



# Impact of a 7-day retreat for people with Parkinson's disease: a phenomenological study

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**Aim:** Early and ongoing access to rehabilitation and exercise may preserve functional mobility and quality of life for persons with Parkinson disease (PwP). The aim of the current study was to describe the experience of PwP who participated in a 7-day retreat. **Materials & methods:** A phenomenological approach was used to describe the lived experience of PwP. **Results:** Three themes emerged from interviews: a community of shared information where participants discussed exercising and learning with other PwP; improved control of Parkinson's disease symptoms, including performing physical tasks more easily and renewed motivation for their long-term plans for exercise because of the retreat. **Conclusion:** A 7-day retreat for PwP positively impacted perceived control of disease-related symptoms and intentions to continue exercise.

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Parkinson's disease (PD) is the second most common progressive neurodegenerative condition that affects multiple body systems. Over 2% of those aged 65 years and older have PD, and its prevalence is expected to more than double to 17.5 million by 2040 [1]. Typically, individuals present with motor symptoms, such as resting tremors, muscular rigidity, bradykinesia or hypokinesia and postural instability, and with nonmotor symptoms, such as sensory impairments, cognitive dysfunction, depression, anxiety, autonomic dysfunction and sleep disorders. Both motor and nonmotor symptoms can impact quality of life [2].

Although physical therapy and exercise for persons with PD (PwP) are often used interchangeably, both offer unique and potentially additive benefits that are shortlived (3–6 months) without sustained practice [3–5]. Research suggests that rehabilitation and exercise may decrease motor and nonmotor symptoms, preserve functional mobility (i.e., gait, transfers, balance and activities of daily living) and enhance quality of life in PwP [6]. Further, exercise may be a component of rehabilitation (physical, occupational and speech therapies) or it may occur as a stand-alone community group or personal training program.

Multiple studies have found that physical therapy effectively improves a wide range of motor symptoms in PwP, including postural instability, balance and physical performance [4,7,8]. A systematic review from 2015 [9] found that intensive exercise interventions were not only safe for PwP, but also led to improvements in muscle strength, cardiovascular fitness, balance, walking performance and quality of life. In that review [9], the duration of interventions ranged from 8 to 104 weeks, and sessions occurred one to three times per week.

PWR! Exercise4BrainChange<sup>®</sup> is a model exercise paradigm specifically designed for PwP and includes an amplitude specific training approach [10]. This approach focuses on high physical effort, cognitive engagement, attentional focus and emotional engagement with redundant practice of large-amplitude, high-effort movements and repetition to reinforce normalcy of large movements and automaticity [11]. A recent systematic review reported that this type of approach more effectively improved motor function than other interventions [12].

Other types of intensive interventions have used a retreat or residential approach where participants stay away from their homes with the purpose of learning or engaging in health-oriented activities or therapies [13]. In most of these previous studies, participants were healthy individuals who participated in activities daily for 5 days–4 weeks and few described using a group format as part of their interventions [13]. In general, participants had significant improvements in quality of life in the short term [13]. It is unclear why retreat-type interventions are not more widely reported in the literature. This may be related to the lack of financial support for these types of interventions by the US healthcare system and limited evidence regarding the impact on people with chronic health conditions [13]. Only two studies reported on intensive retreat or residential interventions for PwP, but the interventions were individual rather than in group format [14,15]. Specifically, participants were admitted to a rehabilitation hospital for 4 weeks and participated in cardiovascular, strengthening and balance exercises and activities to improve gait activities of daily living. At discharge all participants had improved in physical functioning [14,15]. Additionally, participants reported recognizing the importance of an active lifestyle for disease management and intended to continue the program [15].

When participating in community-based group exercise that was not a retreat, PwP had improvements in physical and emotional function, including exercise self-efficacy and social cohesion [16]. The perspectives on exercise by PwP was reported in a qualitative systematic review with only one study on group exercise including the voice of the participant [17]. No studies have explored the impact of a retreat type group format intervention for PwP. Therefore, the purpose of the current study was to describe the lived experience of PwP who participated in a 7-day residential retreat. The retreat included a variety of exercise interventions and educational sessions specifically designed for PwP.

## Materials & methods

The current study used an interpretive phenomenological approach and purposive sampling to describe the lived experience of PwP who participated in a 7-day residential retreat at a hotel resort. Because individual meaning-making is difficult to measure, it requires a qualitative approach. To understand the experience of the retreat by individual participants, a phenomenological approach was used in the study. Phenomenology seeks to understand the human experience within the context in which the experience occurs from the perspective of individuals [18]. The study was approved by the local institutional review board. All participants completed approved informed consent forms before participation.

The PWR! Retreat is a weeklong immersive experience designed to empower PwP through increased knowledge of PD and firsthand experience with a variety of research-informed exercise classes designed to target skills and function specifically impacted by PD. Individuals must pay to attend the retreat. All individuals interested in the retreat were screened for eligibility, health risks and fitness and mobility level by a PD-specialized physical therapist or group exercise instructor. To participate in the retreat, individuals had to self-report the ability to perform the following tasks: get up and down from the floor; walk for 60 min; participate in indoor and outdoor exercises with minimal assistance; tolerate 3 h of exercise during a 5 h period; be free of cognitive impairment so they could follow instructions, schedules and directions from staff or volunteers; and accomplish activities of daily living and navigate the setting of the retreat. After registration for the retreat was received, interested participants were contacted by a PD specialized clinician or exercise instructor to set up a 1-hour Zoom interview to review health and safety risks; medical limitations related to physical activity, fall risk or cognition; medication fluctuations and exercise history. This information was used to assign participants to four groups based on their fitness and mobility; groups were designated by color to hide the grouping parameters from participants. Potential participants of the retreat who were determined to be ineligible were offered other options and resources.

Each of the four retreat groups had 8–14 PwP. Groups were led by PD specialized licensed therapists (physical and occupational) and fitness instructors who had 3–12 years of experience working with an average of 4–5 PwP each day [10]. Each day of the retreat began with 60 min of pole walking before breakfast. After breakfast, there were two 1-hour exercise classes (separated by a 30-min break). Classes were based on quality practice of fundamental skills shown to deteriorate in PwP and interfere with everyday movements. These functional skills were systematically progressed physically and cognitively in all classes so that participants were optimally challenged. Aerobics (sustained or intervals) were incorporated into all classes. After lunch, participants attended lectures, group discussions and sessions that included yoga, mindfulness meditation or tai chi. Participants ate all three meals together with retreat staff and volunteers and were encouraged to congregate at other times when there were no planned activities.

**Box 1. Interview guide for the current phenomenological study.**

- Tell me about your retreat experience.
  - Do you think you gained anything from attending this retreat?
  - Is there anything you did or learned from this retreat that you could implement in your daily life?
- What would be hard for someone on the outside, like me, to understand about this retreat?
- Tell me about the most significant thing you took away from your experience.
  - Why was that meaningful to you?
- Have you noted any changes in your abilities or symptoms since you participated in the retreat?
  - Do you feel more capable of caring for yourself after this retreat?
- Did the retreat change how you think or feel about your Parkinson's disease?
  - Has this changed how you think about working with your family, support system or care partner?
  - Has this changed how you think about having a conversation with your doctor?
- Questions only for individuals who had previously attended the retreat.
  - What about the retreat lead you to attend again this year?
  - So what now?

To recruit participants for the current study, all PwP at the retreat received a recruitment flier in their welcome information. This flier included a detachable form that participants could submit into a box placed on a table during each meal period. Additionally, two study investigators attended the first and last day of the retreat to personally invite retreat participants to the study and answer questions. All PwP who attended the retreat were eligible to participate. Of the 47 participants who attended the retreat, 33 submitted the form and were contacted for an interview within 8 weeks of the end of the retreat. Eight responded and seven were interviewed.

Data were collected through one-on-one semi-structured interviews by one of the study investigators using the participant's preferred method: phone, Skype (Skype Technologies, Luxembourg), Zoom (Zoom Video Communications, CA, USA) or FaceTime (Apple Inc., CA, USA). Because participants were located throughout the US, video conferencing was used in the current study. This also allowed the researcher to observe nonverbal cues similar to face-to-face interviews and can, therefore, serve as a viable alternative when there are time and cost constraints [19]. Further, participants may be more comfortable being interviewed in a familiar setting, making them more likely to share information about themselves [19,20]. Given the physical limitations of some of our study participants, the increased comfort during video conferencing interviews may have been important to obtain data about the lived experience of these individuals. The interview guide for the study (Box 1) was developed by the research team, which included two individuals who had participated in the retreat as clinicians previously. The guide included 1 grand tour question that asked participants to talk about their retreat experience and five additional questions that assessed the impact of the retreat. All interviews were conducted within 5 days of receiving the participants consent documents. The interview protocol was piloted with one individual who was recruited from a previous retreat to establish the clarity of the questions and to refine the interview technique [21].

Interviews were audio recorded (Zoom H4N Pro Handy Recorder, Zoom North America, NY, USA) only and then transcribed to a written transcript by a professional transcriptionist (Landmark Associates, Inc., AZ, USA). The digital audio recording was stored on a password protected computer as an MP4 recording. One of the study investigators verified the accuracy of the written transcripts with the audio recording and de-identified the written transcript. This process was the first phase of data analysis. Next, the written transcripts were uploaded into data analysis software NVivo 10 (QSR International, CO, USA) where participants were assigned a numeric identifier to further de-identify the data. Data were analyzed using the constant comparison method [22,23]. Data saturation was met after seven participant interviews, based on the *a priori* criterion of no new codes for three consecutive interviews [24]. Additional measures to ensure trustworthiness and methodological rigor were employed. The use of a pilot interview allowed the researchers to establish if the proposed questions elicited the desired information from participants as well as to determine some of the logistics of the process including time required for the interview and the feasibility of using conferencing technology [21]. As the data analysis progressed, peer debriefing and continuous assessment of emerging themes by the research team was used. This along with an inquiry audit helped to explore potential biases of the researchers to minimize their impact on the emerging themes. Researchers further used triangulation of sources, in this case different participants, to establish that themes were representative of the experiences of more than one individual [25]. Finally, thick description is used in reporting to allow readers to hear participant's 'own words' and determine any connections they might have with the participants [20,21,25,26].

**Table 1. Participant demographic characteristics of persons with Parkinson's disease who attended a 7-day retreat.**

Participant	Age (year)	Time since diagnosis (year)	PWR retreats attended (n)	Fitness/mobility level
1	76	8	3	High
2	57	6	2	High
3	66	10	2	Moderate-high
4	65	3	3	Moderate-high
5	65	13	7	Low-moderate
6	58	15	3	Low
7	68	29	7	Low

## Results

Seven participants from the 7-day retreat participated in one-on-one interviews. Demographic characteristics of study participants are presented in Table 1. Three main themes emerged during data analysis: a community of shared information, improved control of PD symptoms and renewed motivation. A brief description of each theme and additional exemplars are provided in Table 2.

### A community of shared information

During the interviews, all participants described interactions during lectures or with other participants, or volunteers, where information was learned and shared with the community at the retreat. Participants also spoke about the information presented by speakers at the retreat as being beneficial to their understanding of PD, especially regarding new and emerging research.

*"There are seminars, basically – yeah, I guess 'seminar' would be the best term – expert speakers on different topics including non exercise information, latest research and information and sharing medication experiences with different kinds of Parkinson's medications."* (Participant 5)

*"The speakers are very useful. It's a source of information of what's happening in Parkinson's."* (Participant 3)

Participants also noted the expertise of the individuals guiding the exercise sessions and how they specifically ensured participants understood why the exercises were important and how to correctly perform them.

*". . . the physical therapy staff and the people on the retreat are so knowledgeable and inspiring, and you come away with new information and new rationale for doing your exercises."* (Participant 1)

*"It is a very effective way of communicating it and learning it, having someone touch up the way you do the exercises and make sure you are doing them properly is useful."* (Participant 3)

Finally, participants described the camaraderie of being in an environment with other PwP. These relationships were described as supportive in part because as Participant 2 said, *"you do not have to explain things to each other"*. The support was also described as extending beyond the retreat.

*"You can help the people that have just been newly diagnosed because you have already gone through that yourself. You can help them with things like how you can tell your boss or your acquaintances, or just any things that come in handy for everyday life."* (Participant 6)

*"I think it has educated me on different aspects of the disease, what I might face or what I should be paying attention to. . . . We keep in touch during the year and encourage each other and share things. I think the interaction lets you know you are not dealing with this – the disease – by yourself; that there are resources out there, there are supporters out there. I think that's important."* (Participant 4)

### Improved control of PD symptoms

Each participant expressed perceived improvements immediately during the retreat or as a result of participating in the retreat. Some noted that they felt that they personally experienced improvements in their ability to perform certain activities.

*". . . she could see that my gait was not quite right, and as the session got over she took me out in the hallway and had me walking up and down the hallway. Encouraging and being excited that – just that simple time she spent with me made a difference. I went from dragging my left leg to heel-toe-heel-toe and head up, back*

**Table 2. Theme descriptors and additional exemplars for each theme identified from analysis of interviews with persons with Parkinson's disease who attended a 7-day retreat.**

Theme and descriptor	Exemplars
<p><b>Community of shared information</b> Participants described the impact of shared information between colleagues (other individuals with PD) and from volunteers and experts</p>	<p>"Number one, you do not have to explain things to each other. You know the vernacular in which you are speaking and the vocabulary, and we know we are feeding each other a line about not getting, not doing the work. It is a positive encouragement, but 'getting' on each other when we get lazy" (Participant 2)</p> <p>"You can help the people that have just been newly diagnosed because you have already gone through that yourself. You can help them with things like how you can tell your boss or your acquaintances, or just any things that come in in handy for everyday life" (Participant 6)</p> <p>"I think it has educated me on different aspects of the disease, what I might face or how to – what I should be paying attention to. I started going to a voice therapist, so that I do not lose my voice as many Parkinsonians do, and knowledge of – that your whole body is a muscle and you got to work every muscle, and that Parkinson's is working against that. I think it is just the level of reinforcement of what I need to do to maintain my quality of life" (Participant 4)</p> <p>"It's hard to imagine the experiences that I have just been talking about without having attended a retreat. There's a lot I would not know, not only in terms of physical and medical information, but just the attitude, I guess, through all the classes" (Participant 5)</p>
<p><b>Improved control of PD symptoms</b> Participants described their sense of improved control of their PD symptoms</p>	<p>"[P]atients usually struggle against their diseases – often times they do –and being able to exert some control on the course and nature of my disease is incredibly meaningful and positive thing to me" (Participant 7)</p> <p>"Not noticing any changes after the retreat could be a plus. It could be that I am not physically changing or that maybe the progress of the disease has slowed down. In either case, it could be a great positive in that I have arrested the progression of the disease. To me, that's a giant plus" (Participant 7)</p> <p>"Each time I have gone, I have been able to take those exercises and work them into my regular day-to-day life, and this year was no exception. I am in the best shape that I have been in since before my husband passed away, and that would have to be 2009" (Participant 6)</p> <p>"Now, that kind of thing almost never happens. I still have down periods. I still have freezing-like reactions, but nowhere near as bad as that, and almost always something I can overcome by basically forcing myself to walk in ways that I know are more effective than, for example, if I do heel first walking as opposed to toe walking" (Participant 3)</p> <p>"About 3 years ago, when I was basically rapidly losing the ability to be mobile and, subsequently, now I feel like I am a little bit better every year than I was the year before. The tide has changed. That is a really nice feeling to have" (Participant 3)</p> <p>"I would say that I believe now that I can regain some control of my life and my body" (Participant 2)</p> <p>"At the same time, I was doing things that I believe helped lessen my symptoms, improve my Parkinson's symptoms, my tremor and balance and strength and endurance. It showed me the importance of physical exercise, specific exercises that I feel really have a direct effect on the severity of my symptoms..." "Yeah, I think it actually lessened the frequency in my tremor and the amplitude of my tremor which has always been in my left hand" (Participant 5)</p>
<p><b>Renewed motivation</b> Participants described feeling motivation, optimism and hope after the retreat</p>	<p>"Even memories from the retreat, I think, help me keep myself motivated and doing more exercise than I would otherwise if I had not been to the retreats. That is, I think, the most important, lasting effect of the retreats, the other 51 weeks of the year" (Participant 5)</p> <p>"I remember 2 years ago, I think it was [Name], she got me to get up out of a chair on my own without using my hands. And that was something that recharged my hope battery. I have not been able to do it every time, but I still can do it somewhat in visits and everything else, so it is one of those things that helped. And like I said earlier, if you do not have hope, there is no other point in doing the exercise" (Participant 6)</p> <p>"That sense of feeling that you are among friends. The relief is a sort of process that you go through in the first couple of days that makes you realize when you look around and realize that half the people are there with Parkinson's and half are there as caretakers or helpers. It makes it a relief to be there with that group of people... They are the perfect place to go for people with our disease because it is a group of people who are out to change the world" (Participant 7)</p> <p>"First of all, I liked it, and I like all the people. Even the things that I did not like to do, I knew I needed to do 'em. I needed a tune-up and actually I will be going back in October or November" (Participant 2)</p>

PD: Parkinson's disease.

straight. I know now that if I concentrate – and I remember, too, that she told me, taught me, showed me that I am not gonna be wandering around." (Participant 2)

"That is something that gets altered from being at the Parkinson's retreat. It is altered because you are doing the exercises that are specifically tailored for those of us with Parkinson's. You end up being able to do things that you could not do before or do more of them or doing them looking better or things like that." (Participant 7)

Others commented on changes in the abilities of others at the retreat.

*“Watching some of them go ahead of you in terms of the exercises – how well they can do it. Others will not keep up with you but will also make advances. It is sort of like watching a group of people improve before your eyes.”* (Participant 7)

Participants also indicated that they felt the retreat may not have resulted in improvements in functioning or their symptoms, but that they had not experienced a worsening of their symptoms. For these participants, this outcome was as important to them as improvements, considering PD is degenerative.

*“I have learned, and mainly from the retreats, that I can have more good days if I keep in a regular exercise routine... What I learned there and what I have been motivated to continue after the retreat has slowed the progress of the disease for me personally.”* (Participant 5)

In each case, participants viewed this positive change or lack of decline optimistically and felt they had more control of their disease.

*“Going through this course is meaningful to me because it gives me something to do to fight back against the disease. That is a very meaningful thing to have. It is a very important thing to have. If you have no sense of your ability to act or to change anything, I think you tend to give up more as a patient. If you have something that you know will help in altering the effects of that disease on yourself, then you have got a new tool, and that is a powerful tool to have. . . . You end up feeling at the end when you can do something that you could not do before – that you really made some progress in fighting against this disease.”* (Participant 7)

*“I have noticed that I do not feel as though I have gotten any, I do not want to call it worse, but nothing’s more pronounced. I do not know if that means I am maintaining control of things; maybe it does.”* (Participant 2)

### Renewed motivation

Each participant described a new sense of hope or motivation following the retreat. The participants described this spirit and camaraderie as the thing that motivated them to continue with exercises during the other 51 weeks of the year.

*“There is a camaraderie, an esprit de corps that you develop with others in your exercise class at the retreat. It is fun to go back every year and see the people that you would meet a year before or 2 years before; see how they have progressed or what challenges have changed for them; and gives you ideas and information as well as just a mutually supporting spirit. Helps you keep motivated to do the exercises.”* (Participant 5)

*“Generally, the enthusiasm of the – not only the staff, but the people who attend – kind of is infectious. You know you come away from that with sort of a new lease on exercise and doing things proactively.”* (Participant 1)

*“I think it is inspiring in the sense of you can deal with this disease, slow it down. You can live a healthy life, and I guess look at the rosy side of it, not the dreaded side of all the symptoms that could go wrong if you sat on your butt.”* (Participant 4)

### Discussion

The purpose of the current study was to describe the lived experience of PwP who participated in a 7-day residential retreat focused on disease specific exercise and education. Our findings suggested that study participants benefited from the retreat by being a part of a community with shared experiences and by experiencing new motivation, optimism and hope after the retreat. Additionally, participants reported improvements in their ability to control their PD symptoms.

A systematic review investigated the impact of retreats on health and wellbeing in a variety of groups and found improvements in perceived physical and emotional health that in some cases lasted up to 5 years after the retreat [13]. For individuals with chronic disease, the benefits were similar [13] and supports the perceived physical and emotional benefits experienced by participants in the current study. Studies by Hadgkiss *et al.* [27] and Li *et al.* [28] investigated the impact of a 5-day residential retreat focused on lifestyle modification for individuals with multiple sclerosis and found positive effects on short-term and long-term health-related quality of life. Although we did not specifically assess quality of life measures, our participants indicated better perceived control of their PD symptoms and a sense of optimism that typically support better quality of life.

The impact of retreats has not been directly studied in PwP; however, intensive in-patient rehabilitation interventions have been found to positively influence outcomes of physical functioning and medication use for PwP [14,15]. The participants of these in-patient intensives also reported shifts in thinking about their PD [14,15], like participants of the current study. In those previous studies [14,15], the perceived improvements and changes in functioning of participants were supported by observed measures of physical functioning. Similarly, a study by Claesson *et al.* [29] that evaluated the impact of group exercise reported participants had perceived improvements in physical functioning. In the current study, we did not assess measures of physical functioning, but the similarity of intensity and focus on PD-specific exercise during the retreat resulted in perceived improvements, as indicated during interviews. It is possible that these improvements may be related to objective improvements. Additional studies should investigate this link between meeting social and emotional needs and physical function in PwP participating in intensive retreat group programs.

Several studies support the importance of group-based activities for PwP for continued participation in exercises [30–32]. Participants in the current study described the importance of their interactions with others, including other retreat participants with PD, therapists and experts, as motivation for their continuation of exercise and physical activity. Similarly, Claesson *et al.* [29] found that the connections and joy of exercising with others were motivators to continue. Likewise, Tidman & Skotzke [30] found that 5% of PwP who participated in PD-specific community-based exercise classes three times a week for 8 weeks reported improved motivation to continue exercising. In the current study, the ability of participants to connect with other PwP created a safe and inclusive environment to exercise and share experiences. Other authors have also noted that the impact of exercising with other PwP was important for continued motivation to participate and comfort in the group-based exercise environment [32,33]. The opportunity to learn from others in the group in the current study was cited as a motivator to work harder. Although the PWR! Retreat was not meant as a self-help group, the participants also described the importance of interacting with others with PD for a sense of agency about their symptoms and for ongoing motivation and self-efficacy for exercise.

While recognition of the need to exercise and its importance in maintaining physical functioning is important, it may not be enough to motivate PwP to initiate or maintain an exercise routine. Claesson *et al.* [29] reported that, although their participants recognized the need to exercise, the support of a group exercise intervention was important for maintaining motivation to continue. In a study by Atkins *et al.* [33], apathy and fatigue were substantial barriers to initiating and maintaining physical activity. However, having routines and finding a safe social environment to exercise with other PwP helped the participants find motivation for physical activity [33]. Similarly, our participants indicated that being with other PwP and people who did not judge them for impaired movement as one of the benefits of the retreat. The mixed-methods study by Tidman and Skotzke [30] on community-based exercise for PwP similarly reported improved self-perceived socialization and motivation to exercise, despite a lack of evidence for improved movement [30]. Additionally, the routine of the retreat allowed participants to begin a routine of physical activity that they could carry into the rest of the year.

Barriers to initiating and maintaining exercise are greater for the low-active, sedentary PwP (<3 h/week) who are more likely after diagnosis to decrease their activity, compared with the postdiagnosis increased activity of high-active PwP who report half the number of barriers [34]. While the current study did not focus on differentiating the perspectives of participants from low versus high activity levels, included in our results are the perspectives of the 2 low and 1 low–moderate activity level participants. In a mixed-methods study of relationships between sedentary behaviors and quality of life in PwP, Ellingson *et al.* [35] found that time spent in sedentary behaviors was significantly related to mobility, cognition and communication aspects of quality of life [35]. The increased sense of agency and control over their PD symptoms reported by participants in the current study is supported by several studies on self-efficacy [31,36–38]. Defined as one's perception of having sufficient capacity to engage in a task [36], self-efficacy for exercise has an important role in the likelihood that a PwP will begin and maintain engagement in exercise [31]. In a study of 73 PwP in an outpatient neurology clinic, Estrada-Bellmann *et al.* [37] found that participants with lower scores on the Chronic Disease Self-Efficacy Scale had worse motor and nonmotor symptoms and quality of life. A paper by Stevens *et al.* [38] identified several strategies for increasing exercise self-efficacy in PwP, such as highlighting small achievements and the progression of skills, offering positive feedback and emphasizing the barriers to exercise that have been overcome rather than compliance with an exercise program. Atkins *et al.* [33] also found that, specifically for PwP, exercise was perceived as part of how they regained control of their disease. In the current study, participants reported that they either maintained or improved in their PD symptoms, and they

viewed this lack of decline in their progressive disease as extremely powerful, which resulted in a greater sense of control.

The current study had limitations. Individuals who were involved in the retreat self-selected to participate in the study and only a small number of participants were ultimately able to be contacted for the interview. This may have biased results. During several interviews, the video component of the technology was lost, and the interviews were continued using only audio. These types of technical issues have been noted as a limitation for the use of video technology in qualitative studies [19]. This study used semi-structured interviews which could have influenced the responses of participants based on the interactions that occur during the course of the interview. Since the participants knew the interviewer was a student at the time of data collection and had interacted with her previously during the recruitment phase, they may have responded more favorably to some questions. Additionally, the interviewer was a novice researcher. Several authors suggest inexperienced researchers may use ineffective interviewing and data analysis strategies [39–41]. However, several strategies were used to mitigate potential limitations during the study. For example, criteria for saturation were established *a priori*, which limited subjectivity during data analysis. Peer debriefing and an inquiry audit also helped to limit bias during analysis. While this current study did not use member checks, the credibility of the identified themes and transferability of study findings are based on the exemplars as expressed by the participants' own words.

To better understand the impact of this retreat, future studies should include physical measures, like balance and the ability to perform functional tasks, and quality of life using validated quantitative measures. Most of the participants in the current study described the retreat as a motivator for continuing to exercise for the rest of the year. Therefore, measuring exercise adherence before and after the retreat would be helpful to understand the long-term impact of intensive interventions like the retreat. Second, exploring the perceptions of exercise by low functioning or sedentary PwP could increase the understanding of specific barriers they may face including physical and psychosocial. Finally, future research should focus on individualizing physical activity interventions that include sedentary individuals with PwP and that use biopsychosocial models of health & wellness [42].

## Conclusion

In the current phenomenological study, participants of a 7-day residential retreat for PwP reported that the retreat created a community of shared information, a sense of improved control of PD symptoms and renewed motivation that helped them continue their journey with the disease. In conjunction with existing literature, these findings may provide guidance to future PD specific retreat endeavors and traditional healthcare models in the treatment of the whole person in PwP.

### Summary points

- A considerable body of literature supports physical activity and exercise for persons with Parkinson's disease (PD) (PwP); however, barriers to exercise include self-efficacy, depression, apathy and outcome expectations.
- Retreats (immersive experiences for education or receiving therapies) have a positive impact on physical and emotional health and on wellbeing.
- In the current study, PwP who participated in a 7-day retreat that focused on PD specific exercises and information reported positive outcomes related to their physical and emotional health and wellbeing.
- Being a part of a community of shared information and experience allowed participants to feel safe exercising.
- Participants described strong connections with others at the retreat, which led to continued communication after the retreat.
- Perceived improvements in physical function were reported by all participants.
- Participants reported a renewed sense of motivation driving them to keep exercising into the future.
- A greater sense of control over their disease was noted by all participants.

### Author contributions

All authors contributed to study conception and design and reviewed the final manuscript; LM Bordenave data analysis, interpretation of the data and writing of the manuscript; CF Nelson contributed to data collection and data analysis; BG Farley contributed to interpretation of the data and writing of the manuscript and TL Mclsaac contributed to data analysis, interpretation of the data and writing of the manuscript.



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## Financial & competing interests disclosure

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No writing assistance was utilized in the production of this manuscript.

## Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

## Data sharing statement

Individual participant data will not be shared.

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