant E)

The contrast between *bonding* relationships which form between people of similar backgrounds, and the *bridging* needed to involve people from more diverse backgrounds was also evident.

The ones at the dance class are all thinnish, mostly very thin and very high achieving and kind of pushing, self-pushing. . . I really enjoy it, I mean I find them very nice interesting people. . . I feel that I get on with them because I feel I am like that. (Participant F)

One of the things that we try and do in our group is have a coffee, either before or after. . . We've got people that we can talk to and say 'Hello' to when we turn up, rather than just do the exercises. And then if they want to take it further, we then have a 'walk and talk' . . . (Participant D)

Access to varied local exercise options. Individuals who were able to continue exercising after breaks, or adapt their exercise to their changing symptoms, highlighted how personal resources and a variety of options in their area significantly helped them.

Through the kids I just stopped. Wanted to go back to it [netball]. . . my back just couldn't take it. So, I really needed to find something else that I really enjoyed, and some of my friends were joining this local tennis club, and I thought, do you know what, I'll give it a go. I'm not brilliant, but I just absolutely loved it. (Participant Q)

The need for stable, regular and long-term options was highlighted by one participant who is involved in coaching other PwP.

I'd rather you slow it down and come more regular than get injured and then I don't see you for a month or six weeks. The older we get, the more recovery time is, like we're not young anymore and so we recover within a couple of days. (Participant O)

Interviewees with more severe physical impairments expressed the need to take advantage of any appropriate exercise option available, even if doing so had negative effects.

I do that [dance group], then horse-riding straight after on the same day. Unfortunately, after that I am that wiped out, totally wiped out, so that's probably why I fell over. (Participant E)

Pleasant surroundings. Access to places where people felt comfortable was important, whether it was the natural world, or a friendly gym.

[My physiotherapist] got me on that [exercise on referral]. I went to the gym and it's fine! It wasn't intimidating at all. . . It's very welcoming and the people are very helpful. (Participant J)

Intergenerational activities. Many participants recalled childhood activities that sowed the seeds for exercise in adulthood, such as

countryside walking. In turn, as participants became parents, the need to occupy and stimulate their own children reinforced their exercise behaviours.

We played it [tennis] as a family, when we went on holidays. If there was tennis or table tennis or anything with a ball, we'd probably favour a place like that. That's how you sort of spend two or three hours to keep the younger people occupied. (Participant C)

Theme 3: Exercise with Parkinson's

All participants believed that exercise is beneficial for PwP, though interviewees who had been diagnosed for longer reported that exercise was not promoted to them initially. Many were diagnosed as they were considering retirement or reducing work to make time for themselves, including doing more exercise.

Taking control through exercise. All participants viewed exercise as a means of exerting some control over Parkinson's and ageing, and of retaining independence. Some articulated the tension between this and accepting the progressive nature of the condition.

I don't want to be a vegetable. I want to work within the strictures of knowing I've got Parkinson's. I know I can't beat Parkinson's but I don't want Parkinson's to overtake me massively. If I can contain it I will. (Participant A)

Exercise as a cure. Many participants believed that exercise could delay their disease progression, citing information from healthcare professionals and their own experience.

People that work in health that have dealt with me, like chiropractors, physios, GP, consultants. They all say that they consider that my Parkinson's has not. . . has been slower shall we say in its onset or in its development, because I exercise. (Participant K)

Feeling guilt. The belief that exercise could slow their progression brought a source of hope for

some, but it also brought feelings of guilt about how much exercise they should be doing.

One of the things that I'm constantly being told is that exercise is very good for Parkinson's, so you're always in the back of your mind, right I've got to go and do this exercise. (Participant C)

In some cases, the fear of being a burden to family was a strong motivator, while others felt tension about choosing between family and exercise.

I don't want to be a burden on my wonderful partner and my kids when, the older I get and become a jabbering shaking idiot. I mean, which I will probably be, but if I can delay that for as long as possible. . . (Participant L).

My 21 year old, his girlfriend's pregnant. So that would be amazing, and that will take up a lot of my time. So that's the worry actually, a little bit about the exercise, I'm going to have to fit it in between baby duties as well. (Participant Q)

It gets harder to see the benefits. As peoples' symptoms progressed it was harder for them to exercise, and harder to see the positive effect on their physical appearance or performance, which had motivated them previously.

It's not really much motivation, because in the past when I did [exercise] I was seeing the benefits, especially with my marathon running. . . When I initially did Tai Chi and Pilates, I felt that [it] was helping really well and might stop me falling over. But it hasn't really stopped me from doing that, so, yeah, that's bad really. (Participant B)

This final quotation articulates the frustration felt by the more impaired participants of losing physical ability and having fewer exercise options, while hearing from more and more sources how important exercise is for Parkinson's. It speaks to the importance of exercise-based interventions which facilitate a closer matching of individuals capabilities, opportunities and motivations.

Discussion

This study aimed to examine the social, cultural and environmental factors that influence the meaning of, and attitudes to, exercise. Through interviews with 18 PwP, insights were gained in three areas: their motivations to exercise, their external facilitators of exercise through their lifetimes, and the practical, psychological and emotional challenges of exercising with Parkinson's.

Exercise as part of individuals' identities

The results highlight how exercise motivations, whether aesthetic, psychological or social, often remain relatively constant. Research among stroke survivors has suggested that exercise experiences and behaviours are parts of individuals' identities, and they shape their approach to exercise after stroke (Espenberger et al., 2023). Research into exercise and identity is limited among PwP. Qualitative studies investigating the meaning of exercise for PwP have found that preserving one's identity *as an active person* was important (Eriksson et al., 2013; O'Brien et al., 2016), but differences between individuals' exercise identities were not explored. Other studies have highlighted the importance of *individualised* exercise, but these have focussed on individualisation in exercise prescription rather than meaning or motivation (Amateis et al., 2019; Hunter et al., 2019; Rowsell et al., 2022).

Social support and groups

Social support is an important enabler of exercise (Schootemeijer et al., 2020), and exercise groups are common within NHS services (Parkinson's Excellence Network, 2023). However, our study shows how varied PwP's needs are. For some, exercise is an *asocial* activity. There may also be periods when individuals are unable to engage with other PwP. Interviewees spoke about why some groups worked for them and others didn't, and about

the skills of group leaders in bringing people together. This resonates with other studies. Researchers have found that PwP need different types of social support (informational, emotional and instrumental) at different times (Ravenek and Schneider, 2009). PwP have been found to experience anxiety when joining a group, driven by comparing themselves to other PwP, and to their imagined future selves (Sheehy et al., 2017). Participants in boxing classes cited the importance of love and care from inspirational instructors (Borrero et al., 2022), while a nurturing, cohesive and supportive environment was instrumental in long-term participation in another exercise class (Rossi et al., 2018).

The successful groups cited by interviewees were run by private or charitable organisations. Many participants had the resources to trial different options, which would not be the case for all PwP. Several participants had started exercise groups for PwP (D, O and P), perceiving the need for peer-led initiatives. There has been limited research into these (Soundy et al., 2019). Further studies into PwP exercise leaders could illuminate their experiences and support needs.

Cultural factors

Cultural influences were evident throughout the interviews. Walking in the countryside was a common activity, while being thin was a motivation among female interviewees, several of whom cited the influence of fitness videos such as Jane Fonda's *Original Workout*. Research has shown how women with Parkinson's from different ethnic backgrounds have variations in perceived ideal body shape and how this influences exercise goals and identity (Pentecost and Taket, 2011). The belief that Parkinson's can be 'fought' was almost universally expressed. This homogeneity is unusual, as 'fighting spirit' is only one of several coping strategies among PwP (Charlton and Barrow, 2002; Haahr et al., 2021). It may reflect the predominant cultural

background of the participants or their motivations to participate in research.

Strengths and limitations

The study had several strengths. The sample was well balanced by age, gender, geographical location and symptom severity. Interviewees had interests in exercise and its role in Parkinson's, which enabled deep reflection. The narrative interview structure helped develop rapport to allow participants to speak about difficult topics, including adjustment, guilt and relationship tensions. The stimulus material reduced the chance of important influences on exercise behaviour being missed. A degree of validation of the themes was achieved through discussing them with PwP and physiotherapists.

However, we only recruited a small number of PwP from BAME backgrounds, due in part to the lack of diversity in Parkinson's UK's membership (Parkinson's UK's, 2022b). Efforts were made to reach groups for PwP from different ethnic backgrounds, but there was not time to develop these relationships. Nevertheless, some influences on exercise were found which have been previously documented among migrant or minority groups. Sporting prowess helped participant C assimilate as a child migrant, and climate unfamiliarity was a barrier to exercise for participant G. Participant O discussed how racist abuse led him towards karate as a means of self-defence.

A further limitation is that nearly all interviewees were regular exercisers, and few negative beliefs about exercise were expressed. Additionally, barriers such as pain, apathy and depression, which are common in PwP (Schootemeijer et al., 2020), were not substantially reported.

Implications for research

This research suggests that narrative interviews can successfully identify important influences

on PwP's exercise behaviours. They should be repeated among other groups, particularly among BAME PwP and those who have not regularly exercised. The findings highlight significant variation in PwPs' exercise identities and needs. This supports our premise that deeper, more holistic understanding of individuals could improve exercise interventions. The alignment between the themes identified and the COM-B dimensions suggest that this model could underpin a future theory-based approach to designing individualised exercise interventions among PwP.

Acknowledgements

The authors wish to thank the 18 people with Parkinson's who participated in the study. The authors are grateful for the support from Parkinson's UK in the recruitment of participants and patient advisory groups, and the help from the Association of Physiotherapists in Neurology in recruiting the peer advisory group members. Thanks to the group members themselves: Valsala Benn and Beverley Price; Jennie Meadway, Deborah Whitfield and Victoria Wright. Thanks also to the two anonymous peer reviewers for their positive and helpful comments.

Data sharing statement

The data generated during the current study are not publicly available due to resource constraints, but are available from the corresponding author on reasonable request. Ethics approval, participant permissions, and all other relevant approvals were granted for this data sharing.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by Barts Charity (grant number G-002234).


Ethical approval

This study was approved by the City, University of London School of Health and Psychological Sciences Ethics Committee (Ref: ETH2223-1452, date: 15 May 2023).

Informed consent

All participants provided written informed consent prior to enrolment in the study.

ORCID iDs

Fred Baron  <https://orcid.org/0000-0001-6187-8114>

Angeliki Bogosian  <https://orcid.org/0000-0003-1244-6387>

References

- Allen NE, Canning CG, Almeida LRS, et al. (2022) Interventions for preventing falls in Parkinson's disease. *Cochrane Database of Systematic Reviews* 2022(8): CD011574.
- Amateis AL, Boesel CL, Ehnert BP, et al. (2019) The need for mapping personal goals to exercise dosage in community-based exercise programs for people with Parkinson's disease. *Physiotherapy Theory and Practice* 35(12): 1250–1258.
- Anderson C and Kirkpatrick S (2016) Narrative interviewing. *International Journal of Clinical Pharmacy* 38(3): 631–634.
- Ashburn A, Pickering R, McIntosh E, et al. (2019) Exercise- and strategy-based physiotherapy-delivered intervention for preventing repeat falls in people with Parkinson's: The PDSAFE rct. *Health Technology Assessment* 23(36): 1–150.
- Berger R (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research* 15(2): 219–234.
- Bloem BR, Okun MS and Klein C (2021) Parkinson's disease. *The Lancet* 397(10291): 2284–2303.
- Bogosian A, Rixon L and Hurt CS (2020) Prioritising target non-pharmacological interventions for research in Parkinson's disease: Achieving consensus from key stakeholders. *Research Involvement and Engagement* 6(1): 35.
- Borrero L, Miller SA and Hoffman E (2022) The meaning of regular participation in vigorous-

- intensity exercise among men with Parkinson's disease. *Disability and Rehabilitation* 44(11): 2385–2391.
- Braun V and Clarke V (2021) *Thematic Analysis: A Practical Guide*. London: Sage.
- Burke NJ, Joseph G, Pasick RJ, et al. (2009) Theorizing social context: Rethinking behavioral theory. *Health Education & Behavior* 36(5 Suppl): 55S–70S.
- Campbell K, Orr E, Durepos P, et al. (2021) Reflexive thematic analysis for applied qualitative health research. *The Qualitative Report* 26(6): 2011–2028.
- Caperchione CM, Kolt GS and Mummery WK (2009) Physical activity in culturally and linguistically diverse migrant groups to Western society: A review of barriers, enablers and experiences. *OA Sports Medicine* 39(3): 167–177.
- Charlton GS and Barrow CJ (2002) Coping and self-help group membership in Parkinson's disease: An exploratory qualitative study. *Health & Social Care in the Community* 10(6): 472–478.
- Clarke C, Patel S, Ives N, et al. (2016) *Clinical effectiveness and cost-effectiveness of physiotherapy and occupational therapy versus no therapy in mild to moderate Parkinson's disease: a large pragmatic randomised controlled trial (PD REHAB)*. University of Leicester. Available at: <https://hdl.handle.net/2381/45246> (accessed 24 May 2024).
- Damier P, Hirsch EC, Agid Y, et al. (1999) The substantia nigra of the human brain: II. Patterns of loss of dopamine-containing neurons in Parkinson's disease. *Brain: A Journal of Neurology* 122(Pt 8): 1437–1448.
- Ellis T, Boudreau JK, DeAngelis TR, et al. (2013) Barriers to exercise in people with Parkinson disease. *Physical Therapy* 93(5): 628–636.
- Eriksson BM, Arne M and Ahlgren CC (2013) Keep moving to retain the healthy self: The meaning of physical exercise in individuals with Parkinson's disease. *Disability and Rehabilitation* 35(26): 2237–2244.
- Ernst M, Folkerts A-K, Gollan R, et al. (2024) Physical exercise for people with Parkinson's disease: A systematic review and network meta-analysis. *Cochrane Database of Systematic Reviews* 4(4): CD013856.
- Espenberger K, Fini NA and Peiris CL (2023) Identity, social engagement and community participation impact physical activity levels of stroke survivors: A mixed-methods study. *Clinical Rehabilitation* 37(6): 836–850.
- Goodwin VA, Richards SH, Henley W, et al. (2011) An exercise intervention to prevent falls in people with Parkinson's disease: A pragmatic randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 82(11): 1232–1238.
- Greenhalgh T, Clinch M, Afsar N, et al. (2015) Socio-cultural influences on the behaviour of South Asian women with diabetes in pregnancy: Qualitative study using a multi-level theoretical approach. *BMC Medicine* 13(1): 120–215.
- Haahr A, Groos H and Sørensen D (2021) 'Striving for normality' when coping with Parkinson's disease in everyday life: A metasynthesis. *International Journal of Nursing Studies* 118: 103923.
- Haydon G and van der Riet P (2017) Narrative inquiry: A relational research methodology suitable to explore narratives of health and illness. *Nordic Journal of Nursing Research* 37(2): 85–89.
- Holloway I and Wheeler S (2010) *Qualitative Research in Nursing and Healthcare*. Chichester: Wiley-Blackwell.
- Hunter H, Lovegrove C, Haas B, et al. (2019) Experiences of people with Parkinson's disease and their views on physical activity interventions: A qualitative systematic review. *JBI Evidence Synthesis* 17(4): 548–613.
- Huynh TLT, Silveira SL and Motl RW (2023) Physical activity behavior in persons newly diagnosed with multiple sclerosis: Applying the capability - opportunity - motivation - behavior (COM-B) model. *Multiple Sclerosis and Related Disorders* 69: 104432.
- Jang H, Clemson L, Lovarini M, et al. (2016) Cultural influences on exercise participation and fall prevention: A systematic review and narrative synthesis. *Disability and Rehabilitation* 38(8): 724–732.
- Keus S, Munneke M, Graziano M, et al. (2014) European physiotherapy guideline for Parkinson's disease. *The Netherlands: KNGF/ParkinsonNet* 191: 1–153.
- Khalil H, Busse M, Quinn L, et al. (2017) A pilot study of a minimally supervised home exercise and walking program for people with Parkinson's disease in Jordan. *Neurodegenerative Disease Management* 7(1): 73–84.
- Khalil H, Nazzal M and Al-Sheyab N (2016) Parkinson's disease in Jordan: Barriers and motivators

- to exercise. *Physiotherapy Theory and Practice* 32(7): 509–519.
- Mahmood B, Cox S, Ashe MC, et al. (2022) ‘We just don’t have this in us. . .’: Understanding factors behind low levels of physical activity in South Asian immigrants in Metro-Vancouver, Canada. *PLoS One* 17(8): e0273266.
- Malterud K, Siersma VD and Guassora AD (2016) Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research* 26(13): 1753–1760.
- Mayes J, Castle EM, Greenwood J, et al. (2022) Cultural influences on physical activity and exercise beliefs in patients with chronic kidney disease: ‘The Culture-CKD Study’-a qualitative study. *BMJ Open* 12(1): e046950.
- Michie S, van Stralen MM and West R (2011) The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science: IS* 6(1): 1–12.
- National Institute for Health and Care Research (NIHR) (2023) Payment guidance for researchers and professionals. Available at: <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392> (accessed 4 September 2023).
- National Institute for Health and Clinical Excellence (NICE) (2017) Parkinson’s disease in adults. NICE guideline [NG71]. Available at: <https://www.nice.org.uk/guidance/ng71> (accessed 4 September 2023).
- Nicholson SL, Donaghy M, Johnston M, et al. (2014) A qualitative theory guided analysis of stroke survivors’ perceived barriers and facilitators to physical activity. *Disability and Rehabilitation* 36(22): 1857–1868.
- O’Brien C, Clemson L and Canning CG (2016) Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson’s disease: A qualitative enquiry. *Disability and Rehabilitation* 38(5): 472–481.
- O’Driscoll T, Banting LK, Borkoles E, et al. (2014) A systematic literature review of sport and physical activity participation in culturally and linguistically diverse (CALD) migrant populations. *Journal of Immigrant and Minority Health/Center for Minority Public Health* 16(3): 515–530.
- Parkinson’s Excellence Network (2023) 2022 UK Parkinson’s audit - Summary report. Available at: <https://www.parkinsons.org.uk/sites/default/files/2023-06/2022%20Summary%20Report%20-%20FINAL.pdf> (accessed 11 April 2024).
- Parkinson’s UK (2022a) Written evidence to health and social care select committee on workforce: Recruitment, training and retention in health and social care. Available at: <https://committees.parliament.uk/writtenevidence/42721/pdf/> (accessed 3 June 2023).
- Parkinson’s UK (2022b) Race equality in research. Available at: <https://www.parkinsons.org.uk/research/race-equality-research> (accessed 4 September 2023).
- Pekmezci D and Motl R (2022) Targeting physical inactivity using behavioral theory in chronic, disabling diseases. *Exercise and Sport Sciences Reviews* 50(3): 156–161.
- Pentecost C and Taket A (2011) Understanding exercise uptake and adherence for people with chronic conditions: A new model demonstrating the importance of exercise identity, benefits of attending and support. *Health Education Research* 26(5): 908–922.
- Ravenek MJ and Schneider MA (2009) Social support for physical activity and perceptions of control in early Parkinson’s disease. *Disability and Rehabilitation* 31(23): 1925–1936.
- Riemann-Lorenz K, Motl RW, Casey B, et al. (2021) Possible determinants of long-term adherence to physical activity in multiple sclerosis—Theory-based development of a comprehensive questionnaire and results from a German survey study. *Disability and Rehabilitation* 43(22): 3175–3188.
- Rossi A, Torres-Panchame R, Gallo PM, et al. (2018) What makes a group fitness program for people with Parkinson’s disease endure? A mixed-methods study of multiple stakeholders. *Complementary Therapies in Medicine* 41: 320–327.
- Rowell A, Ashburn A, Fitton C, et al. (2022) Participant expectations and experiences of a tailored physiotherapy intervention for people with Parkinson’s and a history of falls. *Disability and Rehabilitation* 44(5): 727–735.
- Sallis J, Owen N, Fisher E, et al. (2008) Ecological models of health behavior. In: Glanz K, Rimer B and Viswanath K (eds) *Health Behavior and Health Education: Theory, Research, and Practice*, 4th edn. San Francisco, CA: Jossey-Bass, pp.465–485.

- Schootemeijer S, van der Kolk NM, Ellis T, et al. (2020) Barriers and motivators to engage in exercise for persons with Parkinson's disease. *Journal of Parkinsons Disease* 10(4): 1293–1299.
- Schrag A, Jahanshahi M and Quinn N (2000) How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. *Movement Disorders: Official Journal of the Movement Disorder Society* 15(6): 1112–1118.
- Sheehy TL, McDonough MH and Zauber SE (2017) Social comparisons, social support, and self-perceptions in group exercise for people with Parkinson's disease. *Journal of Applied Sport Psychology* 29(3): 285–303.
- Silveira SL, Riemann-Lorenz K, Heesen C, et al. (2021) Current and long-term physical activity among adults with multiple sclerosis in the United States: COM-B variables as explanatory factors. *International Journal of Behavioral Medicine* 28(5): 561–574.
- Soundy A, Collett J, Lawrie S, et al. (2019) A qualitative study on the impact of first steps—A peer-led educational intervention for people newly diagnosed with Parkinson's disease. *Behavioral Sciences* 9(10): 107.
- Tong A, Sainsbury P and Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19(6): 349–357.
- Willig C (2023) Perspectives on the epistemological bases for qualitative research. In: Cooper H, Coughtan M, McMullen L, et al. (eds) *APA Handbook of Research Methods in Psychology: Foundations, Planning, Measures, and Psychometrics*, 2nd edn. Washington, DC: American Psychological Association, pp.5–22.
- World Health Organisation (WHO) (2022) Physical activity fact sheet. Available at: <https://www.who.int/news-room/fact-sheets/detail/physical-activity> (accessed 4 September 2023).