

Engagement in exercise for people with Parkinson's: What is meaningful?

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ABSTRACT

Whilst it is suggested that exercise is integral in the management of Parkinson's, there is minimal literature exploring this population's perceptions about exercise, and how these perceptions relate to standardised physical outcome measures. This mixed method study explored participants' views on an exercise programme which was offered as part of an intervention in a randomised controlled trial for people with Parkinson's. Participants in the intervention group (n=21) received an exercise programme and a cognitive enrichment programme while the control group (n=20) continued with usual care. Semi-structured, face to face, audio-recorded individual or group interviews were undertaken with the intervention group and data analysed thematically. Quantitative data extracted from the clinical trial included the 6 Minute Walk Test and the mini-Balance Evaluation Systems Test (mini-BESTest). The themes: 'Having trust in professional guidance', and 'An understanding and supportive environment' contributed to the overarching theme of 'A sense of individual empowerment'. Together the themes demonstrated meaningful holistic benefits gained by participants, which differed from the non-statistically significant quantitative results from the clinical trial. Small group tailored exercise effectively addressed multiple cornerstones of health in people with Parkinson's, creating an overall sense of individual empowerment. This study also suggests that research may overemphasise reporting of standardised physical outcomes to the detriment of what participants perceive as meaningful outcomes.

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INTRODUCTION

Parkinson's disease is the second most common neurodegenerative condition worldwide (Pringsheim, Jette, Frolkis, & Steeves, 2014). It affects approximately 1% of people over 60 years old, with prevalence increasing to around 4% of people aged over 80 years (De Lau & Breteler, 2006; Hirsch, Jette, Frolkis, Steeves, & Pringsheim, 2016). While traditionally labelled as Parkinson's disease, this condition is not in fact a

disease, nor is it communicable. Thus, instead of Parkinson's disease, people diagnosed with this condition refer to it as Parkinson's (Parkinson's UK, 2017; The Parkinsonism Society of New Zealand, 2017). We have therefore used the term Parkinson's instead of Parkinson's disease in this research report.

Parkinson's occurs as a result of pathophysiological changes to the substantia nigra (Jankovic, 2008) resulting in both motor and non-motor symptoms (Bonnet & Houeto, 1999; Mandir

& Vaughan, 2000). Individuals diagnosed with Parkinson's are almost six times more likely to develop dementia compared to the general population (Aarsland et al., 2001). They are also more susceptible to the effects of inactivity, as the effect of this condition on the basal ganglia leads to decreased activation of motor neurons, thus accelerating muscle atrophy (Glendinning & Enoka, 1994).

Exercise in general has physiological benefits such as improved coronary blood flow, body composition, insulin sensitivity, blood lipid ratios and decreased blood pressure (Hambrecht et al., 2000; Warburton, Gledhill, & Quinney, 2001). It can therefore be argued that it is extremely important for people with Parkinson's to exercise regularly. A large systematic review and meta-analysis found good evidence of the benefits of exercise for people with Parkinson's, with improvements in physical function, health-related quality of life, leg strength, balance, and gait speed and quality (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008). There is an emerging body of evidence examining perceptions of exercise by people with Parkinson's (Crizzle & Newhouse, 2012; O'Brien, Dodd, & Bilney, 2008; Sheehy, McDonough, & Zauber, 2017). While some studies have identified the importance of exercise in a group environment (Crizzle & Newhouse, 2012; Lötze, Ostermann, & Büsing, 2015; O'Brien et al., 2008; Sheehy et al., 2017), others have looked at exercise as a way to promote self-efficacy and improve quality of life (Combs et al., 2013; Lötze et al., 2015; Rodrigues de Paula, Teixeira-Salmela, Coelho de Moraes Faria, Rocha de Brito, & Cardoso, 2006). There is however, limited research that examines the perceptions of people with Parkinson's of small group, tailored exercise delivery.

This mixed method study, nested in a larger randomised controlled trial (RCT), aimed to explore the perceptions of participants in the intervention arm of a physiotherapist-delivered small group, tailored exercise programme, as a way to explore feasibility for exercise interventions for people with Parkinson's. A secondary aim was to compare and contrast the perceptions of undertaking exercise in this way, to the results of standardised physical outcomes.

METHODS

The RCT explored the effect of physical and cognitive enrichment, through enhanced physical and cognitive exercise, on decline to dementia in adults (>60 years of age) diagnosed with idiopathic Parkinson's. Eligible individuals for the RCT were identified through Christchurch Neurology clinics or the New Zealand Brain Research Institute (NZBRI) database. Individuals who lived in the Canterbury region, diagnosed with idiopathic Parkinson's, without any other atypical movement disorders, were screened in 2016 for inclusion in the RCT using the Conversion to Dementia score developed by the NZBRI (Dalrymple-Alford, Anderson, Farrer, & colleagues, 2016). They were invited to participate in the RCT if they had a Conversion to Dementia score of > 5%, meaning they were at risk of developing dementia in the next four years, but were not yet classified as having mild cognitive impairment. Individuals were excluded if they had current involvement in any NZBRI longitudinal studies on cognitive changes in Parkinson's, were involved in other studies that included pharmacological

intervention, were currently using any medications that could impact cognition, had any other current or past neurological or psychiatric conditions, or had a poor comprehension of the English language. They were also excluded if they had a history of major illness in the past year, alcohol or substance abuse or learning disability.

In the larger RCT, 41 eligible consenting participants were randomised to the intervention (n=21) or control group (usual care) (n=20). Participants in both groups completed pre- and post-intervention cognitive and physical outcome measures. Cognitive measures included a range of neuropsychological and neuropsychiatric tests. The physical measures were the Unified Parkinson's Disease Rating Scale (UPDRS) (Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003), the Six-Minute Walk Test (6MWT) (Steffen & Seney, 2008) and mini-Balance Evaluation Systems Test (mini-BESTest) (Leddy, Crowner, & Earhart, 2011). The UPDRS is comprised of four sections, including a motor section, and provides a means to monitor Parkinson's related disability and progression (Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003). The 6MWT measures distance walked on a flat surface over six minutes as a way to gauge aerobic capacity and endurance (Steffen & Seney, 2008). The mini-BESTest is a shortened version of the BESTest that includes only 16 of the original 36 items and is believed to measure dynamic balance (Leddy et al., 2011). These tests have been shown to be reliable and valid in this population (Leddy et al., 2011; Steffen & Seney, 2008). The tests were administered by a trained, blinded assessor as part of the larger RCT.

The intervention group undertook an eight month programme of supervised physical activity and cognitive enrichment exercises. Supervised physical exercise was offered to the intervention group at a community physiotherapy clinic. Participants had a one hour weekly session, in small groups of three to five attendees. There were four sessions on offer each week, with sessions provided by the five clinic physiotherapists, and participants were given some choice as to preference for their own session, depending on numbers of attendees in a particular session. The programme comprised a combination of aerobic, progressive resistance and balance exercises in a circuit setting. The physiotherapists prescribed tailored exercises to reflect individuals' physical capacity. During each session, participants gave feedback of perceived exertion using the Borg Rate of Perceived Exertion (RPE) scale (Borg, 1982). Participants were asked to exercise at a moderate intensity (12 to 14 on the Borg RPE scale), thereby maintaining exercise intensity as exercise capacity improved over time.

This study, nested in the larger RCT, took a mixed method research approach, incorporating both quantitative and qualitative data, to allow for a broader examination and understanding of the research topic (Creswell, 2007; Johnson, Onwuegbuzie, & Turner, 2007). Quantitative data (UPDRS motor, 6MWT and miniBESTest) were obtained from the larger RCT. Adherence data to the exercise programme were obtained from attendance sheets kept by the physiotherapy clinic.

All 21 participants randomised to the intervention group were invited to participate in a semi-structured, audiotaped interview

before or after their last exercise session, at a time and place that was convenient for them. Interviews, undertaken by a researcher who had no previous involvement with any of the participants (HM), were conducted in small groups of two to four participants, or individually according to participant preference. Interview questions, asked in a conversational format, explored participants' experience of engaging in the individually tailored, small group exercise programme for people with Parkinson's (Appendix 1). The Health and Disability Ethics Committee, New Zealand, provided approval for the study, reference 15/NTB/161.

Data Analysis

We calculated the means and standard deviations for the physical outcome measures and the adherence data. We also compared the physical outcome measure results between the intervention and control groups using confidence intervals (CI) and two-tailed Z-tests.

An inductive approach (Braun & Clarke, 2006) was used to analyse the interview data for themes. An independent transcriber contracted for the study transcribed and uniformly formatted the interviews. To ensure contextual accuracy, all audio files were listened to by at least three members of the research team and corrections were made to the transcripts where necessary. Transcripts were then distributed amongst the research team for coding. Information pertinent to the research question was highlighted, coded and given a descriptor. Codes for each transcript were listed. Once the initial readings and coding were complete, transcripts were re-read independently by all other members of the research team. Together, the codes were cross-checked, any additional codes identified, and the codes were collated into a list, thereby obtaining a visual record of the codes. Via extensive and iterative research team discussions and mind mapping, we then grouped the codes into categories, then into subthemes and eventually themes (Farmer, Robinson, Elliott, & Eyles, 2006; Onwuegbuzie & Leech, 2007).

RESULTS

Table 1 provides a demographic overview of the study participants in the intervention group. Table 2 summarises the results of the quantitative data from participants in the intervention and control groups. The intervention group comprised 13 males and eight females with a mean age of 69.4 (SD 6.8) years and a mean UPDRS motor score of 32.5. Attendance at the exercise programme was high at 84%. There were 13 males and seven females in the control group with a mean age of 69.8 (SD 5.4) years and a mean UPDRS of 28.4.

At baseline, comparison of UPDRS (motor) scores for the control and intervention groups showed a clinically significant difference of 4.1 points between the groups. On average, participants in the intervention group scored 9.8 metres less ($p=0.63$) in the post-intervention 6MWT compared to pre-intervention. In contrast, the control group walked 14.8 metres further ($p=0.55$) on their 6MWT at the end of the trial period compared to their initial distance. Mini-BESTest scores decreased 0.6 points ($p=0.52$) over the trial period for the intervention group, compared to a decrease of 0.1 points ($p=0.96$) for the control group.

Table 1: Participant demographics at entry to larger RCT (intervention group)

Participant	Sex	Age (years)	Symptom duration (years)
1	M	82	14
2	M	70	6
3	F	67	2
4	F	74	4
5	M	82	6
6	F	74	5
7	F	62	14
8	M	65	19
9	M	68	10
10	F	82	11
11	M	76	2
12	M	63	6
13	F	69	9
14	M	61	9
15	F	65	2
16	M	74	4
17	M	61	3
18	F	65	23
19	M	62	1
20	M	68	6
21	M	64	10

Notes: M, male; F, female; RCT, randomised controlled trial

All 21 intervention group participants were interviewed (15-40 minutes). All interviews were held at the physiotherapy clinic where they had undertaken the exercise sessions. Most interviews were undertaken in a small group of up to four people, with five participants requesting an individual interview. Three themes were evident in the interview data: 1) Trust in professional guidance; 2) An understanding and supportive environment, and 3) A sense of individual empowerment. Although the three themes were separate entities, with each encompassing separate subsets of the data (Table 3), they were also intrinsically linked. Themes one and two, when applied through the conduit of a small group tailored exercise programme, contributed to the overarching theme of 'A sense of individual empowerment'. This relationship is demonstrated in Figure 1. The themes are described below, with subthemes and supportive quotes taken from transcripts and linked to participants (e.g. P1 = participant 1, etc.).

Table 2: Summary of outcomes measured (intervention and control groups)

		Intervention Group (n=21)					Control Group (n=20)				
		Mean	SD	CI		P value	Mean	SD	CI		P value
				Lower	Upper				Lower	Upper	
6MWT (metres)	Pre	304.6	61.6	-31.0	50.8	0.63	293.6	76.6	-64.9	35.2	0.55
	Post	294.8	69.4				308.4	77.6			
Mini-BESTest (max score 28)	Pre	19.9	5.6	-2.5	4.9	0.52	21.1	6.0	-3.8	4.0	0.96
	Post	19.3	6.0				21.0	6.2			
Exercise adherence (%)		84.1	12.5								
Intervention v Control											
UPDRS (motor)	Pre	32.5	13.4	-12.8	4.7	0.35	28.4	14.3			

Notes: CI, confidence interval; SD, standard deviation; 6MWT, 6 Minute Walk Test; UPDRS, Unified Parkinson's Disease Rating Scale; P value, significance value set at <0.05; mini-BESTest, mini-Balance Evaluation Systems Test

Table 3: Summary of subthemes and themes

Themes	Subthemes
Trust in professional guidance	<ul style="list-style-type: none"> • Physiotherapist knowledge about how Parkinson's affects the body and activities of daily living. Ability to tailor exercise programme to individual needs • Ability to modify exercise programme so that it challenges the individual participant • "Professional leadership" of the group
An understanding and supportive environment	<ul style="list-style-type: none"> • Camaraderie between group members • Empathy from group members who understand the challenges of living with Parkinson's • Encouragement received and given within the group • Accountability of belonging to the group
A sense of individual empowerment	<ul style="list-style-type: none"> • The feeling of improved self-efficacy • The feeling of self-actualisation • Functional gains resulting from undertaking exercise • The feeling of taking back control of one's life after diagnosis with Parkinson's

Theme 1: Having Trust in Professional Guidance

This theme pertains to the repeated reflection of many participants around the benefits of having a trained physiotherapist guiding their exercise programme. This theme was derived from a number of subthemes outlined in Table 3. Participants valued their physiotherapist's knowledge of Parkinson's and their understanding of how Parkinson's affects the body. Participants identified how this felt different to their previous experiences of fitness instructors/personal trainers: "In a normal gym] you wouldn't have someone overseeing who's got the knowledge of what Parkinson's can do and the effect it can have." (P9). Furthermore, participants were less inclined to engage in exercise groups where there was a lack of professional guidance: "I looked at going to a gym... but nobody running the gyms or anybody involved had any experience in managing Parkinson's." (P20). They also felt understood and "challenged within the routine" (P14) because

their physiotherapist was able to individualise the group programme to suit participants' differing physical capabilities. Thus individualising the programme as opposed to "a series of exercises for the sake of it" (P17), created the feeling of a safe, enabling environment and allowed participants to build confidence to challenge their capacity. Moreover, it resulted in holistic and functional benefits: "[the exercises] have helped me enormously. Whether it has helped me more mentally than physically I don't know, but the whole combination has been pretty good" (P7). Participants built feelings of rapport with and trust in the physiotherapist, because of his/her ability to work with each participant personally to suit their level of capability, to prescribe an individualised, variable but sufficiently challenging exercise programme. Participant 11 exemplified this when he said "modifications were given to me [by the physiotherapist] in consultation with me... It gives me a challenge to achieve". By having the physiotherapist

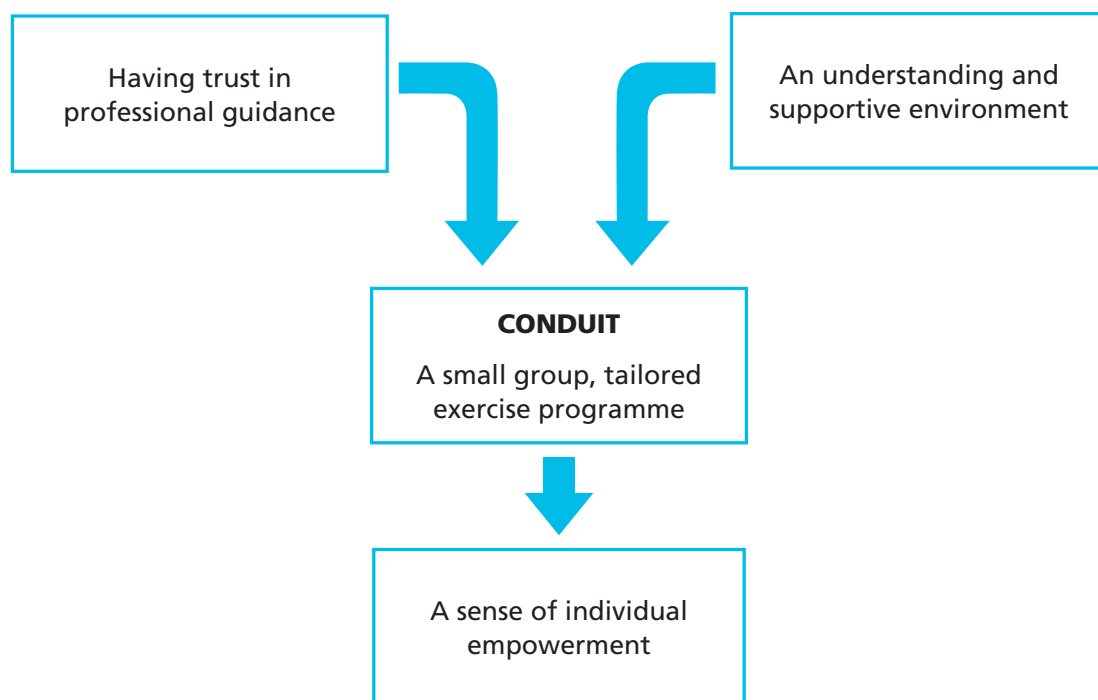


Figure 1: A model for the development of 'A sense of individual empowerment'

present, participants felt encouraged to push themselves with the exercises: *"Having someone overseeing what you're doing makes you try that little bit harder"* (P4). Another participant reflected *"she was watching us all the time making sure she didn't overtax us, but we were pushing ourselves"* (P1). Participants described how they were encouraged by the physiotherapist to reach a level on the Borg RPE scale where they were 'moderately challenged' even if the complexity or level of exercise had to differ depending on how they felt on a particular day.

Theme 2: An understanding and supportive environment

The second theme alludes to the benefits that participants reported from being immersed in the small group setting. This setting provided the opportunity to engage with other individuals who also live with Parkinson's and who therefore understood the inherent challenges resulting from living with the condition. This theme included a number of subthemes (Table 3), illustrated below.

A strong and repeated message throughout the interviews was the enjoyment and motivation gained from the small group setting: *"an ordinary gym tends to be bigger, and a little more impersonal as a result, whereas this is quite a cosy little group"* (P19). Other community gyms were not perceived as able to emulate the understanding and supportive environment created in the small group setting, and hence were not as well received: *"I still do belong to [a gym] and I was going along there at times to [an exercise class] but I felt a bit out of it. They encouraged me but I was clumsy and just couldn't do the things they were doing"* (P8). For our participants, a shared diagnosis of Parkinson's meant bonds were formed within the

group as participants were *"all in the same boat"* (P7). Such commonality created an empathetic and supportive environment with understanding and camaraderie between group members: *"others know what it's like to be the way we are [and] I don't feel so alone"* (P4). This context provided encouragement, competition and fun: *"Well, I've got to beat [named participant] and [another named participant] has got to beat me..."* (P11). Indeed, social interaction with *"like-minded people"* (P5) was a large motivator for weekly participation, because it kept participants accountable to the group. It also provided *"incentive to put extra effort in"* (P3).

Attendance at the group provided an opportunity for what was perceived as routine exercise (for example, static cycling and squats), as well as an *"opportunity to do exercise you wouldn't otherwise do"* (P1) (such as walking along a balancing beam). Participants enjoyed the *"social side of [the group]"* (P20). As Participant 1 mused *"it's no fun sitting out in the garage on your own"* (his usual place for exercise).

Theme 3: A Sense of Individual Empowerment

Our final, overarching theme describes the perceived individual and personal gains resulting from the first two themes (Table 3). Participants described a sense of individual empowerment via feelings of increased self-worth and belief in their ability to be proactive in self-managing their condition: *"[I've learnt that] how you control your life with Parkinson's is up to you. It's only you that can do it"* (P3). An understanding and supportive environment combined with trust in professional guidance provided participants the confidence to engage in tailored exercise: *"That uncertainty when I arrived has gone to total confidence by the time I left"* (P14). Participants were able to transfer exercising to the home environment; *"I've started doing*

weights at home as well. This [programme] has encouraged me to do that" (P8). Through the conduit of exercise, the theme shows the developing self-efficacy and self-actualisation of the participants leading to an individual's sense of empowerment. Overall, this manifested in participants reporting increased confidence to participate in meaningful activities of daily living, with many participants also reporting functional gains. For example, one participant reported now being able to perform activities independently: "[The carers] used to make my bed and help me do my washing, but now I take over a lot of those things back again" (P14). Other participants reported increased ease with daily activities, such as carrying shopping bags into the house from the car and doing "more work in the garden" (P20). Others said they had returned to physical recreational activities, which they had previously given up. This included cycling and running. One participant reported being able to jump without losing balance and felt more confident about not falling because of increased strength and confidence in their physical capability. Participant 9 boasted "I started off at 1 kilogram and I can lift 5 [kilograms] now". Overall, participants felt able to take back control from what they had previously perceived as a dominating force in their lives: the diagnosis of Parkinson's. One participant regained sufficient strength to "steer the car [when driving]" (P14). Although a practical example, this could be a metaphor reflecting participants' sense of empowerment; to 'steer' their lives back in the direction of their choosing.

DISCUSSION

This study explored perceptions about small group exercise for people with Parkinson's who are at risk of decline to dementia, and examined the effect of exercise from a number of perspectives. Analysis of the UPDRS motor scores showed a clinically significant difference between the intervention and control groups at baseline with the intervention group having a higher score, indicating a more severe level of motor impairment (Shulman et al., 2010). Therefore, outcomes between the two groups cannot be compared and may indicate lack of power in the larger study. It was surprising that the intervention group did not achieve quantifiable improvements in physical outcome measures given that the literature provides good evidence for the effect of exercise on physical function. Nevertheless, participants reported they derived wider and holistic benefits from attending the small group, tailored exercise programme. Many participants found the group environment and professional guidance offered in this setting to be very motivating, supportive and enabling. It appeared to result in improved self-efficacy and the power to separate themselves from their diagnosis and restore a sense of personal identity. Overall, we identified this as development of a sense of individual empowerment. Our findings support an Australian study by O'Brien et al., (2008) who also reported that a small group, tailored exercise programme for people with Parkinson's resulted in benefits broader than just physical outcomes. However, two studies from Australasia cannot be seen as providing sufficient information in this area of interest to inform elsewhere in the world and thus this requires further exploration.

The juxtaposition of the non-statistically significant quantitative results against the perceived benefits reported by participants in qualitative interviews, begs the question as to whether research should continue to place emphasis on quantitative outcomes in a 'disease-centred approach' as opposed to a person or patient-centred approach (Zhao, Gao, Wang, Liu, & Hao, 2016). Te Whare Tapa Whā (Durie, 1998) was developed to capture the Māori philosophy of Hauora (wellbeing), which encompasses holistic health and wellbeing (Rochford, 2004). The model which is being integrated into healthcare in New Zealand (Ministry of Health, 2017) has four dimensions (Taha Tinana (physical health/wellbeing), Taha Wairua (spiritual health/wellbeing), Taha Hinengaro (mental/emotional health/wellbeing) and Taha Whānau (social health/wellbeing) which interlink and are each equally important for overall wellbeing. Traditional emphasis in health research and practice both globally and in New Zealand encompasses only physical health, with less or no consideration for the other dimensions that underpin holistic models of health and wellbeing, such as Te Whare Tapa Whā. Our study reiterates the importance of considering all four cornerstones of Te Whare Tapa Whā. Indeed, our participants clearly valued not only their perceived physical gains from participating in the group exercise sessions, but also the social, mental/emotional and spiritual gains resulting in a sense of individual empowerment.

The model we propose for development of 'A sense of individual empowerment' Figure 1 represents how the interview data interacted and can be seen to reflect the holistic nature of Te Whare Tapa Whā. Our model demonstrates the relationship between the three themes that occurred through participating in a small group tailored exercise programme. We therefore suggest that the two themes of 1) Having trust in professional guidance and 2) An understanding and supportive environment are integral components to the development of theme 3) A sense of individual empowerment. It is conceivable that this model could be used in other settings with an alternative conduit. For example, Stephen et al., (2014) explored components of an internet-based therapist-led live chat cancer support group, and two of the important components that were identified were the "important role of the facilitator" and "shared understanding and connection". Through an internet-based cancer support group, patients felt more open about discussing their problems and expressing their emotions to other individuals. A sense of empowerment was not specifically expressed in the study. However, the act of expressing one's emotions to others has been demonstrated to have therapeutic effects in moderating emotional stress and facilitating personal goal setting (Stanton & Low, 2012). It can therefore be argued that the benefits received from a group environment, whether online or face-to-face, give rise to a sense of control over one's emotions and health, and therefore contribute to a sense of individual empowerment.

Contrary to the American College of Sports Medicine exercise guidelines of 2-3 times per week for older adults (Nelson et al., 2007), and a recent review exploring effective exercise training in the older population (Bouaziz et al., 2016), our participants attended the exercise intervention group only once a week. Literature about exercise dose for people with

Parkinson's suggests that a minimum of 2-3 sessions per week is necessary to result in changes to physical function (Allen et al., 2010; Corcos et al., 2013; Ellis et al., 2005). Indeed, the lower frequency of exercise sessions per week in the larger RCT in which our study was nested, may have contributed to the lack of significant results in physical improvement in the intervention group. However, the RCT has not yet collated self-reported data pertaining to other physical activity participants undertaken over the course of the study. In addition, at baseline for the RCT (Peterson et al., 2017), the UPDRS motor scores showed a difference of 4.1 points between the two groups. The clinically important difference for the UPDRS motor ranges from minimal (2.3-2.7) to moderate (4.5-6.7) (Shulman et al., 2010). This suggests that the control and intervention group, were clinically different at baseline and therefore possibly not comparable. However, many of our participants reported fluctuating symptoms (Storch et al., 2013), therefore UPDRS scores taken at one time point may not be truly reflective of a person's fluctuating motor ability.

An interesting result in this study was the high rate of adherence, i.e. attendance and participation rates, in the exercise intervention over the eight month period. A number of recent reviews found that adherence to exercise interventions in the older adult population varies from 58% to 86% (Farrance, Tsofliou, & Clark, 2016; McPhate, Simek, & Haines, 2013; Picorelli, Pereira, Pereira, Felício, & Sherrington, 2014), and is generally higher if the exercise programmes are supervised (Picorelli et al., 2014). Lower levels of adherence were associated with group exercise interventions that had a duration of ≥ 20 weeks, ≤ 2 sessions per week, or interestingly, if the programmes included flexibility exercises (McPhate et al., 2013). In theory, participants in the intervention arm of our study should have had lower adherence scores, given that the exercise class was only once a week for a lengthy period. Research suggests that improved exercise adherence to community-based exercise for people over 65 years of age arises from social connectedness, participant-perceived benefits, programme design, empowering/energising effects, instructor behaviour and personal characteristics of attendees (Farrance et al., 2016). We believe the higher adherence rate evidenced in our study can be explained by the model which we have developed (Figure 1). Both themes which feed into the conduit of small group, tailored exercise had subthemes relating to accountability and commitment. In addition, the resulting sense of individual empowerment encouraged participants to believe they could make a change in their lives, and they, therefore, were eager to keep going with the programme. We believe that adherence can be explained by all three of our themes, and that the participants' experiences as represented by the themes contributed to their level of adherence. Indeed, a study by Crizzle and Newhouse (2012) that examined participation in a Parkinson's specific hydrotherapy programme for older adults reported similar motivators for attendance - having a reassuring instructor, structure and support arising from the group, and improved psychological wellbeing derived from perceived physical improvements. Thus, we hypothesise that our model could be applied with other exercise formats to reap similar benefits in terms of adherence.

In the context of measuring meaningful outcomes, the findings of this study demonstrated the importance of considering not only the use of standardised measures of physical function, but also of gathering subjective data as a means of gauging improvement. Combining the two approaches provides a more holistic view about the benefits of an intervention. Overall, we discovered how individually tailored exercise, offered in small group settings with 'like-minded people', can be an effective conduit for delivery of meaningful outcomes.

CONCLUSION

In this study, participants valued the holistic benefits they gained from participating in an exercise programme and a small group tailored programme is an effective way to deliver exercise to individuals with Parkinson's. The results of this study suggest that the 6MWT and mini-BESTest did not capture the holistic gains reported by individuals. The model we created, that links our three themes, begins to examine which factors are important in creating a meaningful environment in which to engage in exercise. Participants reported regaining the ability to perform functional activities previously lost to them, as well as the ability to apply what was learnt in the small group classes to maintain and improve physical activity levels in other environments. Perhaps research places too much emphasis on standardised measurable gains, compared to meaningful improvements reported by participants. We believe that research limited to measuring standardised physical outcomes to investigate improvements in an individual's physical abilities, neglects important aspects of a person's overall function and wellbeing. Finally, we propose that the use of the model we developed, using alternate conduits, could produce similar outcomes to this study for other population groups.

KEY POINTS

1. People with Parkinson's value individually tailored, small group exercise, supervised by physiotherapists who understand the characteristics and fluctuations common to living with Parkinson's. This should be considered in the design of future exercise programmes for this population.
2. Te Whare Tapa Whā or other similar holistic models could be considered as a useful framework when creating exercise programmes for people with Parkinson's (and possibly other neurological conditions) in order to address all cornerstones of health and wellbeing.
3. The model we created, which integrates our three themes, could potentially be used with alternate conduits to elicit similar holistic health benefits.

DISCLOSURES

The authors report no conflicts of interest.

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Appendix 1

Interview guide

- 1 Overall how has it been for you to front up each week at the exercise group? What has kept you coming?
2. What had been your experience/s of partaking in physical activity/exercise prior to this study?
- 3 Now I'd like you to think back to the beginning. What was it like for you on first being given an appointment at the physiotherapy clinic and then, what was it like joining an exercise group?
- 4 How has it been for you since? How has it been for you to exercise in this way?
- 5 Tell me about the feasibility/practicality – in terms of convenience, ease of access, time and travel commitment.
- 6 Can you tell me about the acceptability/tolerability – have you had to take into account/or has exercising had an effect on energy/fatigue, tremor and medication management?
- 7 Is there anything about the group itself that you particularly enjoy or perceive benefit from? Why? When did this start/stop happening?
- 8 Is there anything about the fact that you have done this in a group that you did not/do not particularly like? Why? When did this start/stop happening?
- 9 Is there anything about coming to this physiotherapy clinic itself that you don't enjoy/would like to have changed, or that you have particularly enjoyed?
- 10 Do you have any definite plans for exercising when this study ends? What are these? Would you know where to find information to assist in making decisions about continuing with exercise once you end here?
- 11 Has being involved in this study encouraged you to incorporate exercise into your daily life? What motivates you to exercise?